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# Public and Patient Involvement in Theory and in Practice

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Submitted by Kath Maguire of the Peninsula College of Medicine and Dentistry  
Graduate School to the Universities of Exeter and Plymouth as a thesis for the  
degree of Doctor of Philosophy in Medical Studies

May 2014

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## **ABSTRACT:**

There is increasing interest in the theoretical underpinning of involving patients and the public, in health research and care, as coproduces and partners. Conducted by a participant researcher, this study theorises involvement from the perspectives of patients and members of the public. It asks: 'What motivates and sustains patient and public involvement from the perspective of lay participants?' Beginning from an ethical position that sees knowledge as a social product, it argues that involvement can demonstrate the public ownership of knowledge.

The study uses survey data and 31 semi structured interviews, with participants from across England, covering a wide range of involvement roles and activities. It explores what inspires and what discourages involvement and how involvement impacts on participants' sense of identity. Theoretical approaches are interrogated asking: what would involvement look like from this perspective and how would a participant's description of involvement be shaped by this approach? These ideas were translated into games and stories, prompting further discussions with both public involvement participants and academics.

Building on the model of public involvement 'knowledge spaces,' participants' stories are used to describe these as liminal, complex and often paradoxical spaces. Rather than the sharply defined cube, described by Gibson, Britten and Lynch, these spaces are more like bubbles, morphing and contorting in reaction to fluctuating external and internal pressures. Knowledge spaces are politically, economically and culturally situated. Within each space different modes of action, rules, and theoretical approaches may coexist. They may have multiple instrumental purposes, while using expressive modes of action. Different involvement opportunities may call for similar skills and abilities. In acting as weak publics they may empower participation in campaigning and decision making. Conservation and change are not only matters of how organisations respond to involvement, individual participants may experience knowledge spaces as arenas through which their sense of self is maintained, transformed or reconstructed, where they connect their personal narratives to the creation of human knowledge.

The complexity of these spaces, the multiplicity of external pressures and participant orientations, makes it all the more important for participants, (clinical, academic and lay) to reflect upon and share their own motivations and values. This means examining drivers and pre-existing theoretical baggage to ensure that none of these obscure the appreciation of and engagement with alternate views. The pursuit of strategic aims through these spaces requires communicative action.

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## **LIST OF ACCOMPANYING MATERIAL**

Capital as resources	board game
Pdf copy of text	on USB memory stick
Copies of games	on USB memory stick
Photographs of games	on USB memory stick
Journey into research (digital story)	on USB memory stick

### **Bibliographical note:**

In order to facilitate access to as wide a literature as possible from my remote rural location I have used a large number of ebooks, many purchased or downloaded over the internet using 'Kindle'. Because of their fluid format, some of these do not do not include page numbers. Where possible I have accessed page numbers, for the equivalent printed version of the editions used, from other sources, to include in references. There are, however, three books for which I was not able to obtain these. In references to these works I have provided 'Kindle Locations' references in the format (Author date, KL 4400-4450).

## **DEFINITIONS and ABBREVIATIONS:**

BSE	Bovine spongiform encephalopathy
CHC	Community Health Council
CLAHRC	National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care
CPPIH	Commission for Patient and Public Involvement in Health
GP	General Practitioner
INVOLVE	National advisory group that supports greater public involvement in NHS, public health and social care research.
Involvement	In this study, involvement in health and social care research means participation in the control and conduct of that research by patients and members of the public, as collaborators and partners, rather than as research subjects or recipients of information.
Knowledge space	An actual, virtual or metaphorical arena in which professional/clinical academic and lay knowledge are shared
KL	Kindle Location
Liminal space	An actual, virtual or metaphorical 'in between' arena in which normal social roles are suspended
LINKs	Local Involvement Networks
MRSA	Methicillin-resistant Staphylococcus aureus
MMR	Measles Mumps and Rubella
NHS	National Health Service
NIHR	National Institute for Health Research
PCT	Primary Care Trust
PenCLAHRC	National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula
PenPIG	National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula Public Involvement Group
PPI	Patient and Public Involvement
RDS	National Institute for Health Research Research Design Service

# 1 Introduction: What is this study about and why?

## 1.1 The starting point

1.1.1 Public concerns about the scope of science or the risk of scientists losing a sense of perspective, when absorbed in their studies, are not new. It is a theme comically explored by Swift with 'Laputa' ([1726] 2001, pp143-179), and darkly by Shelley (1818) in Frankenstein. During the past quarter of a century there have been several high profile cases that have highlighted and fuelled public anxieties about the environmental and human impact of science, and their scepticism about research governance. Examples include: bovine somatotrophin, an artificial hormone used to stimulate milk production at a time of butter mountains and milk lakes (Brinckman 2000); BSE, or 'mad cow disease' (Finucane 2002); risk associated with the MMR vaccine (Stroud 2005); genetically modified crops (Finucane 2002); global warming (Nisbet and Myers 2007); and fracking (Rabe and Borick 2011). Vociferous public protests have prompted an increased interest in public engagement and involvement in science, from scientists and policy makers. This is described by the National Co-ordinating Centre for Public Engagement as not just a 'means of educating the public about research findings, but also as a way of engaging the public in debate about topical issues and promoting dialogue to further inform the process'<sup>1</sup>

1.1.2 This thesis explores issues raised by this agenda, using the results of a three year study, through the application of social theory to reflections on experiences of patient and public involvement in health research and care. While this study has looked at involvement in health research and care, this is part of the wider agenda of public engagement and involvement in science. The thesis uses the concept of 'knowledge spaces' (Elliot and Williams 2008, Gibson, Britten and Lynch 2012) to explore and theorise emerging structures and activities that make up the diverse practices that constitute the field of patient and public involvement. It focuses on the experience of 'lay participants': members of the public, patients, carers, service users.

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<sup>1</sup> <http://www.publicengagement.ac.uk/do-it/different-disciplines/science-engagement> (accessed 15/08/14)

1.1.3 While patient and public involvement and engagement in health research has become increasingly important, to funders, researchers and institutions; without it also being important to patients, carers and members of the public, it would be a slow-moving and artificial institutional activity. Subsumed in the bureaucratic machine of academic funding and management, involvement might not be the fluid, exciting and dynamic field it has become. It is frequently the enthusiasm, energy and emotion that lay participants bring to the field which acts as the engine behind the progress of these knowledge spaces, driving them forward, pushing them into dusty corners and enabling them to cover new ground. It is the importance of public 'buy-in' to these activities that leads to the practical research question for this study: What motivates and sustains patient and public involvement from the perspective of lay participants? The intention is to enrich the understanding of involvement as it appears from the inside, an approach that leads the study to focus on the reflexive use of social theory in developing practice (section 2.1.1-3).

1.1.4 The rationale behind the conduct and the reporting of this study has been shaped by the subject. In order to explore and describe the complex of activities, understandings and relationships that constitute patient and public, service user and carer involvement in health research and care, it has been vital to act as a 'theoretically sensitized observer' (Timmermans and Tavory 2012, p173). This has involved looking at a broad range of literature on social theory, using different approaches as lenses through which to view involvement. It has also been important to engage in 'theoretically sensitized' discussions with both academic and involvement colleagues, other 'lay participants' in this field. This has required the exploration of different ways to present theoretical concepts, including models and games, enabling different conversations to take place and different insights into the data to be gained.

1.1.5 As a result of this approach, the thesis is structured around four major themes, themes which emerged from study data as significant issues for participants, and which are addressed from different theoretical standpoints. These are: the importance, to health research and care, of including a different perspective to that of the clinician or academic; the complexity caused by the interaction of different language and understandings in involvement; the

experience of social and personal transformations; and the importance relationships.

1.1.6 The concept of 'knowledge spaces' (Elliot and Williams 2008, Gibson, Britten and Lynch 2012) has been extremely useful, encompassing the wide range of structures and activities that constitute patient and public involvement. These are structures enabling people with different sorts of knowledge, experiences and understandings of a particular issue to come together, in order to contribute to the development of 'civic epistemology' (Jasanoff 2000), the social negotiation of what may count as knowledge, about a topic. The term 'space' in this context is essentially metaphorical. As well as physical arena's in which these encounters take place, the term 'knowledge space' describes opportunities to share different perspectives and different ways of knowing about a topic or problem. Knowledge spaces may involve face to face or virtual meetings, requiring both a physical space and temporal 'space' to be made in the participants' schedules. Alternatively, knowledge spaces may involve exchanging messages and ideas over time, requiring participants to make the 'head-space' to engage with each other's understandings, and to respond. Knowledge spaces in health research could include: meetings and workshops; brief or enduring groups and partnerships; electronic forums; and activities like providing 'lay reviews' of research proposals.

1.1.7 Patient and public involvement knowledge spaces do not exist in a vacuum. They are embedded and enmeshed in broader social relations and processes. Knowledge spaces are shaped by what is happening around them as well as what takes place within them. The issues, with which participants in knowledge spaces are engaged in deliberating, often concern contested relations of power and the access to resources. In the UK since the 1980s there have been pressures on academic institutions, researchers and healthcare providers to model themselves on private sector organisations. These institutions have increasingly been transferred into the economic subsystem, either indirectly by marketising their modes of operation, or directly by outsourcing their functions to the private sector and marketised voluntary sector organisations. This impacts on and often shapes the field of knowledge spaces, as they are frequently owned, hosted, funded or enabled in some other way by particular institutions. The institutional purpose in creating a space for patient

and public involvement may be explicitly about enabling and including a range of voices, it may also be about containing dissent and deflecting protest. Practical support or professional engagement may be withheld or withdrawn from spaces that do not conform to the requirements of policy makers or managers, sometimes limiting the capacity or durability of the space.

1.1.8 In describing a theoretical model of knowledge spaces, Gibson Britten and Lynch outline a 'cube' with four dimensions which they propose can be 'used to map the diversity and fluidity of different patient and public involvement initiatives and groups' (Gibson, Britten and Lynch 2012, p543). These dimensions draw on the work of Habermas (expressive to instrumental), Bourdieu (monism to pluralism) and Fraser (weak to strong publics), with a fourth, cross-cutting dimension of conservation to change (appendix 15). This study has interrogated the 'cube', while also exploring theoretical approaches participants themselves bring to involvement, drawing on themes identified in study data. While acknowledging the value of the framework, Gibson Britten and Lynch propose, in supporting discussions of involvement; I shall argue that the complex nature of these knowledge spaces means that mapping them along linear scales may prove deceptive and unhelpful. Inclusion of the range participant orientations and drivers, as well as institutional and wider societal contexts, are all vital to theorising patient and public involvement knowledge spaces.

1.1.9 The descriptions of these knowledge spaces, given by lay participants in this study, have shown that they are often experienced as liminal spaces. This metaphor, of a liminal or threshold space, has been used by anthropologists to describe times of social ambiguity, times when one role has been cast off, but before a new role has been adopted, rituals of transition and the places where these are held. V.W. Turner (1964, p4) describes liminality as 'betwixt and between' and 'an interstructural situation', that is it is a gap between the rules that apply to one status or set of social relationships and another. This description of patient and public involvement, as liminal, separate, sometimes semi-ritual, spaces between different worlds, different ways of interacting and communicating, was explicitly used by one research participant. The experience of involvement as necessitating, or creating, either a temporary or a sustained role ambiguity was frequently mentioned by participants. This

was also the focus of many discussions with colleagues working as both patient activists and academics.

1.1.10 The roles of 'patient', 'carer', 'researcher' and 'clinician' each imply different rules and different expectations, different cultures. Participants also bring with them their own, different, theoretical understandings and interpretations. Because of these differences knowledge spaces frequently contain paradoxical or contradictory language, ideas, values and relationships. This can lead to the dimensions, Gibson Britten and Lynch use to outline knowledge spaces, being experienced, understood and perceived very differently by participants from divergent backgrounds. The setting of these spaces, within structural relationships of power and access to resources, can also lead to them simultaneously mapping to multiple or opposite positions on some scales.

1.1.11 These qualities can make the outlines of patient and public involvement knowledge spaces uneven, and irregular. Rather than sharply outlined cubes they may contort and become unstable like irregular shaped soap bubbles. Their outline and orientation can change in response to fluctuations of external and internal pressures. This can cause them to fold in on themselves. One space may divide into separate spaces; several may combine into one; a space may suddenly be abolished and disappear, scattering participants. Internal changes to: group membership, members' interests, capacity or access to resources; external changes from: government policy, economic conditions or institutional reorganisations; can combine to transform or obliterate involvement spaces in ways that may be hard, or even impossible to predict. These multiple pressures and drivers make involvement knowledge spaces complex, intrinsically difficult to map, and trying to measure their dimensions numerically can be misleading.

1.1.12 This complexity of external pressures and divergent participant orientations, acting on these spaces, makes it important for them to be treated as fields of communicative action, oriented towards enabling understanding. Treating them purely instrumentally can lead to them being experienced as tokenistic and divisive. The assumption that there is a shared motivation or goal for involvement in particular projects or activities is not supported by this study.



This implies that participants, (clinical, academic and lay) need to discuss what motivates their involvement and to sort through their pre-existing theoretical baggage to ensure that none of these obscure their appreciation of and engagement with alternate views.

1.1.13 This implies that successful and valuable knowledge spaces are not necessarily either sustainable or straightforwardly replicable. In describing a process that has been fruitful in one place, at one time and with a particular set of participants, we cannot assume that repeating this will continue to deliver the same results, nor that it would be equally productive if duplicated in a different setting, or with different participants. Involvement ‘toolkits’ and methodologies, therefore, cannot provide a blueprint of a straightforward, ‘right’ way to do involvement. Attention needs to be paid to the requirements and aspirations of the particular participants as well as the broader institutional, political, social and economic contexts. Practical support for involvement and ways of working may need to be adapted as these things change.

1.1.14 In this study the term involvement is used to mean participation in the control and conduct of research. This may include: prioritisation of research topics; formulation of research questions; gathering and analysis of data; making funding decisions; project management; research governance; and the dissemination of research findings. In this context involvement does not include taking part in trials as the subjects of research, nor does it include being passive recipients of information about research. The widely used formulation ‘patient and public involvement’ is most often used in the text. In the thesis title, however, this is reversed; a signal of the ethical priority given to the public ownership of knowledge in my approach to this subject.

1.1.15 This project begins from the perspectives of the people involved, looking at how their personal motivations, goals and experiences shape their involvement. That explicit position has meant that a rigid conceptual distinction between involvement in health research and involvement in health services was not coherent. The maintenance of the distinctions between what is done for the purposes of research and what are the requirements of care is vital to good governance, and therefore something that must concern professionals and their institutions. However, the space between health service research and the

provision of services is at best a blurred boundary. In addition, for many in patient and public roles, involvement in research often both comes from and is focused towards the need to improve safety and care for those using services. As one interview participant said ‘most people are practical aren’t they?’

1.1.16 My starting point, as the researcher, has been from an active personal engagement in a range of patient and public involvement activities and groups, as well as a background in community involvement and engagement in other fields. My intention in undertaking this study has been to provide evidence that can be used to make involvement more widely accessible, more inclusive and more useful to people who want to become involved (2.1.2).

1.1.17 This study has not been looking at the impact of involvement on the research process and outcomes, although this has sometimes arisen as is a factor influencing the experience of participants. For me the intrinsic value of the involvement of patients, carers and the wider public in health research is seen as resting on the ability of involvement in research to explicitly demonstrate the social ownership of the knowledge it produces. This in turn is based upon an ethical stance which holds that: as humans are social animals living in complex and interconnected groups, the knowledge we produce is shaped and enabled by our social context. It is therefore a collective rather than an individual achievement. This position recognises that the knowledge produced by academic and clinical researchers is valuable. Equally, it emphasises that without personal care, support and schooling, and the manifold labour of others it would not be possible for researchers to undertake research. This position is rooted in feminist philosophy and what Carol Gilligan has described as an ethic of ‘care’; a moral framework based on acknowledging interdependence rather than stressing individual rights.

1.1.18 The conduct of this study as well as the structure and presentation of this thesis have been shaped by this ethic. It reflects my personal engagement and the many debts I owe to those who enabled this study to take place.

## **1.2 Conduct of study**

1.2.1 This study was funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for

the South West Peninsula (PenCLAHRC). This body was funded to work in the south west of England to address the gap between research knowledge and implementation. This institutional connection gave me privileged access to PenPIG, the patient and public involvement group for PenCLAHRC. Members of PenPIG have not only taken part in interviews as study participants, the group has also acted as a sounding board and as advisors during the course of the study. Their comments and discussions have helped to shape the direction of the study as well as nurturing and emboldening the researcher.

1.2.2 Gaining access to others involved in health research, however, was not straightforward. Some institutions did not seem to have records of patient and public involvement activities or contacts, while in others records were only held within a particular project or department. Any personal contact information that was held had normally been collected for the express purpose of facilitating communication within a project or group. This meant that it was confidential under data protection regulations. Because of this, access to many potential participants in this study was dependent on the capacity and willingness of professionals to distribute invitations.

1.2.3 This issue was addressed by launching a survey, available online and in hard copy, which was advertised through National Institute for Health Research (NIHR) networks, university patient and public involvement contacts and patient groups. The one hundred and five survey responses provided some initial qualitative data about the organisations and activities respondents were involved in but, crucially, they provided a sampling frame with which to identify people willing to take part in semi structured interviews.

1.2.4 Thirty one participants were interviewed, either face to face or over the telephone. Participants were encouraged to tell their own involvement story rather than respond to specific questions, though this was guided by a topic framework which was shared with participants in advance. They were also invited to send any reflections on the study or supplementary information they felt was relevant following the interview. A distinctive feature of this study has been the inclusion of individuals involved in different types of involvement activities and engaging with different institutions, as well as some who have contemplated involvement but not yet become involved.

1.2.5 Another dimension to this study has been provided by reflections on my own experiences, as a participant in patient and public involvement roles in health research. This has inspired a creative interaction between theory and data. As well as surveying theoretical literature I have used stories games and models to relate theories to the data, and these representations have been discussed with public involvement and academic colleagues. Models were then adapted and developed in the light of these discussions. This has involved multiple iterations, circling and interrogating both the data and theoretical approaches, as well as inspiring productive excursions into history and policy literature.

1.2.6 During the planning stage of this study, I had discussions with my supervisors about what would be my most appropriate and useful approach to the literature. At that time a literature review that 'aimed to increase knowledge of the evidence of the impact of public involvement on health and social care research' had just been published by INVOLVE (Staley 2009). We were also aware that another group were preparing to publish 'a systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research' (Brett et al 2010). Given this we agreed that, rather than replicating this work, my time would be better employed looking beyond the literature on patient and public involvement and identifying theoretical perspectives that could be fruitfully applied to the specific aims of this study.

1.2.7 It was anticipated that, in the final year, I would return to the literature on patient and public involvement to identify relevant papers that had been published in the interim. However during that time a colleague, Felix Gradinger, who was working on a study about the measurement of the impact of patient and public involvement<sup>2</sup> (see Snape et al 2014) undertook an extensive review which included: text books; journal articles; policy documents; and websites. Gradinger's work specifically focussed on drawing out the normative values implicit in the literature and he was generous in sharing both insights and sources. These were extremely helpful to me in contextualising the emerging data from this study and provided useful leads to further resources.

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<sup>2</sup> <http://piiaf.org.uk/> (accessed 28/02/14)

1.2.8 At the same time, as part of my continuing patient and public involvement activities, I participated as a member of the advisory panel for that study as well as taking part in an ESRC funded seminar series on ‘Knowledge spaces and public social science’<sup>3</sup> which included a number of leading academics in the field. From those discussions I was able to draw on expert insights and leads to a range of relevant debates in the literature. So, again in consultation with supervisors, it was agreed that it would be redundant for me to undertake a traditional review of the literature.

1.2.9 However that is not to say that this study has not been intimately engaged with the literature. The starting point was a wide ranging review of textbooks on the sociology of medicine, health and illness, intended to identify theoretical concepts that were being employed. This was followed by a broader look at textbooks and anthologies of social theory, history and the philosophy of science. Colleagues have also been extraordinarily generous throughout the study in alerting me to relevant papers in current journals, many of which through their insights and citations led me back to the theory books with new questions and understandings. These interrogations were always made with two specific questions in mind: how might patient and public involvement in health research and care be explained or modelled using this theoretical approach; and how would a participant’s description of their activities be shaped by the implicit or explicit adoption of this perspective?

### **1.3 Policy context**

1.3.1 Public and service user involvement in the creation of public goods is something that has been promoted widely across the public sector and across political parties for some time. It is fundamental to the concept of the ‘Big Society’ which David Cameron described as his ‘absolute passion’<sup>4</sup>. The Conservative Party website described this as a policy of people being “encouraged and enabled to play a more active role in society”<sup>5</sup>. There is a similar strand of thought within the Labour Party. ‘Blue Labour’ describes itself

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<sup>3</sup> <http://www.esrc.ac.uk/my-esrc/grants/RES-451-26-0891/read> (accessed 03/05/14)

<sup>4</sup> Cameron (2011) <https://www.gov.uk/government/speeches/pms-speech-on-big-society> (accessed 03/05/14)

<sup>5</sup> [www.conservatives.com/Policy/Where\\_we\\_stand/Big\\_Society.aspx](http://www.conservatives.com/Policy/Where_we_stand/Big_Society.aspx) (accessed 28/02/14 also quoted in Dunk-West and Verity (2013) chapter 6)

as a: “pressure group that aims to put relationships and responsibility at the heart of British politics”<sup>6</sup>.

1.3.2 Sage (2013) has described both these concepts as representing “an engagement with communitarian ideas”. That is they utilise a conception of the community as something which has a role in defining and shaping individuals rather than as a purely voluntary association of independent actors. This approach also implies a reciprocal duty on individuals to contribute to the production of public goods. Another potential motivation for the political consensus on the value of public involvement has been highlighted by Papagianni (2008). She has argued that openness to public participation plays an important role in the legitimisation of states and governments in the eyes of their populations. This might be seen as a compelling incentive for politicians to emphasise involvement in public services, particularly at a time of economic retrenchment and declining electoral participation.

1.3.3 Whatever the underlying motive, public involvement and engagement is high on the agenda of a range of public bodies. The website for the National Institute for Health Research (NIHR) outlines a number of ways in which it wants patients and the public to be actively involved, in the health and social care research they fund: “Set research priorities; Identify the important questions that health and social care research needs to answer ; Give their views on research proposals alongside clinicians, methodologists, scientists, and public health and other professionals; Help assess proposals for funding; Take part in clinical trials and other health and social care research studies, not just as subjects but as active partners in the research process; Publicise the results”<sup>7</sup>.

1.3.4 Throughout current policy on health and social care, the importance of involving the people who use services, and research and those who pay for them through the tax system or through charitable contributions, is emphasised. Exactly why this involvement is important, how it should be done, and what it implies, is often confused and sometimes contradictory. Involvement can describe: consulting people about the design of services or the allocation of

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<sup>6</sup> <http://www.bluelabour.org/who-we-are/> (accessed 03/05/14)

<sup>7</sup> <http://www.nihr.ac.uk/awareness/Pages/default.aspx> (accessed 03/05/14)

public money; sometimes it describes the inclusion of service user preferences in decisions about their own healthcare; professionals, academics, service users and/or members of the public working together, to co-produce services or knowledge is also described as involvement.

1.3.5 This growth of interest in public involvement, and the requirement of funding bodies for public and service user involvement, has led to an increased demand for evidence of its impact. Evidence from public health has, for some time, implied there are tangible impacts of service user involvement in health. The National Institute for Health and Clinical Excellence produced guidance on community engagement in health promotion (NICE 2008). This argues that while consultation may have only a marginal impact on health literacy closer involvement (e.g. co-production or delegated power) can lead to more positive health outcomes. The World Health Organisation argued more forcefully that wider involvement in health services is a necessary component of 'patient and family empowerment strategies [that] have increased patients' abilities to manage their disease, adopt healthier behaviours, and use health services more effectively, as well as increasing care-giver coping skills and efficacy' (Wallerstein 2006, p4). For some, patient and public involvement is an issue of citizen or consumer rights, for others, it is about improving the quality or value of research and services by tightening feedback loops.

1.3.6 Ellie Cartwright and Sally Crowe in their 'Patient and Public Involvement Toolkit' (2011) describe potential aims and outcomes of involvement including: improving information; improving access; improving quality of services; improving monitoring of services; providing perspectives on changing needs; increasing recruitment to trials; including the views of a 'critical friend'; increasing transparency and accountability. This is a wide range of possible outcomes. Many involvement processes will have multiple objectives, and each objective will be of different importance to the different individuals and organisations involved.

1.3.7 Involving patients and members of the public in research has been seen as potentially leading to 'better research, clearer outcomes, and faster

uptake of new evidence'<sup>8</sup>. Recent literature reviews (Staley 2009; Brett et al 2010) have identified that patient and public involvement in health research has been widely reported as having affected the scope as well as the conduct of research. Impacts have been also reported on researchers and research participants as well as on the service users and members of the public involved. However the robustness of research findings have sometimes been seen as compromised by the weight given to service user perspectives (e.g. see Staley 2009, p34 comments on Krieger et al 2002). Though impacts of involvement, both the positive and the negative, are often poorly and inconsistently reported (Staniszewska et al 2012).

## **1.4 Theoretical context**

1.4.1 Brett et al also identified a lack of the development of theoretical approaches to patient and public involvement in health research. Until recently it has seemed difficult to find theoretical analysis of involvement in this field that stretched beyond Sherry Arnstein's (1969) concept of civic involvement as of a 'ladder' with manipulation as the bottom rung and citizen control at the summit (appendix 9).

1.4.2 This ladder has been criticised as a rather static and linear model, one that overemphasises the dimension of power and fails to stress the importance of knowledge and expertise (Tritter and McCallum 2006). The significance of the particular knowledge and expertise contributed by patients and service users makes this omission in Arnstein's model a serious one in the context of health research and care. Even so, the idea of different levels of power in involvement is very useful. Arnstein's model has been built upon to develop a conceptual framework of patient and public involvement in setting research agendas (Oliver et al. 2008) which can potentially be applied to other involvement activities. Tritter (2009) further builds on this framework, differentiating between types of involvement, their aims and potential impacts, highlighting the differences between rights-based and regulatory approaches.

1.4.3 Relationships and structures that enable people with different sorts of expertise to work together can also be conceptualised as 'knowledge

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<sup>8</sup> <http://www.nihr.ac.uk/awareness/Pages/default.aspx> (accessed 03/05/14)



spaces' (Elliott and Williams 2008). In health research and care these are metaphorical arenas where the knowledge of clinicians, academics, policy makers, members of the public, service users and carers can be brought together on an equal basis. This can involve meetings and workshops, brief or enduring groups and partnerships, electronic forums, and activities like providing 'lay reviews' of research proposals for researchers and funders. Gibson, Britten and Lynch (2012) have devised a framework for mapping these 'knowledge spaces' (appendix 15). It involves looking at four dimensions: expressive to instrumental, drawing on Habermas' (1985, 1998) distinction between the social spheres of lifeworld and system; weak to strong publics, from Fraser's (1990) model of the influence of groups in the public sphere; monism to pluralism, following Bourdieu's (1986) description of economic, social and cultural resources as different forms of capital; conservation to change, which is based on the ability of an organisation or project to respond to involvement.

1.4.4 This concept has been influential on my thinking during this study. The model of involvement as a series of different spaces, containing different balances of participants, and in which different activities take place, is one that I have found really helpful in thinking, and talking, about the wide variety of groups and activities that constitute patient and public involvement. This is a much more flexible and nuanced model than Arnstein's linear 'ladder'. It is possible to imagine a space with multiple entrances and exits, so participants may emerge from them into new and unexpected landscapes. The boundaries of a space may be permeable, allowing easy movement of participants to and fro, or they might be sealed with participants committed for the duration of a task or process. Sometimes these knowledge spaces may be static, monitoring how something is already working or providing an opportunity to deepen understanding between people in a particular setting. Knowledge spaces can be vehicles of transformation or of exploration; perhaps changing themselves over time, using different techniques and involving different people. Such a process can mean participants also need to sort through their own experiences, values and theoretical baggage in order to decide what will be useful and what is best stowed out of the way.

1.4.5 Knowledge spaces can also be seen as liminal spaces, fields of role ambiguity on the boundary between very different social worlds. Involvement can be a way for participants to create a sense of personal and collective meaning; a way to make explicit their contribution to socially produced knowledge. This implies that public participation in knowledge spaces is an important way for people to become active participants in the creation of what Jasanoff (2000) has described as 'civic epistemology'. Knowledge spaces can, therefore, influence how relevant that process seems. In this case it becomes important, for social cohesion and coherence, that these knowledge spaces are made into accessible and inclusive spaces, spaces in which every contribution is treated with respect. Respect is demonstrated by a willingness to listen and by ensuring that all perspectives are equally interrogated. Through articulating and elaborating their own perspectives, comparing them to the views of others, people can better reflect on the knowledge they have, as well as learn from each other.

1.4.6 Through having their joint ownership of those knowledge spaces, and their role in the co-production of knowledge validated, people can both contribute and benefit from involvement. This is not to present this as a prescriptive communitarian civic duty to participate. A sense of ownership may be difficult to achieve through compulsion hence the importance of permeable spaces, which provide the possibility to exit the space as well as to enter.

1.4.7 The dimensions for patient and public involvement knowledge spaces as described by Gibson, Britten and Lynch (2012) are a valuable development in the theory of involvement. Though, this model does not fully capture some of the complexity and contradictions that exist within these spaces. These are spaces that can be simultaneously expressive and instrumental; participants can act as weak publics in some ways and as strong publics in others; knowledge spaces can both conserve and transform. These spaces may also be important as vehicles of narrative reconstruction for participants who have experienced life changing events, enabling them to translate personal experiences into socially useful knowledge. The knowledge people bring to involvement in health research and care is often very fragile and personal. If their potential vulnerability goes unrecognised the experience of involvement can be bruising. Correspondingly, if participants approach

involvement expecting to be protected from all potential distress, they effectively exclude themselves from participating as equals. Modelling these spaces with clear straight edges, or assigning numerical values with which to map them, can, therefore, be misleading; masking contradictions, intrinsically paradoxical tensions, that are important features of these complex structures. A more accurate image is that of an irregular shaped and unstable bubble that may be squeezed and distorted by external pressures or may change shape and direction in response to fluctuating internal forces.

## **1.5 Structure of the thesis**

1.5.1 This study has increasingly become a dialogue between theories and practice. My research has been enmeshed within the practice of involvement, consciously and attentively crossing boundaries between clinical, academic and community, patient or 'lay' knowledge. Throughout it has been infused with discussions that include contrasting and sometimes contradictory views of what constitutes knowledge and what creates value. Frequently my personal position within these spaces has been ambiguous and at times it has been openly contested.

1.5.2 Given that, the traditional rather linear thesis structure of methodology, results and discussion would be an artificial and misleading way to present this study. The conduct of the study was not linear, theoretical discussions were entangled with data collection and analysis. Within this, personal reflections and narratives frame the meaning I have created through entering into these spaces, and so they too are woven into the presentation of the thesis. I have tried to ensure that the reader has sufficient markers to enable them easily to follow the contrasting threads within the text.

1.5.3 The next chapter will outline the ethical, practical and epistemological assumptions of this study. That is it will describe in more detail my perspective as a service user or insider researcher. This includes looking at my underlying belief in the value of involvement, and how this rests upon the concept of research, and the knowledge it produces, as a social process. The chapter will further explain how these practical ethical positions have influenced the methods chosen to conduct the study, and the way it has been presented. This will lead to a discussion of how the study can make a contribution to

knowledge, looking at what that means in terms of a claim to truth and/or usefulness. The chapter will then go on to describe the methods used to conduct the study in some detail.

1.5.4 Chapter three will describe how I have approached and utilised theoretical perspectives from the social sciences. It will begin to outline how they might be seen as tools to help navigate these knowledge spaces or as baggage we carry with us. It will describe my approach to this broad body of literature, how I identified theoretical perspectives that might be useful, how I prioritised and utilised them. This will include summaries of how I have applied some of these theories, and descriptions of the creative and playful ways I have used to facilitate thinking and discussion about their potential value, in reflections about involvement in health research.

1.5.5 Chapter four focuses on different perspectives brought to involvement. It will heed the advice of C W Mills ([1959] 2000) and look at the intersection between individual lives and history. Examining how the boundaries between different sorts of knowledge have been formed, contested, breached and reformed. By following a particularly strong theme that recurred throughout the study, it examines the concept of there being a distinctive 'lay' or 'patient' perspective juxtaposed with one that is scientific, clinical or administrative. It will look at why the expression of views and the finding of voice are such important concepts for many of those involved in health research. Using stories from study participants and drawing on the concepts of 'alienation' (Marx [1844] 1994) and of 'system' and 'life-world', as developed by Jurgen Habermas (1985, 1998); it will begin to explore how knowledge spaces may function as connective or ambiguous 'liminal' spaces. It will go on to see how the concept of juridification can provide insights into the separation of these worlds, and the shaping of knowledge spaces in the context of medicine.

1.5.6 Chapter five focuses on language and understanding in involvement. It will also look at historical and philosophical roots of involvement, but to see how they have created different understandings of involvement between those patients and members of the public who take part. Using insights from the work of Michel Foucault (1971, 1982) it will outline and frame some of the conflicting discourses (ways of understanding, thinking and talking) that are

frequently apparent when people discuss or describe involvement. It will closely examine two terms frequently used in discussions of involvement: 'representative' and 'lay'. As well as utilising literature on these subjects, it will draw on insights from the ways these words have been used by survey respondents and interview participants to describe themselves and others. Using these it will explore why there is so much disagreement, amongst the people who are involved, about what they should be called and how they should be addressed. By re-visiting some of the roots of involvement it will outline the linguistic and political minefield this can create when we move from one knowledge space to another, carrying with us the, often forgotten, conceptual baggage picked up in the way.

1.5.7 Chapter six explores social and personal transformations. It begins with how changes in demography, social attitudes and access to information might be seen as reconfiguring relationships in health research and care, starting with Parsons' 'sick role' (Parsons 1951, 1975). From this structural perspective the second half of the chapter turns to how personal transformations are experienced as the dislocation of roles and identities. Following Michael Bury (1982) and Gareth Williams (1984) it will interrogate narratives of illness, bereavement and personal reconstruction; looking at the role that moving into the space created by involvement in health research has played in reconstructing meaning in individual stories and social understanding.

1.5.8 Chapter seven is about relationships in involvement. Discussion of the social self and its implications for social relations within involvement will be developed further. It begins by looking at involvement as an exchange, drawing on the work of Mauss and Nietzsche as well as using Simmel's concept of the 'stranger' ([1908]1950). It goes on to look at some negative aspects of working in groups and how these might be experienced differently by different participants. A more positive spin is placed on Sherry Arnstein's (1969) concept of participation as 'therapy'. This leads to a discussion of how a debate between Jurgen Habermas and Nancy Fraser, on the formation of public opinion, is related to involvement in health research and care. The important concepts of 'participatory parity' (Fraser 1990) and 'communities of practice' (Wenger 1999) are used to think about how knowledge spaces can enable and empower more people to contribute.

1.5.9 The conclusion explicitly returns to the research question. What motivates and sustains patient and public involvement from the perspective of lay participants? In addressing it I describe involvement in health research, as outlined by participants throughout this study, as complex and varied. Rather than appearing as sharply defined cubes, knowledge spaces can alter their outline and orientation in response to fluctuating external and internal forces. They may change shape or direction, they may divide or combine, they may suddenly disappear. These spaces are situated within social, political, economic and cultural landscapes that create a range of external pressures, the divergent orientations and expectations of participants in knowledge spaces exert pressures from within.

1.5.10 Some participants have demonstrated how perspectives drawn from social theory can be used reflexively to support and inform practice. Reflection can stimulate thought about what participants want from their involvement and what is wanted by others; lay participants, professional researchers and clinicians. This frames effective knowledge spaces as fields of communicative action, orientated towards achieving understanding. They offer opportunities for the exploration and mediation of different requirements and attitudes. Approaching these spaces purely instrumentally is to miss the point, and may be counterproductive. Becoming more aware of the baggage we carry with us into them can help to enable more effective participation; participation that better addresses and respects the needs of all.

1.5.11 The dialogue between study data and theoretical perspectives is developed through all of the chapters. Some utilise study data more thematically whereas other chapters draw heavily on narratives. Thematic data, supporting issues discussed, is included in appendices 10-12. Narrative data and other longer illustrative quotations from study participants are presented throughout in boxes, listed overleaf. In these, text from interview transcripts and diary entries has been edited in order to remove identifiers, repetitions and stumbles, as well as for brevity. The order in which the statements in the stories were made has not been altered.

1.5.12 Where longer pieces of text have been removed for the sake of brevity this is indicated with three dots ... Where a word or phrase has been

added for clarity or substituted to ensure confidentiality this is placed in square brackets [for example].

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## 2. Narratives, themes and threads

*Our concern is not to analyse logically the content of an idea formulated beforehand. Such conceptual expositions are rightly held to be futile.*

*Durkheim*<sup>9</sup>

### 2.1 Introduction

2.1.1 This chapter outlines the research question, as well as the epistemological, ethical and practical assumptions of this study. That is, it describes the purpose of the study, makes a claim about how it contributes to knowledge, and explains what values lie beneath that claim. It also describes how these elements have shaped the methods chosen to conduct the study; and then goes on to lay out those methods in some detail.

2.1.2 The research question being addressed in this study is:

**What motivates and sustains patient and public involvement from the perspective of lay participants?**

The intention behind this question has been to describe a conceptual framework that can enrich the understanding of involvement, as it appears from the inside, and so inform practice. In order to address this I have sought to identify:

- why people become and remain involved in health research
- what barriers and difficulties they encounter
- what causes them to disengage
- how involvement impacts on individual narratives and sense of identity

2.1.3 The conceptual framework that has been increasingly influential is that of 'knowledge spaces' (Elliot and Williams 2008, Gibson, Britten and Lynch 2012). In the interrogation of this framework I have used a wide range of theoretical perspectives, juxtaposed with individual understandings and narratives. There is not a specific hypothesis that is being tested against the data, unless 'access to social theory provides useful ways to view social interactions and to draw lessons from them' can be considered a hypothesis. : Two specific questions were held in mind when looking at theoretical approaches:

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<sup>9</sup> Durkheim [1903]1982 pp 175-176



- How might patient and public involvement in health research and care be explained or modelled using this theoretical approach?
- How would a participant's description of their activities be shaped by the implicit or explicit adoption of this perspective?

2.1.4 In exploring this, the study has used mixed, but largely qualitative, methods to explore participant perspectives on patient and public involvement in health research, and to place these in the context of theories drawn from a range of social sciences. The data from study participants has been juxtaposed with theoretical models. Insights they provide have been drawn out and followed up by referring back to theoretical and historical literature. In order to achieve this, the first stage of the study involved a broad sweeping search of theoretical literature to identify how different theoretical lenses might be used to view involvement in health research and how these might inform different aspects of the study. This was particularly intended to sensitise me to a wide range of different potential theoretical approaches. It resulted in further work on how these theoretical models could be presented creatively and practically; in order to encourage participants to engage with, and critique, what are often quite abstract concepts. This process will be described in more detail in chapter 3.

2.1.5 A survey with questions requesting either multiple choice or free text responses provided some numerical data with which to describe the study sample as well as initial qualitative data to address motivations, costs and benefits of involvement. Vitally, respondents to the survey also formed the basis of a sample frame from which to choose interview participants.

2.1.6 Semi-structured interviews were conducted either face to face or over the telephone. They utilised a topic framework which was shared with participants in advance (appendix 3). However participants were encouraged to tell their own story in their own way, rather than simply responding to the interviewer's questions. The topic framework was used as a checklist to ensure that basic background information was gathered on what sort of involvement activities people had taken part in.

2.1.7 Some participants provided additional information following the interview. This included emails, raising issues they had thought of subsequent to the interview, or suggesting other potential interviewees. Some sent

documents they had referred to during the interview, including CVs; one sent a pamphlet she had co-authored with a healthcare professional and an academic; and one sent references to a book she had written, about the healthcare experiences that prompted her involvement. Several also sent reflections on the transcripts of their interview; including, how the process of being interviewed influenced reflections on their involvement, and on the particular conditions they were dealing with. Three participants also provided records of specific patient and public involvement activities over a period of a few weeks, using log and reflective diary template provided (appendix 4), and one added a reflective photo-diary of a journey he undertook to attend a meeting.

2.1.8 Members of PenPIG, the public involvement group for the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula (PenCLAHRC), some of whom were survey and/or interview participants in this study, were invited to become public involvement contributors. This was fitting as the idea for the study was developed through my participation as a member of PenPIG. The members of PenPIG as well as academic colleagues were invited to attend a presentation I delivered as part of the examination leading to the transfer of my study from an MA to a PhD programme. Some provided written or verbal feedback on how the theoretical perspectives were being applied to the survey data. Members of PenPIG had other opportunities to comment on the conduct of the study through an online forum, email consultations and by taking part in workshops where initial data analysis and the use of social theories applied to involvement in health research were presented in a variety of forms. These discussions have played an important role in the validation and interrogation of the data, as well as the coherence of my use of theoretical approaches.

2.1.9 Another important source of data for this study has been reflections on my own experiences as a participant in patient and public involvement roles in health research. In order to frame this and make the reasons for it clear to the reader, the second section of this chapter contains a good deal of personal biographical information. This is, in part, to describe and make explicit my position as an insider researcher, though it also problematises that position, showing some of the ambiguities and tensions it provokes. This section also is intended to introduce the concept of the importance of personal

and biographical narratives in the field of patient and public involvement. This is something that will be explored more fully in chapter 6.

2.1.10 The third section of this chapter looks at the implications this approach has in both ethical and practical terms. This means examining how my reasons for undertaking this study have influenced the shape of the study, how it has been conducted and how the results have been presented. This naturally leads to the fourth section which looks at the epistemological issues (understandings of what constitutes knowledge) that underpin the approach I have taken, and my understanding of what truth it can claim to describe.

2.1.11 The fifth section describes the qualitative methodologies used in this study. This includes how potential study participants were identified, contacted and invited to take part, addressing the difficulties involved in sampling a poorly defined population that could largely only be contacted through intermediaries. It will explain why particular techniques were chosen to help overcome these difficulties and will look at how that has impacted on what inferences can be drawn from the data gathered. In the final section I discuss how data was managed and analysed.

## **2.2 Biographical background**

2.2.1 This study continues my own personal research and professional practice in community empowerment, as well as patient and public involvement. This is an important statement, because it declares my perspective, not only in relation to the subject of the research, but also in relation to research participants. This interest has not only shaped my approach to the subject, the methodologies I have chosen to study it, and how I have approached the analysis of the data I found; it has also shaped the sort of interactions I have been able to have with the participants in the study. This is because: 'the research relationship... remains, whatever one does, a *social relationship*' (Bourdieu 1999 p608). In this case, my relationship with the people who have participated in the study is not only that of researcher/study participant, but also that of fellow participants in patient and public involvement roles. What one participant, Thomas, described as 'one of us'. This status has been extremely useful in affording me access to participants through involvement networks; although it has also presented me with some challenges.

2.2.2 For Bourdieu, the value of researchers sharing social and cultural characteristics with research participants was not only about providing privileged access, it was also a means of avoiding the infliction of symbolic violence, by using inappropriately stark or rigid questioning, or using of language in a way associated with an 'other' social group; particularly one with different levels or types of power and authority. At the same time, the researcher needs to break from the common sense understandings they share with participants and adopt a position of 'radical doubt' (Bourdieu 1992. p235). This allows them to take a step outside the assumptions and expectations they may have of their encounters as a 'social being' (Bourdieu 1992. p235).

2.2.3 Yet, within the context of this study the role of insider/outsider is not straightforward. The disparate nature of patient and public involvement activities, and the people who take part in them, adds further fields of complexity. This means that while being an insider to involvement I might still be seen as socially 'other' in terms of social class or stigmatised group. This makes it all the more vital for me to adopt a reflexive approach; an approach in which 'the researcher' appears as an active voice in the data rather than a wholly objective narrator.

2.2.4 Being a postgraduate student is in itself a role imbued with cultural and symbolic capital, something that promotes trust in some participants and suspicion in others. Revealing some shared experience of service use, some common social networks or educational encounters can help to support insider status. Nevertheless, divisions within involvement, and sometimes subtle but delicate political currents, can mean that shared networks can also prompt questions about allegiances and conflicts.

2.2.5 Furthermore it is important that disclosure is balanced with the bracketing of views and opinions that might effectively silence a participant who held a different view. This means holding back what might be deeply held views on how things should be done, and utilising professional skills to maintain a non-judgemental, open stance while listening to participants' accounts. Therefore the presentation of different aspects of the self can be either a potential aid, or a potential barrier to eliciting information from participants. So

this can also impact on the credibility of any truth claim contained in the analysis of research findings.

2.2.6 Discussion with others, whose identities also span the division between researchers and patient and public involvement activists, has greatly enriched and informed my approach to this study<sup>10</sup>. It has helped me to utilise the ambiguity of status creatively, and emboldened me to use the telling and retelling of my own story of involvement in a number of different arenas<sup>11</sup>. Sometimes this has been about uncovering and explaining my distinct perspective and approach to other academic researchers, at other times it has been about acknowledging and reciprocating for the stories that participants have shared with me. The detail and emphasis of the story has changed each time according to context, audience and the vicissitude of memory. What follows is a considered and, hopefully, lucid version of that story, intended to combine some of the most important elements of these re-tellings and to clarify the background to my personal ethical approach to this subject. Different, and perhaps conflicting, aspects will be drawn upon to illustrate issues arising throughout the following chapters.

2.2.7 The roots of my involvement are as a participant and an activist. These roles are firmly based in ethical values learned in childhood and developed through political engagement. Coming from a large family in the south east of England in which both parents worked, I absorbed an ethos that valued taking some responsibility for self-care, and for fostering the wellbeing of others. During a large part of my childhood my mother was employed as a home help. During school holidays she would take my brother and I to run errands for the largely elderly people for whom she provided care. We were also encouraged to volunteer at the jumble sales and coffee mornings she helped to run for the Red Cross and other local groups. From this involvement I not only learned how to interact with a range of people with different backgrounds, experiences and abilities, I also learned that it was possible and appropriate for me to take action to make beneficial changes in the world. I was

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<sup>10</sup> In this I am particularly indebted to Rosie Davies, Josephine Ocloo and Jo Welsman

<sup>11</sup> For example see digital story on accompanying USB stick

not just an observer or a recipient of the care of others; I was co-creator and part of a dynamic exchange of information, services and goods.

2.2.8 This was not an attitude that I, as a child, found completely compatible with school. Frequently, and largely inadvertently, I came in conflict with the expectations of teachers and became progressively more withdrawn from school as a place of learning. Increasingly through secondary school I truanted from lessons and eventually also from exams, leaving without qualifications.

2.2.9 After moving to live with an older sibling, in what was a much more socially diverse inner-city area, I became involved in community arts and agitprop theatre. This involvement gave an explicitly political context to community activism, highlighting for me the wider social implications of access to resources and influence.

2.2.10 In 1979 I became the single parent of a chronically ill child. For the next twenty years this produced frequent and protracted contacts with health and social service providers. From the beginning I found that these services were routinely mechanical and disempowering for parents, and that this was particularly so for single parents from poor neighbourhoods. I was in my early twenties, though I looked much younger, and I gained a strong impression that many professionals viewed me as more of a threat to my son's wellbeing than as his carer and protector.

2.2.11 This was brought home to me forcefully when he was three weeks old and I requested to be present during his medical treatment. Medical staff threatened to begin care proceedings unless I left the room, and I was advised by a lawyer that I would be likely to lose custody if I was seen by a court as questioning or ignoring the judgement of health care professionals. The welfare machine seemed to be specifically designed to strip me of choice and control. Although I became much more skilled at navigating these systems, this was far from the last time that medical and social care staff took deliberate action to undermine, infantilise and disempower me as a parent.

2.2.12 I came to see that this disempowerment was rarely intentional. Most often it came about because those working within the system were trying

to prevent their own uncertainty and vulnerabilities from being exposed. Over the next two decades, with the support of some enlightened professionals and many other struggling families, I became skilled in researching, negotiating and managing the best care outcomes for my child and for my family. With the development of networks that connected people in similar circumstances, we were able to make significant breakthroughs in influencing the design and administration of services, while also tackling the social isolation of many chronically sick children and their families.

2.2.13 My role as a carer ended first, for a short while, after my son received a life transforming operation aged seventeen. Although I returned to that role when his health again deteriorated, it ended completely following his death, just before his twentieth birthday. At that time I determined to formalise the skills I had gained in negotiating his care, and make use of them to influence the design of future services as well as the training of the professionals who populate them.

2.2.14 When I first began academic studies I applied to the Elmgrant Trust<sup>12</sup> for a grant, to pay for childcare while I attend an Access to Higher Education course. These grants were intended to help people to change career, and the criteria for awarding them focused on how the award would contribute to the achievement of future goals. The sociologist and social activist Lord Young of Dartington led the interview panel for this. He commented that I was proposing to train for a job that did not exist, but that perhaps it ought to.

2.2.15 My first degree was interdisciplinary, giving access to a wide range of theoretical approaches. The study of the historical roots of social theories and political ideologies was particularly influential in reframing the understanding of my own experiences. This helped me to see how access to a variety of theoretical lenses through which to scrutinize personal experiences could provide a powerful tool for helping to communicate them, and to influence future practice.

2.2.16 The examination for that degree included a dissertation. Mine focussed on the changing nature of the relationships between health care

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<sup>12</sup> <http://www.elmgrant.org.uk/> (accessed 03/05/14)

professionals and the increasingly expert carers of patients with chronic illness. While it was useful for me to undertake this piece of work, it was also extremely painful to complete. I realised that my intention of working with professionals and service users in the health service would be better postponed, until time had helped to create a more distanced, and practical, perspective on my experiences. This led me to focus my work for the next few years on community involvement in national and local government regeneration initiatives, rather than in health services and research.

2.2.17 From 2004-5 I began to take a more active role in patient and public involvement forums. Jobs like those I aspired to in my discussions with Lord Young started to exist and I was able to build a portfolio of professional and voluntary involvement. I have worked with National Institute for Health Research Funding programmes, the General Medical Council, local health service providers and since 2009 the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula (PenCLAHRC). Increasingly, as I had hoped, both my professional work and my role as an activist have become focused enabling others to make their voices heard, and encouraging professionals and policy makers to listen to them. By combining social activism with academic study I have not only been able to help to push open the door of the treatment room that was so firmly closed to parents in the 1970s, I have also been able to contribute to making the arenas where priorities are set, research questions are asked and policies are designed more open to others.

2.2.18 In 2009 I completed an MA in the Sociology and Philosophy of Culture. Part of that study (Maguire unpublished) looked at what motivates lay involvement in civic governance and in NIHR funding panels. This involved assessing and theorising experiences of involvement from a participant perspective. By utilising, as well as academic theories, my own experiences and the understandings gained through close, often raw, contact with other families and professionals in hospitals and social service settings, I found, as a colleague in a patient and public forum stated: 'this...helped me to move forward in life after caring'.



2.2.19 This feeling of moving forward by combining academic study with activism does not only arise through its power to validate my own journey; it is also about acknowledging the debts owe to those many individuals who helped me on the way. For instance, in the days before the internet, a young doctor sent me photocopied articles from a medical journal in order to strengthen my argument for more of my son's care to be carried out at home. Equally I am indebted to Danny, a hulking teenager with a debilitating brain tumour, who put his arm round me and asked 'Are you alright mate?' on a particularly bad day almost fifteen years ago. By using these experiences to help improve services, and helping others to get their voices heard, I am able to feel that I am 'putting something back'. This is in partial payment for what I have received from these individuals, and from many unknown others, through the work, knowledge and resources they contributed to the medical services and welfare system that supported my family, however imperfectly. The role has been personally empowering and validating. It has also led me to see the usually well intentioned, if sometimes fallible, human actors behind the welfare state machine at all levels and to engage with them in improving the system for the benefit of all. It is a 'gift' (Mauss [1925] 1966) that I am able to contribute, one that imperfectly and asymmetrically corresponds to the many gifts I receive from others.

2.2.20 This is a genuine attempt to present an accurate, useful and emotionally honest account of what brought me to the position from which I undertook this study, and from which I am writing this thesis. Clearly it is partial, in terms of being both incomplete and biased. It is not possible to tell all and in choosing what to tell I have both consciously and, in all probability, unconsciously chosen which aspects of my journey to highlight. In a presentation of over fifty years of life experience in 1,500 words this process is apparent. Though I am unaware of any research process where there is no filtering, in one way or another. The following sections will discuss the implications of this understanding of research.

### **2.3 Ethical and practical implications**

2.3.1 The experiences and understandings, described above, are what have led me to approach this study from an explicitly ethical perspective. This perspective holds knowledge to be a socially produced good, and therefore to

be socially owned. Clinical and academic researchers are able to produce their work because the functional prerequisites of this are fulfilled by a social and economic infrastructure that includes: cleaners, carers, taxi drivers, train drivers, fire-fighters and footballers. The value of patient and public involvement in the scoping and governance of health services and research is therefore not something that I have sought to prove or demonstrate. It is assumed on the basis that this involvement makes the social production and ownership of that knowledge explicit; promoting a broader and more inclusive debate about what the ends of research should be, and what means should be utilised to achieve those ends.

2.3.2 I present this as an *ethical* rather than an *epistemological* or an *ontological* stance; that is I am treating it as an issue that arises from how I believe I *should* behave rather than one that is about what I *can know* or what *really is*. This is because my argument rests on insights from the field of feminist ethics and particularly on the work of the psychologist and ethicist Carol Gilligan and the philosopher Eva Feder Kittay. In her paper 'Moral Orientation and Moral Development', originally written in 1987, Gilligan described care as a framework for moral decisions that is 'grounded in the assumption that self and others are interdependent, an assumption reflected in a view of action as responsive and therefore arising in relationship rather than the view of action emanating from within the self' ([1987] 1995, p36).

2.3.3 The view of society as being based on interrelatedness rather than individuals is not unique to feminist ethicists. Socrates (c469-399 BC) is said to have argued that human community arises from mutual need and the division of labour (Plato [c380BC]1955 pp102-103), whereas Aristotle quoted a much older Greek tradition that claimed their city states were based on groups 'suckled with the same milk' ([c330BC]1996a, p12). Yet the predominant image used to describe modern states has been that of an association of autonomous individuals, often explicitly defined as male.

2.3.4 In the 17<sup>th</sup> century Thomas Hobbes argued that we form societies because, in a state of nature, there is so little 'difference between man and man... the weakest has strength enough to kill the strongest, either by secret machination, or by confederacy with others' (Hobbes [1651]1996, p87), making

it vital to appoint a law giver to protect and to punish. For Hobbes the individual has a natural right to everything, a right which needs to be tempered in order to achieve peaceful coexistence (Hobbes [1651]1996, pp91-92). By contrast, for John Locke the foundational right is that of self-ownership and by projection the investment of the labour of the individual's body in the natural world creates a right of property over the products of that labour (Locke [1689] 1823, p116).

2.3.5 Clearly for both these thinkers, and many others who have followed in the tradition of social contract theories, whether the characteristics of individuals in a state of nature are seen as destructive or productive they are always those of adult, relatively healthy and able men: Man. Man, because he is crafted in the image of men, does not need to be suckled or to receive care, nor does he imagine his body containing, producing or hormonally driven to care for and maintain another. This is the independent Man of Rousseau ([1762] 2008): 'L'homme est né libre' (Man is born free); it is also the image of the autonomous contractors behind the 'veil of ignorance' in 'A Theory of Justice' (Rawls [1971] 1999, p11).

2.3.6 The concept of this autonomy as providing the foundation for economics and therefore for society was judged by Marx as an 'inanity' (Marx [1858] 1996 p129). He argued that the human being 'is in the most literal sense a zoon politikon [political animal] not only a sociable animal, but an animal which can individuate itself only in society' (Marx [1858] 1996 p129). In spite of these insights and the empirical evidence that 'people do not spring up from the soil like mushrooms' (Kittay et al 2005, p443), the free and solitary Man is an image that has become widely conflated, combined and confused with what it is to be a human being,

2.3.7 Kittay has argued that traditional epistemology, the theory of knowledge, has become distorted by its 'detached, universalizing, and controlling approach to knowledge' because it rests on this image of an 'isolated knower' (Kittay et al 2001, vii). She sees the adoption of the atomistic understanding of what it is to be a knowing hu-Man being as unsatisfying, unconvincing and alienating to women. A product of this alienation can be seen in Luce Irigaray's description of a psychological and cultural phenomenon in

which '[a] man minus the possibility of (re)presenting oneself as a man = a normal woman' (1985, p27).

2.3.8 This conception of the 'other' being less than the ideal of the autonomous self-maintaining man has been utilised in the field of disability studies: '[t]o be a carer or cared for – male or female, disabled or non-disabled in either role – is to be found wanting, to be other in relation to the masculine subject of modernity' (Hughes et al 2005, p265). This argument highlights that it is not only in infancy that we require care and nurturing. We need support and care throughout our lives, during periods of sickness, injury, or impairment. Also, as in my own story (2.2 above), while we are devoting our time to the care of another we are in need of others to provide us with the support and care we are not able to dedicate to ourselves.

2.3.9 In fact 'within complex industrial societies, no citizen is truly self-supporting; all depend on others to satisfy the most basic needs' (Kittay 2001 p539). While studying for my first degree I received a small grant from the local authority to help support my youngest son. I was acutely aware that this came from taxes paid by my neighbours. These tax payers included a close friend who worked for low wages in a care home. While I am certain she cared for her charges with affection, diligence and respect, it was work that she found personally distressing and repugnant. It was distressing because she was daily faced with her own fears of becoming lonely, incapacitated and dependant on strangers, repugnant because it involved dealing with other people's dribble and excrement, in a society in which 'one is expected to be autonomous in relation to the management of one's corporeal waste' (Hughes et al 2005, p266). I vividly remember one afternoon sitting in the sunshine, my son safely in a nursery and a work of political philosophy on my knee, sending up a silent thanks to my friend and the many others who were doing the work which was necessary to enable me to have the time to think, read and write about what it is to be human.

2.3.10 This continuing awareness of how my personal, intellectual and professional development has only been possible because of the, often distasteful or painful, efforts of others is not something I have widely encountered in academia, or amongst healthcare professionals. Public funding

for research or services seems to be only rarely connected conceptually with the labour of others. The capacity to work in these fields is hardly ever linked with the work done to maintain roads and railways or to empty the bins, except in a negative sense when these tasks are not successfully completed. The contributions of 'others', and the dependency of academics and professionals on them, seems largely obscured by the self-image of autonomous hu-Man actors, the objective and 'isolated knower'. A valid purpose for public involvement in health research and care is, then, to explicitly highlight these underlying dependencies and contributions. This could enable more fruitful exchanges about the goals of human effort as well as the sharing of benefits and glory more equitably.

2.3.11 This argument also connects my claims for the ethical value of involvement to the politics of diversity. Nancy Fraser (1995) has outlined two dimensions in which groups can be disadvantaged, the first is in terms of economic power and the second is in the value status they are afforded culturally. In the context of health research and care patients and care givers can be seen as a group that is disadvantaged in both these dimensions. Clearly this is not an absolute, some patients and care givers may themselves be professionals, or wealthy, or both, although even the rich or the skilled professional can be disempowered through incapacity.

2.3.12 Nonetheless the exclusion of patient and public voices from the prioritisation and conduct of health research and care has sometimes led to serious and damaging disconnections between what is knowable, and those it is purported to be known about. The dangers of this include the possibility of creating a disconnected elite that comes to define 'itself as the sole possessor of a set of properties, properties which, in turn, define it and which give members of the group, as the possessors of those properties, the authority to appropriate goods, power, and other privileges' (Kittay 2005, p121). For this reason if no other I believe that the social nature of the production of knowledge should be made manifest as an ethical imperative and that, in order to facilitate and enable that manifestation, many and different voices need to be heard and heeded.

2.3.13 It is for these reasons the participants in this study were asked to identify what facilitates their involvement and what inhibits it, as addressing these questions can help to broaden that explicit social ownership of research. How involvement impacts the conduct and outcomes of research is treated as an issue only in as much as this influences the experiences and expectations of participants.

2.3.14 This ethical position has not only informed the conduct and analysis of the study but also the presentation of findings and the nature of outputs. In addition to applying academic rigour, it has been important to discuss processes and ideas with participants and others involved in patient and public involvement. This leads to an iterative research process which is helpful in raising additional questions and guiding sampling as well as validating data.

2.3.15 The presentation of findings in ways that are useful and accessible to participants and potential participants in patient and public involvement roles is also intrinsic to this approach. Outputs are intended to help make theoretical frameworks and conceptual tools, which were useful to me in analysing and discussing the data, available to people thinking about health research, giving them an opportunity to make better informed decisions about their own involvement. This again acknowledges the roles that others have played in making this study possible, both directly through the generous sharing of their time and their stories, and indirectly through performing the myriad of everyday jobs that have supported me while undertaking this work.

2.3.16 Other practical implications of this approach include being responsive to the views of participants on methodological and presentational issues. A willingness to substantially redesign parts of the study in response to the views of participants could perhaps be interpreted as falling onto the dangerous ground of 'romanticising' the accounts of respondents (Atkinson, 1997). The perspectives of participants in the knowledge spaces created through involvement in health and social care research, however, is central to this study, so the risk seems justified. By including a sample of participants involved in as diverse a range of involvement activities as possible, and by discussing issues they raised with academic and public involvement colleagues,

I have sought to be receptive to important methodological questions, without allowing the study either to be captured by any particular interest, or to become paralysed by conflicting demands.

2.3.17 Therefore when participants express the view that analysis of data thematically and 'line by line' (Walker and Myrick 2006, p551) can feel reductive and alienating, this needs to be taken seriously. As one participant put it: 'sometimes what I find is ... getting a researcher to tell snippets of a patient's story is second hand, you can't get a true picture... get their stories out there first hand and then you can draw evidence from that and that's a much bigger wealth of knowledge rather than just a few snippets of a sentence.' While acknowledging the irony of using this particular quotation in this way, it does illustrate a view that led me to reflect on whether thematic analysis of the data would be appropriate and sufficient in this study.

2.3.18 What participants seem to be suggesting is that thematic analysis can take their words 'outside a particular language-game' (Wittgenstein [1953] 1998, p22) and can therefore lose or alter meaning. However as acknowledged earlier (2.2) the detail and emphasis of my own story has altered with between tellings and audiences; with each version presenting or masking different aspects of myself or my experience. It is therefore important to interrogate the narrative process and its potential to describe truths, or at least to describe some useful knowledge.

## **2.4 Epistemological implications**

2.4.1 This concern about the potential for our stories to represent external reality could lead deep into the boggy ground of relativism. This is a philosophical position which asserts that propositions cannot have an absolute truth value but may only be said to be true from a particular standpoint (McAllister 200, p405). In Derrida's 'textualism' this leads to the denial of a relationship between language and external reality: 'there is nothing outside the text' (1976 p58). Bauman has described this as the 'all-eroding, all dissolving destructiveness' (1992 ppvii-viii) of a postmodernity which focuses on the annihilation of what has been while proposing nothing to replace it.

2.4.2 Postmodernism has been called the 'code name for the crisis of confidence in Western conceptual systems' (Lather 1991, p159). It is a term that

has been used to encompass a wide range of ideas. Lyotard (1984) argued postmodernism is characterised by a loss of faith in the grand meta-narratives, the big theories of everything. Some postmodern thinkers have questioned the ability of both the natural and social sciences to produce any objective information about the way the world is. They see 'scientific knowledge' as a situated and potentially coercive term; that is a powerful standpoint that can disguise inequalities rather than objective method of discovering the truth. This highlights a particularly serious difficulty within the study of society, because the subject of the research is made up of individual people who hold beliefs and values. This means that theories produced by social science may influence the behaviour and beliefs of those it is studying.

2.4.3 An influential thinker on these issues was Michel Foucault (1926-1984). He emphasises the use of discourse, ways of talking and thinking about the world, to 'analyse diverse configurations of assumptions, categories, logics, claims and modes of articulation' (Miller 1997 p32). Where in Derrida's textualism, there is a danger of sliding into nihilist reductionism, a position where everything is equally true and equally lacking in any meaning, Foucault developed the Nietzschean concept of knowledge/power, and so sought to uncover how 'truth' is constituted as a relationship between power and knowledge (Alvesson and Sköldbberg 2010, pp250-254). This places texts and the discourses in which they are conducted into the context of the tensions between social structures and individual agency; the limitations society imposes, the opportunities it affords, and choices people make within that. For Foucault 'power is not exercised simply as an obligation or a prohibition on those who "do not have it"; it invests them, is transmitted by them and through them; it exerts pressure upon them, just as they themselves, in their struggle against it, resist the grip it has on them.' (Foucault [1975] 1995, p27)

2.4.4 These postmodernist and poststructuralist European philosophical traditions have been criticised by the American academic Noam Chomsky as atheoretical or facile posturing.<sup>13</sup> In particular he has argued that in poststructuralist thought as developed by Lacan and Žižek he was not able to

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<sup>13</sup> Sociological Imagination 2013, <http://sociologicalimagination.org/archives/13725> (accessed 03/05/14)



find: 'principles from which you can deduce conclusions, empirically testable propositions where it all goes beyond the level of something you can explain in five minutes to a twelve-year-old.'<sup>14</sup> This criticism implies a surprisingly positivist conception of the role of theory.

2.4.5 Positivism is the philosophical position which holds that 'constant relations of similarity and succession' (Comte [1825] 1998, p153) constitute laws which may be accessible through systematic empirical study. This is a weaker claim than had been made previously by naturalism, which sought to directly describe relationships of causation, but it still aimed to produce theory that could be used as a predictive tool. The empirical study of sociology as a positive science was developed by Emile Durkheim. He wrote of sociology that: '...like every positive science, it has as its object the explanation of some actual reality which is near us, and which consequently is capable of affecting our ideas and acts...' ([1915] 1976, p1). Durkheim saw social roles, institutions and conventions as 'social facts' ([1895]1982, pp50-59). He described these as 'types of behaviour and thinking external to the individual, but they are endowed with a compelling and coercive power by virtue of which, whether he wishes it or not, they impose themselves upon him' ([1895]1982, p51).

2.4.6 Durkheim argued that the imposition of a constraining power over human action, by these social facts, demonstrated that they express a nature different from that of the actor, and so do not derive from individual consciousness, showing sociology to be a distinct science with specific legitimate fields of study. Social psychology studies of group influence have shown a tendency of individuals to modify their own judgement or perception to bring it in line with that of others (Sherif & Sherif 1969, Asch 1956). This would seem to support the idea of social facts.

2.4.7 However Wittgenstein's philosophy of the mind, as developed in *Philosophical Investigations* ([1953]1998), suggests that the logical linkage between desires or beliefs and actions may be better described as the learning of rules rather than as the actions of laws. This would imply that, in social sciences, the positivist concept of laws may become sterile and misleading.

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<sup>14</sup> Sociological Imagination 2013, <http://sociologicalimagination.org/archives/13725> (accessed 03/05/14)

This is because what positivists imagine to be laws, external to the people concerned and so best investigated through observing what happens to them, are in fact rules, which people have learned in a particular social setting, and so can be better clarified through asking those people relevant questions.

2.4.8 In order to escape both the potentially reductive circle of relativism and the rigidity of empiricism, in this study I have adopted an explicitly reflexive approach. This uses theories as tools for thinking about experiences, ideologies and social relations, rather than as a means of producing predictions or experimentally testable propositions. Although, the provision of meaning that helps us steer future action is still 'irretrievably implied' (Dewey [1916] 2012, p368) in the concept of knowledge.

2.4.9 This, explicitly practical, approach to using social theory, arises from my own experience of the value of learning about social sciences as an adult. The impact of this learning was to deepen personal reflections and to capture glimpses of how my own actions, and those of others, might look from different perspectives. The approach is intended to be, as Žižek terms it, 'inclusive of respect for empirical data'<sup>15</sup> but it is not intended to produce 'laws' that explain and predict the activity and outcomes of patient and public involvement. It is, however, intended to enable thought and discussion about alternate futures, and what might be needed to either enable or avoid them.

2.4.10 Drawing on insights from Alvesson and Sköldberg (2009) I have used layers of analysis, circling and interrogating the data, employing both theoretical and practical knowledge. This methodology uses a process of abduction, that is approaching experiences through a combination of deduction, where theoretical understandings are used to comprehend the data, and induction where that experience is used to further develop the theory. Rather than approaching data with the intention to test a particular theory or with no theory at all, the intention is to act as a 'theoretical agnostic' (Henwood and Pidgeon 2003). This means that 'unanticipated and surprising observations are strategic in the sense that they depend on a theoretically sensitized observer

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<sup>15</sup> Sociological Imagination 2013, <http://sociologicalimagination.org/archives/13725> (accessed 03/05/14)

who recognizes their potential relevance' (Timmermans and Tavory 2012, p173).

2.4.11 On the other hand, in my experience as an insider researcher, this has sometimes been reversed. Things in the data that made me impatient to move on; or an insistence by participants to talk about issues I felt were irrelevant or tedious; these were often signals that I perhaps needed to reflect further on what was being said, and why it provoked these reactions in me. At the viva examination I undertook, in order to transfer this study from an MA to a PhD programme, one of the examiners cautioned me that it would be wasteful if I could have answered some of my questions without undertaking the study. In retrospect, I can see that I might well have been able to predict some of the things participants told me, but without the reflections these assumptions provoked, and the dynamic interaction between data, theory and practice, I would not have been able understand any of these elements in the same way.

2.4.12 Important criteria for a theory in this context are that it is applicable in practice, and that it can 'give the practitioner understanding and some control of situations' (Glaser and Strauss, 2012 p3). This is a proposition that, like the abductive methodology, is drawn from Pragmatism, a philosophy developed in 19th century America, which holds that utility, in practical empirical conditions, is a criterion of truth and knowledge. This approach enables the use of both narrative and thematic approaches, using each to deepen and strengthen insights, which is in line with the study's goals (2.1.2-3), as it supports the gathering and ordering of a range of participant perspectives on the experience of involvement in health research knowledge spaces. It also allows me to explore how the knowledge space model itself can be useful. The purpose of using this approach is to be able to inform the practice of involvement in health research, not just to describe it.

2.4.13 The movement between these theoretical and practical, empirical approaches enables the development of a rich and complex picture of involvement. This has been used to inform and strengthen the development of a conceptual framework of the knowledge spaces created by involvement from the perspectives of lay participants in health and social care research, and the

role of theoretical perspectives within this. The next section will discuss the practical challenges and how they have been addressed.

## **2.5 Research methodology**

### **2.5.1 Exploration of the theoretical literature**

2.5.1.1 The identification, and exploration, of theoretical perspectives as applied to patient and public involvement in health research is a key element of this study. Therefore it began with a review of social theory literature. Although this process will be addressed more fully in chapter 3, it is important to state at this point that the purpose of that literature review was not to identify an approach, or even several approaches, that would then be used to create hypotheses to be tested against the empirical data collected through the rest of the study. On the contrary, its purpose was to ensure my mind was open to a wide range of theoretical approaches, and to explore which of these might be being implicitly, or explicitly, used by study participants in their own understandings of involvement; or how other approaches, that they did not employ, might be useful in helping to shine different lights on the data collected.

2.5.1.2 The review looked widely across theoretical literature in the fields of sociology, social psychology, social anthropology, political philosophy and the philosophy of science. Clearly, given the breadth of this literature, detailed and meticulous study would be more than a life's work and so again a pragmatic approach was taken. I started with theoretical approaches that were being used in the sociology of health and illness, identified in text books, journals and anthologies; I then discussed these with experts in the field and with fellow participants in patient and public involvement groups and activities. I created summaries of different approaches and how I saw these being applied to public involvement in health research and care.

2.5.1.3 In this study, because I am particularly interested in how an access to social theory can provide useful ways to view social interactions and to draw lessons from them, the literature review was not an entirely discrete element. In order to facilitate different ways of approaching, describing and discussing theories I began to create first pictorial and then tactile three dimensional models of how they could be applied to public involvement or sometimes how I could present my own narrative through the lens of a particular theory. These models continued to develop throughout the project

and came to include a range of stories and games that have been used as tools to help present and explore the application of these approaches with academics and public involvement contributors. Some of these will be referred to in the following sections of this chapter but they are explored in more detail in chapter 3, sections 3-4.

2.5.1.4 The models were displayed at the Peninsula College of Medicine and Dentistry Postgraduate conference, PenPIG, the British Sociological Association Medical Sociology conference and the INVOLVE conference in 2012; an ESRC funded seminar on 'Knowledge spaces and public social science', the British Sociological Association conference, a workshop run by the Health Experiences Research Group at the University of Oxford and the New Developments in Public Involvement Research conference in Exeter in 2013; One result of this, as well as fruitful discussions of the approaches I initially identified, has been for others to suggest theories that could be illustrated and explored in similar ways, or historical examples that helped to elucidate a perspective. This has sent me back to the literature often, throughout the study.

## **2.5.2 Sampling and recruitment**

2.5.2.1 Initially identifying participants was a challenge; there is no central database of people involved in patient and public roles in health research, nor even a comprehensive list of activities that they undertake. Where databases do exist they have usually been put together by organisations for a particular purpose or project and there may be ethical and legal inhibitions on their access for any other reason.

2.5.2.2 As an 'insider researcher' I was in contact with a number of other participants and professionals in the field, so was aware of a wide range of activities that people are engaged in, but gaining access to them was not straightforward. In the summer of 2010, while writing the research proposal, I contacted professionals named as the involvement leads in a number of research institutions to ask how many people were involved with them in these roles. Few were able to give even an approximate answer immediately, and many were not able to answer at all. It became clear that, in many institutions, details of involvement had only been recorded within a particular project or department, if at all. Where there were records there was a lack of clarity about whether these were confidential.

2.5.2.3 It was also clear that those nominated as leading public involvement were often given very little time to devote to that part of their role. The responses received from some individuals seemed to indicate that the question had been received as an implied criticism, indicating that I would need to be sensitive when dealing with the professionals as well as the lay participants.

2.5.2.4 These difficulties were addressed by launching a survey which could be accessed online or in hard copy. It asked people about their involvement activities and included questions about whether they would be interested in taking further part in the study. Following ethical approval from the Peninsula College of Medicine and Dentistry Ethics Committee, the survey was distributed through networks maintained by the National Institute for Health Research in England, including INVOLVE (their advisory group that supports greater public involvement in NHS, public health and social care research), the nine Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), lay members of funding panels and people who provide lay reviews for funding applications. It was also sent to the involvement leads in 32 universities in England that were included on a list obtained from the Royal College of Nursing. Leaflets about the study were also distributed through contacts attending networking events held by patient groups.

2.5.2.5 The survey enabled me to gather contact details, both quantitative and qualitative information about the sort of things people were doing in their patient and public involvement roles, and some initial qualitative information about their motivation for involvement. However there was a strong possibility of sampling bias in the way the survey was conducted, given that I had no control over which of my contacts passed on the invitation, or how they decided whether or not to include particular participants in this. Therefore the information gathered through the survey was not sufficiently robust to draw any statistically significant inferences about the actual population of people involved in patient and public roles in health service research. What it did provide was some interesting data about a range of activities and motivations, as well as a vital sample frame for identifying potential interview participants.

2.5.2.6 I received 105 responses from the survey. 30 were eliminated as they did not wish to participate in further parts of the study. Two were eliminated because they were not living or working in England and five were eliminated as they were academics or clinical researchers involved in managing or working with lay participants. This produced a sample frame of 68. Of these 39 were female and 29 male.

2.5.2.7 From this sample frame I chose people to invite for interviews purposively, in order to include both a wide range of different activities and some individuals who were involved in the same activities. These characteristics are summarised in appendix 1. Those working in the same groups were included in order to be better able to examine whether differences in participants' experiences and understandings could be explained straightforwardly by the particular activities or organisations they were involved with, or whether their individual attributes were important factors. I also wanted to include some individuals who had ceased to be involved and some who had considered involvement but not yet taken part. To achieve these contacts I used the 'snowballing' technique of asking interviewees, colleagues and personal contacts to recommend other potential interviewees.

2.5.2.8 Some of the interview participants I had worked with closely, either in groups or on particular projects, others I had met infrequently at conferences or seminars, some were unknown to me prior to this study. Of those I did know I consciously included some who I had, in the past, found challenging to work with, as well as some with whom I had good working relationships.

### **2.5.3 Interviews and other data**

2.5.3.1 Invitations to take part in interviews were sent to 34 survey respondents, 20 female and 14 male. Four did not reply to the invitation, two agreed to be interviewed but did not respond to subsequent requests for an appointment, for three I was unable to set a mutually convenient appointment, two had to cancel and one did not attend or answer subsequent correspondence. Five people who had withdrawn from involvement were contacted, two of whom agreed to be interviewed, both female. Three people who had expressed an interest in involvement in health service research but

had not taken part in any activities also agreed to be interviewed, one male and two female. Two other participants were suggested by interviewees.

<b>Name</b>	<b>Sex</b>	<b>Age</b>	<b>Main involvement</b>	<b>Interview</b>
Abigail	F	40-49	universities, lecturing and advising	Face to face
Alan	M	Over 40	multiple and varied involvement	Face to face
Amy	F	Not given	service user research group	Telephone
Beth	F	50-60	charity, service user research project	Telephone
Cindy	F	40-49	attended workshop, supports partner	Face to face
Daisy	F	30-39	formerly involved in CLAHRC group	Telephone
David	M	70-79	CLAHRC group	Face to face
Dorothy	F	70-79	CLAHRC group and research network	Face to face
Edward	M	60-69	CLAHRC group and funding panel	Face to face
Elizabeth	F	Over 60	university network, s/user researcher	Face to face
Ellie	F	50-59	formerly service user researcher in NHS	Telephone
Eva	F	60-69	CLAHRC group	Telephone
Georgina	F	50-59	service user researcher	Face to face
Grace	F	60-69	university and CLAHRC groups	Face to face
Hannah	F	Not given	multiple and varied involvement	Face to face
Harriet	F	60-69	not currently involved	Face to face
Helen	F	40-49	CLAHRC group	Face to face
Hollie	F	Not given	service user researcher in NHS	Telephone
Isobel	F	80-89	NIHR RDS committee and lay reviewer	Telephone
Jennifer	F	Over 50	multiple and varied involvement	Face to face
John	M	50-59	CLAHRC group and research network	Face to face
Kate	F	50-59	Expert Patient, project steering group	Face to face
Kenneth	M	50-59	research network	Telephone
Linda	F	60-69	university	Face to face
Lotte	F	Over 70	multiple involvement, patient safety	Telephone
Nicole	F	50-59	CLAHRC group and research networks	Telephone
Oliver	M	40-49	medical College	Face to face
Phoebe	F	Not given	CLAHRC group and self-employed lecturing and advising	Face to face
Rosaline	F	70-79	service user research co-operative	Telephone
Ross	M	16-19	not currently involved	Face to face
Thomas	M	Over 50	CLAHRC group and lay reviewer for NIHR	Face to face



2.5.3.2 This gave an interview sample of 31, 23 female and 8 male. This included some people who had been involved in a large number of different ways over several years while some had been involved in one or two activities. One interviewee, as well as having taken part in a workshop themselves had supported their partner's involvement in a range of activities over a period of several years. Most participants were still active in various ways while two had stepped down and were no longer involved in research. Three, when initially interviewed, had only expressed an interest in involvement in research but had not taken any active part. One of these was a tutor for the Expert Patient Programme, and subsequently became involved in a research proposal; one had attended some events with a family member but taken no part themselves; and the third had no experience of public involvement in health care or research.

2.5.3.3 Interviewees were from six regions of England. Between them they named over twenty universities and medical schools they had been involved with, five of the eight National Institute for Health Research (NIHR) clinical research networks at that time, as well as four of the, then, nine NIHR funded Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). A cluster of twelve interview participants had worked with the same CLAHRC on at least one occasion; two were members of the involvement group for a different CLAHRC. A short description of each is included in appendix 1.

2.5.3.4 Interviewees were, wherever possible, given the choice of a face to face or a telephone interview. Logistical and financial constraints meant that five could only be offered telephone interviews. Of those offered a choice 19 chose face to face interviews and six preferred telephone interviews (see table 1). The face to face interviews were conducted in a range of venues, chosen by the participant. These included: their own home, the home of a friend, their own office, a cafe, a mental health resource centre and university meeting rooms.

2.5.3.5 With the permission of the participants interviews were audio recorded, for the telephone interviews this was facilitated using a speaker phone. Contextual field notes were taken at the time of the interview or as soon as possible after the interview had been completed. Interviews were transcribed

verbatim and participants were invited to check for these for accuracy. Following feedback that some participants found the verbatim transcripts difficult to read, or felt that the written presentation of verbal communication made them seem foolish, it became my practice to offer either the verbatim or an edited transcript, maintaining the sequence of the interview but with hesitations and repetitions removed (Bourdieu 1999, pp607-626).

2.5.3.6 From the interviewees six of those involved in frequent activities were asked to keep a diary including an activity log to record interactions (invitations received, phone calls emails etc.) and a reflective sheet for more substantive pieces of work (defined as: meetings, workshops or reviews submitted). A template was supplied (see appendix 4). These were intended to give a more contemporaneous perspective on the involvement activities to help triangulate data from the interviews and to provide some contextual data for follow up interviews or email discussions. Three of these were returned, one which gave a short log of activities over 17 days, one which gave a fuller reflection of meetings and one which gave both. In addition one of the diary keepers also produced a photo diary of one of his experiences with written reflections on the images.

2.5.3.7 Interviews used a schedule of topics that were sent to the participants in advance (appendix 3). This was done in light of my own anxieties before an interview, when taking part in health and social science studies as a participant in the past, and also discussions I have had with other study participants, some of whom would not necessarily be easy to identify as vulnerable. This made me aware that some participants can become very apprehensive about what they might be asked in an interview. The schedule was intended to give a broad brush guide to topics I was interested in, reassuring the participant that these were things well within their capacity to address.

2.5.3.8 The order in which these topics appeared on the schedule was not rigidly adhered to during the interviews. The schedule acted more as a checklist to ensure that participants had a clear understanding of the subject of the interviews. Participants had an opportunity to comment on as wide a range of aspects of their involvement as they wished and were encouraged to tell their

own story of involvement. They were specifically invited to identify ideas and issues that they felt were most important to them or that they thought were missing from the interview schedule. This was intended to ensure that my own experience of involvement did not lead to the study developing blind spots, areas that could not be discussed, or issues that could not be raised, because they were not addressed by the way I had structured the questions.

2.5.3.9 The conduct of the interviews presented a number of challenges. Before some interviews the participants and I had only been in contact by email, or met briefly at a meeting or conference. This meant that we had to do some work in order to create a relaxed rapport within which the participant felt able to talk openly about their experiences and motivations. This was a particular challenge when the interview took place over the telephone because of the lack of visual cues. Even with participants who I knew quite well or with whom I had worked, telephone interviewing involved the need to pay very close attention to intonation and other oral indications to judge the participants' wellbeing, given some of the difficult and painful issues that could be raised or perhaps even some of those that were left unstated.

2.5.3.10 While all participants had been informed that they could withdraw from the interview, or indeed the study, at any point, I was acutely aware that for them to ask to do so could feel emotionally exposing, and so might be difficult for them to do in practice. This might be particularly the case with participants who were discussing bereavement, traumatic injury or humiliating and damaging treatment. It therefore felt incumbent on me to remain vigilant for distress and to create opportunities for participants to withdraw without losing face if necessary. In fact none of the participants did withdraw before the end of the interview. One did signal, with a curt response which contradicted an issue that had been discussed prior to the interview, that there were areas that were, at that time, out of bounds from their perspective.

2.5.3.11 With participants I knew well or with whom I had worked there were different issues. Not only did I need to bracket my opinions and beliefs about that person and their work, I also had to encourage them to talk about things that they believed, sometimes erroneously, I would already know. Another issue that I was aware of, particularly with those I have worked closely

with, but also with some participants I did not know well, because of the wider networks we shared, was the likelihood of participants giving information and opinions about other individuals, some also involved in the study or others known to me in different contexts. Similarly I was aware that my own institutional involvement could influence what I was told and how it was couched. In some cases I was specifically conscious that the terms a participant used reflected their knowledge of who I knew and what organisations I was working with at the time.

2.5.3.12 This leads to another source of data. This has been personal notes of my own involvement activities. These have included both retrospective reflections, things I have written some time after the event, and contemporaneous notes, things I wrote about what was happening at the time. Reflections on my own involvement have been influenced by the experience of engaging with research participants, patient and public contributors and academic colleagues during the course of this study. They have in turn influenced the conduct of the study and led to exploration of a range of other literature including grey literature and contextual history. These have helped to shape my understanding of the data and the data has informed my understanding of these texts.

## **2.6 Data analysis**

2.6.1 Although this study began with a literature review, the process of data collection and analysis drew heavily on insights from the grounded theory approach, outlined by Glaser and Strauss (Glaser 1978; Strauss 1987; Glaser and Strauss 2012). This included the elements of: collecting and analysing data simultaneously; constructing analytic codes and categories from data; constant and iterative comparisons throughout each stage of the analysis; developing theoretical understandings throughout this process; making notes that elaborated on the process of coding and developed theoretical insights throughout; sampling strategy based on theory development, and addressing gaps rather than seeking to create a sample that is in some way representative of the population. In this I am utilising grounded theory as: 'flexible guidelines, not methodological rules, recipes, and requirements' (Charmaz 2006 p9).

2.6.2 Qualitative data from the survey was entered onto spread sheets and coded line by line to highlight recurring themes. The most immediately striking of these was the frequent use of phrases like ‘the patient perspective’ ‘from a service user’s point of view’ ‘a non-clinical viewpoint’. This theme was developed in relation to some historical examples of conflict between the perspectives of medical professionals and the wider public. This formed the basis of a series of presentations given at the Peninsula College of Medicine and Dentistry PHD conference, PenCLAHRC, the British Sociological Association Medical Sociology conference, an ESRC funded seminar on ‘Knowledge spaces and public social science’ in Exeter, a Research Design Service workshop and a seminar of the Health Experiences Research Group in Oxford. These events included different balances of service users, academic and healthcare professionals, each prompting different discussion and insights. These form the basis of chapter 4.

2.6.3 A sense of the narrative threads within the interviews were gained from listening to each audio recording in full multiple times, paying attention to recurring, emphasised or contrasting issues. For instance Abigail was one of a number of participants who frequently emphasised the importance of recognising different perspectives in involvement, explicitly returning to this point repeatedly throughout her interview and stressing its importance to her. She also had related narratives about personal transformation; her transformations were from having a severely disabling condition to relative fitness and from being research-naïve to becoming a lecturer and expert member of a multidisciplinary research team.

2.6.4 Notes were made of these narratives, not only where connections were highlighted by the participant themselves, but also where they did not seem aware of repeated motifs or where the threads were inconsistent or contradictory. An example of this was Alan’s use of jargon in his interview and his frequent references to his connections with prestigious institutions and senior figures within them, creating an ‘insider’ narrative, while talking at length about being excluded by poor governance in some groups or by the geographical nature of some funding streams.

2.6.5 Narrative threads that resonated with theoretical perspectives identified in the literature were anonymised and re-framed as stories told by fictional ‘theorist’ participants. This began following my first interview with David. Following the interview, we had an interesting discussion, about whether the Marxian concept of Alienation could be helpful, in thinking about David’s concern about the objectification of patients in involvement. Later we entered into correspondence on that subject (see appendix 5). After consulting with my supervisors on how to have similar discussions with participants who were less philosophically well-read than David, it was decided to present these ideas in the form of short stories or vignettes (see appendix 6). In selecting and preparing these I asked two questions ‘what understanding of society and of involvement is implied in this narrative?’ and ‘what theoretical perspective best characterises that understanding?’ These have been used during the study as a way of opening discussions about differences in approach between participants, something described in more detail in the next chapter (3.4).

2.6.6 Another way that the narratives were presented was through the development of ‘ideal types’ of approaches to involvement, drawing on the work of Max Weber ([1922] 1964 p110) and using the ideas of archetypes, suggested by the works of Carl Jung (1964) and Liz Greene (1994). This began with thinking about literary references that were brought to mind in the way participants told their stories. The question I asked myself was ‘which hero/heroine might tell a story like this?’ For instance Alan told a story of wanting to become more involved in health research because he had been embarrassed that it was something he did not know about. This led him to investigate not only the terms needed to work within that particular group, but the structures that underpin and enable research: regulators and funding bodies, institutions undertaking health research and powerful individuals within those institutions. The heroes Alan’s story suggested to me were Film Noir detectives, like Sam Spade, or the Da Vinci Code’s Robert Langdon, uncovering secrets and unravelling mysteries. A similar but distinct narrative was one of becoming fascinated by the intellectual processes involved in research; Nicole was one interviewee who emphasised this as central to her involvement. Hers was more a story of exploration than detection, the excitement of reaching higher and further, rather than delving into secrets.



together. Some initial themes included 'deteriorating health', 'improving health', 'bereavement', and 'retirement'. Later these became sub-themes in the overarching category 'transformations'.

2.6.9 As well as drawing together the themes from the line by line analysis these were also compared to the narratives, giving particular attention to conflicts as well as correspondences. This process included exploring where there were similarities or differences in how these themes were described by the same participant at different times and by different participants, threading the thematic coding back into context, to revisit how it related to the narrative. This was an iterative process that also involved returning to previous scripts and re-coding in light of additional data and new emerging codes and ideas, including my own notes as well as comments on the process made by participants, public involvement contributors, colleagues and supervisors. Supervisors also coded some scripts and we discussed overarching narratives and the developing themes.

2.6.10 At this stage the volume and complexity of the data became increasingly difficult to manage, so, with the guidance of my supervisors, I decided to import it all into NVivo 10, qualitative data management software. While this did enable more efficient data management, and provided valuable tools for interrogating and comparison of the different types of data, my lack of experience with this software and the lack of prior preparation for this step also presented me with a number of challenges. Not the least of these was the fact that survey and interview transcripts were not in formats that were easily assimilated by NVivo. This meant that there was a good deal of reformatting that had to be done. This included removing interview transcripts from tables, copying and pasting survey data from a spread sheet into a series of text documents and the copy typing of hand written correspondence, diary and log entries. Once this was done and all the data imported into the software it all had to be re-coded line by line. This was extremely laborious and time consuming and was compounded by the making of novice errors when setting up coding schemes, so that texts often had to be re-visited several times, un-coded, and recoded in a way that better worked with the querying and modelling structures set up within the software.



2.6.11 Yet these seemingly burdensome tasks disguised profitable opportunities to become even more intimately involved with the data, and so were more fruitful than they sometimes felt. Reading and re-reading what people had said, often having to refer back to the wider context to understand what was implied, enabled me to see even more clearly similarities and differences, while some of the tools included in NVivo enabled me easily to cross reference different types of coding and to manipulate the data in ways that enabled new insights. This included easily tracking codes, both within and between cases overlaying the thematic coding onto the coding of theoretical approaches and the ideal types, enabling me to approach the prioritisation and presentation of these with greater clarity.

2.6.12 In this I particularly focussed on how the study data could elucidate the model of patient and public involvement as a knowledge space (Gibson Britten and Lynch 2012), and what people bring to those spaces. In doing this, the themes highlighted were: different perspectives (chapter 4); language and understanding (chapter 5); transformations (chapter 6); and relationships (chapter 7). There are also important cross cutting themes of: power, expertise, alienation and identity.

2.6.13 in this chapter I have given an outline of the perspective from which I began this study and have tried to map the journey that I have travelled from there. The next chapter will describe the theoretical models that I have been testing and how I have approached that task.

### 3. Theoretical toolbox

*Man alone, of all species, is unable to survive by adapting himself to the natural environment, but has instead to try to bend this environment to his own needs. Labour, an activity at once conscious and social, born of the possibility of communication and of spontaneous mutual aid between the members of this species, is the means whereby man acts upon his natural environment.*

Mandel<sup>16</sup>

#### 3.1 Introduction

3.1.1 The passage at the head of this chapter was my first conscious exposure to the literature of social theory. It was my seventeenth birthday and, fired with political zeal, I was attending a stiffling serious workers reading circle in a cramped sitting room in Billericay. Comrade Robert, a part time lecturer in sociology, had decided that our small and fairly new Trotskyist inspired group required proper theoretical education. This was to take the form of semi-religious readings from the big red one volume version of Earnest Mandel's 'Marxist Economic Theory'.

3.1.2 Frankly, while I can honestly claim to have understood all of the words, at that time the ideas and their historical context went straight over my head. Mandel's arguments were drawn from traditions of anthropology, economics and philosophy that were alien to me. I could not even engage with these or see how they related in any way to the political stories in the news at that time: the electoral repercussions of the three day week, the oil crisis, the Common Market and the M62 bombing.

3.1.3 Three pages later, where women first appeared, I was disappointed that they were to 'undertake those activities which can be carried on near the dwelling place: maintaining the fire, spinning, weaving, pottery making' as well as 'gathering fruit and harmless animals' (Mandel 1968, p26). Meanwhile it was the men who invented bows and harpoons, so beginning to

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<sup>16</sup> Mandel 1968, p23

create a 'social surplus product' and drive forwards the development of civilisation. Even then, this characterisation did not fit with my understandings of gender relations. Looking back I would probably not have gone to many of these meetings, even if Comrade Robert had not made a clumsy and unwelcome pass at me.

3.1.4 The purpose of this story is to illustrate that, even at seventeen, I was approaching ideas with my own theoretical frameworks. These frameworks not only helped me to make sense of my world, they also made some, alternate, perspectives seem too alien for me to engage with, even critically. Reflecting on this, in the context of knowledge spaces, led me to think about how people bring their theoretical understandings as well as their knowledge into these spaces. If these understandings are not explicitly shared and discussed they may inhibit both the expression and the reception of knowledge.

3.1.5 It was not until twenty years after my first encounter with Mandel, when I read social theory across a number of disciplines, that I came to see how valuable it could be to be able to understand the roots of different theoretical and philosophical positions. Access to these discussions enables us to see the world from a range of quite different viewpoints, particularly if we are able to approach issues as 'theoretical agnostics' (Henwood and Pidgeon 2003). By developing an eye to how theories might help our understanding and inform our practice, rather than seeking facts that confirm or refute a particular theoretical position, we can see both ourselves and others differently.

3.1.6 Sometimes exposure to a personally alien viewpoint can produce dramatic revelations about social relations. The reading of Plato's Republic was particularly significant for me. In this work justice is defined in terms of a tidy and functional social order. His 'magnificent myth' (Plato [c380BC] 1955, p159-160) suggests that rigid social class can be described and made palatable by allusion to the levels of gold, silver or bronze in an individual's makeup. I realised that this was something that many of the public school educated professionals I had encountered would have, if not read, then absorbed during their formative education. The 'simile of the cave' (Plato [c380BC] 1955, p178-183), where only the philosopher has seen the sun, explained why my ideas might be seen by them as merely an interpretation of shadows rather than as

genuine knowledge. In particular I remembered taking the report of a study I had read to an appointment with my son's consultant paediatrician, when asking for his support for a request to be rehoused. He waved it aside saying: 'I write papers like these, I don't read them!'

3.1.7 The impact of this particular dismissal was such that his words are remembered vividly. Still, this was only one of many encounters in hospitals and in government or housing offices with powerful individuals, often but not always men, who bullied, cajoled and lied to me in order to force compliance with some regimen or regulation. On many occasions their behaviour had seemed incomprehensible to me; often I had left appointments and meetings wondering 'who the hell does s/he think s/he is?' and here, finally, was the answer. They could be well intentioned and still believe that deception, threats and manipulation were valid ways to obtain my submission to what they were certain was the greater good, and therefore just. Developing that understanding did not in itself change my social status, but it certainly enabled me to think differently about how I might respond to these behaviours when I encountered them in the future.

3.1.8 Becoming capable of imagining and adopting these different responses is like activating what in complexity theory are called 'adjacent possibles' (Durie and Wyatt 2007). That is, it enables different ways of interacting that we may remain blind to, if locked into calcified patterns of thinking and behaving. Interactions that might never be possible, if we allow our own tracks run parallel to the patterns of others they will not meet, unless we make an effort to build bridges between them. Once these adjacent possibles are activated, however, they can, in turn, create a new set of possibilities that did not previously exist. In this way, discussions about the theoretical baggage we carry into our involvement might enable 'the dialectic between data and generalization' (Timmermans and Tavory 2012, p167) to become, rather than a way to account for empirical findings, a tool for visioning different relationships. This seems to me to be a powerful model for enabling knowledge spaces to become vibrant and creative exchanges rather than static exhibitions of alien landscapes. It is also why I chose to explore what theories are implicit in how people approach and discuss involvement in health research, as well as how theories might be used to frame these discussions in different ways.

3.1.9 The next section of this chapter will look at the practical way that I set about opening my study to a wide range of theoretical perspectives. It will describe my approach to this broad body of literature, how I identified theoretical perspectives that might be useful, and how I began to map and explore them, using data from study participants and discussions with academic and public involvement colleagues to guide further reading. The third section will look at how I have applied some of these theories to involvement. It will describe the creative and playful ways I have used to facilitate thinking about their potential value in reflections about involvement in health research. The fourth will look at how stories from the study data have been woven together with the theories to prompt discussions about what is important about involvement for participants. The fifth section will draw on developing literature on theoretical approaches to involvement in health research. The final section will look at the application of the concept of knowledge spaces and will begin to map where I believe this study can help to take these discussions forwards.

### **3.2 Identifying approaches**

3.2.1 Although the study began with a literature review, the purpose of this was not only to identify theoretical models that are used in the current involvement literature, but also others that could be usefully applied, to inform thinking about patient and public involvement in health research. I additionally wanted to sharpen my ability to identify those that might be implicit in the way participants discuss their involvement. Therefore the two specific questions at the heart of this review were: ‘How might patient and public involvement in health research and care be explained or modelled using this theoretical approach?’ and ‘How would a participant’s description of their activities be shaped by the implicit or explicit adoption of this perspective?’ This was not only about which theoretical perspective best explained or encapsulated the phenomenon of involvement in health research, but also, how the activity of involvement could be imagined as demonstrating or re-formulating these theoretical models. In this context I am using theories in the pragmatist sense which means ‘theories are ways either to ask new questions or to make new observations possible’ (Timmermans and Tavory 2012, p174)

3.2.2 From the previous chapters it is clear that this task was not one I approached from an atheoretical standpoint. Theoretical agnosticism does not

require naivety, but openness to the possibility of a wide range of potentially useful, or utilised, perspectives. Some theories had already proved valuable to me personally, both in gaining perspective on my own experiences and in framing the initial research proposal. In addition to the ethical and political insights drawn from feminism Bury's (1982) concept of illness as 'biographical disruption' and Williams' (1984) 'narrative reconstruction' helped me explore the tasks of identity building that had faced me, first with the birth of my son, throughout his developing disability and again when he died. Similarly the concept that a sense of social belonging is woven from threads of obligation and asynchronous reciprocity, something I drew from reading Nietzsche and Mauss as well as Marx and Kittay, gave valuable insights into the role my involvement in the community, and in health research, played in these reconstructive processes.

3.2.3 Since the task was to take the position of the agnostic, rather than the theoretical zealot, I needed to think about how other approaches could be used to inform involvement differently. A starting place for this was to look at two comprehensive reviews of literature on patient and public involvement in health research published shortly before the beginning of this study (Brett et al 2010 and Staley 2009). It was clear from these that there was a paucity of theory explored in this literature. In most of the papers examined in these reviews, the authors' theoretical perspectives tended to be implicit in their approach rather than explicitly stated or investigated, and there was even less information about the theoretical understandings of participants.

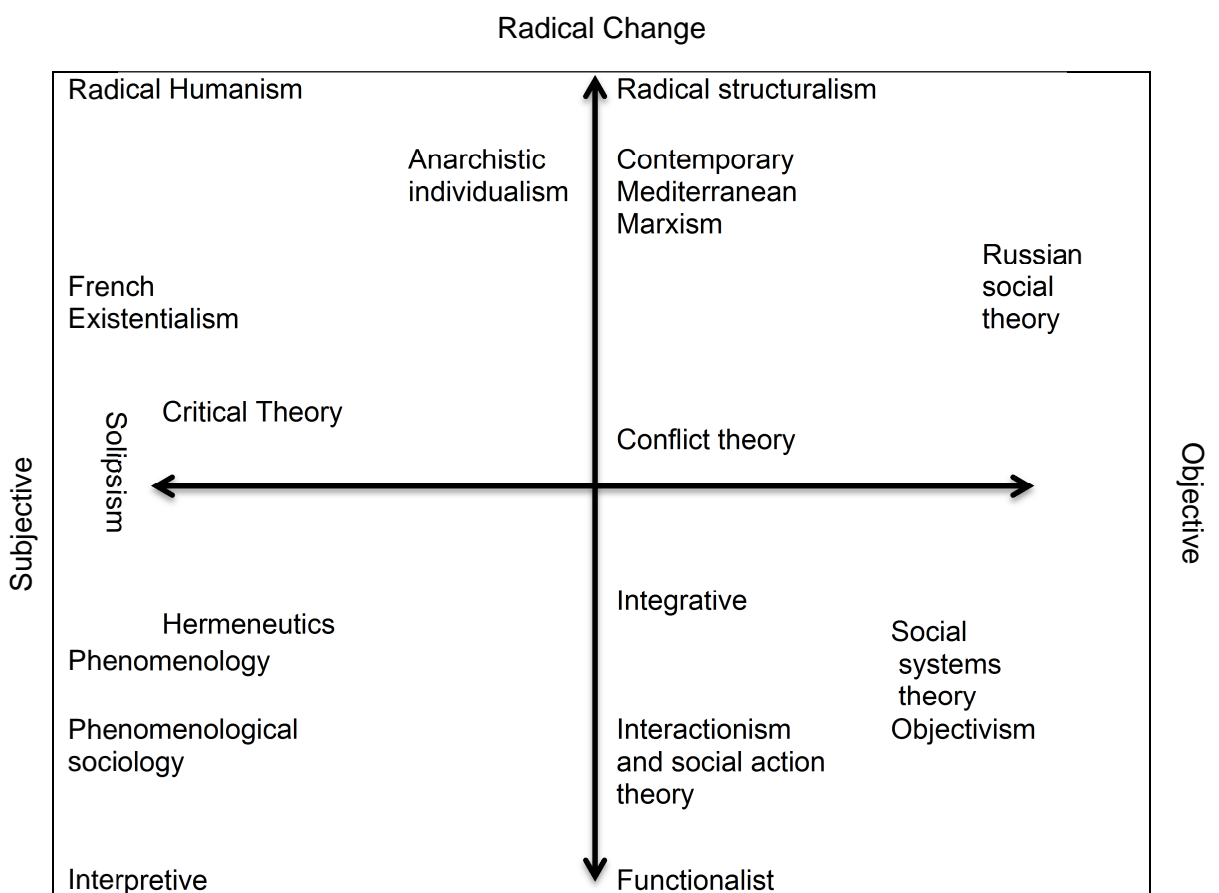
3.2.4 This led me to look beyond studies of patient and public involvement in research to texts about social theory. My initial focus was on identifying the theoretical categories underpinning texts in the sociology of medicine, health and illness that might illuminate the experiences of those engaged in patient and public involvement. From this I also looked at service user/citizen involvement in broader theoretical literatures.

3.2.5 This involved a scoping search of the online catalogue of the University of Cambridge. This was chosen as a copyright library which enabled the identification of key textbooks in the field. As the focus was the identification of theoretical perspectives particular attention was paid to the titles, the contents listings and bibliographies of these books. From these I initially

identified the overarching theoretical approaches of: Critical Realism; Critical Theory; Citizenship and Democratic Theory; Feminism; Functionalism; Phenomenology; Political Economy; Postmodernism; Poststructuralism; Rights Theories; Structuralism; Symbolic Interactionism.

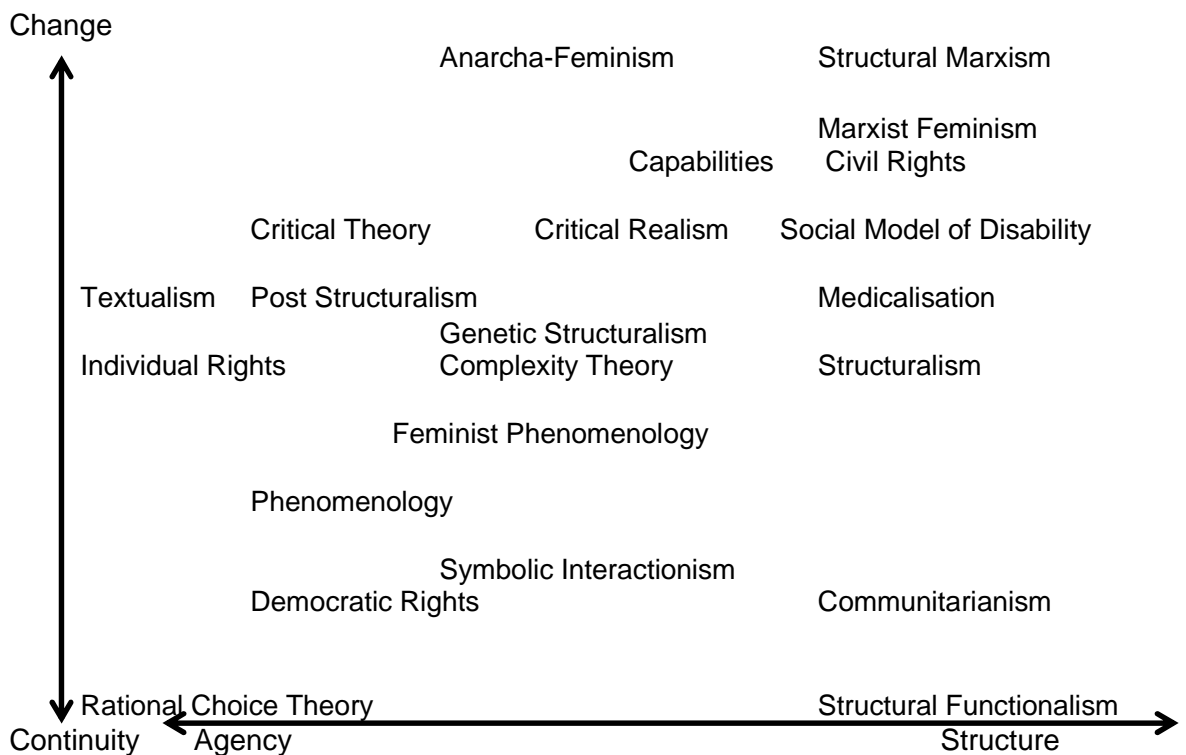
3.2.6 While doing this I discussed the project with both academic and public involvement colleagues as well as my supervisors. I also attended conferences and seminars where I paid particular attention to both implicit and explicit theoretical debates and standpoints. From an early stage qualitative data, from survey responses and interviews, was also introduced into these iterations. This led me to read further and to sketch ideas about involvement in terms of: capabilities; complexity; knowledge spaces; medicalisation; social, cultural and symbolic capital; the sick role; and the social model of disability.

3.2.7 In looking for a way to map these approaches I began by thinking about how they might fit into the four paradigms Burrell and Morgan (1979) outlined using the two dimensions: *Subjectivity-Objectivity* and *Radical Change-Regulation* (fig 1).



**Fig 1: Burrell and Morgan 1979**

3.2.8 However, so much work in the social sciences over the past four decades has been focussed on bridging these paradigms (for example Giddens 1986, Habermas 1985, Bourdieu 1992) that these divisions seemed rather heavy-handed and to produce somewhat misleading picture of rigid partitions across the centre. By moving the axis to the edge and re-defining them as *Agency-Structure* and *Continuity-Change* this was softened and created a more fluid picture that I found more helpful (fig 2).



**Fig 2: mapping approaches**

3.2.9 This was still not completely satisfactory. Some of the approaches suggested in the literature became unstable when mapped in this way. For example ‘Political Economy’ is the root of both Structural Marxist analysis and Rational Choice Theory. While Marxism emphasises the role of the economic base in structuring relations of social conflict, Rational Choice Theory emphasised the potential for individual agency to create stable systems. This places them diagonally opposite each other.

3.2.10 Feminism on the other hand has been used to interrogate the role of gender from a number of different perspectives, including both Marxism and Phenomenology. While mapping these approaches in this way has some heuristic value, that is, it is as a tool that can help when thinking about the



relationships between different approaches, for the purpose of this study a broad brush approach seemed more useful than an attempt to create an exact or at least an increasingly narrow schema.

3.2.11 With that end in mind I read widely from a range of literature written about and from different perspectives. From these I began to develop summaries of approaches that might be applied fruitfully to patient and public involvement in research and to use these to help inform my observations, discussions and reflections.

### 3.3 Theoretical models

3.3.1 Although the purpose of a model is to simplify reality, these theoretical models of involvement began as rather wordy documents like the one in table 2 below.

<b>Table 2. Example of initial theoretical model</b>
<b>Theory:</b> Discourse/Genealogy/Archaeology
<b>Key words:-</b> Structure, meaning, language, thought, power, knowledge
<b>Key thinker(s):-</b> Nietzsche; Foucault; Butler
<b>Related Theories:-</b> de Saussure (structuralism) Becker (Labelling) Zola etc. (Medicalisation)
<p><b>Summary:</b> This was built on the foundations of Saussure’s structural linguistics and Nietzsche’s ‘Genealogy’. Saussure described languages as consisting of two distinct elements: Parole, the utterances made and words as used; and Langue, an underlying structure of shared rules. A central idea in this is the ‘arbitrary nature of the sign’ i.e. there is nothing intrinsic about a particular word that attaches it to the object, action or idea that it signifies apart from the fact that users of that language ascribe that meaning to it and that, within that system, it is different from other words that are ascribed different meanings. The signified and the signifier are attached through their relationship to other signs, and it is this system of attachments that both enables and restricts the communication of meaning.</p> <p>Nietzsche argued that by looking at how language changes over time it is possible not only to map changes of meaning, but also of values. He said the concept of ‘evil’ displaced ‘ill’ as the opposite of ‘good’ between the pagan and Christian eras in Europe. He saw this as not only reflecting a change in the dominant moral culture, but also acting to reinforce that dominance by altering the categories by which what is ‘good’ could be judged and thought about. So the language both reflected and enforced moral categories.</p> <p>Foucault also reflected on transformations of meaning at different times in history. He described the uncovering of meaning in texts from the past as ‘Archaeology’ or, following Nietzsche, ‘Genealogy’, arguing that they needed to be understood in the context of social and power relations that produced them. While rejecting the label of ‘structuralist’ or ‘post-structuralist’ he saw the nature of what could be understood as knowledge being defined by the accepted relationship between signs and signifiers and how they could be used to construct meaningfully ‘truthful’ statements at any given time or within a particular social group. He went on to describe these discourses as systems of repeatable relationships between signs, actions, objects and subjects that</p>

shape both understandings and relations. Different discourses co-exist in unequal relationships of power or perceived legitimacy. A discourse may reinforce resist or subvert existing power relations. In this way what is known and knowable is a product of power relations.

Foucault and other Postmodernist thinkers rejected the search for an empirical truth and instead see truths as socially produced, maintained and contested through discourses. Knowledge and power become fused within social relations and language. Judith Butler described specific discourses as defining the 'limits of acceptable speech', and therefore a discourse marks out what may be presented as 'truth' or 'knowledge' within them.

**Criticisms:** If discourses co-exist and overlap, without clear relationship to an empirical truth, then the line between them may be very subjective and their truth claims become meaningless. Foucault's work has been described as being filled with 'empirical insights and normative confusions' while Judith Butler's writing has been described as deliberately obscure.

**Application to PPI:** Clinicians, academics and service users may each be seen as using different and often competing discourses. These discourses have different power and truth claims. Patient and public involvement can be seen as attempting to bridge between discourses, exchanging insights into the actions, beliefs, motivations and truths of the other. It might also be seen as empowering and re-valuing lay discourses, alternatively it could be argued that continuing unequal relationships mean that PPI is captured and disarmed by the more powerful scientific/medical discourse.

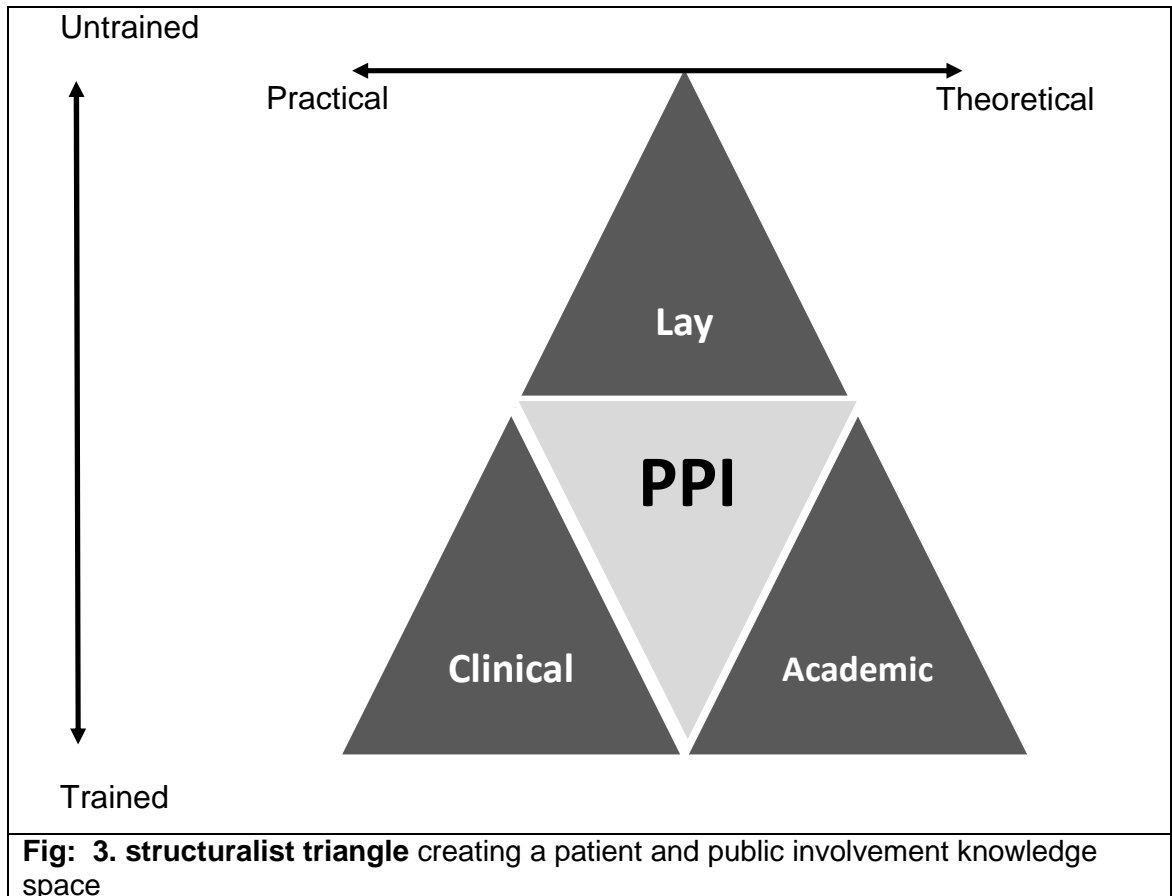
There are also competing discourses within involvement 'patients', 'service users' 'clients', 'survivors' etc. these have different histories and different legitimacy depending on context.

An image Foucault uses in 'The Birth of the Clinic' is that of the scientific/medical 'Gaze', an almost mystical power to see illness and health which carries privileged truth claims, strengthened by the invention of the stethoscope and later diagnostic technologies. Patient and public involvement can be imagined as a new technology that enables the clinicians' gaze to capture a view of themselves from the perspective of the service users. Alternatively it is a reversal of the technology in that, like the Wizard of Oz, clinicians become visible.

3.3.2 These were extremely useful to me in developing my own theoretical sensitivity, deepening and broadening my understanding of how these perspectives could be used to interrogate or explain involvement activities and experiences. Although they facilitated my engagement in academic debates, I also wanted to open discussions about these perspectives with colleagues in patient and public involvement roles. To many of these colleagues the summaries I produced seemed overly wordy, complicated and abstract, in much the same way as Mandel's Marxist Economic Theory had seemed to me, before I had the benefit of contextual teaching or reading. The challenge was to present the issues more accessibly and in a way that encouraged engagement with the ideas.

3.3.3 One way I saw that I could do this was by creating pictorial representations of involvement from different theoretical perspectives. For

instance the structuralist anthropologist Claude Lévi-Strauss (2009) used pairs of binary opposites to map out cultural practices into a triangle. In fig 3 I have used this idea with the oppositions of *trained* – *untrained* and *practical* – *theoretical* forms of knowledge to create a pictorial image of where the patient and public involvement knowledge space might sit.



3.3.4 This led me to think about how to display some of the other theoretical approaches more vividly. While studying for my first degree I had been the primary carer for my youngest son, who was under five when I began. This meant that time for revision was easier to maximise if it included games that could be shared with a young child. We therefore built the circles of Plato’s Republic with different coloured Lego bricks and dined on Hobbes’ ‘accident of bread and cheese’ ([1651]1996, p34). This not only created an (imperfect) bridge between my conflicting duties as a student and as a parent it also provided me with new and different insights into the ideas I was studying and helped me to remember key ideas and useful quotations.

3.3.5 This use of games and activities is something I developed further as a tutor for adult learning in community development and active citizenship.

During training for a City and Guilds Award in Preparing to Teach in the Lifelong Learning Sector I found theoretical work that supported my experience of games as providing a useful platform for active learning. This is because they enable 'learning by doing rather than listening or reading' (Ulicsak and Wright 2010, p14), that is, games can be adapted to the requirements of the learning environment and the needs of the learners. Games can allow players to explore ideas actively and discover new relevance of existing knowledge. They can provide rapid and reflexive feedback and encourage discussion of ideas between players. This can lead to better retention of information (Ulicsak and Wright 2010)

3.3.6 Given this, games became part of my professional practice not only in adult community learning but also as a tool I habitually use in reflective practice and continuing professional development. It was therefore natural for me, when thinking about theoretical models for this study, to begin to envisage them as games and objects. The first models were fairly simple. Their purpose was to embolden theoretical engagement and discussion rather than teach specific social theories.

3.3.7 The Structural Marxism perspective on health and social care was represented by a tree with an expanding canopy of knowledge creation, clinical expertise and expectations of services. As this was growing its economic roots were shrinking, having lost the wealth of empire and much of its industrial manufacturing base. So, as the tree struggled to support its heavily laden branches, props, made of public involvement and commercialisation, were needed to prevent branches breaking or the tree toppling over.

3.3.8 A model for a more Durkheimian structuralism was a maze of social facts through which marbles were steered past social and institutional barriers into involvement. With reference to Foucault's concept of the medical 'gaze' (Foucault [1973] 2003) I built a 'Foucaultscope' through which the viewer could see an eye looking back at them (appendix 8). This was intended to provoke thought and discussion about how involvement both provides researchers with a different view that is useful in their work and also changes their own public visibility; providing them with insights into how health care and

research look from a patient or public standpoint, but also opening their work to more public scrutiny.

3.3.9 To demonstrate the biological metaphor, Functionalism used the game 'Operation' where players have to remove 'organs' from indentations in a picture of a body without touching the sides and setting off a buzzer. In the 'Functionalism' version each organ represented an institution with a nominal and a tacit function. For example the message for the heart was:

"'Patients at the heart' of the NHS is a genuine statement of ethics. It may also serve the function of giving the public a sense of ownership, keeping the life blood of funding pumping round the system."

and at the throat there was the voice which read:

"Peer reviewed journals are intended to share high quality scientific research. They may also have the function of ensuring that the scientific establishment retains control of what is defined as high quality research."

3.3.10 With 'Functionalism' the models were already becoming more complicated and wordy. This was, perhaps inevitably, even more the case when I came to represent some of the ways in which sociologists have theorised the interactions between structure, agency and power. 'Structuration' led to a complicated board game for six players; with dice, cards and a long list of rules (see annex 8). Because of this the game has rarely been played, but it has provoked a number of useful discussions about the difficulties people face working with institutions, the adjustments this requires and the choices they can make in that context.

3.3.11 It was during a discussion, with fellow PhD students at the 2012 British Sociological Association Medical Sociology conference, that representing the concept of different sorts of capital (Bourdieu 1986) as a game was suggested. This led to the development of a board game in which players started by choosing cards, allotting different combinations of wealth, education and social networks, each of which had different impacts on their opportunities during the rest of the game (see insert). A version of this game was used to introduce a group of community learners in Cornwall to the concept of different sorts of capital, something they were able to describe in the context of community development at a follow up workshop the next week.

3.3.12 The 'Capital as Resources' game was also played by academics at a workshop with the Health Experiences Research Group at the University of Oxford. Discussion on that occasion was about how the cards' prescription of initial capital is balanced with the element of chance, through the throw of the dice. This was seen as addressing the issue of determinism in the concepts of social and cultural capital. The use of this game in such very different settings and the very different discussions it elicited demonstrates the value of this way of exploring theories, both for the theoretically naïve learner or public participant and the academic researcher. Games not only provide an accessible and memorable way of introducing ideas they also enable people who are familiar with them to explore them from a different perspective, perhaps eliciting new insights.

### **3.4. Telling Tales**

3.4.1 These examples demonstrate that these games are not just simple, or simplistic, presentations of social theory. In that case their increasing complexity and wordiness, from their complicated and wordy theoretical beginnings, would be circular. Their point was to create different perspectives on the ideas, starting places that would be culturally more familiar and therefore accessible to people from non-academic backgrounds. This goal was perhaps most explicit in the presentation of 'Tall Tales', theoretical vignettes created using stories drawn from preliminary data analysis.

3.4.2 The idea for the vignettes originally developed from an interview with David, a participant I knew and had worked with in a public involvement group for about a year at the time. During that interview David talked at length about his feeling of having been objectified in some research forums (box 3). Following the interview we discussed the Marxian concept of alienation and during an email correspondence that followed I sent him an extract from Marx's Paris Notebooks. This was accompanied by a re-written version with some of the words changed, so that it addressed a patient experience rather than wage labour (see appendix 5).

3.4.3 This was a natural correspondence to have with David, connecting as it did to other conversations and shared interests. Clearly, the idea of presenting the relationships between patients and healthcare providers or

researchers in terms of 19<sup>th</sup> century class struggle would not have appealed to many participants. In discussions with supervisors about how to make these parallels more accessible, the idea of personifying the concepts and creating theoretical vignettes was developed

Table 3 PenPIG Tall Tales workshop					
Total votes		Like other people		Like me	
Roberta (social capital)	15	Emile (structuralism/Durkheim)	7	Talcott (the sick role)	9
Talcott (the sick role)	14	Mick (discourses)	7	Roberta (social capital)	9
Karl (structural Marxism)	12	Roberta (social capital)	6	Maxine (bureaucracy)	8
Mick (discourses)	12	Karl (structural Marxism)	6	Marcel (gift exchange)	7
Nancy (weak/strong publics)	11	Gareth (narrative reconstruction)	6	Nancy (weak/strong publics)	6
Maxine (bureaucracy)	11	Nancy (weak/strong publics)	5	Karl (structural Marxism)	6
Marcel (gift exchange)	10	Talcott (the sick role)	5	Emilia (functionalism)	5
Gareth (narrative reconstruction)	10	Ivana (medicalization)	4	Topal (Plato's Forms)	5
Emile (structuralism/Durkheim)	9	Georg (the stranger)	4	Claude (structuralism/Levi-Strauss)	5
Georg (the stranger)	8	Karla (alienation)	4	Mick (discourses)	5
Topal (Plato's Forms)	8	Michelle (surveillance)	3	Georg (the stranger)	4
Jurgen (system/lifeworld)	7	Maxine (bureaucracy)	3	Max (rational/scientific)	4
Claude (structuralism/Levi-Strauss)	7	Marcel (gift exchange)	3	Jurgen (system/lifeworld)	4
Emilia (functionalism)	6	Topal (Plato's Forms)	3	Gareth (narrative reconstruction)	4
Ivana (medicalization)	5	Jurgen (system/lifeworld)	3	Emile (structuralism/Durkheim)	2
Max (rational/scientific)	5	Claude (structuralism/Levi-Strauss)	2	Michelle (surveillance)	1
Karla (alienation)	5	Emilia (functionalism)	1	Ivana (medicalization)	1
Michelle (surveillance)	4	Max (rational/scientific)	1	Karla (alienation)	1

3.4.4 This involved looking at the narratives I had identified in the data, and my notes of discussions about the issues raised, and using these to create a single paragraph story that captured what, in that narrative, suggested the theory. The participant approaches identified in this way were: social capital, the sick role, structural Marxism, discourses, weak/strong publics, bureaucracy, gift

exchange, narrative reconstruction, Durkheimian structuralism, Levi-Strauss' structuralism, Simmel's stranger, Plato's Forms, system and lifeworld, functionalism, medicalization, rational/scientific authority, alienation and surveillance (see appendix 6). These were presented to nine members of PenPIG as part of a full day workshop, which had earlier included an exercise mapping personal involvement journeys, and which went on to explore experiences of involvement in PenPIG using the Gibson Britten and Lynch (2012) dimensions of a knowledge space.

3.4.5 The 18 vignettes were printed on A4 sheets and stuck on the walls. Participants were asked to read them and to think about whether the approach to involvement, shown by the character in the story, was similar to their own, or to that of someone they knew. If they identified it with themselves they were to write an 'I' on the sheet, if they recognised someone else they were to write an 'O'. The results of this exercise are shown in table 3.

3.4.6 While this was a very small scale exercise, so it would be dangerous to draw conclusions about the prevalence of these perspectives from it, yet none of these stories were completely unfamiliar to the participants. At least one person identified themselves with each perspective; each perspective was identified by at least one participant as like that of someone they knew. Vitally the exercise prompted discussions about the purpose, value and meaning of involvement.

3.4.7 Two members of the group who had not been able to attend the workshop were sent the vignettes by email and were asked to comment on whether they saw the characters depicted as similar to themselves or others. One did not reply, and later, when we next met, told me that the task, arriving by email 'out of the blue', had seemed nebulous and unclear. The other person I sent them to, Nigel Pyart, not only engaged with me in a discussion about the vignettes I sent; he also produced his own 'Nietzschean' version. This was an involvement adventure-story, a power struggle between his need for self-actualisation and the instrumental requirements of research. After editing this, in order to match the single paragraph format of the other vignettes, Nigel's 'Fred' was added to 'Tall Tales' (see appendix 6).



3.4.8 These exchanges, both within the workshop and by email with Nigel, encouraged me to see this as a useful tool to encourage discussion about theoretical approaches to involvement. I presented the vignettes as a poster and leaflet at the INVOLVE conference in 2012 and the seminar on 'Knowledge spaces and public social science' in Exeter in 2013. Presented all together in this way they were very wordy and, like the PenPIG member mentioned above, people found it difficult to know how to engage with them. This led me to turn them into a card game, which, as well as being more tactile, meant that people were only confronted with one story at a time rather than a block of words. This was presented as part of an interactive display at the New Developments in Public Involvement Research conference in 2013, eliciting far more discussion than the poster or leaflets had.

3.4.9 The development of the 'Involvement Zodiac' was another way of presenting the different theoretical understandings and practical approaches to involvement that emerged from the data. Strong narratives, and themes that were associated with them, were drawn together to create twelve short character descriptions, one for each zodiac sign. The format of these was intended to mirror the sort of popular astrology character snapshots with which people would be likely to be familiar. This allowed for both positive and negative aspects to be presented. The zodiac was emailed to PenPIG members, with the question 'do you recognise yourself or any of your involvement colleagues in these?' With this I also included an optional 'post script' explanation of: the concept of ideal types, concerns about the normative content of words like 'ideal' and 'pure', archetypes in psychology and folk-law, and my intention that the zodiac would be a more accessible and value free way of presenting these ideas (appendix 7).

3.4.10 The feedback I received on the zodiac character descriptions was much more detailed than that from the 'Tall Tales'. As well as saying which they identified with and which reminded them of other people, the replies I received also suggested how the descriptions could be improved, what was missing, and where it might fit. Many of these suggestions were incorporated and the new descriptions were sent back to see if the issues had been addressed. One person reported finding it difficult to 'get past my star sign', others describe beginning there, as they would with a horoscope, but moving on to read other

descriptions, finding aspects of those that they recognised. Another participant wrote that he felt this sort of approach could help facilitators and participants to open up discussion of the values they bring to involvement and help their practice to become more inclusive. He went on: "I personally would not want to see the zodiac employed as a closed dumbed down "tool" but having clear salient commentary of the kind you have provided." The revised zodiac, with a 'post script' explanation, was presented as part of a poster at the British Sociological Association conference in 2013 and as a card game at the New Developments in Public Involvement Research conference in 2013.

3.4.11 The value of these processes of moving between data, theory and discussions was not just in enabling me to explore ways to frame my study data. It was also valuable as an active exchange of ideas and understandings with others involved in health research, both academic and involvement colleagues. This has been a useful and rewarding process that I hope to continue beyond this study because, like the PenPIG member who relished opening up discussion of the values people bring to involvement (3.4.10), I also believe that promoting these discussions enriches involvement, and helps to manifest the public ownership of knowledge (2.3).

### **3.5. Democracy, power and knowledge**

*The captain is larger and stronger than any of the crew, but a bit deaf and short-sighted and doesn't know much about navigation. The crew are all quarrelling with each other...If one faction is more successful than another, their rivals may kill them and throw them overboard*

*Plato*<sup>17</sup>

3.5.1 The movement between theory and practice is also important because it speaks to the value in which many involvement participants hold the sharing of knowledge and experiences in the involvement process. That is, the potential for patient and public involvement to move beyond the role of a kind of superior research participant (i.e. as a source of additional and validating data)

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<sup>17</sup> Plato ([c380BC] 1955 p249)

and to create a role that enables the co-production and application of knowledge in the lives of participants. This is about participants developing voices that can be better heard, while also deepening their own understanding; and researchers learning to listen more attentively, to engage in conversations rather than simply making observations.

3.5.2 Ives et al (2012) have argued that this speaks to a paradox at the heart of patient and public involvement. They use Plato's metaphor of a ship (Plato [c380BC] 1955, p249) with a forceful but failing captain; a drunken, rebellious crew; and a skilled but timid navigator to demonstrate the danger of putting: 'unskilled lay people in a position where they can direct a process about which they know and understand little'(Ives et al 2012, p3). However they further argue that up-skilling participants to enable their fuller involvement would lead to their 'lay perspective being "tamed" to make theirs more congruent with that of the professional researcher' (Ives et al 2012, p3). They conclude that involvement in health research is therefore only coherent within a limited range of governance roles.

3.5.3 A different, but related, issue is what Shelia Jasanoff has described as a tacit democratic theory underlying the Public Understanding of Science agenda. She questions the presumption of ignorant publics with a need for science 'forming, and informing, an educated citizenry' (Jasanoff 2000, p252). Jasanoff argues that this reduces human cognition to a single dimension by privileging the knowledge of facts over 'mastery of more complex frames of meaning' (Jasanoff 2000, p270). This reduction fails to recognise the complex institutionalised practices that are used in any society to evaluate and use knowledge in decision making processes, what Jasanoff calls 'civic epistemology' (Jasanoff 2000, p255).

3.5.4 If, in response to the paradox posed by Ives et al (2012), we imagine a ship that is not Plato's, one that uses a different 'civic epistemology'. The captain is a competent manager, the crew are sober and conscientious, and the navigator is sufficiently confident to ask for advice when they pass beyond the edges of the maps they have been using. The cook's assistant is native to the approaching shore, so understands local sandbars, tides and the dialects spoken on passing fishing boats. The captain and navigator can see

that by framing this crew member solely in terms of a narrow job description the ship could be endangered. So they share their skills with the cook's assistant who is empowered to take the helm, for a while. After the ship is brought to land the assistant cook may go back to washing pots or use their new skills in other ways. Whatever they do next the captain, the navigator, assistant cook and probably other crew members will all have developed new knowledge that might not have been achievable otherwise; and the ship will be landed safely.

3.5.5 The concept of creating a new 'civic epistemology', based on mutual respect and knowledge exchange, requires researchers to move from a position of translating people's 'personal troubles into public issues, and public issues into the terms of their human meaning for a variety of individuals' (Mills [1959] 2000, p187) to one in which they work with and support the people they involve in translating their individual experiences, connecting them to the sum of human knowledge. This involves juxtapositioning personal experiences to those of others and developing ways to frame them that are personally and societally useful; combating the alienating objectification, which implies that only some are the expert 'knowers' while others are known about.

3.5.6 This speaks to a concept of democracy which 'implies that those vitally affected by any decision men (sic) make have an effective voice in that decision' (Mills [1959] 2000, p188). It is the potential for health research to 'vitally affect' individual lives that motivates some people to become involved. Harriet is an interview participant who is contemplating becoming involved in health research. She currently works as an administrator in a university and so reads a wide variety of research proposals submitted within different faculties. She said: 'I think: "What planet are these people on?" Now if they're doing something about the musicality of stone-age man they ain't gonna hurt anybody are they? But health research affects all of us, and it can affect people in a very detrimental way and it's important that lay people have input'. For Harriet involvement in health research is seen as a form of democratic vigilance, disciplining research practice and steering its goals by making it more open to question. This concern about the potential for academic and clinical researchers to become detached from wider social values is something that will be returned to in chapter 4.

3.5.7 Involvement as democratic vigilance could also be seen as reflected darkly in the use of involvement as what have been called 'technologies of legitimation' (Harrison and Mort 1998, p.68), ways of seeking democratic legitimacy for how researchers, service providers and policy makers use public funds. Public participation plays an important role in the legitimation of states and governments in the eyes of their populations (Papagianni 2008). This might be seen as a compelling incentive for politicians to emphasise involvement in public services, particularly at a time of economic retrenchment and declining electoral participation (see section 4.7).

3.5.8 The discussion of democracy above demonstrates that even where the same theoretical discourse is used there can be a wide gap between the understandings and motivations of different participants in a knowledge space (see chapter 5). This is particularly disempowering if the space is explicitly or implicitly owned by researchers, service providers and/or policy makers but never by the patient or public participants.

3.5.9 Julie Gosling (2010) looking at involvement in mental health services, argues that what is presented as involvement can sometimes be a dishonest form of management. She differentiates involvement as: *collaboration, innovation, empowerment and redistribution* from involvement 'hijacked' by service providers to become: *compliance, coercion, containment and incorporation*. In the latter case Gosling describes service users as taking the role of guests, never having an opportunity to decide who can be invited to join them at the table.

3.5.10 This resonates with Sherry Arnstein's (1969) concept of civic involvement as citizen power. She created a 'ladder' of involvement that has manipulation as the bottom rung and rises through informing, consulting and partnership to citizen control at the summit (appendix 9). In the context of involvement in health research a simplified model of this has developed, with three levels of empowerment from 'consultation' through 'collaboration' to 'consumer control' (Boote et al. 2002, pp224-226)

3.5.11 While the idea of different levels of power in involvement is useful, both the three levels of consumer involvement and Arnstein's model have been criticised as rather static and linear. They can be seen as overemphasising the

dimension of power and failing to emphasise knowledge and expertise (Tritter and McCallum 2006). In the context of health research in particular the knowledge contributed by participants from the public, patient, clinical and academic perspectives is central. The wide variety of experience and expertise contributed by patient and public participants has been neatly summarised by Rosemary Davies<sup>18</sup> (figure 4).



3.5.12 Yet it is not only the concept of knowledge that is omitted from these linear models they also imply that each project will adopt a particular 'level' of involvement. Given the complexity of many health and social care research projects it is likely that there may be scope for more than one form of knowledge to be applied during the course of the process, from identification and prioritisation of research questions, through the planning and conduct of the research, and on to dissemination and implementation of results. This also implies that the individuals or groups involved, and nature or 'level' of their involvement, which is appropriate at one point in the research process, might not be appropriate at other stages.

3.5.13 These linear models have been built upon to develop other, more textured, conceptual frameworks, for example for patient and public involvement in setting research agendas (Oliver et al. 2008), which can potentially be applied to other involvement activities. Tritter (2009) further differentiated

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<sup>18</sup> From 'Becoming Them' a joint presentation between Rosemary Davies and the author at the 2012 INVOLVE conference

between types of involvement, their aims and potential impact, highlighting the differences between rights-based and regulatory approaches.

3.5.14 Through the recognition of both knowledge and process as central tenets of health research, and by extension of patient and public involvement in health research, imagining involvement as a 'knowledge space' comes to seem both natural and useful. This framework not only explicitly highlights the importance of knowledge, the concept of a space also allows us to imagine it as somewhere in which different activities and engagements can take place; somewhere people might move into, and out of, over time; perhaps leaving objects or messages behind them; perhaps encountering new objects, or meeting different people when they return. The image of a space also allows us to think in terms of how it is bounded, how easily its boundaries can be crossed, what lies within and how it might change over time.

### **3.6. Mapping knowledge spaces**

3.6.1 'Knowledge space' has been described as a field of interaction that is brought to life by the initiation of human relations that are rooted in ethical principles (Lévy 1999). This concept has been utilised as a way of describing the building of relationships and structures that enable people with different sorts of expertise to work together (Elliott and Williams, 2008). In health research and care these are arenas where the knowledge of clinicians, academics, policy makers, members of the public, service users and carers can be brought together on an equal basis. Gibson, Britten and Lynch (2012) have devised a framework for mapping this 'knowledge space'. It is mapped as a cube with an additional fourth dimension (appendix 15).

#### **3.6.2 Conservation to change**

In this model conservation to change is a fundamental issue that cuts across all of the other three dimensions. It is about how well an organisation or project is able to respond to involvement. If involvement builds an expectation of change that the organisation is unable to deliver this can be a major source of frustration. On the other hand there may be situations where the legitimate purpose of involvement is to maintain and monitor rather than to innovate. This can itself change over time – for instance when services or processes are being performance managed the legitimate purpose of involvement may be mapped

at the 'conservation' end of the line, but, when planning future activities, it might move towards change.

3.6.3 I have come to see this dimension in terms of whether the knowledge space itself is, intentionally or incidentally, either static or moveable. This led me to map the continuum below from observation post to space shuttle with a range of potentially mobile spaces in between. Each of these may be suitable, depending on the purpose and the distances to be covered.



#### 3.6.4 **Monism to pluralism**

Following Bourdieu (1990) this dimension describes a struggle for economic, social and cultural resources. The value of resources varies at different times and in different places or circumstance. For instance it might be very valuable for a young person at an inner city school to be able to use 'street talk' but it may not be so useful at a job interview. If the way people can be involved is frequently shaped by professional people, then it may not be accessible to people who are not professional. 'Monism' describes a single way of involving people, for instance as board members. 'Pluralism' describes having different ways for people to be involved.

This is about how people get in and out of a knowledge space. Does the vehicle have one door or are there many? How are these doors placed? Are they high up and difficult to reach or easily accessed? Are they wide or narrow, locked or unlocked?

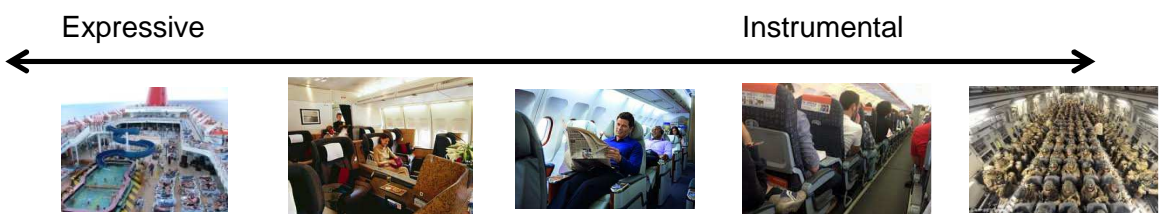
#### 3.6.5 **Expressive to instrumental**

This is about both the intentions of the involvement and the methods of communication used. It is based on Habermas' (1985, 1998) distinction between the social spheres of lifeworld and system. The 'expressive' end of the line is concerned with 'lifeworld'. This contains everyday knowledge, the language used in social settings to interpret and share experiences or express emotions; it also includes public opinion, shared cultural norms and values.



The more instrumental 'system' contains the purposeful mechanisms for organising and maintaining society, like bureaucracies and market mechanisms. In health and social care 'system' might include government policies, economic management and administration. This is a concept that became increasingly important as I looked at the way study participants identified themselves with a distinctive 'patient' or 'service user' perspective in opposition to an 'academic', 'clinician' or 'service provider' perspective. The issues this raised will be explored more fully in chapter 4.

3.6.6 In this model the expressive-instrumental dimension speaks to me of the furnishing of the space. Does it enable relaxed and incidental communication or is it designed to move people along as quickly and efficiently as possible, even at the cost undermining individuality. Is it a cruise liner or a troopship?



### 3.6.7 Weak to strong publics

Drawing on Fraser (1990) this describes private individuals who come together to discuss issues publicly as 'publics'. A 'weak public' discusses issues, but has little influence on decisions. This might include patient groups who are invited to information days or lectures on research that is taking place. A 'strong public' is able to influence decision making processes. This might include groups who make recommendations about what services or research proposals should be funded. This is something that will be explored further in section 7.5.

3.6.8 Thinking in terms of the vehicular analogy this dimension would be represented by the type of ticket held by those on board. Does this only entitle them to a direct trip to a specific destination decided by the driver(s) or can they request extra stops, follow some interesting detours or even insist on a complete change of direction?

3.6.9 This model of the theoretical framing for knowledge spaces has been extremely influential on my thinking during this study. It addresses a

number of key issues that require attention when designing or managing a knowledge space, or a process within a knowledge space. It is particularly useful that the dimensions need not represent one pole as 'good' versus the other as 'bad' involvement. Expressive involvement in a relatively weak public can be really useful to help people develop confidence, share experiences and become more informed. When they want to effect changes, however, they may need to become a more instrumental, strong public and they might want to develop other ways of being involved. If the intention is to involve a specific group, perhaps contributing one of the types of expertise suggested by Davies (3.5.11), monism may be the correct strategy; if wider involvement is required, a more pluralistic approach would be needed.

3.6.10 These are all important issues, issues that I would urge someone setting up a group or a process to think about. Yet, seeing these as linear dimensions along which a knowledge space may be charted is not without difficulties. In the following chapters I will demonstrate some of these difficulties by discussing four strong themes that emerged from the study data: different perspectives (chapter 4); language and understanding (chapter 5); transformations (chapter 6); and relationships (chapter 7). Finally (chapter 8) I will explore how fluctuating external and internal forces can squeeze, buckle and distort these dimensions, making knowledge spaces seem much like more fluid, dynamic, bubble like structures.

## 4. People and Bodies, Stories and Data

*The maintenance of Civill Society, depending on Justice; and justice on the power of Life and Death, and other less Rewards and Punishments, residing in them that have Sovereignty of the Commonwealth; it is impossible that a Common-wealth should stand, where any other than the Sovereign, hath a power of giving greater rewards than Life; and giving greater punishment than Death.*

Hobbes<sup>19</sup>

### 4.1 Introduction

4.1.1 This chapter will examine a recurring theme in the survey and interview data, that there is a 'public' or 'patient' or 'service user' perspective which needs to be explicitly attended to in health research; one that is distinct from a 'researcher' or 'clinical' perspective. This was a concept that I initially found rather puzzling, I had become personally attuned to the range and variety of voices and views being expressed, causing me to wonder 'in what space would that single, inclusive division have its existence?' (Foucault [1970] 2007, pxviii).

4.1.2 It was reading C. Wright Mills 'Sociological Imagination' (Mills [1959] 2000) that led me to follow this particular thread in an unexpected direction. The insight that I drew from this was that an understanding of the life of an individual is bound with the history of the structures of their society, so that the task of sociology becomes 'to grasp history and biography and the relations between the two within society' (Mills [1959] 2000, p6). In order to understand what I found puzzling in the stories of individual participants, I looked not only into their words and actions, and the current political and social context of their experiences, but also into the historical roots of these events, institutions and understandings.

4.1.3 This led to the examination of issues arising from the access to bodies, body parts, and bodies of data that medical research requires. Looking

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<sup>19</sup> Hobbes [1651]1996 p306

back it seems that these demands have sometimes led to wounds being inflicted on the body politic. In observing these it was not clear whether or not patient and public involvement is intended as a knowledge space in which these wounds may be healed (or at least mitigated). It might sometimes turn out to be one in which smoke and mirrors are wielded, in order to transform the interests of academic and commercial researchers into an artificial public interest.

4.1.4 In order to explore these issues, the next section of this chapter begins with a reflection on what was the emerging policy of the UK Conservative-Liberal Democrat coalition government at the time these puzzling participant responses were received (through 2011 from the early summer). The third section will reel back to look at some of the public scandals that led to the Anatomy Act of 1832. This is a piece of legislation that has been described as leaving a bruise on the culture of working people in Britain that lasted well over a century (Richardson 1989, pxvi).

4.1.5 The fourth examines how these scandals were echoed in developing public concerns about the practice of hospitals retaining human organs for teaching, research and commercial use. These are the concerns which led to the enactment of the Human Tissue Act of 2004. The fifth section looks at the impact on women from the Bristol Cancer Help Centre, when a research study they were participating in was published prematurely, in 1990, and lessons that might be drawn from that to inform current debates. It will begin to frame these as issues arising along the interface between different frameworks of value and understanding.

4.1.6 The sixth section presents participants' stories drawn from interview data. These stories illustrate some of the issues that arise along this interface and describe some of the compromises that need to be made from both perspectives. This is characterised by one participant as the creation of a 'liminal' or near ritual space where different worlds meet.

4.1.7 Finally, the seventh section will frame these discussions, using Habermas' (1985) concepts of 'lifeworld', 'system' and the paradox inherent in the process of 'juridification' as an administrative mechanism to manage social conflict. It will draw parallels between his description of juridification of western societies and the histories of involvement described in earlier sections.

## 4.2 Body politic

4.2.1 At the time when I began analysing survey responses, the UK Prime Minister, David Cameron, was reported to be announcing a fund of some £180m for the commercialisation of ‘medical breakthroughs’. He also announced consultations on a scheme to make new drugs available in NHS hospitals more quickly, by giving drug companies access to data on NHS patients<sup>20</sup>. The report (Department for Business, Innovation and Skills 2011) pledges to ‘unlock the power of our unique patient data’ and, in response to calls from charities, to consult on ‘changes to make it easier for patients to be involved in research’ (ibid: p8). The proposal was for patient data to be made available as the default, with some mechanism to enable patient opt-out. While there were assurances that data would be unidentifiable at a patient level the ‘capacity to link patient data to biological samples is also being strengthened’ (ibid: p8). This led some patient groups to question whether individual confidentiality could be adequately safeguarded<sup>21</sup>.

4.2.2 These proposals were embedded in the unfolding policy context of the health White Paper ‘Equity and Excellence: Liberating the NHS’ (Department of Health 2010) which pledged to ‘replace the relationship between politicians and professionals with relationships between professionals and patients’. This discourse was an important step in the shift towards an increasingly personal, individualised, and marketised, relationship within the National Health Service. This is a shift that can be traced from the Thatcher government of the 1980s and through the Major and Blair years that followed. This is a relationship belonging to the private rather than the public sphere, idealised as you-and-your-doctor making personal decisions about your own health rather than as a collective provision for our-community/nation-and-our-health-service.

4.2.3 This additional step taken by the coalition seems to lead discussions of patient and public involvement not only into the realms of increasing individualism, but also a rather passive dependence on beneficent

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<sup>20</sup> BBC News 2011a, 5 December 2011 <http://www.bbc.co.uk/news/uk-16026827> (accessed 03/05/14)

<sup>21</sup> BBC News 2011a, 5 December 2011 <http://www.bbc.co.uk/news/uk-16026827> (accessed 03/05/14)

experts. What is offered is not collaboration, control or even consultation but the inclusion of their information in large data sets, the possibility of access to information about research, the right to benefit from the fruits of research and the opportunity to become the subjects of clinical trials. This falls some way short of involvement in research governance and the setting of research agendas.

4.2.4 In addition, where previously medical research may have been seen as explicitly involving what Foucault called ‘the controlled insertion of bodies’ (Foucault [1976] 1998, p141), current proposals suggest that the controlled insertion of body parts (specimens) and bodies of data may increasingly be a more accurate description. This may disrupt individual senses of the spacial integrity of the body and of life, breaching what Helman (2000, p15) describes as ‘symbolic skins’. In these cases it is not individuals who are concerned in research but alienated samples, parts of individuals or alienated data, information about masses of individuals. Only as a recipient of information or treatment, or perhaps as a taxpayer footing the bill, are whole individuals able to see themselves in this knowledge space. In this way, whether providing specimens and data, or receiving information and treatments, in current policy documents the role of the public and of patients becomes passive; one of being led rather than of leading. They do not appear as partners and co-producers but as both commodities and a potential market for the NHS, researchers and partners from industry. This debate led me to wonder whether the release of even fully anonymised data in a way they feel to be beyond their control, could impact on people’s sense of integrity and well-being.

4.2.5 These issues can be seen as an extrusion of underlying and abiding issues of power and potentially conflicting interests embedded in medical research. As Eliot Freidson ([1970] 1988, pp342-343) has argued, while specialist clinical and scientific knowledge are essential to judge disease processes and causality, what constitutes disease, and therefore constitutes the proper domain of medicine, is a moral rather than a technical judgement therefore open to all. Sometimes this ground has been contested, at other times those who might mount a challenge to medical definitions have been marginalised and silenced.

4.2.6 Discussions about patient and public involvement in health research have often utilised discourses of social justice and the value that people with lived experience of a condition or issue can contribute; involvement as a right, or as a source of distinctive data. Competing discourses will be explored in detail in the following chapter. However it is important here to acknowledge that there has also been a persistent sub-text of the legitimisation and the pacification of objections to the practices of medical institutions, and their partners in the public and private sectors. Involvement takes place within institutions that are competing for resources, and therefore may wish to ensure that they involve the public in ways that supports their objectives, rather than risk an involvement enforced by the public, one that militates against the interests of those institutions.

4.2.7 Groups of patients and the public have organised in a number of different ways to protect their interests and to resist actions and powers they judged as opposing these. In the UK involvement as co-production arguably can be traced back to the mutual societies that were formed by working people in the mid-19th century in order to avoid the workhouses (Green 1985); involvement as protest was in evidence when people resisted the public health agenda of doctors and local government in the cholera riots of the 1830s (Burrell and Gill 2005) and when they voiced opposition to the anatomists' use of stolen corpses by attacking medical students and a theatre of anatomy.

### **4.3 Bodies**

4.3.1 On Monday the 19th of December 1831 the Aberdeen anatomy theatre of Mr Moir was burned and razed to the ground by a mob described by The Aberdeen Magazine (1832: p54) as consisting of about 'forty or fifty active ruffians in the admiring presence of some 10 or 12,000 spectators'. This was also witnessed by the 'magistracy' with a 'strong military and constabulary force', who declined to intervene. Mr Moir was forced to leave somewhat ignominiously by a window, pursued by the apprentices to a baker and a bricklayer, while two medical students were chased by separate mobs into the houses of neighbours where they were eventually aided to escape out of the back (The Lancet 1831a).

4.3.2 The cause of this angry and ad-hoc form of public involvement was discovery, by two boys and a dog, of improperly interred human remains. A contributory factor may well be seen in that this occurred less than three years after William Burke had been hanged for supplying 17 murder victims to Robert Knox at the Edinburgh College of Surgeons and less than a fortnight after the execution of Bishop and Williams, the 'London Burkers', for similar crimes. There was a widespread belief that the surgeons in these cases were deeply implicated in the crimes of their suppliers. The Lancet proclaimed that 'the anatomists, the professionals, the trading dissectors stand self-condemned if not self-confessed as accessories before and after the fact' (Lancet: 1831b). It was also rumoured that Knox's interest in at least one of the corpses was motivated by prurient rather than scientific curiosity (Richardson 1989, pp95-96). The moral standing of the medical profession had been sorely undermined by these scandals.

4.3.3 Nationally this was a time of widespread political and administrative change with public disturbances, including attacks on the home of the Duke of Wellington (Hibbert [1998] 2010 p299), during the passage of the Reform Act. Public administration and policing was becoming increasingly formalised and bureaucratised, with an emphasis on public accountability through Parliament. Therefore the regulation of the supply of bodies to the anatomists was the obvious response to popular concerns about the practices of bodysnatching and 'Burking' as murder for the purpose of dissection became known.

4.3.4 It has been suggested that the roots of both scientific research and utilitarian philosophy in England sprang, as unintended shoots, from the fertile soil of seventeenth century puritanism (Merton 2001). The leading political radical and Utilitarian philosopher, Jeremy Bentham, argued that 'the art of legislation is but the art of healing practiced upon a large scale' (Porter and Porter 1993 p1). In which case it is not surprising that he strongly supported the case of the anatomists, going so far as to bequeath his body for dissection



at the University of London (later renamed University College London or UCL) where it remains today<sup>22</sup>.

4.3.5 The driving force behind the 1832 Anatomy act in Parliament was Henry Warburton, MP for Bridport and a prominent Benthamite. His first attempt to pass an Anatomy Bill was stopped in the House of Lords; his second succeeded and resulted in the 1832 Anatomy Act. This Act provided for the recording and licensing of the dissection of corpses and created three public Inspectors of Anatomy, answerable to the Secretary of State at the Home Office. In this way it was hoped that the public, and particularly the poor, who most feared the Burkers and were therefore actively hostile to the anatomists, would be content with bureaucratic involvement, and refrain from further active intervention.

4.3.6 As Turner has pointed out (1992, p206), dissection was traditionally practiced on the corpses of executed criminals, as part of their sentence; it was a moral and judicial sanction that reached beyond death. For *The Lancet* (1881b, p375), this in itself had been an important cause of the problem and practice of 'Burking'. While the public held in their mind the view that the use of a corpse for medical research was shameful, they would continue to be reluctant to donate their bodies, or those of deceased loved ones. Anatomists were then tempted to trade with the body snatchers, and this opened a market, where the value of corpses was raised to a level which could tempt the less scrupulous traders to murder. *The Lancet* greatly applauded the repeal of the judicial sentence of dissection which was contained in the Act and therefore implied the removal of the stigma of punishment that had been attached to the anatomist's table until then.

4.3.7 The purpose of the 1832 Anatomy Act, then, was not just to regulate the practice of the dissection of human corpses, but also to increase the supply of bodies through regulated channels, satisfying the anatomists while simultaneously undermining the market for cadavers. The act facilitated release to the anatomists of the bodies of those who died in hospitals by legalising the donation of any corpse that had been lawfully obtained. A body was deemed

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<sup>22</sup> See: [http://www.ucl.ac.uk/Bentham-Project/who/bentham\\_ucl](http://www.ucl.ac.uk/Bentham-Project/who/bentham_ucl) (accessed 03/05/14)

legally obtained provided the next of kin or responsible authority had agreed and that, during their lifetime, the individual concerned had not specifically stated their opposition to dissection. The bodies of the poor, particularly residents of workhouses who had no one to enforce their wishes, collect their remains, or pay for burial, were frequently assumed, by default, to have consented to dissection. William Roberts (1843, p14) complained that inducements were given to the medical directors and masters of workhouses, in order to ensure the release of bodies to the anatomists. He argued that these practices could incite further Burking, and believed that the provision to pay the inspectors an allowance for expenses encouraged what was tantamount to continued trafficking.

4.3.8 The increasing demand for anatomy certificates, in order for medical students to achieve qualification, certainly meant an increased demand for bodies. Yet the authorities were able to increase supply through administrative manipulation, like the withdrawal of the support for pauper's funerals (Hurren 2002), and this does seem, eventually, to have effectively destroyed what had been a profitable market in robbed graves and murder. From a utilitarian perspective it also had the benefit of adding to the disincentives for the poor to enter the workhouse. Ruth Richardson has described the Act as supporting: 'the ruling elite in a re-definition of poverty, and the use of dissection to terrorise the poor' (1989, p152).

4.3.9 One thing the 1832 Anatomy Act did not fully clarify was the legal status of the cadaver. Under common law, since at least the 17th century, a cadaver had been seen as incapable of being understood as property (CMS Cameron McKenna 1999 p10). This created a legal difficulty in bequeathing one's own body to the anatomists. A judgement from 1882, relating to a dispute about how a body should be disposed of stated that: 'It follows that a man cannot by will dispose of his dead body. If there be no property in a dead body it is impossible that by will or any other instrument the body can be disposed of.' (ibid p12)

4.3.10 Perhaps more confusing, there was the potential for a corpse to become property, according to the judgement in *Doodeward -v- Spence* (ibid: p18), if someone 'by the lawful exercise of work or skill so dealt with a human

body or part of a human body in his lawful possession that it has acquired some attributes differentiating it from a mere corpse'. Roberts (1843, p14) accused the medical schools of exploiting a grey legal area, one that arose from the differentiation between bodies and body parts, by charging students high fees for their use, in the dissecting rooms, of parts of the bodies obtained so cheaply from the workhouses. This lack of legal clarity would, much later, be central to another public outcry against the anatomists and medical researchers.

#### **4.4 Body Parts**

4.4.1 On March 27th 1996 Mrs Helen Rickard saw a programme on the television, this was raising concerns about the safety of cardiac surgery being undertaken on young children at the Bristol Royal Infirmary (Bristol Royal Infirmary Inquiry undated, p31). Her daughter, Samantha was one of these children, and had died four years earlier. The issues raised in the programme led Mrs Rickard to contact the United Bristol Health Trust, and ask to see the notes on her daughter's care. From those notes she discovered that her daughter's heart, which had been removed during a post mortem examination, had been retained by the hospital and not released for burial with the rest of her body.

4.4.2 After a campaign by what the BBC described as 'angry families'<sup>23</sup> an inquiry was instituted into management of the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary between 1984 and 1995. During the course of this inquiry, it was revealed that parents who gave consent to the hospital conducting post mortem examinations were not informed of what these procedures involved or that, following these examinations, the hearts of their children might be retained by the hospital. Consent forms for these examinations were, normally, signed at a time when parents were in great distress and, although they referred to 'tissue' potentially being retained, it was not explained that this could mean entire organs (Bristol Royal Infirmary Inquiry undated, p7). Professor Roderick MacSween, then President of the Royal College of Pathologists, said: 'if organs were to be retained for use as museum specimens etc., it was felt that "doctor knows best" and that relatives should not

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<sup>23</sup> BBC News 1999a, Tuesday, January 19, 1999  
[http://news.bbc.co.uk/1/hi/health/background\\_briefings/the\\_bristol\\_heart\\_babies/257853.stm](http://news.bbc.co.uk/1/hi/health/background_briefings/the_bristol_heart_babies/257853.stm)  
(accessed 03/05/14)

be further distressed by being presented with a list of organs which might be retained.’ (Bristol Royal Infirmary Inquiry undated, p8)

4.4.3 The question of the legality of these practices was raised in press coverage of this story. Professor MacSween was quoted by the BBC criticising this and describing the retention of children’s hearts in Bristol as: ‘all strictly legal’<sup>24</sup>. The Human Tissue Act of 1961, however, stated that a person lawfully in possession of a body, including the representative of a hospital or nursing home, could give permission for the use of parts of that body ‘for therapeutic purposes or for purposes of medical education or research’ unless: ‘a) the deceased had expressed an objection to his body being so dealt with after his death, and had not withdrawn it; or (b) that the surviving spouse or any surviving relative of the deceased objects to the body being so dealt with’ (Redfern 2001, pp521-2).

4.4.4 The Bristol inquiry heard from parents, whose children’s organs had been retained as specimens in spite of their having expressly objected to their removal for the purposes of transplant, and who felt that their objection to retention for other purposes might reasonably have been extrapolated. Other parents simply objected to the lack of transparency. Lynne Lloyd stated: ‘I suspect that, had we been asked, we would not have minded her [daughter’s] organs being used for educational purposes. We did not know, however, and it came as a terrible shock to me to learn that some of her organs were retained.’ (Bristol Royal Infirmary Inquiry, undated: p41).

4.4.5 It also became clear that the hospital had retained organs that were removed during post mortem examinations, held under the authority of the coroner, a practice that was probably unlawful. In legal evidence presented to the inquiry the law firm CMS Cameron McKenna (1999, p38) submitted that, as normally understood under the 1961 Act, post mortem examination under the order of a coroner would not permit for the retention of body parts, for education or research.

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<sup>24</sup> BBC News 1999b, Thursday, February 11, 1999  
<http://news.bbc.co.uk/1/hi/health/277676.stm> (accessed 03/05/14)

4.4.6 The inquiry accepted it was often an intention to protect parents from distress that led clinicians and support staff to keep details of what was done during and after post mortem examinations from them. However the report argued it was clear that, in taking this course of action, staff had greatly underestimated the damage of discovering this information at a later time. This is a clear example of what Freidson described as the medical profession being 'made myopic by the way its work encourages specially curious practices which merely put out of sight that which offends'(Freidson [1970] 1988, p 381) .

4.4.7 The Kennedy report strongly recommended that the professions open up their practices to greater scrutiny, in order to prevent other similar misunderstandings in future. The final report of this inquiry included a full chapter on 'Public Involvement Through Empowerment' (Kennedy, 2001, pp399-412) which states that: 'the starting point for a consideration of how the public's interests may effectively be reflected and safeguarded, is that the public itself, in some shape or form, must be directly involved'

4.4.8 As well as taking evidence from parents, carers, clinicians and support staff directly involved, the Bristol inquiry also took evidence from experts working in other institutions. Professor Robert Anderson, President elect of the British Paediatric Cardiac Association, in his evidence, revealed that he knew of a number of large collections of retained hearts. He believed that the largest was at Alder Hey Children's Hospital, with an estimated 2,500 hearts; the Royal Brompton and Great Ormond Street hospitals each had about 2,000; Birmingham Children's Hospital of about 1,500 and there were smaller collections in Leeds, Bristol, Southampton, Newcastle and Manchester (Bristol Royal Infirmary Inquiry undated, pp6-7) .

4.4.9 These revelations led to widespread public concern, and the examination of these other centres. The most controversial practices were uncovered at Liverpool's Alder Hey hospital. It was found that, as well as the collection of hearts indicated by Professor Anderson, a deeply flawed and failing paediatric pathology service at Alder Hey had created a stock pile of other body parts, including whole organs and unborn fetuses. This repository was ill documented and poorly managed. Practices at Alder Hey became the subject of another inquiry (Redfern 2001). A national scandal ensued during which it was

also revealed that thymus glands, removed from children during heart surgery, had been routinely sold, to a drug company, by some hospitals, including Alder Hey, without the knowledge of the patients or their parents and carers (Bunyan 2001).

4.4.10 On Saturday December the 4th 1999 the front page headline of the Daily Express read: 'They promised to save my baby but she died and then they cut her head off'. Media coverage of this scandal has been described as having 'fetishized' certain body parts (Seale, Cavers and Dixon-Woods 2006, p32). This claim is based on the emphasis news articles of the time gave to the retention of heads, hearts and brains. This analysis seems flawed, in that it underestimates the extent to which these organs already carried deep cultural and emotional significance; it was unnecessary for news stories to fetishize body parts that the public already widely 'believed to carry a magical or spiritual force' (Seale, Cavers and Dixon-Woods 2006, p32).

4.4.11 The argument that underlies the Seale, Cavers and Dixon-Woods paper is that the sensationalist tone of press coverage of the uncovering of information about how the medical profession dealt with organs removed from dead and living children was a commodification of those body parts. This also seems fundamentally flawed. They compare the use of the scandal to sell newspapers with the sale of glands removed from children during surgery, as if these issues are similarly commodification of those body parts. In my view this demonstrates a fundamental misunderstanding both of commodification and of the role of the press in a capitalist liberal democracy. Selling a thymus gland removed during surgery to a drug company who intend to use it to create products, and therefore profit, is clearly to treat it as a commodity, alienated from the individual who produced it. To use information about these issues to create sensationalist headlines that sell newspapers is to commodify that information, to make it into a marketable story through choices of perspective and presentation. This is the stock in trade of the press, what Champagne (1999a) refers to as the media contributing to the 'creation of the reality it claims to describe'. In fact that commodity is more valuable to a newspaper (i.e. a 'better' story) if it is attached to a named individual situated within a family and wider social context not alienated and anonymous like the products of the organs sold to drug companies.

4.4.12 While the concept of objectivity is highly valued in science, particularity and perspective are essential to storytelling and, for most people, to the creation of individual, family and social identities, especially after traumatic or life changing events, like serious illness or the death of a child. This is what Williams (1984) has described as the 'narrative reconstruction of their changing relationship to the world' (this is discussed further in section 6.5). Clearly the media and the tabloid press in particular, are in the business of commodifying those narratives.

4.4.13 Media retelling of these stories may be a part of the process of transforming a personal problem into a societal problem, one to be resolved politically so that: 'what was a personal responsibility becomes a collective responsibility' (Champagne 1999b, p213). This might be constructive or damaging to the individuals involved, perhaps even both. Yet this argument does not only stand in the case of media coverage, the outputs of research can also be seen as commodified narratives; though narratives that have been reconstructed from a particular scientific perspective and often anonymised. These are stories that have been further alienated from the individuals involved and transformed into data. It is the interplay of these, narratives and data, which will be discussed in the next section.

## **4.5 Bodies of data**

4.5.1 On September 6th 1990 the front page of the Guardian carried the headline "Doubled risk" at cancer unit' (Mihill 1990a). It went on to report that women with breast cancer attending the Bristol Cancer Help Centre, which offered complementary therapies that were additional to usual allopathic cancer treatments, had been shown to have significantly poorer prognosis than patients at a London centre, who were receiving the allopathic treatments alone. The article went on to speculate that dietary advice given at the Bristol Centre could be the cause of these outcomes, worse in terms of both relapse and death.

4.5.2 There followed a bitter debate in the press and medical journals, which exposed a number of shortcomings and sources of bias in that study. By November the authors were admitting that there were errors in the analysis of data and recognising that there were some potentially confounding factors in the study design. One of the researchers, Professor Tim McElwain, who had

previously said that he would have to warn patients against attending the Bristol centre, retracted this saying 'it seems unlikely if you go to Bristol it will do you harm.' (Mihill 1990b).

4.5.3 Professor McElwain killed himself shortly after this (Mihill 1990c) and while it would be unreasonable to attribute that act to the Bristol study alone, it has meant that his name remains more closely linked with a study he described as 'not as good as it could have been' (Mihill 1990b) than with the achievements of a career in which he did 'much to further the development of medical oncology' according to colleagues (Hince and McVie 1991).

4.5.4 This controversy not only caused personal and professional damage to the researchers it also had reputational impacts on the funders, Cancer Research Campaign and the Imperial Cancer Research Fund, who were subject to a formal complaint that resulted in a Charity Commission report censuring them for failing to supervise the study adequately (Smith 1994). It also undermined the work of the Bristol Cancer Help Centre, reducing its funding, frightening potential patients and almost causing it to close permanently.

4.5.5 But among the most damaging effect of this study was the distress it caused to the women participants and their families. In the autumn of 1990, when the story hit the news, the study was not due to be completed for a further two years. Participants had not been warned of the early press release, or the content, of what were to be described as the study's findings. One woman was travelling home on the London Underground when she saw these headlines, in another commuter's evening paper, announcing that she was twice as likely to die because she had been to the Bristol centre. She was quoted as saying: 'I actually wondered whether I would make it home'. A second woman described her discomfort at work, imagining what colleagues were thinking. Another spoke of waking in the night to find her twelve year old daughter watching her, in case she died in her sleep (Hunt 1993).

4.5.6 In referring to these women's stories of the impact of this news, I am in no way trying to imply that the researchers in this case did not care about cancer patients. It is far more likely that their rush to publish was motivated by a desire to prevent harm. However, if this is the case, by keeping their eyes on



what they believed to be the bigger picture, they failed to see, or take action to avoid, the reasonably predictable danger of doing immediate, and potentially lasting, harm to individuals represented within their data set. For the women concerned, those data were parts of their particular, individual life stories. Those data were morally attached to the women concerned and embedded in their family, occupational and community networks. They were representations of some of the most intimate and personal details of their lives, and possibly of their deaths. The publication of those data in that unheralded and sensational way would have been damaging to the study participants, whether the findings were flawed or not.

4.5.7 By utilising the methods and the language of science, health research itself becomes 'increasingly distant from the language and perceptions of everyday life' (Williams 1984, p197). This is not simply a matter of the public failing to understand science and research. In looking for big truths that hold for populations, truths that are able to inform policy and lead to better treatments, health researchers, perhaps particularly those who are routinely dealing with large anonymised data sets, can lose sight of the obvious, the mundane and the personal. This then may well be the 'clinical' 'academic' or 'scientific' view that the respondents to my survey were referring to as the alternative to the 'patient' or 'service user' perspectives.

4.5.8 By contrast to this scientific perspective the 'patients' view' does not have a shared methodology and negotiated agenda, nor any agreement of what can constitute answers. It simply retains an explicit awareness that bodies are people and that culturally bodies may remain people even after death. By extension body parts remain parts of people, with some parts holding greater cultural significance than others. Vitally, data about people also remains culturally and ethically attached to them; data is part of their lives and their story.

4.5.9 As was the case with the different body parts (4.4.10 above) different data have different levels of cultural significance. The retention of a blood smear, or biopsy on a microscope slide, might be easier for a relative to accept than a jar containing their loved one's head or heart. Similarly an anonymised series of blood pressure readings might be more happily shared

than notes from a consultation with a GP, perhaps about an embarrassing urinary dysfunction or the emotional impact of a terminated pregnancy.

4.5.10 The purposes to which samples or data are to be put and the nature of the relationship within which this is done might also be relevant. The sale by hospitals of the thymus glands removed from children during heart surgery was seen as abhorrent by some, not only because they were used in the manufacture of drugs rather than for the purposes of education or research, but also because the relationship in which this was done was explicitly commercial<sup>25</sup>. Similarly the sharing of NHS data with universities to increase the knowledge of a disease and to improve treatments might be seen differently from its sale to private healthcare providers wishing to sharpen their marketing based on the patient vulnerabilities exposed in it.

4.5.11 The problems described in these illustrations can be seen as examples of what Habermas has defined as 'the encroachment of administrative and monetary steering mechanisms on the lifeworld' (Habermas 1985, p332). That is: what from a 'patient perspective' is viewed primarily as personal, as a social interaction or a relationship is in danger of being treated according to the rules that are widely understood to apply to the impersonal, the instrumental or the commercial. It seems that sometimes professionals, including academics, clinicians and politicians, can become so familiar with the rational of their particular professional requirements, and their collective practices, that they can begin to overlook or misunderstand the framework of social rules that their patients, clients or electorate believe apply.

4.5.12 This can lead to serious misjudgement of how the actions of professionals might appear to others, whether this involves the removal of an organ against the wishes of the next of kin or claiming for a duck house on a Member of Parliament's expense account<sup>26</sup>. Shared goals, customs and assumptions can make these issues 'hard to see from inside the goldfish bowl' (Lawrence 2002, p5). In that case engagement between those on the opposite

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<sup>25</sup> For example see: <http://www.dailymail.co.uk/news/article-18953/London-hospital-sold-body-parts.html> (accessed 03/05/14)

<sup>26</sup> See: [http://www.channel4.com/news/articles/politics/domestic\\_politics/mpsapos%2Bexpenses%2B10%2Bcontroversial%2Bclaimants/3383512.html](http://www.channel4.com/news/articles/politics/domestic_politics/mpsapos%2Bexpenses%2B10%2Bcontroversial%2Bclaimants/3383512.html) (accessed 03/05/14)

sides of the glass could be extremely beneficial, although, if this process is not well managed, water may be spilled and there can be casualties.

4.5.13 Patient and public involvement exists explicitly, and necessarily, in between these different frameworks of understanding and ways of being; often at points where rub together. If this is to create more than friction burns and blisters, the work of translation in both directions needs to be planned, resourced and facilitated. The next section will present stories from some of the interviewees for this study, who have been engaging with researchers in knowledge spaces. These particular accounts have been chosen because, although they each have a different orientation, clearly, each have thought about the issues that arise from the different perspectives they and their involvement colleagues bring to research. What they have presented is their considered view of difficulties they have personally encountered in managing this interface.

## **4.6 Spaces travellers**

4.6.1 Elizabeth (box 1), an interviewee for this project who has a professional background herself, saw professionals within the NHS as having sometimes underestimated the challenges involved. She argues that researchers need to identify the support required by the people they involve, recognising that most often they are inviting them into an unfamiliar field. She also suggests that, in order to attract more and different people to contribute they first need to be convinced of the practical value of their involvement in research. This last is a point made by many of the participants in this study, one that undermined my initial orientation to treat involvement in research as an entirely separate phenomenon from involvement in service improvement. For many, the purpose of their involvement in research is identical to that of their involvement with health service providers.

<b>Box 1 Elizabeth on engaging with different people</b>
The senior managers said: 'Oh, yes, yes, yes we've got to have patient involvement', but not everyone really understood what it was all about, I mean it is a slightly different way of working you know, you have got to have extra resources, you have got to be prepared to think about your project in a slightly different way because involving the mo- I say the mob, but involving people outside the NHS is a challenge, you know?

They aren't employed, they haven't got the same attitudes to things– that's the whole point, they have got a different point of view and they're not worried about their careers, and this that and the other, in the same ways.

So it is a challenge to positively engage such people and you need extra time, because depending on - I was going to say the level of expertise but it's not that; I mean, coming in from outside they're obviously not kind of particularly trained or experienced necessarily in the field you're either providing for or looking at. So therefore there's gonna be need for explanations and extra care all that sort of stuff.

So I mean if you want to do involvement, properly that's what you've got to do you know, you've got to think about how you're going to involve them from the beginning, how you're going to support them throughout, make sure the obvious things, I mean we always talk about the old chestnut of if you want volunteers to come to a meeting have you made sure they've seen the meeting notes that everybody else has got? It's that sort of attention to detail, [to] the needs of the people and feeding back. I mean when people volunteer their time people would prefer to have the results, have the feedback whether their contributions made any difference. ...

What do you need – if you want more people to participate – you need to know why more don't participate now, don't you? See what their reasons are. It is a very small field I suppose as well, although it's growing, it is actually a tiny area isn't it? I suppose there's the difficulty that a lot of people would think maybe it's all academic it's never going to get anywhere anyway. I mean [laughs] – most people are practical aren't they? I mean the majority of the population are practical, and oh well you know, that's a load of theories sort of stuff - aren't they?

[Getting people to see the practical applications of research] that's a whole task in itself really isn't it? I mean I dare say some of it is - confidentiality is probably an issue as well. You're cutting in all sorts of ways, researchers in a way have got to be quite brave to let the public into their lives haven't they? You know they're a different species and won't have the same boundaries about confidentiality and everything necessarily and the less academic, the more ordinary people you've got, the less they're going to be used to all that sort of stuff I suppose.

But a lot of it is about, a lot of it gets down to our society doesn't it. You know, what education do we offer and what are we aiming for in society, you know because if we were much keener on power coming from underneath [laughs] things would be more open anyway wouldn't they? Things are changing, obviously.

I don't think we've got enough respect in our society for ordinary people you know, sort of common sense and intelligence that an awful lot of people have got that never really got anywhere formal in their jobs. I think there's an awful lot to be captured from people – people educated at Oxbridge and the people in the government and all the rest of it at the moment they come from such a narrow area on the whole, don't they?

4.6.2 The desire for the practical application of research that Elizabeth raised was also an issue for Ellie (box 2). She is an interview participant with a lot of experience of involvement in research in different ways, including prioritising research questions, reviewing research proposals and undertaking research as a service user-researcher. When I spoke to her she had decided to withdraw from these research activities altogether, while remaining deeply involved in health service governance roles.

4.6.3 Ellie told a number of stories about how the work she had done on research projects had often left her frustrated and disappointed with the outcomes. Sometimes she had been frustrated by the length of time academic research processes took, meaning that services were reconfigured before projects could be completed, leaving them unfinished and unreported or redundant because the mechanisms intended to share the learning with frontline staff were no longer in place. These were issues raised by other service user researchers including Hollie (box 26). A major issue, one that recurred in a number of the stories that Ellie told, was a growing distrust she felt of the narrow instrumental motivations of some of the professionals she encountered.

4.6.4 It was not that Ellie herself lacked any instrumental orientation. As mentioned above her approach was extremely practical, emphasising that the point of involvement in research for her was to achieve tangible improvements in services. Yet she sometimes experienced researchers as being overly focused on their own career progression. This sometimes manifested as a lack of respect for the impact their research had on research participants, both patients and frontline staff, and on the service user researchers working with them. This was particularly noticeable in terms of under valuing their time and effort.

4.6.5 One experience illustrated the difference in the motivations for undertaking research between Ellie and the health service professionals she sometimes worked with. On this occasion she was working with two clinicians, Specialist Registrars, who were required to do a piece of research in order to enable them to apply for posts as consultants. In this story Ellie emphasised that these were not academic researchers.

4.6.6 She identified that the design of the research protocol, relying on a questionnaire that was repeated monthly, in itself limited the capacity of the project to answer the question they were ostensibly investigating. This was because the frequency of being asked the same questions antagonised participants, leading to many of them dropping out early and damaging her relationship with some patients. What Ellie saw as the narrow professional instrumentalism of the clinicians, led them to report only the quite limited results of their questionnaires and not the, perhaps more useful, qualitative data Ellie had collected on participants' very negative responses to the research process.

**Box 2 Ellie on being a service user researcher**

I had another really, really bad experience more recently, a few years ago when I was looking at, well I'm the ward visitor for one of the mental health wards, well, two of the mental health wards here actually. But for this particular one what I do is I go in and get patients' views, it's a part of the governance, picking up what's working, what's not working and feeding into the Trust's governance structure but also giving patients a voice.

So anyway, the consultant, they were quite new, no there wasn't even a consultant at that point. There were two SPRs on the ward – Specialist Registrars, and they had to do research to become a consultant, both of them, and they wanted to do some research into whether the exercise from [games consoles] would actually improve the physical health of people who had long term mental health problems and were on medication that increases their weight – 'cause weight gain is a massive issue for people on anti-psychotic drugs.

So they thought they would do this research to you know, go towards their consultancy and stuff, and further. They had picked some questionnaires – they didn't design some questionnaires, they used some questionnaires that were already out there for assessing people's physical health. Some sort of general ones, so they used these questionnaires and they asked me if I would go in and interview the patients and get these questionnaires filled out you see.

So the idea was that I'd interview every patient in the ward, initially about the idea of taking part and stuff and then if they were taking part in it, I had to go back every, I didn't realise that in the beginning, but it turned out I had to go back every month to talk to anybody that was taking part and do another assessment with the same questionnaire about their physical health.

Well the first time it was absolutely you know, they all know me, so they said: 'Oh yeah we'll give you a hand!' and that so they and so they - all bar two and those two actually were quite ill so that was fair enough.

So, did all those, and I thought 'oh yes okay'. Anyway, next month, some of them were going 'we did those questions last month! I'm not answering them again.' Anyway, as it went on and on over the 6 month period less and less people would answer the questions because they just said 'I'm not doing it again!' [laughs] And I'd be still there with the same questions, you know and every single month you know?

To do it maybe at the beginning perhaps half way through even and at the end, but every month and every time I turned up there, they would say to me, 'you haven't got those wretched forms again have you?' [laughs] So anyway, so that was really difficult which meant that you know, the drop off rate was quite high.

But the other bit was, when it was actually analysed and it was presented, I wasn't mentioned at all these two doctors had done it as part of getting their consultant posts which they've both got, but there was no mention of the fact that I'd actually been the one carrying it out – they 'd analysed the results but they just put them into a computer, into a software package because they were standard health form questionnaires you know that gave them all the answers and they presented that. And, when, I heard one of them presenting this it was like, it was quite surreal because I thought 'well at some point they'll probably talk about how it was done,' did they heck! [laughs] So, yeah so now I'm wary of any doctor that might like to, have me do their research for them! [laughs]

After being on the receiving end of being told to 'eff off' and stuff, on a regular basis because this was what I was doing – they didn't get any of that! You know people get quite angry after a while with some of it.

And I told them some of that during it as well, and none that was fed back as part of the findings – because I thought I'd like give them all the researcher perspective of how it is to do this with people who have psychosis. You know, they were sort of, young people, very angry. I thought people could learn from that so I documented it all and they were like oh this is really good but they never included it! They never presented it, and actually I think that could have been quite useful!

So it was like I didn't exist. Even when I was sat... I was sat in the room and I made eye contact with the person presenting it and not mentioned. So that was-yeah. So I have had some bizarre experiences with the NHS research I'm afraid.

4.6.7 Another interviewee who found the instrumentalism of some researchers off putting was David (box 3). He had become involved initially with a condition specific research network but at the time of the interview he had started to step back from that group and was working with the public involvement group within a different research organisation. He explained the difference between these groups in terms of feeling 'objectified' in the one and finding the other more 'valuing conversation'.

4.6.8 The issue of power was apparent and important to David both in the context of these groups and more generally in health and social care. He reflected very deeply on his experiences, including his changed status from having been, in the past, someone who commissioned and provided services to a service user; a shift from 'doing' to 'being done to or done for' as he put it. This transformation caused him to think profoundly about his own performance in both these roles as well as giving insights to his reflections on the performances of others.

4.6.9 David was particularly unhappy when he saw professional instrumentalism shaping involvement so that it denied space for the people involved to raise their own concerns and to pursue their own research interests; particularly where he felt this was not managed honestly. He described the treatment of the people involved with research as being sometimes 'false or discourteous' and wondered whether, through involvement in these uncomfortable fields, 'are you damaging yourself, damaging your soul?'

4.6.10 Sometimes David deliberately mocked or disrupted power relations within the groups or projects in which he was involved. He described greeting a consultant with a 'signum cruces' at the beginning of a meeting in order to both highlight and dislocate his authority. By the same token, when asked if he would meet with a researcher or network manager David would sometimes agree, only if the meeting took place away from their office in a location of his choice.



4.6.11 David also reported regulating his own involvement by frequently asking himself the question 'is this what I want to spend my time doing?' This was a way of explicitly reminding himself that, if his involvement was not experienced as enjoyable or useful to him in some way, he had the power to withdraw at any time, should he choose.

**Box 3 David on objectification and conversation**

I was carrying on in the [condition specific research network] Working Party and as part of my contribution to that, as well as looking at projects, looking at approaches, looking at how to attract people into the network - because primarily it's a top down arrangement, the main focus, seems to me, to get people into the network as subjects of research. It's very straightforward about that, which was fine.

I was immensely flattered to be part of that. But I also, as a result of that, began to involve myself in other ways, for example, I deliberately attended a [voluntary sector group for people with particular condition] to, to find out what it was like and that was an eye opener and as a result of that I tried to have put forward a project for the [condition specific research network] around the assumptions that underlie [voluntary sector group for people with particular condition]. What was interesting about that was that I thought my proposal was carried to the management committee in good faith.

However it turned out that in fact it wasn't reported. The person who was supposed to make a hash of it and actually apologised to me. The [network] manager didn't realise that and was a bit disingenuous at the next meeting when she turned to me to ask further about it, not indicating that in fact the proposal hadn't been presented. So as a result of that, it was a sort of 'the worm had entered the apple' and from then on I began to be much more sceptical about how valued my actual presence was. And that has been borne out subsequently, in terms of membership of another project around [condition].

Another forum where I was invited along with, I think it was probably nine others, a group of about ten of us by a psychologist. We met in the hospital. It was quite a different experience to being in some of the other medically led forums and I thought it was very well managed, it was a good meeting.

What was very interesting, however, it was said towards the end of the meeting that he wasn't sure whether everybody could then go forward to the second stage. That would be a smaller group of people, to be fully engaged in the discussions around forming the project and so on. About three months later, I thought, well I haven't heard anything, so I contacted the person who was doing the project, to find that, in fact, that it had already occurred. These meetings were already going on with a sub group. This, it was claimed, was

randomly selected.

However when you think that the four people who weren't selected were all members, including me, of the [condition specific research network] Working Party, you begin to doubt the veracity of that. They didn't know that I knew about the other three so here was another doubt in my mind about how properly we were being treated.

So I felt objectified. That objectification of people in research is something that I found a very interesting idea - I haven't felt objectified by my GP, I don't feel objectified by the people I encounter within [other research body] but I have found it in other areas and I think it's possibly because the ethical controls aren't as, maybe, robust as they could be or should be. Or the style of approach, which [in other research body] is very much valuing conversation.

4.6.12 For David, the concept of being part of a community of learning and knowledge production is what is vital and nurturing about involvement in research, 'to feel part of that, genuinely to be accorded courtesy'. He sees this encounter as taking place in what he called a 'liminal space' that is a space created on a threshold between two different worlds, different ways of being. As Elizabeth also argued, in David's view support for participants by people who 'can bridge the gap to that world ... who can fill that gap appropriately and facilitate it' is crucial to the success of this meeting. He described this facilitation as demanding both particular skills and qualities from those working in patient and public involvement roles.

4.6.13 Although David was equally clear that, for him, while this is a space in which the two different and distinct worlds meet, and boundaries are indistinct, it is not a complete merging of those worlds. Research institutions do not exist, he argues, in order to 'service the needs' of those patients and members of the public interested in being involved. A sense of responsibility for self-care, for not becoming overly dependent on any organisation, or activity, to provide him with his sense of wellbeing and purpose were also important to him.

4.6.14 Another strong advocate for patient and public involvement, Jennifer also recognised the danger of losing sight of the value of using an instrumental, rational approach. While championing involvement throughout research projects herself, she was exasperated by some of her fellow patient and public representatives on research funding panels, who argued to reject

good quality research addressing genuine issues, purely on the basis of inadequate involvement. She found it 'even more frustrating, you get the direst piece of research imaginable. Where even a lay person can see that this is really, really crap [laugh] and you find the [other] PPI representative arguing for it on the grounds that it's an important subject and it's got a lot of PPI in it!'

4.6.15 Jennifer argued that this sort of behaviour did reputational damage to involvement 'you can see why researchers resent it - I mean I would resent it in my professional life if outsiders, lay people as it were, had come in and started telling me how to do my job. I would have been mad as hell'. So, she argued, there was a need for those involved to take a sensible and practical stance on the purpose of involvement: 'it's important that we're represented; let's do it properly - let's be helpful'.

4.6.16 She recognises that there are inherent risks that patients take by stepping into the world of the researchers (box 4). Like David, Jennifer argued that some of the risks participants may encounter are such that it is simply not practical for researchers to shield them. In her view the best solution is to ensure that people have realistic expectations of the tasks they are undertaking and understand that the nature of the subject makes it likely that it may involve things that can be personally distressing at times. Another priority Jennifer shares with David is the value she affords to honesty and respect from the research community. If the risks are made clear, then it becomes the responsibility of the participants to choose the sort of involvement they feel able to undertake.

**Box 4 Jennifer on what the work requires**

I get uneasy about the demands - this is something I feel, I get uneasy about the demands of PPI representatives to be treated differently, in the sense – I was once present at a meeting where there were two researchers who were discussing re writing their protocol – no whether it should be the case that protocols or applications or whatever that were going to be shared with PPI representatives and lay people, should be written in a way that would avoid them being upset by anything that was in it.

They'd recently been involved in a situation where there had been two PPI representatives present at a meeting and one of them had got desperately upset reading through the protocol, because it revealed that the condition that she herself was suffering from did not have a particularly good prognosis and

she'd freaked out and the meeting stopped and they had to get everybody out of the room because they couldn't go on - and I thought no! If you can't stand the heat you just can't be allowed in the kitchen, you really, really can't!

You cannot have people wasting time by re-writing these - I mean they're long, long documents - in order to avoid upsetting the PPI representative. You can't, it's so counter-productive. So I think we need ourselves to have a clearer view sometimes of what's involved.

It may even be a good idea to say to people who are interested in becoming PPI representatives that you will hear things that you may... you may wish you hadn't heard, and if you were suddenly to discover that your own condition was terminal in the middle of the meeting, imagine how you'd feel? If you don't think you could cope with it, then it's probably not for you. And I know that's hard but I think we need to be realistic about these things and [we're] not always terribly realistic, it's all inclusiveness and light and [laugh].

Real life isn't like that, real life is that there are people that are good at being PPI representatives, there are people that are good at running support groups, there are people who are good at providing helpline information and they're not necessarily the same people. [laugh] I mean me on a helpline – WHAT? You know: 'Pull yourself together!' [laugh]

You're representing other people and you cannot represent other people if - I mean you're putting forward the point of view of other people, you're putting yourself in somebody else's shoes and saying: 'if I were this person in this piece of research what is it going to mean to me, how would I want to be treated, what do I need to understand?' and all those things and if you simply cannot stand the reality of the research in relation to yourself - you can't do that.

4.6.17 Admittedly Jennifer is specifically describing involvement roles like: assessing full research applications, acting as a member of a project steering group or working on a project as a research partner. There are some involvement roles, for instance reviewing a questionnaire about dietary choices or a patient information sheet about how to access an online forum, which carry less risk. But these things are not always predictable and I have found for myself that involvement can sometimes hit on unexpected emotional vulnerabilities in a way that cannot reasonably be avoided.

4.6.18 Another very experienced interviewee was Thomas. He had become involved in research when a healthcare professional asked him to be part of the steering group for her PhD study. This was an evaluation of the

service she provided, and that Thomas had experienced as a patient. Because that study was 'being done on a shoestring' Thomas volunteered to take on some of the work inputting survey data. This was not a task he had previous direct experience of undertaking, but he brought to it professional expertise from his former career including project management and computer literacy skills.

4.6.19 Since then Thomas had been involved in a number of ways, including being a member of patient panels and reviewing research proposals. He had also been given paid work inputting survey data for another study. He felt that he approached this task with a lot more commitment than some of the people he met, who had taken on this work as short term casual labour, with no particular interest in the outcome of the research project. He also admitted that he found the work could change his orientation to the data, something he had to consciously address to bring himself back to 'see it as a patient rep'.

4.6.20 This question of moving between different perspectives was explicitly raised for Thomas when he received feedback from a research proposal on which he was named as co-applicant. Reviewers of that proposal asked whether he had begun to over-identify with the researchers objectives.

#### **Box 5 Thomas on retaining perspective**

One of the bits of feedback [from a research proposal on which I was a PPI co-applicant] was I look a little bit too close to a 'professional' PPI rep. I almost took that as a backhanded compliment, but I am aware of this danger, that if you get too involved you can start to 'go native' as it were.

I'm very much aware that as I'm doing this data input work, [on a different study] which I've been doing for a few months now. I can start to think like one of the team a bit too much: 'Oh, flipping heck, they haven't even read the question properly!' you know? I can.

Yet actually, when I see it as a patient rep I can see that some of the questions that I'm typing the answers to have been so confusing that really - but they were already out there by the time I started. They've been so badly framed that it's no wonder people are getting confused. You know?

In one place the people are given five boxes, five separate questions: 'What's your current work status? Are you: out of work; on sick leave; retired; at home not looking for work...' and they are supposed to tick each one, yet they could very easily read that as a multi choice and just tick one of them. So they've left four questions blank so I'm typing in 'not answered' to four questions. I know

darned well they actually have answered it, by just not ticking it!

Had I been there to go through those questions before they went out, that's the kind of thing I could have picked up on. Now it's too late, on this one, on the [other study] I was able to head these kind of things off, because I got in there before the questionnaires went out and so I could see the wrongs.

Timing is everything, you have to be in at the start to be most effective. You can have an effect by joining midway through but you've got a diluted effect; because it's already happening. Really if they've already established their treatment protocol, they've already got the questionnaires out there, they're already recruiting, your influence over how the project is basically running, basically structured, the basic protocol it's working by, is going to be that much more limited. Yes I still get some results, put the patient view to them, which I am doing, but had I been there six months before, more like a year before I suspect, I might have had more effect. But that's - you can't change what's happened. I wasn't there a year before.

4.6.21 The five stories above all deal with issues encountered in trying to achieve a balance between the different priorities and values brought into the patient and public involvement space by participants and the researchers they work with. Elizabeth points out the need to recognise that including people with different backgrounds not only introduces different sorts of understanding and knowledge; people also bring with them different aspirations and support needs. Without some translation between their perspectives and those of researchers they might be unable to engage effectively, in the same way I had been unable to engage with Mandel's idea of social history (3.1).

4.6.22 For Ellie, someone deeply committed to the wellbeing of mental health service users, engaging with research had failed to deliver the tangible improvements and practical results she had hoped for. When working with academics she felt their focus on their own institutional requirements and their lack of an immediate connection with the imperatives of service provision meant that the results of research were not delivered in a timely manner, if at all. She was frustrated that the clinicians she worked with seemed focused on their own career progression rather than on understanding the needs of young people with psychosis. She felt that they had only gone through the motions of undertaking research and so had both upset participants and missed an opportunity for genuine knowledge production. Perhaps they had also missed

the point of having a service user collaborator, by squeezing the space so that it excluded her insights.

4.6.23 David's acute attunement to power relations has led him to make choices about which organisations to be involved with and how to work with them, as well as sometimes deciding where he would prefer that involvement to take place. For him the balance is achieved by engaging in conversations across the interface between these worlds, rather than being observed like an interesting but essentially mute object. He also reminds himself of his responsibility for self-care in choosing those conversations and in maintaining ownership of his choices.

4.6.24 Jennifer is also aware of the need for people involved in health research to take responsibility for themselves. Being a patient representative in this field is, for her, a very different role from that of being a patient or a study participant. This implies a different relationship with researchers; a relationship that does not require the representatives to be treated with kid gloves. This role of patient representative was something that for Thomas needs to be consciously maintained rather than assumed; in case he began 'to think like one of the team a bit too much'. He is also very aware that research is a process and there are some points in that process where the patient perspective might be able to make more of a difference than at others. This again echoed some of the points made earlier by Ellie.

4.6.25 Although all these stories identify differences within each of the two orientations, patient/public and academic/clinician, the primary issue is one of communicating between the everyday world and the formalised, systematised, world of research. They are about connecting the frameworks of personal, individual and relational values with epidemiological, statistical and institutional approaches, creating a kind of equilibrium that enables a meaningful interchange and practical outcomes to be achieved.

4.6.26 Elizabeth, Ellie and David highlight that, in order to achieve this, it is not enough to invite patients into the researchers' world; researchers too need to take a step onto the threshold and share that ambivalent, 'liminal space', as it was described by David (4.6.12). For Jennifer and Thomas, stepping into that space not only constitutes a commitment to trying to achieve

that balance, but to actually embody it; taking on a Janus-like quality of seeing into both worlds. What another participant, Abigail, described as having ‘that dual perspective because I’ve been through it myself but I also understand the clinical side of it’.

#### **4.7 Legitimizing spaces?**

4.7.1 This already complex relationship sits within a representative democratic welfare state system which, at the time of writing, has been undergoing both state retrenchment and an expansion of private health and social care provision. The complexity of the roles is compounded with the addition of those of citizen and client and, with the introduction of an explicit agenda to sell medical data (see section 4.2), the role of commodity.

4.7.2 Simon Denegri has argued that this current debate about patient data in research has been ‘conducted in a sort of suspended animation; in blessed isolation from what is happening more broadly across society and for its citizens’ (Denegri 2013). He goes on to ask whether the treacle like flow of this discussion was due to a lack of overall leadership and responsibility, because it was largely framed by self-interested parties, or whether this seeming sluggishness was due to a lack of any real attempt to engage the public in a wide and open debate about the issues. This means that when there is disagreement between politicians, managers, researchers and campaigners about whether it is really plausible a) for individuals to opt out of the sale of big data sets or b) for the data used to be completely and securely anonymised, the public are unlikely to know who to trust, who to engage with or how to go about engaging effectively.<sup>27</sup> I would argue that these are all symptoms of the fundamental complexity of this debate and its roots in the struggle between the

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<sup>27</sup> for examples of this debate see: <http://www.pulsetoday.co.uk/home/finance-and-practice-life-news/gp-leaders-consider-boycott-of-nhs-englands-data-extraction-programme/20004354.article#.UmaEQnC-p30> (accessed 03/05/14) <http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx> (accessed 03/05/14) <http://www.genewatch.org/sub-569340> (accessed 03/05/14) <http://medconfidential.org/how-to-opt-out/> (accessed 03/05/14) <http://www.opendemocracy.net/ournhs/phil-booth/your-medical-data-on-sale-for-pound> (accessed 03/05/14) <http://www.telegraph.co.uk/health/healthnews/10250585/Jeremy-Hunt-plans-to-give-anonymised-patient-medical-records-to-private-firms.html> (accessed 03/05/14) [http://www.mumsnet.com/Talk/in\\_the\\_news/a1830491-Opting-out-of-NHS-health-data-sale](http://www.mumsnet.com/Talk/in_the_news/a1830491-Opting-out-of-NHS-health-data-sale) (accessed 03/05/14)



jurisdictions of these different worlds to control the mechanisms of 'civic epistemology' (Jasanoff 2000, p255).

4.7.3 Habermas describes the 'lifeworld' of everyday relational communications and attitudes as being colonized by the rational-purposive thinking proper to the economy and state. In this he outlines four stages of 'juridification' (1985 pp358-373). That is the increasing use of legal regulation to define and administer legitimate authority in order to contain and manage social conflicts and political struggles. While this, like any theoretical model, is a simplification of what are immensely complex social processes, it does provide some useful insights into the development of flawed mechanisms of involvement. In this section I will suggest how Habermas' four stages of juridification can be mapped to the story of patient and public involvement outlined in this chapter. A different perspective of these processes, gained from considering different discourses of involvement is explored in section 5.5.

4.7.4 The early modern stage involved the codification of relations between individuals, defining them as strategic actors capable of owning property and engaging in contracts. This reflected the loosening social bonds of feudal relations, separating kinship relations in which people are aware of themselves primarily as a 'member' rather than an 'independent person' (Hegel [1820] 1991 p199) from the relations of 'particular persons' with one another . This latter is a relationship of 'civil society', a relationship which creates a space between the family and the state (Hegel [1820] 1991, p220). It is this process that Habermas sees as enabling the abstraction of money and power, into the subsystems of the economy and the state, while allowing the lifeworld to retain the negative liberty, which Hobbes describe as defined by the 'Silence of the Law' (Hobbes [1651]1996, p152). This means that, while the sovereign power defines an overarching legal structure to maintain social order, what is not explicitly regulated by those laws remains something that can be socially negotiated.

4.7.5 In relation to medicine and health research, during this phase it can be seen as consisting mainly of speculative scholarship, and the recording of observations at the level of the 'uncritical experience' (Jonson 2000, p43). That is, the recorded expertise of practitioners including physicians,

apothecaries and barber or military surgeons. It is regulated on an individual level through the mechanisms of social relations and negotiation within the context of religious traditions and with reference to ancient authorities like Hippocrates, Aristotle and Galen.

4.7.6 Also evolving in this 'tension-charged field between state and society' (Habermas 1992 p141) was a new space in which people came together to share information and form opinions. Habermas describes this as the 'public sphere'. He says: 'a portion of the public sphere comes into being in every conversation in which private individuals assemble to form a public body' (Habermas, Lenox and Lenox 1974, p49).

4.7.7 It was through a second stage of juridification, and the further development of the system for the administration of the law, that the individual citizen or corporate body became able to take action against the sovereign power itself. This instituted the concept of the 'rule of law'. For Habermas, this enriches the legal order, through the acknowledgement of the rights of the citizens and the institutional protection of interests belonging to their lifeworld. He also sees it as the beginning of a process by which the state claims legitimacy on the basis of its role in protecting a modern individuated interpretation of lifeworld. This is the stage at which the medical professions become incorporated in the Royal Colleges; institutions that are in, but not of, the state, serving to both regulate and defend professional status and freedoms.

4.7.8 The third stage was that which Benjamin Constant described as instituting the 'liberty of the moderns' ([1819] 1988 pp308-328). This included not only the protection of the citizen but also their right to participate in the formation of the law, through public debate, petitioning and through representation in law-making bodies. The legitimation of this constitutional form necessitates a further differentiation of the state, separating legislative, executive and judicial powers. For Habermas this stage is a further assertion of the modern lifeworld of citizens, in resistance to the abstract domination of the state, but, at the same time, it further rationalises and differentiates the lifeworld itself.

4.7.9 This is the political and judicial shift that reverberated through 19<sup>th</sup> century English Parliamentary reform and was the background to the 1832

Anatomy Act (4.3.5). In order to legitimise the regulation of anatomy it was not sufficient to cite its value to the state, the ruling elite or to abstract science. The Report from the Select Committee on Anatomy emphasised in particular the benefits increasing the supply of bodies to the theatres of anatomy would produce for the poor:

Though all classes are deeply interested in affording protection to the study of Anatomy, yet the poor and middle classes are the most so ; they will be the most benefited by promoting it, and the principal sufferers by discouraging it. The rich, when they require professional assistance, can afford to employ those who have acquired the reputation of practising successfully. It is on the poor that the inexperienced commence their practice, and it is to the poor that the practice of the lower order of practitioners is confined. It is, therefore, for the interest of the poor especially, that professional education should be rendered cheap and of easy attainment; that the lowest order of practitioners (which is the most numerous), and the students on their first entry into practice, may be found well instructed in the duties of their profession.

(House of Commons 1828 p12)

4.7.10 The fourth, and for Habermas the final stage that is currently describable, is the democratic welfare state. He sees the legitimacy of the state as resting on the maintenance of the modern, structurally differentiated lifeworld and the limitation of social conflict. The state takes on redistributive and managerial functions designed to reconcile and subdue economic class conflicts while guaranteeing political, economic and individual freedoms.

4.7.11 These are not achieved without creating tensions. The systemic codification of welfare rights, in order for them to be applicable through state bureaucracy and the judiciary, are inevitably generalised and impersonal. Needs, on the other hand, which are of the lifeworld, are individual and personal. This can lead to paradoxical situations. For instance, I was once informed by a social worker that although my family qualified for assistance on the basis of our level of need we had the 'wrong needs' and therefore they were

not actually able to assist us. It also explains a recurring theme in the interview data, described here by Linda.

**Box 6 Linda on payments**

The pay's nice! But the pay is a nightmare – to claim it! [Laughs] Oh god, it's a nightmare! It's a nightmare. That is, I think that is the worst part of it all. It is, you know, the system of how it's paid and then if you're on benefits that fouls you up big time. You've got to be careful of what you earn and what you don't but even then even then! I used to have it so planned [Laughs] because before I were on pension I were on income support and I could only earn certain amounts. So I used to [think] 'Right, can I be paid for this, this over this time and this – yeah'. They used to do that for me, but then when it goes from the office where we was – I worked with somebody else in the building – you present your pay claim thinking: 'Right, I'm gonna get paid in July for that' – they forget about it! So you might get [paid] in August, September, you might have done some work then so it messes up all the rest of it.

Then speaking to the payroll All you get is a number and on your wage slip you're just getting the amount; you don't get no breakdown and then you've got to ring them up and say 'Can you tell me what I've been paid for, I'm keeping a check on it–' That is a utter, utter nightmare...

There's people who are on a limited amount of money. If they've got to travel and they've got to get buses or they've got to get taxi's and they're going to have to wait 2 months for this money! People in full time work don't realise what a barrier that is. Sometimes you know it can be less than a fiver but that's your food for the day. I mean a tenner, like I say if you get a taxi it's like ten each way; that's 20 quid – you get £67 on dole that's a big hole! That's your gas, your electric, your water; you know, that is your bill money for the week.

And I also think that the expenses should be paid in cash, I really do. [University] say they can't do it because of whatever, but I know they can!

4.7.12 This sort of conflict between the aims of the system and its concrete implementation undermine legitimacy. In addition there is a tendency to centralise administration, for the sake of economic and technical efficiency, that leads to an increasing distance - spatially, temporally, socially and psychologically – between citizens as clients and welfare bureaucracies.

4.7.13 This distance in itself can cause tensions where legitimacy rests on democratic political accountability as well as the rule of law. Certainly in the 1944 White Paper 'A National Health Service', public accountability in the National Health Service was envisaged as being through the system of political

representation, which 'centrally and locally is answerable to the public in the ordinary democratic manner' (Ministry of Health and Department of Health for Scotland 1944) . Not only the Ministry of Health and the Minister but also the county and borough councils were to be given increased control of services. It was not until 1946 that the Bill was enacted. Even then, deadlock between ministers and the British Medical Association, on the employment of GPs, continued until the spring of 1948 (National Archives (a) undated<sup>28</sup>).

4.7.14 By the end of government negotiations with the professional bodies, local authority representatives on the Family Practitioner Executive Councils, responsible for Primary Care services, were outnumbered by practitioners 12 to 8 with an additional 5 Ministerial appointees (Parliament 1946). Local authorities also lost control of the former Poor Law infirmaries and asylums which they had previously administered. Consultants gained greater control of hospital services, important in terms of resources and influence (Doyal 1991). Regional Hospital Boards were appointed by the Ministry of Health. The big teaching hospitals, however, where medical research was largely based, negotiated a direct relationship with the Ministry bypassing the control of even the Regional Boards. The legitimisation for investing public money in these institutions then came to rest largely on public trust in professional self-regulation, and the indirect centralised representation of the public through the Secretary of State.

4.7.15 In 1974 there was a major reorganisation of the NHS and Community Health Councils were founded with the stated aim of broadening representation in the National Health Service. It has been argued that the value of Community Health Councils was more symbolic than material, as they had no executive power and only a limited capacity to investigate or publicise issues of concern. All members were nominated by local interest groups including the Regional Health Authority (one sixth), local government (three sixths) and recognised voluntary organisations (one third). This led to some marginalised groups continuing to feel poorly represented (Doyal 1991).

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<sup>28</sup> <http://www.nationalarchives.gov.uk/cabinetpapers/themes/national-health-service.htm>  
(accessed 03/05/14)

4.7.16 In the early 1990s the Conservative government began to encourage health authorities to consult local people before making decisions about commissioning services (NHS Management Executive 1992). The Patient's Charter (Department of Health 1992) was intended to advance this, based on the broader 'Citizens' Charter', which John Major had introduced the previous year with the aim of finding: 'better ways of converting money into better services'<sup>29</sup>. However, with no statutory requirement to involve service-users or the public, and little guidance about how to involve people, in practice many authorities did very little consultation (Baggott et al. 2005, p27). From 1996 onwards, national policy makers made increasing moves to involve voluntary and community organisations representing service users in national policy development (Baggott et al. 2005, p35). At this time INVOLVE was established to support public involvement in NHS, public health and social care research. Patient Partnership Strategy (NHS Executive 1996) aimed to support more effective user involvement. The government also made a commitment to fund research to evaluate different ways of involving service users and the public in the NHS.

4.7.17 Increasingly, in the last decade of the twentieth century, involvement in public services was seen as essential in tackling a growing 'democratic deficit' (Cooper 1995). This is the feeling that people have become progressively more distanced from control over decisions that affect their lives, decisions are seen as being made by authorities, governments and international bodies, they cannot reach or influence. Fall in voter turnout, particularly in local authority elections was seen as a consequence of the structural centralisation of power since the 1940s. A number of initiatives were initiated to revive local democracy. However average turnout for higher tier local authorities, in those years where there is not also a general election, has remained below 40 per cent and has sometimes fallen considerably lower, leaving many commentators to conclude that 'local election turnouts are too low to provide sufficient democratic legitimacy for local government' (Wilks-Heeg et al 2012 p29).

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<sup>29</sup>BBC On This Day: 1991: Citizen's charter promises better services  
[http://news.bbc.co.uk/onthisday/hi/dates/stories/july/22/newsid\\_2516000/2516139.stm](http://news.bbc.co.uk/onthisday/hi/dates/stories/july/22/newsid_2516000/2516139.stm)  
(accesses 03/0514)

4.7.18 Under New Labour the policy of ‘new localism’ included Local Strategic Partnerships and the creation of Foundation Trusts, with the intention of providing better services and increased participation by local people in the planning and running of services (Allen 2006). The devolution of powers in Scotland, Wales and Northern Ireland led to increasing divergence in policy and in the structures developed to plan and monitor services. When CHCs were abolished in England, in 2003, the Commission for Patient and Public Involvement in Health was established as an independent, non-departmental public body to set up and support Patient Forums. At the same time there were increasing local and national initiatives, involving people in research networks, universities and hospitals; in teaching medical students and allied health professionals; and in the governance of professional bodies.

4.7.19 After four years, Patient Forums themselves were abolished, accused of failing to reach widely enough. The chair of the Commission for Patient and Public Involvement in Health, Sharon Grant, argued that, as they had been given no budget for publicity their limited reach had been inevitable<sup>30</sup>. This argument characterized a strong feeling Grant identified in the Forums; that their real fault in the eyes of government had been in beginning to create a powerful national platform from which service user concerns could be raised.

4.7.20 One of the factors that encouraged this view was the nature of the involvement structures that replaced the Patient Forums in 2007. Local Involvement Networks were funded through local authorities, though the budget allocation for them was not ring-fenced. While the authorities had a duty to ensure there was a Local Involvement Network in their area how this was to be achieved was not prescribed, so some authorities ran their own organisation while others commissioned a service from the voluntary and community sectors. This led to an extremely varied approach across the country and while some Local Involvement Networks were very visible and closely connected to local service providers and users, in other areas even a highly motivated citizen could find it quite difficult to work out how to engage with them. In 2013 Local Involvement Networks were replaced by a network of Local Healthwatch groups

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<sup>30</sup> This statement was heard by the author during evidence Ms Grant gave to the National Community Forum Panel on Participation (Morris undated)

linked to a national Healthwatch<sup>31</sup>. At the same time the statutory role of local councillors in healthcare governance was strengthened and the management of public health services were moved back into local government.

4.7.21 The increasing rapidity with which these structures are being burst and reformed could be interpreted as implying a crisis of confidence. INVOLVE has been an exception in this, perhaps because of its position within the National Institute for Health Research and its distance from the provision of services. Elsewhere there may be increasing difficulties for the centralised administration and weak local government to manage the contradictions between the needs of subsystems and lifeworld. The demands of economy, based on individuals as consumers, the state, based on citizenship, and the lifeworld of social relations may be increasingly experienced as coming into conflict.

4.7.22 This speaks to what Habermas has called the 'paradoxical structure of juridification' (Habermas 1985 p372). Law is used to protect the lifeworld, which rests upon social norms and values, from encroachments from the subsystems of the economy and administration. The paradox is caused when law, intended to protect these areas of life and minimise social conflict, itself imposes inappropriate administrative mechanisms. This implies that, if there is a purely instrumental aspiration for any of these public involvement mechanisms to fulfil, its function of legitimising health services or research is likely to be frustrated. If the outcomes of the spaces are to be of strategic instrumental use, their mode of operation needs to be communicative, to enable understanding.

4.7.23 One of the barriers to this use of involvement as one of the 'technologies of legitimation' (Harrison and Mort 1998, p68) is that participants are often acutely attuned to identifying tokenistic mechanisms, intended to pacify or legitimise without allowing any real change or exchange (e.g. see Ellie and Georgina's stories boxes 2 and 25). This is a serious cause of frustration and disillusionment for participants and can lead to a cynical rejection of any legitimacy or truth claimed on the basis of this type of involvement.

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<sup>31</sup> <http://www.healthwatch.co.uk/> (accessed 03/05/14)



4.7.24 The elements of what can be characterised as the lifeworld, embodied in patient and public involvement, are necessarily vulnerable, raw and elemental. They frequently involve experiences of injury, pain, fear, birth, death and grief. People will often have become involved because of deeply wounding, life changing or life threatening experiences; their involvement frequently necessitates substantial emotional work. Involvement in these fields is not just a matter of the lifeworld attempting to defend itself against colonisation by rational purposive administrative and commercial forces. It is also an attempt to mount incursions of the wild and emotional into ordered and rational systems.

4.7.25 The value of these 'liminal spaces' where patients and the public meet researchers and service providers can only be fulfilled if all those who enter it are willing to take the risk, described by Jennifer, of hearing something that they may wish they hadn't. While there, professionals need to loosen their collars and take off their white coats; patients need to manage their own symptoms. These are places where roles are suspended; this means everyone there needs to be able to take responsibility for themselves and to be mindful of the vulnerabilities of others. If this is achieved it is possible to create the conditions for honest and productive exchanges, between the different perspectives, which may lead to better strategies. Attempting to use these spaces to pacify concerns and legitimise existing strategies or practices can be counterproductive, causing people to feel further alienated and distrustful.

4.7.26 An important additional factor, mentioned at the beginning of this chapter, is that the patient and public 'perspective' often encompasses a wide variety of voices and views; of cherished values, norms, and theoretical understandings. Professionals, researchers, clinicians, and policy makers also bring different approaches. This means that a patient and public involvement knowledge space may be less of a dialogue and more like the Tower of Babel. Language and interpretation can be barriers to understanding if their intended and received meanings are not explored. This will be the subject of the next chapter.

## 5. Talking about involvement

*What then is so perilous in the fact that people speak, and that their discourse proliferates to infinity? Where is the danger in that?*

*Foucault<sup>32</sup>*

### 5.1 Introduction

5.1.1 The words that are used to discuss involvement, in health care and research, are frequently a source of dispute. At the 2012 INVOLVE conference in Nottingham, I was present at a workshop session during which there was a discussion about what is the 'right' way to describe the people who are not health service professionals or academics, but who are involved, or who we might wish to involve, in health research. At the outset of this discussion my heart began to sink, as I had ridden on these particular linguistic and ideological roundabouts in many different forums. By the time the facilitator called a halt the room had developed a faux-consensus to talk about 'involving people' and I was profoundly depressed. I well understood the desire to escape from the traps of language that imply less value to some contributions or inadvertently exclude or marginalise some potential participants; but saw in the super-inclusivity of the term 'involving people' that the specific intention to reach beyond academic and clinical participation had become obscured, and so the concept of involvement was rendered effectively empty. I recalled Nietzsche's 'great danger', the 'most sublime temptation and seduction to what? to nothingness?' (Nietzsche [1887] 1994, p7).

5.1.2 In an essay on 'The Analytical Language of John Wilkins', Georges Borges cites a report of a Chinese encyclopædia where: 'it is written that the animals are divided into: (a) belonging to the emperor, (b) embalmed, (c) tame, (d) sucking pigs, (e) sirens, (f) fabulous, (g) stray dogs, (h) included in the present classification, (i) frenzied, (j) innumerable, (k) drawn with a very fine camelhair brush, (l) et cetera, (m) having just broken the water pitcher, (n) that from a long way off look like flies' (Borges [1942] 1999). The encyclopædia, and even the report of it that Borges cites, are both, in all probability, bogus. However the point Borges was making is useful: the categories we use to sort, make sense of and describe our experiences of the world are created by us in

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<sup>32</sup> Foucault, 1981 p 52

negotiation with those in the society around us and are not necessarily the same categories that others might develop in other circumstances or in other company.

5.1.3 Foucault used this idea to look at how, over time, changes in language have interacted with changes in what was known and what was knowable. He saw that we not only create categories to describe what we know, but also, the categories we learn themselves come to shape our understanding of the experiences we have. These categories, then, help define what and how we can know. He also saw that knowledge and language are situated within political and social relations of power. This gives some ways of viewing the world the ability to make a stronger claim to truth than others, not necessarily based on their fit with reality or experience, but often based on the strength with which they can be enforced socially and politically.

5.1.4 So words do matter, but what matters more are the ideas and the values that they signify within any particular 'language game' (Wittgenstein [1953] 1998, p39) or discourse (Foucault [1971]1981). The linguistic theory of Ferdinand de Saussure described the structure of language as being composed of 'signs' that consist of an arbitrary, but set, connection between a concept or an object that is 'signified' by a word used as its 'signifier' (Baert 1998, pp15-20). This means that each sign is only meaningful in the context of its difference from the other signs within a particular language. It is the difference between the sounds made by utterances 'horse' and 'course' that allow us to speak meaningfully about horses for courses, not an essential or mystic connection between the words and the objects they describe.

5.1.5 It is through these differences that we are enabled to speak about and explore ideas. By implicitly or explicitly being denied these distinctions we are silenced and the concepts are rendered unknowable. If we are only permitted to speak of 'people' how do we make a compelling case for the inclusion of those particular people whose voices are not currently being heard, those who are not academics or clinicians, those uncomfortable or unable to participate in ways designed by the articulate and committee trained? How can we make a case for moving from Gibson Britten and Lynch's 'monism' to 'pluralism' (2012, p540)? For academics and clinicians **are** people and are

already involved in research. This potential of language to silence as well as to give voice is how discourse becomes 'not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle, discourse is the power which is to be seized.' (Foucault [1971]198, pp52-53) The danger of trying to identify a safe word is that all difference and disagreement becomes obscured or unspeakable, and the potential to challenge and disrupt existing relations of power is neutered.

5.1.6 The problem in a knowledge space then, if it is to enable and include all participants, is not to create a cosy, compliant and consensual language that makes dispute impossible. It is to facilitate translation between different discourses, and to interrogate them all equally; to identify the range of meanings, understandings and visions participants are able to contribute from their different perspectives. This is about uncovering the different ways that signs are constructed, and the power relations that are implied by the speakers and/or the listeners, some of the internal forces involved in shaping knowledge spaces. What are the theoretical and experiential understandings that lead people in some involvement forums to talk about patients and members of the public; while in others they may say service users, clients, consumers, survivors or people with lived experience? Even when people use the same terms they may intend markedly different meanings, when they come from competing discourses. In some contexts 'service user' indicates any of the people who access, have accessed or may access a particular service; alternatively it can indicate the specific intention to include both patients and their carers; then again 'service users' may be intended to identify only people who use services extensively or frequently (Purtell and Gibson 2012). The juxtaposition of terms can also be important in defining relationships of legitimacy and power (Morrow et al. 2012); the 'service user' voice might be seen as more legitimate than that of someone not using a service, but the 'service user' may have a weaker position compared to the 'service provider'.

5.1.7 Similarly the words chosen may make important individual identity claims that serve to validate difficult experiences. For example the word 'survivor' often indicates people living with long term conditions or with impairments following serious illness who reject the role of 'victim'. Alison Faulkner points out that it may also be a more political term indicating that

people have 'survived mental health services and/or treatments' (Faulkner 2004, p2). Both of these uses can be seen in terms of the narrative reconstruction of an identity that has suffered some traumatic disruption (6.5). The predominant discourse will depend on the background, culture and experiences of the people in any particular forum; it is likely to be contested, sometimes hotly, by people with different perspectives. Often there is a substantive difference in concepts that is in need of clarification and exploration. In this people are, implicitly or explicitly, engaging with some big ideas. These are not conversations that should be rendered impossible by sterilizing the language it is permissible to use.

5.1.8 These different discourses echo the tangled historical, social, political and theoretical roots of involvement. In order to demonstrate this I will explore in detail two examples of important words in the language of involvement: 'representation' and 'lay'. In each case I will highlight the way these words have been used by study participants and discuss this drawing on the literature and on my own experiences. The next three sections focus on these two terms, this is both because they are important in themselves and because, I think, they demonstrate the complexity of language in this field particularly well. Sections two and three both look at the concept of 'representation', contested understandings of what it implies and how it may be judged as 'legitimate'. The fourth section provides a view of issues alluded to in the previous chapter, the difficulties with the opposition of 'lay' and 'professional' perspectives or knowledge, through this, very different, theoretical lens. Here the discussion will focus specifically on the content of the word 'lay'. The fifth section reflects more broadly on how some of the historical political forces outlined in the previous chapter are reflected in the language used by lay participants and by others to describe lay participants.

## **5.2 Representation as an artificial presence**

5.2.1 In 'The Order of Things' ([1970] 2007), Foucault describes the representation of social relations in the Spanish Court of Philip IV made by Velázquez's painting 'Las Meninas'. Velázquez's painting uses position, orientation, lighting and reflection to underline and explore what the child at the centre of the picture represents in her society. Foucault acknowledges that his description of the composition can highlight locations and distinctions, that

naming the protagonists gives additional information, but he points out that what language can tell us is not identical to the understanding we gain from looking at the picture. He argues that this is not because of the imperfection of words or the superiority of the picture but because 'neither can be reduced to the other's terms: it is in vain that we say what we see; what we see never resides in what we say' (Foucault [1970] 2007, p9). In that case how much more difficult accurately to define exactly what we are and how precisely we represent what is other in concrete social situations.

5.2.2 The concept of representation is clearly an important one in involvement. This might arise as the representation of a particular interest or section of the population, through being a patient/service user/PPI 'representative'; it can be an individual who is representing a group or an organisation; or an organisation might be said to represent individuals, a profession or a more abstract idea ('cancer research', 'arthritis care', 'the environment' etc.). Representation was mentioned in fifteen survey responses (14%), but by fifteen of the thirty one interview participants (48%), with some using the terms 'representative' or 'rep' frequently to describe themselves or others (appendix 11). Most used it in a way which implied that 'representative' was a role description they found comfortable and self-explanatory. For others it was a complicated and knotty problem that they sometimes struggled with.

5.2.3 The participant who talked about representation in the most complex and problematised way was Oliver. This is unsurprising, as his background is that of an academic sociologist as well as a member of the lay advisory group for a medical specialism College. During the course of his interview Oliver describes the College in turn as representing 'the specialism' and as representing 'a particular professional group' of specialist doctors. While these two roles may often coincide it is also easy to imagine instances in which they may not. For instance, a move to shift decision making power from this professional group to another within the specialism (i.e. from doctors to nurses or managers), or from professionals to service users, might be conceived of as being in the interest of the specialism, without necessarily being in the interests of that particular professional group. Already the use of the term representation is rendered far from straightforward.

5.2.4 But Oliver also uses representation to describe his own role. Here he describes being present at a meeting between the College and the Department of Health: 'I kind of think "oh right; so I'm sitting here representing 20 million patients", [specialism] see roughly 20 million patients a year... but, you know actually, that, that just becomes sort of paralysing, if you kind of think that'. This does lead him to concerns about what it means for him to stand in this role:

**Box 7 Oliver on representativeness**

I always worry about that, well I'm not exactly representative. But then how can anybody be representative for those kind of people? ... I'm absolutely the sort of person who is consulted 'cause I'm, you know, appallingly well educated ...and middle-class and white and male... at the same time I think if I wasn't all of those things I wouldn't really get in the door of the Department of Health, so what... you gonna do?

5.2.5 Some of the problems Oliver has with his role as a representative can be seen as being created by the inherent complexity of the concept of representation. It has been argued that there is a fundamental paradox rooted in the etymology of representation; in that it is about making present someone or something that is absent (Pitkin 1972, Runciman 2007). This in effect it is to 'say that something is simultaneously both present and not present' (Pitkin 1972, p9). This leads to two serious questions at the heart of the idea of representation:

- in what way can representation be considered to make an absent individual, group or entity present?
- and how is it possible to make a judgement about what count as legitimate forms of representation?

5.2.6 Here I will address the first of these questions; the second will be dealt with in the third section of this chapter. Unlike Pitkin (1972), Runciman (2007) Phillips (1995) and others who have written on the subject of representation, I am not seeking to find an accommodation for this paradox within political structures or 'a better fit with the institutional arrangements of contemporary democracies' (Runciman 2007, p94). Rather this is an exploration of some of different ideas and experiences people have about how they experience their activities as embodying or failing to embody this paradox. This

is about opening up and looking into the baggage they bring with them into the knowledge space.

5.2.7 Runciman suggests that the question of simultaneous absence and presence can be addressed by imagining representation as an artificial or manufactured presence. In the same way that an artificial leg may be described as both 'artificial' and 'real' so might an individual, a group or an interest be described as having a 'real' presence in its absence through an act of representation (Runciman 2007, p95). In the context of involvement in health, the representation of patients and the public at tables previously exclusively occupied by professionals (policy makers, researchers, clinicians and/or managers) might be seen as service users shaking their 'gory locks' like Banquo's ghost; invoking an explicit consideration of their interests.

5.2.8 This symbolic aspect of representation was clear to Oliver in the College's motivation for inviting him to the meetings with ministers and civil servants. This was representation acting as banner or a totem, something which almost metaphysically conjures the presence of that which is represented.

**Box 8 Oliver on symbolic representation**

The president kind of made a point of taking me along to all of those. Now I think that's partly because he thinks I've got something to contribute; partly because err, I guess some of my expertise around policy and politics and professionalism and those kinds of things...I think that he finds helpful and kind of, of good to have - it is that thing about having a perspective on it from someone who's not physician... **I think also, I had a kind of symbolic role...** I was sort of decorative erm, [laugh] perhaps decorative is the wrong word to describe me but **I think it, it helped them make a political point**'.

5.2.9 During my first term as a lay member of a regional health research funding panel I was privileged to work with some very skilled and competent professionals; several of whom were experienced in patient and public involvement. Unlike colleagues in other regions, it was rarely necessary for me, or my fellow lay member, to raise difficulties with the treatment of study participants, or any weakness in the patient and public involvement proposed, in applications being reviewed by clinical or academic panel members. They would identify these issues themselves, in their initial presentations to the panel. I did sometimes catch their eye, however, and wonder if the knowledge that two



lay members would be sitting on the panel, listening to their assessment, was something that influenced the way they had read the proposal and framed their presentation.

5.2.10 A similar type of artificial presence was illustrated for me when I witnessed the contribution of a public involvement colleague at a research prioritisation meeting, one which included representatives from a range of NHS and academic institutions. He gave poignant and powerful personal testimony, about the need to research the effectiveness of continuing stroke rehabilitation services beyond the arbitrary period that was in effect at that time. Through his intervention the focus of the meeting shifted from the clean, impersonal paperwork to the often messy and deeply personal impacts illness and treatment options can have on people's lives. In this way he also helped to make present the other human stories embedded in the statistics.

5.2.11 Bringing personal stories into the impersonal, professional research arena is also the concept of patient representation suggested by Abigail during another interview. Her involvement led from her being consulted as part of other people's studies to becoming a member of a multidisciplinary research team. One of the projects they worked on was investigating an intervention she had designed, drawing on her patient experience. Other team members also would ask for her input in the initial design stages of projects, before going to their service user group. She described this changing role: 'I don't do very much actual patient representation because I've kind of moved beyond my experience'. This again places the focus of representation on the act of drawing on personal individual experience. However Abigail was also concerned about the potential for research to be 'skewed' by overreliance on a few 'expert' patients, or even through an overconcentration on experiences of illness rather than being open to broader social contexts. She felt that useful input could come from experiences of 'just being a healthy participant'. She explained 'sometimes I think you can lose sight of what's normal as a result [of only involving patients]'.

5.2.12 Ellie, an interviewee with experience as a service user researcher, found involvement as a patient representative in a broader research prioritisation process took her beyond her experience in a way that caused her

concern: 'I just didn't feel I had the personal knowledge ... or experience to be assessing some of those. Some of them I felt very comfortable doing but... there were a number that I thought actually, I'm probably not the right person to be doing this.' A different perspective came from Jennifer, a participant with wide experience of involvement on research funding panels as well as project steering groups. She sees herself representing others by 'putting yourself in somebody else's shoes and saying: "if I were this person in this piece of research what is it going to mean to me, how would I want to be treated, what do I need to understand?" and all those things'.

5.2.13 This version of representation goes beyond the provision of personal testimony. It calls for an imaginative act of wearing 'somebody else's shoes'. This may not draw upon individual health care or research experience and could mean overcoming or masking your own feelings rather than calling on them directly. Therefore, Jennifer argues, representation in health research is a role that requires particular skills and aptitudes: 'there are people that are good at, at, at being PPI representatives, there are people that are good at, at, at, running support groups, there are people who are good at providing helpline information and... they're not necessarily the same people' (box 4).

5.2.14 As can be seen from its employment by these interviewees, the concept of representation is not unified or consistent, it is used in a number of ways. When Oliver speaks of the College representing both the specialism and a particular professional group, he implies that it works to present the interests of either the abstract concept 'the specialism', or the people in the professional group. Yet, when he reveals his concerns about his representation of 20 million patients, the meaning is less clear, particularly as he later cites his high level of education as one of the reasons for not being representative, something that could be seen as aiding the ability to represent in the first sense. Here he seems to be using it in a sense closer to the idea of being statistically representative, or at least sharing similar characteristics to, the population of patients in this field. Elsewhere he also refers to the imbalance of his role of representing so many patients on his own, in a room where the far smaller population of professionals has 25 representatives.

5.2.15 Oliver is also very aware of the totemic impact patient representation can have, particularly in a politicised field. For Abigail and Ellie the symbolism of patient representation seems less important than being in a specific role that focuses on sharing knowledge drawn from personal experience. Whereas for Jennifer the role is explicitly about examining research processes from the perspective of potential study participants and ensuring the potential impacts on them are fully considered. Given this wide range of understanding it starts to become clear why the ‘representativeness’ of patient and public involvement in health and social care research is so vulnerable to challenge (Beresford and Branfield 2012, p33, Boote et al 2002, p223).

### 5.3 Representation as legitimacy

5.3.1 This brings us to the second question about representation that was raised earlier: how is it possible to make a judgement about what count as legitimate forms of representation?

<b>Table 4 Competing concepts of ‘representation’ as legitimisation</b> (from Maguire and Truscott 2006)	
Elected by	Has achieved a majority vote in a process agreed as legitimate by those represented
Similar to	Has characteristics, experiences, interests or skills in common with the population, group, community or organisation represented
Nominated by	Has been asked, invited or appointed by a group, community or organisation
Presenting a case for	Is present to advocate a particular cause or protect a particular interest. This may be on behalf of group, community or organisation or for a more abstract constituency – e.g. the environment
Answerable to	Will in some way be held accountable for their actions and decisions. This may be at formal meetings, through briefings and reports, or what was described as ‘walking on the streets’ i.e. by living/working in close proximity to those they represent

5.3.2 The accusation of being ‘unrepresentative’ is one that will be familiar to most people with experience in public or community involvement or engagement across a number of fields. Research into Local Strategic Partnerships, partnerships between local government, service providers and communities set up under the Blair government, showed that the concept of ‘representation’ was frequently ‘used to claim privileged legitimacy in contrast to

an “unrepresentative” other’ (Maguire and Truscott 2006 p13). That study identifies five meanings of the concept of representation used by members of Local Strategic Partnerships: elected by; similar to; nominated by; presenting a case for; and answerable to (table 4).

5.3.3 All of the categories that were identified in Local Strategic Partnerships have featured in the interviews for this study (table 5). For Amy, her election by group members onto the board of a national organisation, and her nomination by that board to represent service users on the board of a professional body, were important factors in legitimising her role, particularly after she had ceased to be a direct user of those services herself.

5.3.4 John was a member of a patient and public involvement group attached to research body. This group included people with a range of different health and social care issues, including patients and carers. When discussing researchers seeking patient and public representatives for their projects, he identifies within that group: ‘five people now who’ve got [condition] ... So there’s five people who can go to represent people.’ In this then he is clear that legitimate representation within these research studies is, for him, based on having personal experience of the particular condition.

5.3.5 However John also talked of representing the patient and public involvement group as a whole at board meetings of the research body. This contribution he saw as being legitimated by the act of ensuring that all the group members knew he was taking on this role, and therefore could hold him to account: ‘I sent the answer back to everybody - you know to ‘all’ so that everybody knew that I was putting meself forward’.

5.3.6 Interestingly, this is a position that was explicitly reversed by another interviewee, Alan, who argued that by not positioning himself as a ‘representative’ he was relieved of being held accountable for what he said: ‘I’ve got a code of conduct that I have to adhere to with any organisation and I wouldn’t represent an organisation if I wanted to be challenging...’ He had been involved in a wide range of forums, panels and projects and was actively seeking more involvement opportunities. He described his role in a number of forums as ‘public contributor’ and saw this as substantively different from acting as a ‘patient’ or ‘lay’ representative. He acknowledged that his behaviour in this

role was sometimes perceived as difficult and challenging: ‘... I can do that [challenge service providers] as an individual – I don’t need to be with a body of people, because people know how I am – people say I’m aggressive but I’m assertive...’ Alan’s claim seems to be that to ‘be challenging’ is legitimate as long as he does not do so as a representative of any specific group able to hold him to account.

Elected by	Amy: ‘the trustees of [national organisation representing service users] are voted for by the membership ’
Similar to	John: ‘I think there’s five people now who’ve got [condition] within the group. So there’s five people who can go to represent people.’
Nominated by	Amy: ‘[professional body] asked for a [national organisation representing service users ] representative on its board and they nominated me’
Presenting a case for	Jennifer: ‘it is essential that the people who are going to be participating in this research have somebody to represent them’
Answerable to	John: ‘I sent the answer back to everybody - you know to ‘all’ so that everybody knew that I was putting meself forward.’
Petitioning	Oliver: ‘we did a lot of erm, activity around the Health and Social Care Bill... which generally the College... didn’t think was a terribly good idea... so we had – I think in the end four meetings with ministers.’
Symbolising	Oliver: ‘I had a kind of symbolic role... I was sort of decorative... it helped them make a political point’
Statistical	Abigail: ‘just being a healthy participant, so you don’t actually necessarily have to be a patient to be involved in research... the more people who get involved or anyone who is in research is going to make research better... sometimes I think you can lose sight of what’s normal.’

5.3.7 In addition to the competing concepts of representation in table 4 this study has also highlighted representation as petitioning or ‘making representations to’ which is in some ways similar to ‘presenting a case for’ but perhaps reversed or seen from the other end of the relationship, specifically implying a significant and conscious difference in power between the

petitioner(s) and those being petitioned. This is, for instance, demonstrated by Oliver's story of the Royal Colleges meeting with ministers to express concerns about the Health and Social Care Bill. Another addition is representation as totemic, creating a symbolic presence. This is discussed above in the cases of Oliver's personal role in the visit to the Secretary of State, my role on the funding panel and that of my colleague in the research prioritisation meeting (5.2.8-9). Abigail's comments about how research can 'lose sight of what is normal' (5.2.11) also raised the issue of statistical representativeness. This is a concept that is particularly important in the context of research.

5.3.8 The problem of using the concept of statistical representativeness in involvement is a particularly thorny one. Clearly it is not practical to demand the same sample size for the public involvement representation on a project steering group as would be required within the study to ensure statistical significance. How then can public involvement of any affordable dimension be seen as representative in these terms? This issue has led to some bizarre contortions, where public bodies have tried to apply completely inappropriate measures of diversity and inclusion. For instance the 'People's Commissioning Board' a public involvement initiative by the Clinical Commissioning Group in Cornwall pledged to include: 'representatives from the nine protected characteristics groups'<sup>33</sup>.

5.3.9 This is a damaging misunderstanding and misuse of the concept of protected characteristics. It is a conflation of the discourses of diversity and equality. Under the 2010 Equalities Act protected characteristics are defined in order to afford protection from unfair discrimination or exclusion based on irrelevant individual qualities or group affiliations (appendix 13). To envisage these characteristics as constituting groups in themselves is an absurdity, particularly as they include the characteristics 'age' 'sex' and 'race'; characteristics that most of us could own to in some form, without necessarily considering that this makes us members of a particular group consisting of

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<sup>33</sup> <http://www.kernowccg.nhs.uk/get-involved/peoples-commissioning-board/> When accessed on 19/04/14 this page read 'representatives from the nine protected characteristics groups.' following correspondence from the author the wording on was amended to 'representatives of people with protected characteristics'. This interesting, but still leads one to wonder who might be seen as people without protected characteristics. (accessed 03/05/14)

‘people having an age, sex or race’. The fact that, in practice, these groups are likely to be defined more narrowly simply opens the question of who has the power to delineate those definitions, and on what basis is that done.

5.3.10 Within this study, several male respondents reported concerns about the fact that there are more women than men involved in many patient and public arenas. Sometimes this left them feeling excluded or marginalised. Alan said ‘They’ve [particular condition groups] got defined people. Dominantly again, female, maybe men are less likely to be involved for whatever reason but erm, they stick with the same people’. He saw this as an endemic problem and later, speaking of a national organisation supporting involvement, he went on ‘ – if you wanna demonstrate that you can walk the walk after you’ve talked the talk, you only have to look, the whole staffing compliment are female, [organisation’s] , and I’m not knocking that because they’re competent and they’re the best person then that’s fine, but you have such a thing as a gen... you know, a genuine occupational qualification, if you want to include your diversity’.

5.3.11 In practice this sort of thinking about diversity as represented through a numerical spread across delineated groups can create a circular relation and an illusion of representation, similar to that identified by Bourdieu. The ‘protected characteristic group’ would not be representable, i.e. ‘would not exist fully as a represented group if [the representative] were not there to incarnate it’ (Bourdieu 1991, p204). So the ‘protected characteristic group’ for instance for ‘race’ can only exist, as a ‘group’ represented on the ‘People’s Commissioning Board’, through the choices the organisers make about how representation of that group might be constituted. It might also be imagined that these choices would be most visible, to potential participants, through who is excluded from representing ‘race’. This sort of mechanism then leads to the perception, voiced by another interview participant, Edward, that ‘the most unrepresented person in this whole country is the white, working man’.

5.3.12 A result of this, once again, is to leave any actual involvement open to the accusation of being ‘unrepresentative’ either on the basis of where the boundaries of the ‘groups’ represented have been set or because an alternately defined ‘group’ is not present. There is perhaps little wonder that

mechanisms of involvement have sometimes struggled to define, measure or defend their 'representative' qualities and why lack of 'representativeness' can be a useful way to delegitimise whatever is done in practice. Representation seems to be far too complex to be contained mechanistically within any one of these definitions. As Oliver so eloquently discussed, it is possible for an individual acting in a single role to demonstrate a range of different 'representations' and also to be aware of how they are 'unrepresentative' in yet another sense.

5.3.13 Perhaps this also implies that it is not always possible, or necessary, for there to be explicit 'mechanisms through which lay members can act as representatives of broader constituencies' (Barnes 1999). I was, however uncomfortable with Alan's idea that that the lack of such mechanisms meant one was relieved of accountability for the views put forward. This seems to be a very narrow interpretation of the words 'public contributor', and one that ignores values other participants have suggested are implied by taking a seat in a patient and public involvement knowledge space. These have included ensuring public funds are well spent and that issues of public concern are addressed, in addition to contributing service user experiences and ensuring participant safety. To put myself into the role of 'public contributor' or 'public representative' would feel like a substantial responsibility, a feeling that was echoed by Jennifer's statement 'it's important that we're represented; let's do it properly'. This is important, because to do otherwise can undermine the whole enterprise; 'when the salad bowl is passed, all one of us has to do is spit in it and it's all his, since no one else will want any more of it' (Serres 1995 p33).

5.3.14 Representing, or contributing on behalf of, 'the public' is to put yourself simultaneously into many 'somebody else's shoes' and, as Oliver says, this can be 'sort of paralysing' if you stop to think about the responsibility inherent in that act. This is a conscious intrusion of the anguish that Sartre describes as asking do I 'have the right to act in such a manner that humanity regulates itself by what I do'? (Sartre 1989a, p32). This being the case, I have some sympathy with Alan's reluctance to shoulder this responsibility, but it is not, to my mind, a responsibility that can be discarded by changing a word in the role description.



5.3.15 My own experience as a patient or lay representative has frequently been a complicated one of moving between these different roles. As a member of funding panels I took part in the assessment of research proposals covering very many different conditions and constituencies. I relied on a wide range of life experiences, not just my own health and caring role. Of enormous value were the written reviews, clinical, academic and lay, that helped to steer me to issues beyond my competence to assess. This experience in turn makes me take the role of providing lay reviews for research proposals very seriously.

5.3.16 Sometimes my experience is not a direct match to the project I am asked to review. Recently I reviewed a proposal for research into a rare and debilitating genetic disorder. It is unlikely that the funders could have found someone with that exact condition to comment on the proposal. Because my son's condition was genetically transmitted, I was able to extrapolate from my family's experience of issues like disclosure to other family members, and antenatal diagnosis. While drawing on my own experience I still needed to remain aware that others may feel very differently. To achieve this I also drew on conversations held over the years, in hospital waiting rooms, round the table at the children's hospice or over the garden fence. While not wanting to become prissy about my acts of representation, in taking this on I do see myself as accountable, not only to the funding body and the research applicants, but to potential study participants, patients and carers, taxpayers and all those who I have learned from or been helped by in order to be able to tackle this task.

5.3.17 Equally, if I am nominated by, or answerable to, a particular group or constituency in some role, that relationship will be held in mind, but I will also draw on other personal knowledge and skills in fulfilling that representation. Therefore the complex web of accountability would still apply. This notion of accountability, 'being answerable to', is key to representation for me personally, linking representation to the ethic of the public ownership of knowledge (section 2.3). This accountability may not be manifested through any set process, of attending meetings or writing feedback. It manifests in how I approach the work, through an imaginative consciousness of other perspectives, through reflecting on and assessing my performance of the tasks I undertake, and through being open and honest about how I fulfil those roles I take on. The idea of sidestepping that accountability by not aligning oneself to any particular group is

one I find perplexing and dangerous. One of a number of dangers, like that of disabling discussions by over generalising (section 5.1.1), that seem to arise from a preoccupation with words over meaning.

5.3.18 As well as provoking these personal anxieties the complexity of this multifaceted concept, 'representation', has frequently led to confusion and incoherence in involvement policy. A discourse analysis of publicity materials produced by the Commission for Patient and Public Involvement in Health (CPPIH) found that it appeared that the people they were looking to involve needed to personify a 'strange mix of representativeness, diversity, ordinariness, knowledge and expertise' (Martin 2008, p46). Martin quotes a CPPIH leaflet which requests involvement from 'ordinary people only' going on to explicitly exclude 'experts' (Martin 2008, p47). In the next section I will try to open out the content of this idea of 'ordinariness' or more specifically how 'ordinariness' as opposed to 'expert' is encapsulated in the term 'lay people'.

## **5.4 What is the opposite of Lay?**

5.4.1 Lay was one of the words rejected as unacceptable, even offensive by some people, in the discussion at the INVOLVE conference described above (section 5.1.1). The word was seen as implying a lack either of status or of expertise. These are both qualities that could be seen in Bourdieu's terms as institutionalised forms of cultural capital (Bourdieu 1986, pp241-258). This problem perhaps comes from the definition of the term 'lay' in opposition to the terms 'clerical' or 'professional' as well as to 'learned' or 'expert'. Collins and Evans (2002) specifically dismiss the term 'lay expertise', describing it as an oxymoron, on the grounds that 'the dictionary definition of "layman" includes the sentiment "someone who is not an expert"'.

5.4.2 However, in the dictionary on my desk (the eighth edition of the Concise Oxford Dictionary) that definition of 'layman' reads 'a person without specialized or professional knowledge in a particular subject' (Allen 1990, p671). This is a subtle but, I would argue, important difference in definition which does enable lay expertise to be seen as a coherent concept. It is coherent as knowledge that is not specialized, but that is contextualized. It is coherent as containing knowledge about that which is common, ordinary and

everyday. It is coherent as an expertise that is not professional, an expertise that is unprofessional or an expertise that is, in effect, anti-professional.

5.4.3 The rejection of this word at the conference saddened me because its etymology is one that has particular personal appeal to me, as a community activist. In this meaning 'lay' is derived from the Greek word 'laikos' (λαϊκός) (Torjesen 2008, p390) meaning of or from the people, from that it came also to mean unofficial or civilian (Liddell and Scott 1940 p1024). It was also used to describe the ordinary and everyday (i.e. that which is not ritually sanctified) when applied to places, to bread etc. This concept, of ordinariness and being of the people, implies a much broader constituency than the one which stems from the root of 'democracy', the 'demos' (δῆμος). The demos referred to the sovereign citizens of a particular Athenian political unit (Liddell and Scott 1940 p386). This would always be a limited group that did not include all the people. In Athens at the time of Aristotle's collection of political constitutions at the Lyceum (335–322 BC) the demos meant only adult men who could demonstrate their position in the lists of citizen families through the lineage of both parents (Aristotle [c330BC] 1996 b, p243).

5.4.4 Laikos, in its sense of meaning 'unsanctified', was used by those who translated the Hebrew bible into Greek and by extension it came to be applied to church members who were not ordained. It has been argued that one of the social forces leading to the division of the Christian church into 'clergy' and 'laity' was the need to adapt to the importance of social class and patronage that existed within Roman society, as wealthy and influential Romans were integrated into the church leadership (Torjesen 2008, p392). It is by a further extension, into secular practices, that lay also became the opposite of the authority of the learned and the professional, particularly in the fields of law and medicine (Allen 1990, p671). Of these medicine has the additional claim to authority that comes from its close bonds with the scientific knowledge, which 'holds a privileged status in the hierarchy of belief' (Starr 1982, p4).

5.4.5 I therefore relish the title 'lay representative' as a connection with the ordinary, the mundane and the profane. This not only reflects my background as a grass roots community activist it also calls to my irreligiosity and egalitarianism. As a lay representative I can be seen as a contributor of

unsanctified knowledge, or 'common sense', reminding researchers 'that science is a search for truths rather than a particular set of methods' (Popay and Williams 1996, p766).

5.4.6 In the fields of environmental and public health it has long been argued that 'lay knowledge' is a valuable resource. This resource can help us better understand the impacts on people's health, which are inherent in the complex relationships of individual behaviour with environmental and social circumstances (Wynne 1989, Popay and Williams 1996, Popay et al 1998). With the shift of emphasis in health care from the treating of acute illnesses to the management of chronic disease (Holman and Lorig, 2000 Wagner et al 2001), these complex relationships become ever more apparent, and important in shaping our understanding of health, illness and care (this is an issue that will be discussed further in chapter 6).

5.4.7 It has also been argued that there is a limit to the value of 'lay expertise' (Prior 2003), and that lay people sometimes get things wrong. I doubt many of those involved in health and social care research would argue with the latter statement. However I think it is an abuse of that argument to extend it, as Prior does, to blame the poor and possibly actively fraudulent research of Andrew Wakefield (Wakefield et al 1998 and 2000) on the fact that a question about a link between the MMR vaccine and developmental problems in children was raised by lay people. Prior even goes so far as to suggest that Wakefield, in attempting to research an issue beyond his field of expertise, was in fact acting as a layman rather than a scientist. My response to this point is to refer the reader back to Ellie's story in the previous chapter (box 2) and ask them to reflect on the role of research publications in the career structure of clinicians and academics. I believe that offers a better explanation for shoddy and overstated research than any lay involvement in scoping questions, while the idea that scientists are not scientists in a true sense when they are wrong is a wildly anachronistic claim, ridiculed by Plato (Plato [c380BC] 1955 pp68-71).

5.4.8 Within this study the word 'lay' was used extensively in interview and survey data (appendix 12). In interviews it was used 85 times by 16/31(52%) of respondents in the survey 63 times by 27/105 (26%) of respondents. As with 'representative' it was most often used as a given term, to

describe a role (e.g. Dorothy: ‘they had vacancies for **lay** members...’) or to describe a task (e.g. Helen: ‘I’ve just done a **lay** review recently’) or to as part of a group’s name (John: ‘we now have a **Lay** Panel group’). It was also used to describe a particular viewpoint, as I discussed in detail in chapter four (e.g. Kenneth: ‘my experience of good and bad leadership and management in the health service from a **lay** perspective’).

5.4.9 The role of ‘lay member’ was seen by some respondents as carrying a different level of responsibility to that of the professionals (e.g. John: ‘I’m just sort of there as a **lay** member, there’s no pressures on me and I quite enjoy just going to the meetings and listening to it’). It was also sometimes used in a slightly disparaging way (e.g. Elizabeth: ‘I was just er, a **lay** person helping a researcher’ or Dorothy: ‘but you review somebody’s complete thing, not just the **lay** members’ part of it’).

5.4.10 The characterising of lay knowledge as of less value than scientific knowledge was sometimes seen as an issue (Ross: ‘I think there’s a severe underestimation of **lay** knowledge which is endemic to the medical community and it’s a very serious problem’). This led some participants to find the term itself problematic (Harriet: ‘I think that’s a bit patronizing to be honest. **Lay-ness**, what’s that supposed to mean? So “somebody who isn’t in the know” we’re talking about.’)

5.4.11 This lack of clarity, about the content of ‘lay’, was sometimes seen as leading to confusion and to confounded expectations. Ellie, coming from a tradition in mental health research of the involvement of ‘experts by experience’ (Weinstein 2010), found the involvement of ‘lay people’ in assessing research proposals, on issues of which they had no direct experience, uncomfortable and not necessarily useful. She argued ‘I do think, you know in terms of reviewing proposals for funding and stuff then actually having people who have the related experience is more valuable than just having a group of so called “**lay** people”’.

5.4.12 Another respondent who has been involved in a wide range of health service and research arenas, Alan, also said that he felt for some roles ‘people should be recruited on their conditions and not necessarily on interests’. Although he then went on to argue that acting as a ‘**lay** or public contributor’ did not always demand personal knowledge or first-hand experience of a condition

or a service. He spoke of contributing to projects based on what he had learned of the condition from 'Google' and was confident of his ability to provide lay reviews in a wide range of fields: 'I'll learn you know, vascular dementia or sort of like about stroke rehabilitation or whatever it is, but I'm not the expert 'cause I've not got that experience, but if somebody wants somebody to quickly do a **lay** review... I can do that quickly'.

5.4.13 He also discussed approaching early career researchers, to offer advice on their funding applications, based on his experience as a lay reviewer and public contributor on a research funding panel, in exchange for being given a paid role, should the proposal be funded. He expressed frustration and perplexity that the funding body he worked with had vetoed this suggestion. He went on: 'I'd like to be able to phone up that researcher on a one off, on the basis that there's no payment, but you get to lay review, and should they be successful, then you be a part of that particular team. And to me, I think that's right – that's okay'. In this Alan seems to be framing the role of lay reviewer of a research proposal as an expert in the patient and public involvement requirements in health research funding. This is not a view I found to be widely held. The role of co-applicant and the issue of how accessible and transparent recruitment to these roles is or is perceived to be are both things I will return to shortly (5.4.16).

5.4.14 Here I want to expand on the issue of confusing roles, conflicting interests and how this might impact on the issue of 'layness'. I think there is a real problem with Alan's suggestion that lay members or even former members of funding panels should approach researchers in the way that he suggests. Funders issue specific guidance, which is frequently updated, and have qualified staff that can advise applicants. They may invite lay participants to talk about their experiences or to discuss why they believe patient and public involvement is important, but this is fundamentally different from advising applicants on what to say in their particular application in order to get funding.

5.4.15 A lay review is a formal assessment of a proposal with a particular focus on issues like: the importance of the research question and prospective outcomes to patients or care givers; the clarity of information for participants; the likely acceptability of protocols; as well as the contribution patients and

carers made to the proposal. It is intended to act as a counterbalance to the focus on clinical and methodological concerns that are addressed in peer reviews from other professionals<sup>34</sup>. In this context I would feel that an expectation of a paid role within that project, should it be funded, would represent a substantive conflict of interest. In this Alan seems to have confused the role of a lay reviewer with that of a consultant or an advisor.

5.4.16 Other interview participants, who had acted in this sort of consultancy role in funding proposals, whether they had gone on to become co-applicants or not, brought to those roles some specific experience of the condition or service that was the subject of the research and/or a particular expertise that was relevant to the role, rather than a more general public perspective. As well as having extensively used the services being evaluated in the project on which she was co-applicant, Elizabeth's previous career had also involved conducting interviews and analysing responses. She acknowledges that developing relationships with active researchers, through her involvement in groups focused on service improvement and other networks, has meant that she has become someone seen as approachable and competent.

5.4.17 Other interviewees including Phoebe, Thomas, Edward and Grace, described these sorts of developing relationships leading to them being invited to become increasingly involved. For both Ellie and Georgina this was sometimes presumptuous on the part of researchers and health service professionals, putting them under unwelcome pressure. Georgina described herself as becoming the 'go to person' for a particular condition. This tendency, to return, repeatedly, to contributors who have proved valuable on previous projects, can also be seen as an explanation for Alan's feeling of being excluded, and therefore for him looking for other routes to become more involved. Researchers who had experienced his behaviour as challenging and aggressive, or assertive, in the past might not choose to invite him back. While researchers might see this as expediency it may be experienced by participants as favouritism and exclusivity or, as described in David's story (box 3), dishonesty.

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<sup>34</sup> Adapted from 2013 guidance to lay reviewers for the Research for Patient Benefit programme, the National Institute for Health Research.

5.4.18 It is perhaps also understandable that researchers might find it easier to work with people who have some research experience, particularly when they are contracting to deliver specific outcomes for funders. For both Nicole and John their extensive personal and familial experiences of particular medical conditions were central to their involvement as contributors and co-applicants on projects. However both admit that, initially, they had not recognised, or had it adequately explained to them, that by becoming co-applicants they were making a formal commitment to a piece of research. This was a different level of involvement that they had not felt prepared for. In his diary for this project, John wrote:

**Box 9 John on becoming co-applicant**

As the meetings progress I found a little more about what was required of me but not everything, as a member of [public involvement group] you are free to attend the meetings that you want to, but being involved in a project as a co-applicant you come under a different umbrella as you are signed up as to the project and you have been put down as being involved in the project say for instance 2% per week or per month to be involved in the project, this then becomes a requirement not a choice, unfortunately this was not explained before we signed up as this may have given me a different outlook on whether I would have been involved as a co-applicant.

5.4.19 In spite of the concerns he expressed here, John went on to put himself forwards as co-applicant on several other projects. The difficulty he had with the role was that he felt unprepared for the difference between making a voluntary contribution, as and when he felt able, and making a contractual commitment. For him 'lay' had, until then, implicitly included the concept of voluntarism.

5.4.20 Jennifer has been involved in a number of roles in research that related to the services she had used, she also had a professional background in communication. When I spoke to her she had been helping to developing an extensive patient and public involvement element of a project on which she was co-applicant. To have a continuing role written into a proposal in this way, specifically on the basis of your knowledge of patient and public involvement, I would suggest, is beginning to move towards taking on an 'expert' rather than a 'lay' role. In which case it becomes essential to be able to demonstrate that expertise, something Jennifer was able to do.



5.4.21 This also resurrects the issue of the potential professionalization or ‘taming’ of lay contributors through their interests becoming too closely aligned with those of the academic or clinical researchers. On this issue, and against Ives et al (3.5.2), I would argue that training participants in the skills they would need to participate in a range of on-going research roles and activities is not necessarily something that leads to such congruence of attitudes. It is, in fact, often a lack of appropriate support and training that tends to lead researchers to involve people who already have a professional background and who may therefore also already share many of the researcher’s social characteristics and understandings, something Jennifer highlighted in her interview (box 19).

5.4.22 As explained in section 2.5.2, the sampling methods I have used do mean that the characteristics of respondents to this study may be significantly different to those of the population of people in patient and public involvement roles in research as a whole. However it is probably still worth noting here that over 56% of survey respondents reported having been educated to the level of a Bachelor’s or a higher degree.

5.4.23 Interview participants frequently referred to their educational attainment, or professional skills, as something they brought to their involvement, whether in terms of being able to tackle the paperwork, understand the numbers or advise on project management. Thomas talked of his managerial background; Elizabeth and Jennifer had worked in fields that involved investigation and research; Nicole and Hannah were among those who talked of their degrees as providing useful skills. Oliver felt that his academic background had probably played a part in his selection, as a member of the lay advisory group for a medical specialism College: ‘I think they were quite keen on the idea that I’m a sociologist, I’m a qualitative researcher. Because I think they, they’ve got all the scientists they need.’ However he was also aware that this, to some extent, muddied the waters of his ‘layness’: ‘[W]here does, does - the boundaries - where do you draw it? And I think “Am I there as a **lay** person or am I there as someone who's actually kind of an expert?” But it's an expertise that they've not got. ’

5.4.24 Some of the professional experiences and expertise that are brought to patient and public involvement may be more closely related to the field. Three of the interview participants in this study had previously worked in allied health service roles, one as a nurse, one as a pharmacologist and one as a medical administrator. All three had profound knowledge of health and social care as services-users, but they also felt that their professional training or work experience gave them different or additional insights. This is a similar, but reversed, claim to Abigail's description of her 'duel perspective' (4.6.26).

5.4.25 Some participants felt that there were specific dangers in including people professionally involved in healthcare, either previously or currently, within nominally lay groups. When I first spoke to John he had been particularly unhappy that a Lay Panel he was involved in, within a condition specific research network, was chaired by a practicing healthcare professional who was also a patient. John felt that this skewed the nature of the group, and effectively disempowered other members. At one point he had considered resigning because of this and he did refuse to stand as vice chair. Yet, when I spoke to him some months later the network had a new manager who 'has got the, the same views as myself and a few others, that clinicians even if they have got the problem should not be allowed to take a position on the management, you know on the like, yeah like chair or vice chair or whatever. Because I just think, feel that they're you know, they're trying to get in their clinical goal, you know, sort of thing and they're not really for the actual **Lay Panel**'.

5.4.26 Describing the outlines of 'layness', what it is and what it is not, can, as we found with representation, prove to be a thorny conundrum. Even the interview participant who had probably given this issue the most considered thought, and who had the most honed theoretical tools with which to frame it, still struggled. Oliver said 'I think it's important to say you know, when you're this thing or that thing; you're advising because of that, and not because of – I don't know'. However as Thomas Haskell has argued, in a discussion of the related terms, 'amateur' and 'professional' 'our inability to agree upon the exact line of demarcation ... does not make these categories themselves unintelligible, any more than the indistinctness of the boundary between the colors red and yellow in the light spectrum prevents us from describing some objects as "red" and others as "yellow."' (Haskell 1981, p490)

5.4.27 Even if we cannot draw exact boundaries it may be possible to set out terms and ideas that form the content or the context of layness and other discourses of involvement. In the next section I will begin to place these contested discourses in relation to some of the social movements and political forces that have effected changes in involvement in health and social care, some of which I have previously described through the lens of juridification (section 4.7).

## 5.5 Words, structures and movements

5.5.1 As discussed in section 4.7, the involvement of government in the governance and provision of health and social care can be seen as based on its need to contain and manage social conflicts and political struggles. The relationship between the rising importance of illness and medicine to government and the professionalization of medicine is complex. During the 19<sup>th</sup> century scientific medicine gained a level of social legitimacy that was 'quite divorced from its practical achievements' (Shortt 1983, p63). It has been argued that, in part, this was achieved by the use of 'science' not only as code for a particular methodology, and a claim of expertise, but also as a 'vehicle for social mobility' (Shortt 1983, p64).

5.5.2 The purpose of the 'many medical men'<sup>35</sup> and others who met together in organisations like the Manchester Literary and Philosophical Society from the late 18<sup>th</sup> and early 19<sup>th</sup> century, may have been for secular discussions 'promoting the advancement of education and the widening of public interest in and appreciation of any form of literature, science, the arts and public affairs'<sup>36</sup>. In this they were ideologically a body of the 'public sphere' (4.7) 'intending to grant their members the freedom to express and publish their opinions about matters of general interest' (Habermas Lennox and Lennox 1974, p49). However it was also a movement for the ratification of a new rational scientific world order (Shortt 1983, p64) and for the place of this equally new, largely industrial and nonconformist, social class within that order. It was by aligning themselves with the authority of science, that the members of these aspiring medical professions supported their entrance into the political class, of 'urban

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<sup>35</sup> <http://www.manlitphil.ac.uk/#> (accessed 03/05/14)

<sup>36</sup> *ibid*

and rural bourgeois notables – *gentlemen*’ (Weber [1917] 1994, p120). This was central to the power of the academic and medical institutions that developed through the 19<sup>th</sup> and 20<sup>th</sup> centuries. In this way the development of medicine as a profession can be seen as not simply an action of ‘self-interested economic actors, but regulated by a normative code’ (Scambler 2002, p14).

5.5.3 A consequence of this social movement was the re-definition of the terms in which health and illness might, respectably and plausibly, be discussed. This moved understandings of health and illness into an explicitly ‘scientific space’; a space that, while nominally public, was in fact restricted and difficult to access (Shapin and Shaffer 1989). Doctors were initiated into a language appropriate to scientific diagnosis and patients became increasingly reliant on the doctor in order to access sanctioned treatments. Through this means, the men of the new medical middle class were afforded ‘a secure occupational niche and a share of power far out of proportion to their numbers’ (Ehrenreich and English 2005, p78). Patients were increasingly alienated from this privileged understanding of their own bodies and health.

5.5.4 Developments in science, including the biosciences have tended to distance it from the language and understandings used in everyday life (Williams, 1984). Policy makers also use language in order to address their own priorities. It is perhaps not surprising that this has sometimes led to the sort of damaging miscommunications discussed in the previous chapter. The development of mass communications has meant that scandals and conflict have been subject to increasing, and increasingly speedy, publicity.

5.5.5 By the end of the twentieth century there had been a marked decline in the deference people showed to doctors and a range of other experts, as well as a greater sense of personal responsibility for health and lifestyle decision making (Elston 1991). This was part of a reassessment and re-politicisation of the limits of science and medicine and part of another social movement, contesting power structures that had become settled. The civil rights movements, which became prominent in the 1960s and 70s, highlighted issues of inequality and power across a wide range of social and political institutions. These challenged the boundaries between the personal and the political.

5.5.6 Feminist literature promoted becoming informed about your own body as emancipatory political action (Phillips and Rakusen, 1978). The medical profession was particularly targeted as a representation of the patriarchy. It was accused of pathologising the feminine, treating women's bodies and behaviour as abnormal because they were not the same as those of men (Ehrenreich and English 2005, p120). The increasing use of lobotomy on women in the mid-20<sup>th</sup> century was seen as a stark example of this. This is highlighted by studies like that of Braslow, who undertook a retrospective study of medical records from the late 1940s and early 1950s at one California state psychiatric institution. It showed five times as many women as men were lobotomised. The study concludes that, although psychiatrists believed they based their decisions on science, in practice they 'incorporated prevalent cultural views concerning women... both in how they determined surgically treatable psychiatric disease and how they measured a woman's response to the surgery' (Braslow 1999 p294).

5.5.7 One response to the controversial psychiatric practices was the Mental Patient's Liberation Movement (Alvelo 2009), activists and 'survivors' of the psychiatric system who campaigned for reform. Academic writers like Szasz (1960) and Goffman (1961) were also strongly critical of the definition of an increasing number of experiences and behaviours in medical/scientific psychiatric terms. Illich argued still further, that biological medicine had widely moved beyond an attempt to 'enhance what occurs in nature' into trying to 'engineer the dreams of reason' (2002, p39).

5.5.8 The disability rights movement and the social model of disability (Oliver 1983) provided further challenges to some of the assumptions underlying the design of services and priorities for health research. This drew a distinction between impairment and disability, arguing that disability is something imposed by society on people with impairments, by excluding them from full participation. In 'Nothing about us without us' James Charlton (2000) uses this explicitly political slogan to demand that people with disabilities should be more involved in decision making processes and research.

5.5.9 The disability rights movement also campaigned to force those in power to 'recognise that the experiential knowledge of these people is pivotal in

making decisions about their lives' (Charlton 2000, p17). This raises the importance of involvement as a source of distinctive and valuable social knowledge. In this tradition, many people involved with mental health services and research describe themselves as 'people with lived experience'. Disability rights activists and people with experience of mental health services have been particularly forthright in their arguments that these movements should not be confined to shaping services, but should also shape knowledge. This involves developing a relationship between researchers and the people being researched, in which: 'researchers have to learn how to put their knowledge and skills at the disposal of their research subjects' (Oliver 1992, p111)

5.5.10 Another civil rights struggle which went on to have a profound impact on involvement in health research was that of the gay rights movement. Gay people ran a prolonged campaign to have homosexuality removed from the Diagnostic and Statistical Manual of Mental Disorders in the US and the World Health Organisation's International Classification of Diseases (McLaren 1999; Smith, Bartlett, and King 2004). The movement used civil disobedience and a campaign of 'zapping' (Conrad and Angell 2004), flamboyant and often humorous disruptions of psychiatric conferences. My own first experience of an academic conference was the 'zapping' of a congress on 'Psycho-sexual Disorders' at the University of Bradford in the early 1970s.

5.5.11 It has been pointed out that one of the reasons for the, at least partial, success of this campaign was the fact that the gay community, at that time, was dominated by white middle class men including: intellectuals, artists, scientists, educators, and health professionals (Epstein 1996). However that it did succeed demonstrated that people can contest the boundaries of medicine through political action, a moment at which the creation of civic epistemology became visible, and truth was altered by public protest. This was an important shift in the landscape. It also meant that, when people affected by HIV AIDS felt that medical research was not addressing the issues that were of vital importance to them, they had a model of direct-action, and their ranks included a self-identified group of activists, expert in techniques that they knew could effect change.

5.5.12 Activism by service users and patients is now well established in a range of health and social care fields, both in service improvement and in research, they are part of a recognised social movement (Williamson 2010). Two of the interview participants in this study identified themselves as ‘activist’: Kenneth as a ‘[condition] activist’ and Lotte as a ‘radical patient activist’. Lotte, someone who has been extremely involved in the patient safety movement, explicitly applied Williamson’s definition of a radical patient activist to herself. That is one ‘who consistently engage[s] in opposing the status quo of current healthcare practices and standards, if they think that they harm patients’ interests’ (Williamson 2010, pxi). Lotte described herself as ‘driven’ to speak out by a ‘need for justice’.

5.5.13 Lotte’s description of her activities, writing to politicians and journals, sending freedom of information requests to health care and research organisations, is indeed closely in line with Williamson’s concept of the independent radical patient activist. That is: someone who seeks to replace coercive policies and practices with new ones that encourage respect and support for the autonomy of patients. Someone who works to ‘unpick part of the tapestry woven by more powerful, dominant social groups and try to weave a new pattern into it’(Williamson 2010 p4).

5.5.14 The role of activist, with its roots in the civil rights movement, already speaks to the existence of communities of interest and identity as well as communities of place<sup>37</sup>. The word ‘community’ was used by 10/105 (10%) of survey respondents and 17/31(55%) of interview participants. Sometimes it was used to describe local geographical areas or groups associated with them, but sometimes it referred to services delivered in people’s homes or in primary care settings rather than in hospitals. There were also mentions of specific communities of identity, for instance the ‘Afro-Caribbean community’ or the ‘traveller community’. Communities of interest were also mentioned: the ‘lay community’, the ‘medical community’, the ‘academic community’ and the ‘radiotherapy community’ for example. An interesting use of the word was in terms of there being a developing ‘community of practice’ amongst those people

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<sup>37</sup> <http://www.cdf.org.uk/content/about-cdf/about-community-development-2> (accessed 03/05/14)

involved in health research and service development. This will be explored in more detail later (section 7.6)

5.5.15 Here it is worth emphasising that in the study data ‘community’ was less likely to be used as part of a given title than the words looked at earlier, ‘representative’ and ‘lay’. Where it was used in this way it often related to having formally been a member of a Community Health Council. The local involvement bodies set up during the 1974 reorganisation of the NHS (4.7). These were bodies charged with feeding local community views into Health Authorities and Family Health Service Authorities. This role was seen as having been undermined by the introduction of a more individualistic consumerist model of health provision into the NHS (Lupton, Buckland and Moon 1995).

5.5.16 One of the organisations Lotte had been involved with was described as a ‘Consumer Panel’. However this was the only reference to ‘consumers’ in the data; none of the survey or interview respondents described themselves as health service ‘consumers’ and , even in the limited context of the ‘Consumer Panel’ the term sounded anachronistic. In the late 1980s and 1990s the term was used widely to describe health service users. It reflected the then Conservative government’s policy of introducing more private sector mechanisms into the public sector, with the stated aims of increasing the influence of people receiving services as well as driving up standards and efficiency through promoting competition. This was a new and different understanding of the relationship between the NHS and service users.

5.5.17 Although it continued to appear in the literature (e.g. Boote et al 2002) it was widely criticised for a number of reasons. These included: a recognition that people using the NHS did not have the same choices as the customers or consumers in the retail sector; a concern that ‘consumer’ does not imply an active partnership in shaping their design and delivery of services (Baggott et al. 2005); a feeling that people access public services as citizens rather than consumers (Denhardt and Denhardt, 2011); and a market approach introduces a ‘competitive, contractual, insular and adversarial culture’ (Pratchett and Wingfield: 1996, p125). On the other hand there is a well respected tradition of consumer activism intended ‘to make individuals as powerful as the



organisations they deal with in their daily lives'<sup>38</sup>. Some groups have been able to use opportunities created by this consumerist approach to influence health service providers and researchers (Barnes et al. 1999).

5.5.18 The New Labour government, at the turn of the millennium, began to promote the word 'citizen' to describe the way people are connected in a welfare state. Lord Goldsmith described this: 'whereas we may once have extended our protection only to other people who were in our family, or on the basis of religion or social class, we do it now on the basis of the much broader relationship of citizenship' (Goldsmith 2008). It has been argued that this demonstrated that involvement in health research and care was becoming more than a passing phase. Instead it had become part of, and was embedded in, fundamental social changes, particularly changes in the way the state relates to its citizens (Kemp 2010).

5.5.19 At that time 'citizen' had not been widely used by ordinary people in Britain when describing themselves (Frazer 2000). Indeed this may still be the case. Certainly in survey and interview data for this study 'citizen' was only used once, when Elizabeth was discussing the need to extend involvement beyond the active middle classes to a broader citizen constituency. However, as I discussed with the roots of the word 'democracy' (5.4), the concept of political and social citizenship can also be seen as narrowing entitlements. It can be seen as providing conditional access to benefits and services based on the individual's lineage or contributions to society. This can leave people at the margins excluded rather than part of a strong cohesive society (Dwyer 2002). It is not clear whether this is why it has not been more widely embedded in discussions of involvement in health research and care.

5.5.20 Certainly, when New Labour abolished the Community Health Councils they did not replace them with 'Citizen Panels' but with the Commission for Patient and Public Involvement in Health and local Patient and Public Involvement Panels. 'Patient' and 'public' are terms that do seem, from the study data, to be more natural in the context of involvement in health research and care. 48/105 (46%) of survey respondents and all but two

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<sup>38</sup> E.g. see <http://www.which.co.uk/about-which/who-we-are/overview/> (accessed 03/05/14)

interview participants (95%) used the word 'patient'. 'Public' was used by 24/105 (23%) and 23/31 (74%) respectively.

5.5.21 Since the Commission for Patient and Public Involvement in Health was abolished in its turn, the bodies set up by government to involve people in NHS service provision have been named more coyly. Both Local Involvement Networks (LINKs) and Local Healthwatch infer geographical proximity rather than identifying constituent groups. This speaks to the rhetoric of decentralising power, whether that is seen as 'Double Devolution' (Mulgan and Bury 2006) or 'Localism' (HM Government 2011). Although Healthwatch England is intended to bring together evidence to influence national policy, the focus of and access to involvement in health services has clearly been steered to the local level<sup>39</sup>. Tritter and Koivusalo (2013) have pointed out that these new bodies have been only weakly connected to governance and commissioning structures (section 6.4).

5.5.22 Similarly they do not connect closely with research. The National Institute for Health Research (NIHR) funded INVOLVE<sup>40</sup>, is one of very few national government funded programmes in the world working in this field. It was founded in 1996 as a national advisory group bringing together expertise and experience of public involvement in research. While INVOLVE has been a consistent vehicle for information and advice on involvement, across England and Wales, its public profile has not been very visible beyond those already involved. Meanwhile, even within the NIHR, there have also been a bewildering number of regional and national bodies with differing patient and public involvement remits and opportunities<sup>41</sup>. Several interview participants discussed their difficulty navigating this complex landscape. Thomas explained how he struggled to orientate himself.

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<sup>39</sup> see <http://www.healthwatch.co.uk/> (accessed 03/05/14)

<sup>40</sup> Initially called the 'Consumers in NHS Research Support Unit'

<sup>41</sup> For example:

<http://www.ccf.nihr.ac.uk/PPI/Pages/default.aspx> (accessed 03/05/14)

<http://www.rds-yh.nihr.ac.uk/ppi/> (accessed 03/05/14)

<http://www.crn.nihr.ac.uk/ppi> (accessed 03/05/14)

<http://www.nets.nihr.ac.uk/ppi> (accessed 03/05/14)

<http://clahrc-peninsula.nihr.ac.uk/meet-the-penpigs.php> (accessed 03/05/14)

### **Box 10 Thomas on organisations**

CLAHRC... is, of course, based at, in and around, it sits somewhere between the university and the hospital but really it's part of the, well it's not really formally part of any because it's a partnership between the university and local, health boards, PCTs or soon to become Clinical Commissioning Groups... I started going to [meetings] but with no explanation as to what these meetings were, where they fitted in, again I just had to learn it all, what's a CLAHRC? How does it fit in with this thing called NIHR? Then what's this INVOLVE thing? So you get, now I know how all this jigsaw fits together but when you first start this is a minefield if nobody signposts you through it. It's a minefield. ...

NIHR were looking for reviewers for proposals that were looking for funding and I got involved with that. But again, not totally clear, I was getting confused in the first stage with, this is NIHR, this is CLAHRC, why am I reading this paper as opposed to that paper and it ended up with separate lever-arch files and just laying it all out - just to separate it in my mind.

5.5.23 These NIHR structures also need to be navigated in the context of: other research councils; patient groups attached to particular research teams, medical schools, universities and hospitals; public involvement with the big funders in the charitable sector; involvement in local Healthwatch and Patient Participation Groups etc. Many of these groups have their own distinct cultures and ways of using language. In relation to community engagement the National Community Forum has argued that people's capacity for involvement can be diminished 'as they spend time navigating the complex web of structures intended to facilitate participation' (Morris undated). This noisy background and the rapidity with which involvement structures have been reorganised by government and government agencies may also help to explain why involvement opportunities have remained largely invisible to most people in the community. While different groups and different organisations may involve several of the same members, there may be little structured sharing of information or learning.

5.5.24 Since 1948, government visions of and rhetoric about the scope and purpose of public and patient involvement in the NHS have changed from: passive recipients, to informants in the monitoring and reviewing of provision, through consumers in a system of internal markets, to citizens engaged in co-production and now involvement has the aim of 'transforming care through shared decision-making' (Department of Health 2010, p13). In the white paper

'Equity and excellence: Liberating the NHS' (Department of Health 2010) the slogan of the disability rights movement 'nothing about us without us' (Charlton 2000) is personalised into 'no decisions about me without me', an individualistic phrase, transposing it from a call to collective action into an appeal of consumerism. This language implies a political agenda of moving involvement in health back into the sphere of private, personal decision making rather than the public spheres of politics and governance. Involvement knowledge spaces have been pinched and shaped by these external forces.

5.5.25 Technological and social changes have impacted widely on public discussions, understandings and perceptions of medicine, science and research. These have also been impacted by changes in the character of disease, life expectancy and access to information. The implications of these changes, for involvement in health research and care, will be discussed in the next chapter.

## 6. Transforming identities

*When Gregor Samsa awoke from troubled dreams one morning, he found that he had been transformed in his bed into an enormous bug.*

Franz Kafka<sup>42</sup>

### 6.1 Introduction

6.1.1 This chapter will explore structural transformations that have influenced relationships, particularly between patients and clinicians. It will also highlight the importance of narratives of personal transformation within peoples' individual life stories.

6.1.2 The next section begins with the work of the American Sociologist Talcott Parsons who developed the concept of the 'sick role' (Parsons 1951, 1975). It looks at whether social, epidemiological and technological changes, in the eight decades, since Parsons undertook the research on which this theory was grounded, have rendered it invalid or have proved it useful. The third section will return to the concepts of knowledge and expertise. The fourth section will look at the role of involvement in the creation of norms, through governance structures, particularly the governance of healthcare in England.

6.1.3 The fifth section will look at personal stories of transformation; the re-orientation of individual identity following life-changing events. In this I draw on the work of Mike Bury (1982) about the disruption that chronic illness causes to a sense of biographical continuity and Gareth Williams' (1984) insights about how narratives are used to repair these. The final section will use Giddens' ([1991] 2013) ideas about 'high modernity' and the role of reflexivity in identity building. It illustrates the importance of creating meaning with a story from Abigail, an interview participant who has experienced a transformation from chronic pain and limited mobility to a different version of what is 'normal'.

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<sup>42</sup> Kafka, F. [1915] 2012 page 11  
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## 6.2 Transforming roles

6.2.1 In his theoretical construction of the 'sick role' Parsons (1951,1975) uses ideas drawn from Weber's work on authority and Freud's psychoanalysis to describe an asymmetrical relationship between doctors and patients. This is a relationship in which doctors have to use their skill to diagnose what is wrong and to prescribe treatments. They also often have the authority to excuse the patients from fulfilling their normal duties, sanctioning a temporary deviance from the behaviour that would usually be expected of them. In return the patient has the responsibility to carry out the prescribed treatments, and to get well promptly.

6.2.2 The role of 'doctor' is intended to be a more enduring one than that of the 'patient'. The latter role is intended to map a temporary position, a permitted 'time-out' from the job description that would normally designate their place in the world of social and economic exchanges. The sick role starts from the important premise that 'illness is not merely a state of the organism and/or personality, but comes to be an institutionalized role' (Parsons 1975). This is a powerful statement and can be seen as providing a distinctively sociological, rather than bio-science, perspective on illness. However this model of medicine has been widely criticised as reifying the role of the medical expert while representing the patient as a passive supplicant (Parsons 1975, Turner 1995, pp42-6; Armstrong 1989, pp126-230).

6.2.3 From a 21st century perspective some aspects of the sick role do seem dated, even at first glance. I would argue, however, that this may be part of its power. Seen as a complex of social roles rather than a simple empirical biological fact, illness, and with it both doctoring and 'patient -ness', is very likely to change as society changes. Parsons himself acknowledged that the asymmetry of the doctor/patient relationship is 'inherently extremely complex, and... it is entirely reasonable to suppose that the lines should be shifted from time to time in the light of new knowledge and changing conditions' (1975 p272). Though he further argued that it was unlikely to become an equal relationship because of fiduciary responsibility, the professional duty of care, that doctors and, to some extent, other healthcare professionals have within the system. He saw this as inevitably ascribing a higher status to the role of 'doctor', even when the 'patient' had an equal or higher status in whatever role they

occupy in another social sphere, for instance 'Prime Minister' or 'High Court Judge'. He likened the doctor-patient relationship to that between a parent and a child, which he also saw as inevitably unequal, at least until the child grew up and left home: 'a stage when such equality makes sense is normally the signal for ceasing to be in the role of child in the family orientation' (Parsons 1975, p277).

6.2.4 As an old feminist I do find that the tone of pipe-and-slippers-paternalism, which Parsons uses to frame his arguments at times, has the capacity to make my toes curl. However it would be unfair to judge the sick role on the basis of some anachronistic analogies and implicit mid-20<sup>th</sup> century social attitudes. Certainly I know some patient activists who might almost take off from the ground, if I were to talk to them about the 'institutionalized superiority of the health care agent, notably the physician' (Parsons 1975, p277). However they might be interested to discuss the 'hierarchical component of authority, power, prestige', issues with which Parsons populates this institutionalised superiority.

6.2.5 The successes of medicine in reducing the number of deaths from acute infectious diseases and in improving the survival of people with impairments and chronic conditions (Stacey 1998) mean that people are likely to live longer and are more likely to suffer from some chronic or intractable condition at some point in their lives. It has been argued that the sick role, with its emphasis on recovery, fails to describe the role of those patients living with a chronic illness. Yet Parsons (1975) has further argued that, by substituting the concepts of the management of a chronic condition and the optimisation of health for that of 'getting well promptly', the sick role can still be useful to describe the structure of relations in chronic illness. He suggests that only in the case of acute illness is being a patient likely to be a full time occupation and, in that case, this would only be for the short period of time, for instance while they are hospitalised or bedridden. Among chronically ill patients, he argues, the management of their condition is likely to be little more than a peripheral part of their daily activities 'requiring only partial attention' (Parsons 1975, p269).

6.2.6 When talking about the management of a chronic condition as demanding only partial attention, Parsons explicitly draws on his own experience of what he describes as 'mild diabetes'(Parsons 1975, p269). An

experience contrasting to that of Parsons was given by Nicole, an interview participant in this study who told me:

**Box 11 Nicole on diabetes**

You know, one person with diabetes is so far removed from another that it's almost as if they don't have the same disease. Because I think, you know, I'm on an insulin pump now that I'm type 1, whereas I used to be type 2, whereas before that I used to be gestational, so you know I've gone through the whole gamut of diabetes types and, and how I live my life and how my treatment impacts on me is very, very different to say, compared to somebody who has recently been diagnosed with diabetes type 2 who are just watching what they eat... My life is, is a lot more complicated than that – I have to test my blood sugar sort of 10 or 12 times a day, I've got you know, to check my insulin pump twice a day, I've got to change my insulin pump every other day, you know, all the rest of it and I have to go around with a handbag full of kit to make sure it all keeps on working.

6.2.7 In this case the demand is not only for temporally 'partial attention': remembering dietary advice when buying food or cooking, remembering to take your pills before (or after) eating etc. For Nicole what was needed, to effect the active management of the condition, was more than the short applications of her full attention to perform specific tasks, changing the insulin, checking her blood sugar. It also demanded constant at least partial attention to the functioning of the equipment and to her own physical wellbeing. Does she feel as if her blood sugar level is OK? Does she have something she can eat in case it drops? Is the pump functioning properly? Does she need to re-test? This is what Charmaz has described as 'intrusive illness' (1997, pp41-72).

6.2.8 This is similar to taking on the role of providing 'alert assistance' as it was defined by Clare Williams (2000). That is where a carer, even at times when there is no particular caring task for them to undertake, has to remain watchful for developing problems and danger signals. However, for Nicole and others with serious chronic conditions involving complex management and constant monitoring, the 'alertness' is focused on the care of the self. While Nicole leads a very full life and turns her attention to many other things, at no time can she safely forget her need to manage diabetes. In this case the being a 'patient' – or at least being someone with diabetes – is more than what would



be considered a full time occupation; it is pivotal in everything she does 24 hours a day, every day.

6.2.9 It has been pointed out that chronic conditions may involve periods of relative stability as well as exacerbations. During the stable times symptoms may be well controlled and daily activities undertaken. Exacerbations may be experienced more like the sick role (Bury 1982). However in interviews for this study participants spoke about the continuing need to manage their involvement commitments around their conditions, particularly symptoms like pain and fatigue. In this, participants needed to take into account not only the requirements of involvement work, but also the accommodation of sometimes complex treatments, the need to eat at regular times and problems with mobility. In a diary entry John, who lives in a remote coastal location, writes about attending a meeting at his nearest NIHR funded CLAHRC. This involves his wife dropping him off at the station at 7.30 am and picking him up thirteen hours later. He has a train journey of three hours in each direction.

**Box 12 John on travelling**

When I get to [hometown] station at 20.35pm I am feeling very tired, as for me the journey and the meeting takes a lot out of me and I cannot do more than 2 of these 2 hour meetings in a week as with all my health issues that I have and the medication that I take makes this hard for me but [I] would think that someone who is very healthy would be able to manage this with ease.

6.2.10 There is an increasing likelihood that, at some point during their lives, people will need to balance the management of a chronic condition with other elements of their life that are important to them. Therefore they are likely to want to be actively involved in the decisions that are being made about the sort of health and social care they receive. Chronic conditions may be very different from one another but they do commonly create a need for patients, their families and carers to interact with medical professionals over a long time and to become skilled at managing specific treatments. The better care becomes, and the longer patients with these conditions survive, the greater is the chance of them developing co-morbidities, additional chronic conditions that may or may not be directly causally related to their initial illness.

6.2.11 At the same time, more mobile and portable technologies have been developed. These enable increasingly complicated treatments and the

monitoring of conditions to be undertaken in or from the home. Therapies and equipment that in the past were only found in hospital settings, including intravenous antibiotics, pulse-oximeters and dialysis machines are now part of routines that can be self-administered in the community (Deagle 2001, NHS Choices 2013). The increased use of technology in the home can also mean that the patient and/or home carers are more highly trained in the use of some equipment or the administration of some specialised treatments than are their local medical advisors<sup>43</sup>. This movement, of what once were seen as hospital services into people's homes, also means that patients, carers and families have a much more direct influence on how treatments and monitoring are undertaken and managed.

6.2.12 People with chronic illnesses and their families may not only alter their own behaviour in order to manage the physical, social and emotional impacts of symptoms (Wagner and Groves 2002); they are also likely to adjust regimens to their particular physical and social environment, as well as to their personal preferences. This means patients and carers may become skilled at managing their condition in ways that are different from those practiced by medical professionals, in order to make treatments fit better with other priorities in their lives. How central the illness is to their daily activities may not only depend on the seriousness of their condition and the complexity of its management, but also on what resources they can draw on to support them.

6.2.13 This also needs to be put into the context of the increasing specialization of health care professionals and the division of labour in the NHS (Stacey 1998). Specialisation means that patients with multiple and complex conditions and their carers frequently have a more complete picture of their own needs and different treatment regimens than any one healthcare professional. They may also have a more complete understanding of the practical challenges of carrying out this combination of prescribed regimens in concert with each other and in the context of other life demands. This can lead to increasing motivation and capacity for self-management.

6.2.14 Through the practical integration of all these factors different sorts of knowledge about health and illness are created. This interaction of situated

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<sup>43</sup> I am obliged to Faith Harris Golesworthy for making this point when reviewing this chapter  
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elements gives patients and carers privileged and particular forms of lay expertise (Popay et al 1998) which is something that will be returned to in the next section of this chapter (6.3). Here it is important to point out that the often protracted nature of their interactions with, what may possibly be a broad spectrum, of health and social care services can further provide them with a much more extensive overview of structural institutional interfaces than some individual healthcare professionals can achieve. They may be not only less 'medically innocent' (Strauss et al 1997 p193) than once assumed by the passivity of the patient in the sick role, they also may be less institutionally or structurally innocent.

6.2.15 This increasingly savvy population of patients can challenge the asymmetry of the sick role. They further contest what Scambler and Scambler (2010 p3) have described as already 'problematic norms of normality and normalization'. Part of Parsons' 'institutionalized superiority of the ... physician' rests not only on their expertise, but also on their power and authority to act as gatekeepers to resources. A medical diagnosis can be central to an individual's ability to access drugs, equipment, services, sickness benefits etc. An involvement colleague recently told me about conversations she had witnessed in mental health forums about which symptoms to report and which to withhold in order to be prescribed a preferred drug or therapy. I have witnessed similar discussions in patient groups and in the parents' rooms of paediatric wards, in relation to both health and social services. Abigail also referred to this sort of phenomenon: 'I've been in a room with a lot of chronic pain patients, and all they talk about is drugs and it's almost like being in a drug user event'. Kate described informal exchanges of information more positively 'I've got some really good tips from people you know? I didn't want [prescribed medication] because of the side effect and somebody told me to take it mid-evening and my God they're right! I've taken it now with no problems at all.' Kate also described practical advice sometimes having more force when it came from other patients.

**Box 13 Kate on impact of patient experiences**

But the best advice [for the period following surgery] was hit the ground running. They said "I wouldn't wait till you feel better to start doing the exercises, start when you come 'round from the anaesthetic" [laughs] Which I didn't do, I waited till the next day, [laughs]

But, true enough they said that the early days are crucial. They said “There’s no point waiting 2 or 3 weeks if you feel better and then starting, you’ll never make up the ground you’ve lost. Even if you’re not gonna exercise much, you know, do it in the beginning”

They said “The later it is the less benefit there’ll be. It’s really key the first 2 or 3 weeks you know to exercise, exercise, exercise.”

I mean the physiotherapist told me to exercise but that’s kind of what physiotherapists do you know! [laughs]. They don’t go round and say: “No you take it easy, let me plump up that pillow for you!” [laughs]

So it yeah, it had more force coming from a patient and also the physiotherapist told me to exercise, they didn’t say now is the time to do it. Whereas the other patients I spoke to and some of them were quite blunt about the fact that they hadn’t done it and had found out too late that it didn’t matter that they’d worked really, really hard after 3 weeks and they felt they would have had a better result had they, you know? They’d just thought: “Oh I’ll just wait ‘til I recover, you know, give my body a chance to recover”

No, the physios said “it’s important to do the exercises”, they didn’t say “it’s important that you do them **now**”

6.2.16 This sharing of knowledge, attending differently to advice from other patients, and the use of tactics to take back some control over access to treatments, does not contradict Parsons’ asymmetric ‘sick role’. The power imbalance in the relationship between patients and doctors is not refuted; in fact it is made manifest ‘through the antagonism of strategies’ (Foucault 1982 p780). If there were no structural power difference between themselves and healthcare providers, patients would not need to find and share ways to get around it. These struggles represent both forces acting on involvement knowledge spaces and forces exerted from within, pushing to and fro, often responding to each other.

### 6.3 Transforming knowledge

6.3.1 Today it is far easier to access information about medicine and illness than in the past; it can be accessed more quickly and there is far more information available. Rapid developments in information technology have created new ways of accessing and sharing knowledge. Since its first public demonstrations, in the 1970s, access to the internet has spread rapidly across the world. It was reaching almost two and a half thousand million people by

June 2012<sup>44</sup>. Not only is information far more accessible, that accessibility itself can create new problems of information reliability, filtering and management. By typing 'dementia' into a search engine at the time of writing (December 2013) in 0.16 seconds 14,200,000 results were found. This information will be of variable quality and not all will be either useful or accurate. Even information from reputable media sources can be actively misleading representing what Goldacre (2009) has characterised as 'Bad Science'.

6.3.2 The NHS has developed web based resources (e.g. NHS Choices<sup>45</sup>) in order to help people find medically sanctioned information of a high quality. However, the internet is an arena that also allows people to share their own understandings of health and illness. The websites Healthtalkonline<sup>46</sup> and Youthhealthtalk<sup>47</sup> are academically mediated forums that share video, audio and written interviews with over 2,000 people who have experiences of more than 60 different conditions. It signposts people to reliable and useful information about conditions, treatment and support. Another website 'Self Help UK'<sup>48</sup> has the strap line: 'The guide to patient support and self-help'. This holds a database of over two thousand groups that offer support and information.

6.3.3 Arguably the potential for increasingly knowledgeable and informed patients has led to more equitable doctor-patient relationships; more mutual exchanges that include the patients' priorities and understandings of health and illness as well as those of the practitioners. As already noted, in the rhetoric of policy makers at least, the balance of the relationship has moved increasingly towards the right of the patients to make informed decisions about their own health and care. Evidence has also indicated that a more patient-centred practice can have a positive impact on health outcomes and reduce the need for diagnostic tests and referrals (Stewart et al. 2000). This might be hoped to reduce costs for the NHS and for patients. However, few of these benefits of involvement have been demonstrated to be either short term or

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<sup>44</sup> Internet World Stats: <http://www.internetworldstats.com/stats.htm> (accessed 03/05/14)

<sup>45</sup> <http://www.nhs.uk/Pages/HomePage.aspx> (accessed 03/05/14)

<sup>46</sup> <http://healthtalkonline.org/> (accessed 03/05/14)

<sup>47</sup> <http://healthtalkonline.org/young-peoples-experiences> (accessed 03/05/14)

<sup>48</sup> <http://www.self-help.org.uk/> (accessed 03/05/14)

explicitly financial. These are more likely to be future focused and reach wider than the interests of particular individuals (Tritter and Koivusalo 2013).

6.3.4 In addition the vested interests of privatised health service providers, the pharmaceutical industry and health technology companies are in increasing health spending, from both public and private purses. Some of these businesses have been accused of distorting what information is available (The Campaign for Safer Medicine 2013). They have sometimes been seen as directly or indirectly manipulating patient groups (Herxheimer 2003, Sample 2013). In some cases it has been argued that marketing tactics have been tantamount to 'disease mongering' (Moynihan et al. 2002). Certainly, in what seems to be an interesting development in the progress of Illich's 'Medical Nemesis' (2002), as a self-identified patient activist I now frequently receive requests from patient groups to sign petitions for: a new diagnosis to be added to the International Classification of Diseases; for an expensive drug to have its licence extended; or for a screening test to be applied more widely across the population<sup>49</sup>. This could be seen as a further democratisation of civic epistemology, or a dangerous movement towards the assertion of truth by pester power.

6.3.5 As discussed above (6.2.15), diagnosis is the gateway to a range of resources, a gateway guarded by healthcare professionals. This means patients are making a rational choice in seeking a medical definition of anything they experience as distress or disadvantage. Psychologically a diagnosis also provides them with a validation of their subjective judgement that they are unwell (Charmaz 1997, pp23-25). Both of these incentives could leave people vulnerable to manipulation by economically motivated organisations.

6.3.6 A related problem is that many medical professionals struggle to understand how to interpret and use research data effectively in decision making (Wegwarth et al. 2012). It is hardly surprising then, that patients and the

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<sup>49</sup> Recent examples of petition requests  
<http://epetitions.direct.gov.uk/petitions/55388> (accessed 03/05/14)  
<http://epetitions.direct.gov.uk/petitions/52733> (accessed 03/05/14)  
<http://epetitions.direct.gov.uk/petitions/57807> ((accessed 03/05/14)  
<http://epetitions.direct.gov.uk/petitions/55946> (accessed 03/05/14)  
<http://www.whooshers.com/aboutwhooshers.html> (accessed 03/05/14)

public can find this difficult as well. One way to address this is for researchers to become better at communicating their findings effectively, and for pharmaceutical companies to be more transparent in their relationships with patient groups (Herxheimer 2003, Colombo et al. 2012). Another way would be to build patients' confidence as well as competence to assess information, and to play an active role, not only in the management of their own care, but also in the shaping of research and services.

6.3.7 John, unlike many of the participants in this study, is someone who has not got a university degree. In the past he had worked as a baker and as a truck driver until ill health led him to retrain as a bookkeeper. Eventually his deteriorating health and his increasingly complicated and intrusive management regimens led him to resign from employment altogether. He had been involved in voluntary and community groups for many years and set up a condition specific support group in his local area. Through that he met other service users and was introduced to the condition specific research network.

6.3.8 He admitted that reading had not been his strong point and when he first became involved in health research he had sometimes struggled with scientific language and the long, complicated documents. He attended a series of short courses on searching for evidence and on the critical appraisal of research papers. He then went on to do a course with the Open University about one of the long term conditions that he has. He spoke enthusiastically about the training and skills he had accessed through his involvement and the impact this had on his confidence.

**Box 14 John on confidence building**

The [condition specific network] paid for me to do an Open University course, and I've got good results from that and, I gained a lot of knowledge and as a colleague from [research organisation] said the other day I seem very very confident about speaking about [condition] to other people with [condition]. So my experience has gone up a little bit... or probably a lot.

6.3.9 John had gone on to be part of the research team on two different studies and to be co-applicant on two other proposals. He also provided lay reviews of research proposals for one funding body and served on the funding panel of a condition specific funder. He chairs his GP's Patient Participation Group and has taken part in a number of NHS forums. He is quite clear that

training was key in building not just his skills but also his confidence to consider taking on some of these roles.

6.3.10 The White Paper, 'Saving Lives: Our Healthier Nation' (Department of Health 1999) was the first major policy document proposing that the NHS made use of the growing expertise of patients. Following this a task force was set up to build on initiatives already taking place in the voluntary and statutory sector in the UK. These drew on the US Chronic Disease Self-Management Programme (Lorig et al, 2001) and developed a patient self-management system that was called the Expert Patient Programme.

6.3.11 Expert patient programmes have in common the rejection of instructing patients about their condition and then measuring their compliance with prescribed regimes. They are intended to develop self-management skills like goal setting and problem solving. The concept is to encourage people to become key decision-makers in their own care (Department of Health 2001). Courses are led by people who have long term conditions themselves and who act as mentors. Their role is to help people to develop the confidence and motivation to make better use of skills and knowledge they already have. This holds the intention of enabling them to take control over their own lives. Two interview participants in this study talked about having acted as course leaders in this sort of programme. Kate was part of the programme that is still closely linked to Stanford University and which uses the programme handbook developed by Lorig. Kate's involvement in research came directly through her involvement in the Expert Patient Programme. Grace had delivered a condition specific initiative and for her this was one of a number of steps towards involvement in research.

**Box 15 Grace on involvement through Expert Patient Programme**

I'll start with a little bit of background about me, OK? So that you know how I came to be involved and what I'm involved in. Back in 2003 I had a breakdown and was in the psychiatric hospital for a couple of months. At that time I was, I was living in [county] working in [city] and, to cut a long story short: that all stopped and I moved here to [coastal town]. At that time I wasn't really quite sure what I was going to do with myself. I was in the happy position of not absolutely having to work then. But neither did I want to sit around and do nothing...



I needed some, some more help with my depression and I, I went along to a, a group which at that time was very new part of the Expert Patient Programme; I think it was a seven week course? I can't honestly remember, but something like that. Where various things were shown to us as to how we could manage our depression ourselves. So I went along to that, which was fine.

As a result of that I became a tutor for the course, and I, I tutored several courses; I think probably about a dozen or so? Over a period of maybe a year? Maybe a bit longer. And then, when I was tutoring one of the courses, one of the participants said to me: 'Well, you know, this is great, this is fine, but it's like everything else in mental health, you know, you go and see your therapist or you go along to these courses or whatever it is, and that's all very well and good but at the end of that you're on your own. So, you know, where do you go from there?' I said: 'Well presumably there are groups that you can belong to?' and she said 'Well you try and find one in [coastal town] because I can't!' And indeed I did have a look and there are lots of groups for all sorts of things but nothing specific for depression.

So I thought 'OK. Well either I can sit around and moan about that or I can start one.' So I did. I set up a Depression Alliance group in [coastal town]. And that went through its sort of ups and downs, you know, of having lots of people there and then not many people there. It's a fact of life when you're dealing with people with depression [Laughs]. Sometimes they don't feel like going and talking to other people with depression! [Laughs]

So, anyway I sort of kept that going for a while, but was also looking for something more. But didn't really know what. Anyway as it happened, when I was setting up the Depression Alliance group, [university] contacted Depression Alliance because one of the researchers there was looking for someone locally to help them with a project...

So that's, so I got together with them and they wanted someone to look through a protocol, and the ethics documentation for a study. They were applying for a grant, unfortunately the grant didn't materialise for that. But I then got to know other people within the [university]. As a result of that one of the first things I did there was to do with the candidates for the doctorate in clinical psychology. Which is a huge sort of three, three dimensional process for selecting the candidates. Part of that was to listen to their research presentations and comment on you know, how, how well we thought they had done the research from the point of view of so, of someone with, with depression. Complete, you know, don't know anything about the clever bits, but I know what depression is and what it feels like and what I would like them to do. So I did that and that was, that was great.

6.3.12 The Expert Patient Programme was piloted by the NHS, between 2002 and 2004. This provided generic courses aimed at anyone who defined themselves as suffering from a chronic condition. A small to moderate improvements in self-efficacy and a significant reduction of fatigue was demonstrated; fatigue was identified a major problem for the people who took part in the evaluation (Rogers et al. 2006). Additionally, social support from the groups was something that was highly valued by participants. However, as might be expected, given the discussion above, some health professionals have been ambivalent or even hostile to the concept of 'expert patients' (Shaw and Baker 2004). Their reluctance to refer people to the programme has been described in terms of them being 'non-receptive to the idea of user-led initiatives' (Kennedy et al. 2004). Kate reported that this was indeed sometimes the case in her experience:

**Box 16 Kate on professional responses to Expert Patient Programme**

It's a bit like Marmite, you know you get practices who are fantastically pro the program and send lots of patients to it and you get other [health care professionals] who see you as the enemy and wasting money and you know I've heard of one or two put in, "why are you wasting money on this rubbish if people have a long-term condition they can come and see me and solve it!"

I think it's the "lay-led" that gets up their nose. You know, they think, you know "What can they possibly tell them I couldn't tell them" and the point is [doctors] don't have time to tell them. Overall I'm giving them 15 hours of my time and you'll be lucky if you can give them 15 minutes of yours. Well also it comes better: "I have painful [condition] but I exercise", or "No, I do know what it's like when you can't sleep because you're in so much pain, or you're having terrible medication side-effects".

With their GPs people think: "Oh, well it's easy for you to say that, what do you know, you don't know what it's like!"

6.3.13 Since 2007, along with voluntary sector groups like Arthritis Care and the Depression Alliance, a community interest company has delivered the Expert Patient Programme in England. There are courses specific to conditions, like rheumatoid arthritis and diabetes as well as the generic 'chronic conditions' courses. There are also courses designed to address the particular communication and support needs of people who have both learning difficulties and chronic conditions. However the availability of courses is geographically

patchy as it is subject to local commissioning policy as well as the preferences of particular practitioners.

6.3.14 These courses are significantly different from those undertaken by John. What they have in common is that they provide participants with strategies for: identifying information needs; accessing and assessing information; and above all building confidence in self-efficacy and their capacity to contribute to decision making processes. Self-confidence and control have also been important concepts in the work of people with lived experience of mental health services. Recovery, with a capital 'R' is used by Weinstein (2010) to describe the process whereby people adapt to an illness or disability rather than the symptoms being cured. Gosling (2010) takes this further arguing that deciding to live in ways or in situations seen as inappropriate or risky by professional advisors can represent personal choices that may be important aspects of Recovery.

6.3.15 Frequent service users, particularly working age people with long term conditions, have articulated demands for more flexible social care service provision (Glendinning et al. 2008). Dissatisfaction with how services are delivered has led people to argue, as a matter of right, for more choice and control over the support they need to live independently. Giving people more control over how money is spent on their individual care and support needs is one way that this has been seen as achievable. The White Paper 'Caring for our future: reforming care and support' has described its second principle as:

'...people should be in control of their own care and support. Things like personal budgets and direct payments, backed by clear, comparable information and advice, will empower individuals and their carers to make the choices that are right for them. This will encourage providers to up their game, to provide high-quality, integrated services built around the needs of individuals.'

(HM Government 2012, p3)

6.3.16 The evaluation of individual budget pilots, however, found that this might have profound implications. Service users, in order to make informed

choices, will need to have options explained effectively by practitioners who, as discussed above (6.3.6), may sometimes struggle to use evidence effectively themselves. Practitioners and organisations will also need actively to manage the expectations about what is available. For many people to be enabled play a meaningful role in choices about their care, they may need effective self-advocacy skills and support. Organisations moving from the role of campaigners and advocates to commissioned service providers will need to radically change their internal arrangements, processes and culture in order to fulfil these very different professional roles (Glendinning et al. 2008).

6.3.17 The choices offered may not always be those people really want to make. If the available services are not all equally accessible, appropriate, affordable, and sensitive to cultural needs the 'choice' is not a real one. Another issue is that people may not find it very helpful to have to make choices at a time when they are very ill and most in need of care (Weinstein et al. 2010). Perhaps rolling out individual budgets at a time of reducing resources could leave some of the most vulnerable members of society at greater risk. Those with complex needs to manage may find it particularly challenging to take on additional responsibilities for the management of direct services or of employing people to provide their care. It is possible that in making choices people may also be blamed for any poor outcomes of their care, which may be seen as the result of their own poor choices rather than as the consequences of public policy and social inequalities.

6.3.18 In managing fixed budgets people will inevitably need to manage new risks. Not only service users but also commissioners and service providers will need to develop different skills and manage new relationships in order to deal with these risks. For example if a commissioner were to negotiate a specific integrated care pathway, with a preferred provider, but a patient chose to spend their personal budget allocation elsewhere for part of their care, might the commissioner end up paying twice? Given the context of public spending cutbacks this could create tensions between the collective planning and commissioning of services, and individual choice.

6.3.19 Individual budgets can be seen as an attempt to use an economic model to re-map relationships of resource allocation within the welfare state that

have become unsustainable. The changing nature of social relations means that Parsons' 'institutionalized superiority of the ... physician' may no longer be a sufficiently legitimate mechanism to hold the gates controlling access to health and social care resources. Marketisation can be seen as an attempt to build new gates, or perhaps turnstiles, shifting and re-defining the involvement spaces between the system and lifeworld. Juridification, as we have discussed, (4.7) is another tactic used to contain and manage social conflicts and political struggles.

## **6.4 Transforming governance**

6.4.1 As discussed in section 4.7, in the UK, since the end of the 18<sup>th</sup> century, Colleges and Royal Colleges have developed as the corporate bodies that represent the interests of doctors. Clinical governance was closely guarded by the professions in the NHS negotiations. Since the 1858 Medical Act<sup>50</sup> the General Medical Council (GMC) has controlled the List of Registered Medical Practitioners. There are other councils, governing different professional groups in healthcare: Health Professions Council, Nursing and Midwifery Council, General Dental Council, Royal Pharmaceutical Society of Great Britain, General Osteopathic Council, General Optical Council, General Chiropractic Council, and Pharmaceutical Society of Northern Ireland.

6.4.2 The medical profession in the UK still enjoys a high degree of public trust (Ipsos MORI 2013). The level of unquestioned autonomy, however, that the public are willing to accept, and the degree of authority the medical profession is able to exercise, have changed over time. As discussed above, changes in the expectations of the public and of patients have shifted their relationships with medical professionals. The rising cost of health and social care has also prompted the state to introduce managerial approaches derived from the private sector (Propper, Burgess and Abraham 2002), on the assumption that it would drive up efficiency. These forces have all impacted on the shape of clinical governance, including the need to open it to public involvement and scrutiny.

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<sup>50</sup> Available from [legislation.gov.uk](http://www.legislation.gov.uk) <http://www.legislation.gov.uk/ukpga/Vict/21-22/90/contents> (accessed 03/05/14)

6.4.3 Additionally there have been a number of high profile scandals that have called self-regulation into question. The inquiries that followed the conviction of Beverly Allitt in 1993, for the murder and harm of children at Grantham and Kesteven Hospital (Hansard 1994), and that, in 2000, of the GP Harold Shipman (National Archives (b) 2002<sup>51</sup>), linked to at least 250 suspicious deaths over his career, raised serious questions about the ability of healthcare professionals to identify and challenge colleagues who use their power to harm the patients in their care. As discussed above (section 4.4) the public enquiries into services in Bristol for young children needing open-heart surgery between 1984 and 1995 and that into the paediatric pathology service at Alder Hey led to similar questions. The Bristol enquiry found that organisational barriers and internal politics delayed the raising of concerns about the quality of the service (Kennedy, 2001). This led the government to take action by ordering hospitals and health authorities to appoint a senior manager to protect ‘whistle-blowers’ who spoke up against incompetent colleagues<sup>52</sup>

6.4.4 Other issues of safety have also prompted public concern. The development of what the media have called ‘superbugs’ like methicillin-resistant staphylococcus aureus (MRSA) (Easton et al. 2009) has raised questions about patient safety, hospital cleanliness and about prescribing behaviour. There have also been individual organisations that provoked wider concerns about governance, notably the Mid Staffordshire NHS Foundation Trust, which was the subject of a public inquiry<sup>53</sup>, and the private hospital Winterbourne View, where the Panorama programme exposed serious abuse of residents with learning difficulties<sup>54</sup>.

6.4.5 When things go wrong people can feel that they have a responsibility to speak out. The need to work to achieve justice for themselves and others can be an extremely strong driver. Lotte told me:

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<sup>51</sup> <http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/firstreport.asp> (accessed 03/05/14)

<sup>52</sup> BBC News 1999c, Wednesday, 1 September, 1999  
<http://news.bbc.co.uk/1/hi/health/434789.stm> (accessed 03/05/14)

<sup>53</sup> <http://www.midstaffspublicinquiry.com/> (accessed 03/05/14)

<sup>54</sup> BBC News 1 June 2011 <http://www.bbc.co.uk/news/uk-13548222> (accessed 03/05/14)

### **Box 17 Lotte on speaking out**

I came to it without meaning to, if you like. Out of the need for justice because of my own treatment. Things were very wrong in the [condition] treatment I had. Not medically wrong but in other ways...

I helped set up a [condition specific] support group because there were none in our area. And it was really for anyone who had been affected in any way by [condition] and I ran that for 12 years and so I heard other peoples stories and I realised no one was speaking out and only people like me could speak out because health professionals all seemed to be gagged, the patient was too frightened, or if they were bereaved they were just too deflated, you know, couldn't cope with speaking out.

But I have a need to speak out and I just felt driven... other people looked in admiration at me and thought I was great but actually I wasn't – I was just driven, I couldn't help it!

And it's just gone on from there, it's become my life's work if you like, erm, I don't only do it, it's not my only thing in life but it is on-going and the more you do it the more you realise there's so much that needs to change.

6.4.6 The Kennedy Report laid great emphasis on the importance of patient, carer and public involvement in creating a culture of accountability and openness in the NHS. It also encouraged greater awareness of the importance of patient involvement in monitoring the quality and safety of services. It argued that 'strategic planning at national level and decisions at local level must involve the public' (Kennedy 2001 p18). Issues of transparency and trust also led to the 2007 White Paper 'Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century' (HM Government 2007) proposal that the councils regulating health professionals have, as a minimum, equal numbers of lay and professional members. This is intended to lead to greater openness, and to make sure they are not overly influenced by the concerns of professionals. It argues for: 'better systems for patient and public involvement panels within the regulatory bodies, with terms of reference to ensure that wider societal interests and concerns are taken into account in the conduct of councils' business and the shaping of their policies' (HM Government 2007, p25)

6.4.7 This means that governance structures increasingly have to take on some of the qualities of a multidimensional 'knowledge space' where different types of knowledge are brought together (Elliott and Williams 2008;

Gibson Britten and Lynch 2012). To this end some professional councils have developed a range of ways for people to be involved in their work, including the General Medical Council Reference Community which includes 28 medical professionals and 27 lay representatives (GMC 2009).

6.4.8 However, working with professional organisations can demand high level understanding of professional culture, the ability to process large quantities of paperwork rapidly, and availability during working hours. This militates against broad engagement. Although the practice of giving the role of 'lay member' to a retired member of the College is no longer an accepted practice, it is still not unusual to find it occupied by someone from an allied profession. Oliver described the lay group he chairs:

**Box 18 Oliver on involvement and work**

It's not an enormously time-consuming role but equally if you had a you know, had a proper job, it would be- you know I, I'm an academic so I've got a degree of autonomy about how I use my time.

Also I'm in a medical faculty, all be it within a school of [allied profession]. So the view of the school is reasonably- I'm sure if I went to the Dean and said 'Royal College' you know, he'd have said: 'Oh yes, that's the kind of thing that you ought to be doing!' because that's the kind of thing that we do, because that's a part of how this institution sees itself, and sees its role and just lots of my medical colleagues are officers or whatever of Royal Colleges.

So I come from a work place that doesn't have a problem with it and is supportive of it; that wouldn't necessarily be the case. [Colleague on lay panel] kind of... works part-time and is self-employed as a consultant, [another colleague] is a consultant and again is self-employed, [another colleague] and [another colleague] are both retired, [another colleague] works... yeah she has, she calls it a portfolio career, in the third sector she has a variety of roles none of which are a kind of permanent full-time paid. So then again, you do get in to problems with representativeness there, because of the nature of the role. The meetings take place in London, and they happen during working time.

For people who had small children certainly, or if you have... if you worked as a nurse for instance, and had to work shifts....

6.4.9 The difficulty with having to take time off work to attend meetings was one of the reasons that Daisy gave for dropping out of involvement with a research organisation (box 30). For Jennifer this was also a cause for concern, making it difficult to address the need to broaden diversity in terms of age and



class. She was not sure whether some of the problems in involving a broader cross section of the community in these sorts of roles might be intractable.

**Box 19 Jennifer on diversity**

Getting it younger would be terrific, but people work I mean there's a terrific amount of work involved in some aspects of PPI, and it can mean taking time off during the day and that's hard, I think as far as getting younger people involved, there are genuine practical barriers and I'm not at all sure how you can overcome them. Some of the bigger employers will allow time off to do this kind of thing, but people who work with small companies, who are in increasingly precarious jobs, aren't gonna be able to take time off to come to meetings in London or, or even locally where they live they're not gonna be able to take afternoons off for that kind of thing I suspect. I mean, when I was chair of the [speciality college] patient liaison group I desperately wanted to get a) man, erm, b) somebody young, and c) somebody from one of the ethnic minority groups on it... I killed two birds with one stone with a very, very bright, very good, young black woman, who could only come because she worked for Transport for London and Ken [Livingstone (former mayor)] was very good about all sorts of public participation and would let her have the time off. But I think for most people it just isn't on and it's not on much more now, than, than it was before, so that, that I think is quite difficult, because there are real, solid, practical reasons that is not within the remit of anybody in the academic community to overcome.

As far as broadening it, making it less middle-class, that is a difficult one, because I think there is a certain level of education that you have to reach to be able to do it properly. If you aren't capable of understanding the totality of a research project, I don't think you're capable of deciding whether it's any good or not.

6.4.10 Jennifer was mainly discussing involvement on governance boards and research funding panels. However Dorothy, who was involved in patient groups for a condition specific research network and a patient and public involvement group attached to a university, agreed that there were difficulties making involvement in health research and care more accessible to 'Joe Public'.

6.4.11 Many of the Colleges have patient and public reference groups. Among participants in this study, as well as Oliver and Jennifer, Lotte and Kate also mentioned that they had been or still were involved, each with different Colleges. Other regulatory and governance bodies also have lay involvement at

board level. These include The NHS Commissioning Board, Monitor, the Care Quality Commission, the Health Inspectorate Wales and The Regulation and Quality Improvement Authority.

6.4.12 The National Institute for Health and Clinical Excellence (NICE) involves a range of people in developing public health guidance, referred to as 'community members'. As well as lay members of its board NICE has a Citizen's Council that advises the board on ethical and social issues. They have at least two lay members on every committee and working group. They also keep a register of patient and voluntary sector groups who are identified as stakeholders on particular topics. In an evaluation of patient and public involvement in NICE, participants gave a mixed assessment of their influence overall, though the majority agreed that they had a lot of influence on programme development (Ursu and Cowl, 2010). Both Alan and Hannah from among the interview participants had been involved with NICE panels, something Hannah described as 'a really good experience'.

6.4.13 Another role NICE encourages people to become involved in, is monitoring how guidelines are applied in practice. The Care Quality Commission<sup>55</sup> involves service users as 'experts with experience' who work as part of inspection teams in hospitals and care homes. From October 2012 Healthwatch England became a channel for local experiences of care to influence national policy. From April 2013 Local Healthwatch organisations covering every local authority area in England became responsible for providing both information and support to local people and helping them use their experiences to shape local services. However, as mentioned above (5.5.21) Healthwatch has been criticised for the lack of clarity in the mechanisms that would enable it to connect to governance structures, influence commissioning effectively and for the contradiction between the responsibility for promoting individual choice and representing broader community interests.

6.4.14 Formal complaints both about the NHS (Ramesh 2012) and about Doctors (GMC 2012) have been rising. However the GMC argues that this might be because of 'improved clinical governance systems that enable

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<sup>55</sup> <http://www.cqc.org.uk/node/101> (accessed 03/05/14)

improved reporting of concerns' (GMC 2012, p46). Support and advice on making complaints is available, making the complaints system more accessible<sup>56</sup>. There are also a number of charities and voluntary sector groups that campaign on issues of patient safety and clinical governance. Most are concerned with the governance of services accessed by a particular population, or people who have a particular condition; some are also involved in raising funds for research. Other groups address issues of patient safety more generally, like the Patients Association<sup>57</sup> and Action against Medical Accidents<sup>58</sup>. Most of these patient groups, with differences of emphasis, combine support for patients with campaigning about the provision and standards of care (Williamson 2010 p 36).

6.4.15 The role of patient groups will be explored more extensively in the next chapter but here it is worth pointing out that they can play an important role in providing a bridge into involvement. This is not only by providing a point of contact, somewhere potential participants may be found, but also by changing the dynamic of power between professionals, institutions and service users. Phoebe, an interview participant who now earns her living as a trainer and consultant in the field of mental health, described how this came about:

**Box 20 Phoebe on support group**

My very initial ever sort of involvement in research, or what I see as involvement in research...I remember the [support group] being really strict on sort of ownership and the people sort of owned it rather than [researchers] coming in and saying "I want to find out this, this and this and this is how I'm going to do it", so it was like straight away I realised that we don't have to at the mercy of people dictating [laugh]

6.4.16 This is particularly important, if these patient and public involvement roles are to reach beyond the 'committee ready' and include voices from across society. This is not just about providing access to skills, like those John needed to acquire. It is also about demonstrating a culture of openness and providing people with opportunities to contribute that can be reasonably accommodated with the other demands of their lives. This is why the focus of

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<sup>56</sup> [http://www.gmc-uk.org/concerns/making\\_a\\_complaint/3841.asp](http://www.gmc-uk.org/concerns/making_a_complaint/3841.asp) (accessed 03/05/14)

<sup>57</sup> <http://www.patients-association.com> (accessed 03/05/14)

<sup>58</sup> <http://www.avma.org.uk/> (accessed 03/05/14)

the second half of this chapter shifts from where public involvement fits in the big picture of organisations and institutionalised social roles to look at how it is embedded in people's individual life stories; beginning, again, with one of my own.

## **6.5 Transforming myself**

6.5.1 The issues of self-transformation and identity have emerged as recurrent themes in the data for this study. One of the reasons that the different discourses of involvement, explored in chapter 5, are so important and hotly disputed is that they frequently contain, either implicit or explicit, identity claims. These claims have often been crafted following life-changing traumas, and for some participants they may be both vital and fragile. This is why, in choosing to dissect one of these identity narratives, I have decided to use one of my own, rather than that of another participant.

6.5.2 When I first wrote the proposal for this study I still occasionally served as a patient and public panel member of a health research funding stream. A proposal that I was asked to assess included, as primary applicant, one of the academics I had asked to supervise me. Having served on a number of panels over the previous few years, I had frequently witnessed the dance in and out of the room, performed by academic and clinical colleagues as the names and affiliations of study applicants were announced. So I was familiar with the etiquette and informed the chair, a senior academic, that I felt I had a conflict of interests that disqualified me from assessing that particular proposal. His response was 'I hope you're not going native!' a phrase that Thomas also used in his interview (box 5).

6.5.3 This issue was raised again shortly after my PhD course began. I received an email from the patient and public facilitator of another funding stream I had been working for, providing lay reviews of research proposals. In this the question was raised of whether I still qualified to do that work, given that I was now studying in a medical school. I was very interested in the idea that, by actively studying patient and public involvement in health research, I could disqualify myself from continuing to work in that role.

6.5.4 It led me to reflect on how learning about involvement could alter my approach to health research. Was working on this study within a medical

school likely to change my orientation in a way that my two previous social science degrees had not? Had the learning I received while working on funding panels or being involved in research projects already damaged my 'layness'? This was a different level of thinking about 'layness'. In chapter 4 'layness' was examined as a 'patient' or 'public' perspective; voices from the lifeworld of relating and feeling rather than the purposive, goal orientated 'system'. Chapter 5 explored 'layness' as one of a number of contested terms and concepts within involvement. Here I am thinking about what it is like to embody 'layness'. How is that personal label constructed, and maintained, or lost? Important insights into this issue have come from utilising Bury's (1982) description of disruptions that can be brought about through illness, but also from other life events, and Williams' (1984) concept of 'narrative reconstruction'.

6.5.5 To begin with disruptions, for Bury maintaining the relationship of the self with others is, at best, a 'precarious enterprise' (Bury 1982, p178). Disruptions can undermine what we have always taken-for-granted, necessitating conscious attention be paid to what previously had been assumed; the systems normally used to describe and explain can be disrupted, altering our sense of self by altering the orientation of the self to the world. There also may be practical disruptions to relationships and access to resources, altering or even reversing relations of dependency and need fulfilment.

6.5.6 In managing our sense of self in the world, we can be seen as utilise 'cognitive packages', ways of thinking and understanding 'which are more or less successful in structuring and maintaining meaning' (Bury 1982, p178). Parsons' sick role for instance can be seen as one of these packages, where medical sanction helps us renegotiate relationships at times when we are not able to fulfil normally expected duties. However where the disruption is more than temporary, where what was taken for granted cannot be re-established, and when expected duties cannot be resumed, this cognitive package may not be sufficient. Williams points out that our search for meaning at these times often 'breaks the bounds of traditional scientific discourse and shifts into a complex of social psychology and practical morality' (1984 p197). In these circumstances we may use stories, narratives, to reconstruct our experiences and help us to make sense of them, and to make sense of ourselves.

6.5.7 Most changes happened over time, with old patterns of behaviour becoming obsolete leaving space for new opportunities to be considered. For example when my oldest son, Sam, had transplant surgery he became increasingly independent. As my time and energy gradually became less bound to his care I was able to return to education; at first part time at a local college and then onto a full time degree course. The new way of being overlapped and was rooted in the old, leaving obvious trailing threads that could be woven into the new pattern.

6.5.8 Some cleavages are quicker and clearer. They are experienced not just as an interruption (Charmaz 1997 pp11-40) but as a stark, sudden and irrevocable end to a way of being. Like that experienced by Kafka's hero, who went to bed as a respectable salesman with obvious and understood roles in his family, his community and his place of work. When he awoke he was a bug, with bloated body and weak wriggling legs. All his social markers were gone; he was almost unrecognisable to himself as well as to others. Selves severed in this way can be harder to reconnect.

6.5.9 Two of these irreparable breaks that have occurred in my life were Sam's birth and his death. In common with many parents, the birth of my first child was experienced as an awakening to adult responsibility. Suddenly, as well as being emotionally and hormonally besotted with this new individual, I was also responsible for the life or death of another human being, legally and morally and practically. The fact of his illness, and how close this brought him to death, the threat of the hospital to remove him from my custody (2.2.11) and their grim prognosis that he was unlikely to survive infancy, all magnified that cleavage. It was not just a 'loss of self' (Charmaz 1997, p57) it was also the loss of an imagined, idealised, future self. This radical shift left me almost unable to remember who I had been, what I had intended to be, or what had been important to me just a short time before. But it also provided a clear focus for what had become important.

6.5.10 The threat of custody proceedings was never explicitly made again. Nevertheless it was something that I remained actively conscious of, from that moment until my youngest child reached maturity; more than thirty years later. Similarly the prognosis-horizon became blurred, but the threat of

immanent death was never lifted. Being aware of these did not turn us into a compliant and domesticated parent/patient unit, passively accepting the medical model and concomitant power relations that had descended on our lives. It created a ninja like resistance. Stealth and dissimulation became important powers in the management of our relationships with professionals. Through the following years Sam and I learned what it was safe to share with health care professionals, when to keep information to ourselves, and what tactics we could use to try and get the support we needed. We created ways of using dark humour and feigned stupidity to manage the damage done to us, intentionally or inadvertently. We learned a lot about how health and social care systems worked, and where they didn't work well. We learned the importance of appearing to trust, while seeking verification and alternative views. We learned how to look up the drugs he was prescribed in the British National Formulary, and how to ask questions of pharmacists and microbiologists in a way that encouraged confidences.

6.5.11 Nursing staff in one hospital, against the stated preferences of the consultant paediatrician, trained and encouraged me to administer a wide range of Sam's treatments. This helped keep us at home and in control of our own lives as much as possible. However, even after doing this for years, and winning the support of consultants and allied health staff, I still was being told by newly qualified doctors that it was safer for Sam to be treated in hospital. They argued he could be more closely monitored and the drugs could be administered more regularly. These claims were not supported by our experience. In fact it was an accidental overdose prescribed and administered in hospital, when I was not present, that eventually precipitated renal failure, ultimately responsible for Sam's death in 1999.

6.5.12 The rage I felt about this mistake was never directed at the individual practitioner. I was aware of the pressure under which staff were working. The system in which consultant paediatricians had to divide their attention between the care of patients and petitioning visiting charity representatives for funds, that did make me angry. I was also angry that, in spite of his having had violent seizures in response to the overdose, no one queried the prescription until I arrived and checked his charts. Nevertheless, the fact that these checks were not routinely instituted was a systemic issue, not the

fault of the individuals concerned. I was acutely aware of the many risks Sam and I had taken when choosing between social and medical priorities. There also had been numerous times when I had been close to making potentially fatal errors during my own care for him. Blaming healthcare staff for being equally fallible did not seem useful. I remember walking round behind the hospital screaming into a hedge in distress and frustration.

6.5.13 This was also a time in which I encountered what has been well described as the 'infinite movement of resignation' (Kierkegaard [1843] 2003 p143). I removed Sam from the hospital and took him to a hospice. He was drifting in and out of consciousness and suffering violent seizures. After taking advice on what options were available, I chose to have life sustaining treatments withdrawn. This was not just a medical decision but one in which 'moral or religious and, indeed, political and sociological factors become central to elucidating illness experience and rendering intelligible the biographical disruption to which it has given rise' (Williams 1984 p197). Personally I found this the loneliest responsibility imaginable, the anguish of needing to decide between abhorrent alternatives, a frozen and perpetual moment of being 'left alone without excuse' (Sartre 1989a, p34).

6.5.14 In fact bereavement was an overwhelmingly isolating experience. Not only had I lost someone who was dearly loved and had an identity that I had lived for almost half my life violently stripped away, other relationships were also lost. Hospital staff, our fellow frequent attendees at clinics and hospital wards, community nurses and a range of other health professionals had been among our closest social contacts. 'Sam's Mum' had almost become my name in the eyes of some members of staff on paediatric wards, much to my irritation and to Sam's amusement.

6.5.15 As well as these losses, I no longer had the responsibilities and duties that had shaped daily life: drugs, oral intravenous and nebulised; physiotherapy; managing appointments; cleaning equipment etc. Immediately after his death I sat and played 'Mega-Bombberman'<sup>59</sup> on the games console for days, in order to give my brain and hands something to latch onto. I had

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<sup>59</sup> <http://www.ssega.com/mega-bombberman>



arranged time out from university to care for him and his death came too close to the beginning of term for me to change that arrangement. Yet I was driven, like Lotte (box 17), to make sure that I used what we had learned; and I knew that, in order to do so, I had to keep moving; fearing that I too might completely disappear. Within a week I had started an A level maths course, in part a sublimation of 'Mega-Bombberman', but also a tactic to force myself to have social contact, particularly with people of Sam's age, who it would have been tempting to avoid.

6.5.16 To the relief of some and the disapprobation of others I did not litigate or even lodge a formal complaint about the mis-prescription. I met with the nursing sister in charge of the ward where the accident happened. She was someone Sam and I had known for a number of years. She told me they were planning to put processes in place to avoid similar accidents. I decided that, in this case, trusting that they were motivated not to harm patients was a better option than instigating a juridical process that would, inevitably, divert further attention and resources from patient care.

6.5.17 This was also a tactical decision; a self-defence moulded by our long and complex relationship with medical authority. When unable to do something for ourselves we had needed to suspend distrust. In spite of evident failings, we sometimes had to allow ourselves to depend on the healthcare system, and the professionals working within it. This was such a time. Following Sam's death I was extraordinarily fragile. The energy it takes, to translate the emotional intensity of twenty years spent resisting both the death of a child and the power of medical authority into rational arguments, was not available to me. Like a dragonfly emerging from a nymph, my new self had to struggle free of the wreckage, stretch out and wait for its shell to harden. Academia seemed a better setting for this process than either the hospital or the courts.

6.5.18 But, the question that I raised at the beginning of this section still remains. Once the veneer of academic training has been applied and toughened by experience of committee work, is the layness still intact? As discussed above (3.1.5), learning social theory has given me tools with which to reflect on my own experiences and also provided me with insights into the behaviour of others. It is worth noting, though, that it was not the study of social

sciences that caused concern about my layness. The question was specifically about whether studying involvement, in a medical school, would render me less able to see things from a 'service user perspective' (4.1.1)?

6.5.19 Certainly attending courses on statistics and evidence based medicine have strengthened my understanding of science as a useful way of sorting and tidying knowledge. They have not led me to mistake science for the truth. Training in research methodology has taught me the value of being methodical, keeping records that allow seams of thought to be traced, They have certainly not undone the learning obtained from years of managing sputum, vomit, blood, shit, and all the other socially unacceptable leakage that emanates from a chronically ill child. These courses have not obliterated the marks left by the accumulation of humiliations and indignities inflicted by professionals defending themselves from our pain, nor the memory of many kindnesses.

6.5.20 Clearly there are some 'service user' perspectives I am not qualified to provide<sup>60</sup>. There are services that I have not and am never likely to use. There are also roles that require current or at least recent knowledge of particular services. Again I may not be the best candidate for those roles. In whatever role I do inhabit, however, my approach will be centrally characterized, not by professional objectivity, but with the cellular memory of being unheard, excluded and marginalised. It will be infused with an understanding of how it feels to be considered incompetent and unreliable by stint of social class; with the experience of needing vigilantly to manage the expectations and judgements of people with the power to remove my children, and destroy my family. These aren't just things that happened to me, they are who I am. However much training and education I receive, centrally I will remain 'lay'; common, of the people (5.4.3). This is the abiding thread that has been woven through and between my different narratives, my different selves, connecting them and describing my orientation.

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<sup>60</sup> I am obliged to Rosie Davies for developing these ideas in joint presentations at the 2012 INVOLVE conference and the Exeter 'New Developments in Public Involvement Research Conference' 2013

6.5.21 As well as being a field in which to utilise my 'lay knowledge', involvement in health research and care has been a tool with which to validate it. It has been an important medium through which to reconstruct a narrative in which even the most painful and humiliating events have meaning, become contributions rather than ordeals. As Sue Lethbridge, one of the members of PenPIG who contributed comments on the theoretical models and games, wrote 'one questions the value of keeping life's pains for private consumption, and finding that a "brave face" isn't always the best solution.' Helen, another parent of a chronically ill child said:

**Box 21 Helen on not just whinging**

Well you just feel more – your opinion's more valued. You know – what you're saying you're actually saying it to somebody who might listen and take some action – like positive action, you know? And that you're not just whinging to your friends, you know, or the health visitor. Because you tend to talk about things in like, little clicks of your friends – and then you think 'I'm actually really bothered about this' – and you know you just get a bit more inspired to get involved and take part about changing the whole process.

6.5.22 This narrative process is why, when I ask about involvement in health research, Grace begins with the story of her breakdown, her retirement and her relocation; both Thomas and Kenneth begin by describing road traffic accidents; Lotte begins with being harmed and humiliated by medical treatment; and so on. Each has their own story of loss and of reformation. This is also why it is essential for me, as a researcher and as a fellow traveller, to listen to these stories respectfully and to validate them in what I write. While these answers might sometimes seem tangential to my spoken question: 'how did you become involved in health research?' they are central to the unspoken question 'what does involvement in health research mean to you?' Or perhaps 'how does involvement help you create meaning?'

## **6.6 Transforming meaning**

6.6.1 Giddens ([1991] 2013) has argued that, in modernity, the philosophy of critical reason and radical doubt has leached into everyday life. In the absence of strictly enforced religious or traditional practices, reason has become the institutionalised way of judging knowledge. This leads to the understanding that 'all knowledge takes the form of hypotheses: claims which may very well be true, but which are in principle always open to revision and

may have at some point to be abandoned' (Giddens [1991] 2013, p216). Knowledge is no longer identical to truth, it is contingent and contestable, something we need to judge and make choices about. While this may be a view from academia, it does also chime with a widespread loss of faith in long held certainties. At the same time as knowledge has come to seem impermanent, our understandings of the potential risks of applying that knowledge, as well as the risks of not applying it, have become magnified. Chernobyl and Fukushima; BSE and MRSA; global warming and super-typhoons; as well as the way that terrorism and pandemics might be borne across the planet on cut-price airlines; can lead us to feel we are 'living on the volcano of civilization' (Beck 1992, pp19-90).

6.6.2 Risk assessment and disaster planning have become increasingly common currency. Through these mechanism 'the future is continually drawn into the present' (Giddens [1991] 2013, p3) as we try to use past experience to manage future risk. But because our knowledge is uncertain; because predicting complex systems may require more than we can know; disaster may arise 'from what we do not know and cannot calculate' (Beck 2006, p330). What seems to be reassuring prudence can, like the UK response to 'swine flu', turn into a 'shocking waste of public money'<sup>61</sup> While years of careful personal foresight can fall into a 'pensions black hole' (Verity 2013, Hosking 2013).

6.6.3 Within this shifting landscape ,mapping the self in relation to the world becomes an increasingly reflexive project 'which consists in the sustaining of coherent, yet continuously revised, biographical narratives' (Giddens [1991] 2013 p5). Through these narratives we transform experiences into meaningful accounts that mark our paths through the world with reassuring notations: 'I was there, now I am here, I am heading in this direction.' This is a thread we can use to reconnect selves that have been severed; turning losses into learning and painful experiences into a resource.

6.6.4 This process of creating meaning is clearly something centrally important for Abigail:

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<sup>61</sup> BBC 2013, 21 May 2013 <http://www.bbc.co.uk/news/health-22608671> (accessed 03/05/14)

### **Box 22 Abigail on what is important**

Basically it came about, I had the [orthopaedic surgery] so basically I grew two inches out of it and changed my whole perception and whilst I was getting better I came up with quite a few ideas to help other patients and one [of these], three and a half years later, we're just about - it's peer reviewing in [journal]...

Before I had my [surgical procedure], how I ended up getting my [surgical procedure], there was a lecture on [orthopaedic surgery]. I phoned [lecturer] a bit later and took my X-rays up there. I realised my surgeon was not a [condition] specialist he was an [different] specialist. He'd not even, he'd only done three [of these specific] operations and he'd not done them in my age group. I shouldn't have been under him; and I was under him for 16 years. He kept saying I was too young.

Actually what I realised was that I had a choice of surgeon – I didn't know that because you are ignorant unless you are made aware. That threw up a whole, whole world to me, because I realised that actually doctors don't have the power, I do. So, once I went and saw [lecturer] and once I realised I could use the 'choose and book' I got referred to [new surgeon] within three months. He said: 'I can't believe that you've been left with this so long!'

In the meantime, you know I didn't have any education because I was in chronic pain as a child – I mean I don't feel sorry for myself by any means, it's just my story, but I was left in this situation and I mean, you know the economic impact of me being signed off work all those years - which would have paid for four or five [surgical procedures]. I want my mobility now – sod it if my [implants] fail when I'm sixty so I'm in a wheelchair! I don't care then! Though I've had my children and they are a good focal point I don't feel like I've contributed to society in any way, because you don't when you're signed off.

So I ended up with this [surgical procedure] then I wanted to give something back. So then I went to [lecturer] and said 'Well, could I raise some money?'... Well I like swimming and it was a big part of my rehabilitation so I managed to get two surgeons and a researcher to do [a] swim and then we did a series of talks... so we raised about £20,000 the university matched and the government matched.

Because I talked about, I suppose, just my experience, in a way that was quite cathartic – because it was very traumatic what I went through. It was kind of like, it healed a wound but also I thought 'oh, my experience isn't wasted, it's educational.' And it's educational for the public; it's particularly educational for clinicians. And I've sort of started to look at myself as an educational resource rather than as a patient experience.

But also realising that being signed off work for all those years and being in

pain was not, it's not wasted. And that was the most important thing really.

6.6.5 Transforming experiences of pain and loss, grief and anger into useful knowledge in this way does not stop them hurting. It does, however, help to validate those experiences, ensures they are 'not wasted' by giving them a thread of meaning that can run from past selves, through the present and towards future ways of being.

6.6.6 It also can help rebuilding or maintaining connections to others, where these too have been damaged or destroyed. Elizabeth, following retirement was 'not really ready to stop being in the world yet so that's one of the important things to me, to feel that I'm part of fabric of life still' For Isobel providing lay reviews for research proposals 'makes you feel wanted, as though being an octogenarian isn't so bad after all, your views are still appreciated and you can contribute to society as a whole'

6.6.7 It is these connections, threads of meaning acting through and symbolised by relationships, groups and institutions that will be the focus of the next chapter

## 7. Space-craft

*No more fiendish punishment could be devised, were such a thing physically possible, than that one should be turned loose in society and remain absolutely unnoticed by all the members thereof.*

*William James*<sup>62</sup>

### 7.1 Introduction

7.1.1 This chapter follows the idea that our connections with other people and with wider society are intimately connected to our personal sense of meaning and of wellbeing. It goes on to look at how this maps onto relationships with groups and organisations. Aristotle described people as ‘social’ or ‘political’ animals ([c330BC] 1955 p37; 1996 p 13); Hess claimed ‘Man could not begin to say “I” without considering you, his alter ego’ ([1844] 1997, KL 4866-4867); and for Marx we are ‘species’ beings ([1844]1994, p76). These ideas each place us in a position relative to other people; kin, communities, nations, colleagues, clients and customers or strangers.

7.1.2 In social psychology William James wrote that ‘man’s Self is the sum total of all that he CAN call his, not only his body and his psychic powers, but his clothes and his house, his wife and children, his ancestors and friends, his reputation and works, his lands and horses, and yacht and bank-account’ (James [1890] 2007, KL 4405-4407). For Charles Horton Cooley ‘even the miser gloating over his hidden gold can feel the “mine” only as he is aware of the world of men over whom he has secret power’ (Cooley [1902] 2013, p151).

7.1.3 So this is not a cosy, exclusively comradely vision of the sociality of human nature. Not only do we create meaning for ourselves in relation to others; our relationship to others may also challenge our sense of meaning. The image we see in this social ‘looking glass self’ (Cooley [1902] 2013, p152) may be grotesquely distorted or unachievably idealised. It can discourage and limit us as well as encourage and empower us; denying us hoped-for selves as well as making unimagined selves possible. It is the risk inherent in this process that led Sartre’s character, Garcin, to claim: ‘There’s no need for red-hot poker. Hell is – other people!’ (1989b p45).

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<sup>62</sup> James [1890] 2007 KL 4434-4436

7.1.4 Whether positive or negative, the quality of relationships, both between participants and between participants and researchers or clinicians, have been important in how people have described their involvement. Nicole told me 'I've just got so involved in the social side of meeting others and becoming friends with some people that I've met'. She also argued that ethos, as set by senior management and researchers in the organisation she worked with, was crucial in creating an atmosphere where these relationships were possible.

7.1.5 David, a member of the same group as Nicole, agreed.

**Box 23 David on obligation and value**

'[researcher 1's] ideas, stimulates me enormously, he has tremendous insights, sociological insights, whereas [researcher 2] has this care element that comes through in all kinds of little ways, this probably more than anything else, is the support I need to continue. Without that I think I'd start to fade, but because of that I feel, partly an obligation to her but partly I feel it's worth it. It's not just an intellectual – it's all about relationship, conversation.

7.1.6 Kenneth was still recovering from a serious injury. He told me that one of the major benefits of involvement was the way that interactions he has and the feedback he receives 'constantly gives me objective evidence of my recovery which is hugely motivational'.

7.1.7 The following sections begin to look at how people experience and manage the benefits and risks of engaging with others when they take up involvement roles in health research and care. Section two expands on David's ideas about obligation and exchange, drawing on the work of Mauss and Nietzsche. In section three Simmel's ([1908] 1950) concept of the 'stranger' will be used to frame three very different participants' approaches to involvement. Some of the more negative aspects of working in groups will be examined in section four. Section five puts a more positive spin on Sherry Arnstein's concept of participation as 'therapy' by looking at how working in groups has helped some participants find an effective voice. This is framed in terms of developing what Fraser has described as multiple 'publics' (Fraser 1990, p62). Section six develops this into a discussion of how some groups have managed to continue beyond the purpose they were set up to achieve, or have been able to set their own goals. It looks at how Fraser's concepts of 'weak publics' and 'strong



publics' can inform the development of self-supporting communities of practice in involvement.

## **7.2 Gifts and exchanges**

7.2.1 Abigail's story (box 22) and the statements Elizabeth and Isobel made about staying engaged with the world after retirement (6.6.6) highlight the importance of relationships with other people and wider society in maintaining a sense of personal meaning. This suggests that knowledge spaces, like those created through patient and public involvement in health research and care, can help people develop meaningful relationships and markers of 'self'.

7.2.2 This is not 'therapy' in Arnstein's (1969) terms: a way of diverting individual or community involvement into dealing with trivial and inconsequential matters in order to neutralise individual anger or wider political goals, or even in the more positive way that will be described by Linda in section 7.5 (box 34). This is more a matter of people finding a way to participate in what Mauss described as the 'perpetual interchange of what we may call spiritual matter' (Mauss [1925] 1966, p12). These are the bonds of obligation, both to give and to receive, that connect us to others.

7.2.3 Mauss looked at the phenomenon of the ritualised exchange of goods between groups and communities. Examples he described include: the practice of Potlatch among indigenous peoples in the northwest of North America; the 'Kula' exchange of shell jewellery between the islanders of the Massim archipelago; and the Taonga among Maori people, who believe that the spirit which is implanted in these gifts binds the people and the land together. Mauss also saw echoes of these exchanges in European society, for instance the Russian tradition of Koliada, where children beg for eggs and flour in the name of the Slavic sky goddess (Mauss [1925] 1966, p13) similar to traditions of guising or trick-or-treat that are more familiar to us in the UK.

7.2.4 The purpose of these exchanges was not making a profit or even achieving like for like value. Mauss argued that they were symbolic demonstrations of alliances, rivalries and social connections. They created on-going obligations to give, to receive and to repay. The lavishness of the giving not only recognises the importance of receiver it also demonstrated the status and power of the giver. This display of giving is prominent in heroic tales; for

instance in Beowulf Hrothgar is described as 'that king who of all the lavish gift-lords of the north was the best regarded between the two seas' (Heaney [1999] 2009, KL 2590-2592).

7.2.5 Each gift exchange was not complete in itself but was intended to continue obligation and sustain relations. Some of these obligations might reach across generations, gifts received as a child might be repaid to the children of others when you have reached maturity. Mauss concluded that this asymmetry in the exchange of gifts helped to connect individual people and peoples. This ties them into a web of obligations in which 'things have value that is emotional as well as material; indeed in some cases the value is entirely emotional' (Mauss [1925] 1966, p63). While many of these rituals may seem archaic and irrelevant today, the continuing cultural importance of cards and gifts on holidays and birthdays would suggest Mauss was not altogether wrong in marking this as an important social phenomenon. The value exchanged might be informational as well as emotional; for instance when we say 'I owe so-and-so a phone call or an email'. It might be more symbolic, like including an acknowledgement that an idea we use in a paper arose from a discussion we had with someone else.

7.2.6 Open ended exchanges do seem to be an important element in maintaining human relations and, vitally, in maintaining a sense of self in relation to others. The threads which hold us in this web seem to be spun from the imperfection of the exchanges made, and the enduring obligation to repay. Nietzsche argued that this is why the execution of a duty can be experienced as self-empowering. He wrote 'when we do something for others in return for something they have done for us, what we are doing is restoring our self regard' (Nietzsche [1881] 1994, p151). This seems to be important in driving the internal dynamics of involvement knowledge spaces.

7.2.7 The concept of 'giving something back' is one that is certainly important in the stories told by survey respondents and interview participants about their own involvement. One survey respondent wrote 'After surgery for Cancer, I wanted to do something positive to put something back into the service from which I had received good care'. Similarly Nicole told me 'I had a very positive experience [course attended] and it's made such a difference to

me, that I felt that I wanted to give something back'. Sometimes the catalyst for becoming involved is a more personal feeling of indebtedness; a feeling of gratitude or obligation to a particular organisation or to an individual. Thomas was initially approached by a healthcare professional who had helped him during his rehabilitation following a serious injury.

**Box 24 Thomas on giving back**

One [healthcare professional] gave me a lot of advice on rehabilitation... So that return to work service was something I benefitted from, it got me back. This lady has quite a high degree of success in getting people back to work, but this service isn't offered everywhere. In fact there's a minority of places do so...

I'd gone back to work, and then there was about an eighteen month break in our relationship. But she started her PhD and was working as the researcher for a study called [study name]. It was a study into the type of service she was offering, getting people back to work...

So her study, which at this stage was a pilot, just a proof of concept study really, was to take about fifty people who she was offering her service to and comparing their experience and success in getting back to work with about fifty people from surrounding areas who were not offered such a service. So they were the usual treatment group and [researcher's] patients became the intervention group. Out of the blue, I was invited onto the steering group of that project and I really think that's because the [supervisor] is a bit of an exemplar when it comes to involving patients and members of the public in PPI and I suspect she had said: 'you need to get some public representatives' and [researcher] like I suspect with a lot of studies, just picked up on people she knew. She invited me to join the steering group for this project, so I found myself on the steering group for this project...

Why did I get involved with [this researcher's] study? Well actually because I knew [researcher] and I wanted, I was quite happy to pay back what she'd done for me... It's quite a close relationship – with this lady who was my nurse and was then the researcher – [that was] why I then helped with the data input work. So I get much more than it costs, than it could possibly cost... It's helped make me feel good about myself, I suppose. There was never much danger I simply retired to vegetate. I took early retirement but it was my intention to give back to society some of what I'd been taking out. To help me to feel good about myself, that I am giving back, you know.

7.2.8 In this exchange the respect shown for Thomas' contribution was important. He talked of being included on the steering group on par with professors and other experts. This was something other participants remarked

on too. Grace spoke of feeling that her views were taken as seriously as those of senior academics and added: ‘when a professor of something clever says: “That’s really helpful!” you go away thinking: “yeah well there is a place for you in this world” you know?’

7.2.9 Thomas explicitly acknowledges the continuing exchange, both giving and receiving. These ideas resonate with other involvement participants, who I have frequently heard talk both about ‘putting something back’ and ‘getting so much out of it’ commonly as corollaries of each other. Maintaining this precarious balance is often important to participants. Georgina became involved in health research when her husband was a participant in a study of the chronic degenerative condition he developed. At the time I spoke to her his condition had deteriorated to a point where he was no longer able to communicate. Georgina had continued to be involved in both research and service development but she was pessimistic about the quality of some of her more recent involvement experience, which she said ‘as an educator just made me feel depressed!’

#### **Box 25 Georgina on reciprocity**

[Husband] said from the beginning, because we've always been educators - that's what we've spent our lives doing, and he said from the very beginning: 'I want to do whatever I can if it will help other people' and so I've held to that...

[Initially] I just got a lot out of it because [researcher] and I used to talk about the different models that you could have for supporting people and in different societies how people with [condition] might be treated differently. Looking at, you know how possible it might be to include people in particular societies. And that was all just interesting and relevant and also very strengthening for me to have someone like that, that I could talk things through with whether email or person to person you know? This wonderfully thoughtful and compassionate person and he knew a lot, so that I could see – so you were both making a contribution and getting a lot from it...

[More recently] the director of nursing or something booked a conference call with me and ‘a conference call’ consists of him talking at me for an hour and a half and then he said what would you like to do so I said: ‘well out of all these things that you're telling me, this is what I’m quite interested in’ and then somehow it was: ‘What we'd really like you to do is– we'd really like you to have a walk around the hospital’!

So I booked this date and went to walk around the hospital; spent another

hour in his office, listening to him going on and on and on and about ten minutes doing something which I found really useful, because I actually got to the particular ward [where service initiative was taking place] ... but I never got really to talk to the nurse who was doing these ideas – because of this person in the way! And I guess that's kind of symbolic of how it often, is you know.

They've all got to have a [condition] strategy now because the government says you have to have a [condition] strategy, so you want to tell people how wonderful it is, but the extent to which they can be bothered to listen to anybody, or they actually want anybody's ideas is so limited.

7.2.10 Like Ellie (box 2), Georgina felt disillusioned with academic and clinical institutions that she felt made it difficult for patients' and carers' contributions to be properly heard and acted on. The imbalance in this latter exchange, and others like it, left her feeling more like an observer than a participant. Her place could have been filled by anyone; nothing unique to her, or that recognised either her skills or her needs, was being received or offered.

### **7.3 Strangers and outsiders**

7.3.1 In the story above the failure of a healthcare professional, to listen as well as talk, left Georgina feeling frustrated, seeing it as an indication of a tokenistic approach. Many public involvement roles, however, include a more positive element of acting as an outside observer as well as a participant. In this a degree of detachment from the clinical and/or academic perspective is necessary. As Elizabeth put it (box 1) '[patient and public representatives] haven't got the same attitudes to things – that's the whole point, they have got a different point of view and they're not worried about their careers, and this that and the other, in the same ways'.

7.3.2 This is a sociologically interesting position. Elizabeth describes her role in involvement as 'research partner'. She is part of a network working with a university and has particularly close links to two researchers with whom she had worked on a number of different projects. In these ways she is definitely an 'insider'; but, as her statement above indicates, she is at the same time still an 'outsider'. This is similar to the ambiguous identity that was described by Georg Simmel in his essay 'The Stranger' ([1908] 1950)

7.3.3 Simmel wrote: 'If wandering is the liberation from every given point in space, and thus the conceptional opposite to fixation at such a point, the

sociological form of the "stranger" presents the unity, as it were, of these two characteristics' (Simmel [1908] 1950, p402). While the wanderer comes and goes, the stranger is someone comes and stays, and yet, of necessity, remains strange. Where clinicians and academics represent relatively fixed communities, patients and research participants might be seen as the wanderers, while patient and public representatives or 'research partners' are, perhaps, the strangers who come and stay.

7.3.4 The stranger is in a position of tension between being part of a community and being external to it. The stranger is necessarily connected to, even part of the group, but they are also always, to some extent, apart from the group. The stranger brings qualities to the group which it does not already possess and cannot create from within itself. Strangers are identified more by their 'strange' origins than by the individual characteristics that usually distinguish different group members from each other. Perhaps this is the quality the chair of the research funding panel feared I would lose when he hoped I was not 'going native' (6.5.2).

7.3.5 To some extent the stranger's position of semi-detachment from the group affords them a degree of licence, to say and do things full members would be unable or reluctant to do. In his interview Kenneth said 'not being in a formal paid role does give a freedom, it gives a choice'. This is something I recognise from both community organisations and involvement in health research. Lay participants can sometimes ask questions or raise issues that it would be politically difficult for the professionals to broach.

7.3.6 Held in this role of stranger in which 'one has only certain more general qualities in common' (Simmel [1908] 1950, p405), but in which what is often required is a view from the perspective of particular experiences, the patient or public representative creates another tension. This is a tension between the general and the particular, the objective and the subjective (Ives et al. 2012; Litva et al. 2002). This is the tension that leads to Georgina's frustration at being asked to visit the hospital, but not being listened to; being there but not being present in the eyes of the health service professional. It is perhaps also what led to David's feelings of 'objectification' in the research network and in particular projects (box 3).

7.3.7 Strangers, for Simmel, are no owners of ‘soil not only in the physical, but also in the figurative’ ([1908] 1950, p403). In patient and public involvement the literal ownership of soil resonates with participants’ concerns about where involvement activities take place. In the interviews for this study Edward strongly argued that researchers should engage with people in places outside the universities and hospitals; while both David and Phoebe gave examples of meeting with researchers in cafés rather than their offices or institutions as a way of addressing power imbalances.

7.3.8 The ‘figurative’ soil that participants lack can be symbolised by access to academic libraries and journals. This can mean that patient and public representatives do not have an opportunity to access the results of studies they have contributed to. Hollie, from a completely different geographical region, has had experiences very similar to Ellie’s (box 2) of studies that are not written up and disseminated. Hollie has been involved as a service user researcher in both NHS service improvement and in academic research, but she was aware that service user researchers had an unequal status.

**Box 26 Hollie on the lack of joint ownership**

I didn’t quite ever feel an equal partner on those projects, I don’t know why but it’s still a little bit of a professional kind of service users divide which you couldn’t quite get over, like where I work now, you go out to lunch together or whatever, don’t you? They’d never do any of that outside meetings interaction, you know? As service users working on that project we’d go for a coffee or whatever. The professionals would never come along to that which is really interesting isn’t it? There’s still a bit of distance, but it is interesting.

I did get involved in a working group that’s trying to improve the secure ward there and it was the most poor experience I’d been involved in because they wanted service user input, so they set up a group for service users to feed into what was happening. [One] person then would go along to the main meeting with all the staff and feed in what we’d said. The most remarkable thing about all of this is that at the end of the year, we actually received, I can’t quite remember what award it was but it was for the work that we’d done jointly with the staff team. I had to go up and collect the award, it was the first time we actually met the staff because there’d been this in-between person who was feeding the stuff back...it was very weird meeting the people [when] they went up and got the award.

The other downside, I suppose is in all research, it's that whole thing where you get the report at the end and it's about how do you influence that going into practise and certainly on a number of those we did, it did seem a little bit like: 'Well we've done this report now, but are we actually gonna take that on?' And that was quite hard to disseminate because really the professional who's in charge of that – it's about whether the lead person will include people.

There was one project that was finished but which was never written up and I'm still annoyed about it not ever being written up because it was quite important and there was a quite a lot said by people I interviewed that was quite startling and it wasn't properly written up. The project lead had an opportunity for a DVD to be made by some kind of leadership program in the NHS which she'd been on. So we actually found [out about] this DVD all about how wonderful it was to work together and about service user research and about how that project had been. I've never actually seen the DVD although I've asked for it several times. On that project when it came to it, she moved on to another post it never got written up.

I feel an obligation to those service users that I interviewed you know? We were telling them 'your views will be taken into consideration' – and it was never even written up! And I think that's where you don't have any control ultimately you're not an equal partner then those kind of issues are a little bit out of your control.

7.3.9 Like Hollie, Phoebe feels that her primary commitment is to other service users, and to study participants in particular. As someone who now earns her living advising and training researchers, and health and social care professionals, she feels that the maintenance of her distance from academic and clinical perspectives is extremely important. She is very aware of pressures on academic colleagues to publish peer reviewed papers, but she is determined not to get pulled into what she sees as a mechanical process in which she would be in danger of losing her identity.

7.3.10 Phoebe in wishing to remain 'naïve' 'mundane' and 'like a member of the public' brings to mind the previous discussions of 'layness' (5.4) and in particular of my own 'layness' (6.5).

**Box 27 Phoebe on staying 'strange'**

It's funny, because I find it really hard – I always think of myself as being a person rather than any roles, so I really struggle with words to describe my role because I just see myself as me, which is probably quite wrong in many ways



especially when I get asked 'what's my role?' I'm like 'we'll I'm me'. So I struggle hugely actually with that. I mean like, I've been in a medium secure unit and interviewed people to find out around recovery within detained settings and that sort of thing and, but I've always seen it as me going in and interviewing, rather than me doing any certain role - not even the word interviewing but talking with them to find out. What I feel I've done is to talk with people and get things that are important to them so that research community can then use that in ways that they're going to benefit. That's how I feel I don't know if I have, but that's what I feel.

It's almost like my language, the language; the way that I interpret it is so different than I think what the academic worlds might see it as. There's a real conflict there. I also like to see myself as quite a mundane person so I don't want to do anything that's going to make me think that I'm not that... I don't really feel like I'm involved in research anyway, full stop. So that's my bottom line of how I see it. I just do things....

God, [one of the costs of involvement is] the intellectual side of it. I struggle so much, so, so much with it, so much. I just don't get it. I just don't get it at all and I feel like part of me doesn't even want to get it because I feel then I'll change from being, sort of, naïve. I don't want to change, I don't want to lose the fact that I'm like a member of the public. I don't want to get my head stuck into all this stuff. I want to be always able to relate to people. I think there is an element, definitely that researchers can't, [always relate to people] if they haven't – I suppose most of the things I do is around mental health issues and there's such a taboo around that, and for researchers to be able to say, yes I've had these issues and yes I'm a researcher too, [it] separates people....

Starting off with [support group] and [two research projects] were just so important in building my confidence. But then I sort of expect all teams to be like that [laughs] d'you know and they're not! ... I keep like getting told that 'you know Phoebe that was an exception' those two research projects that I was involved in and then it's almost like y'know that I've banged on about them, how it's done and expecting that everything was done like that and to be told that it's not, and it's like wow, to me it's like 'why not?' Why not? You know, why isn't it done like that and it, and it pisses me off to be honest because it's [laughs] but it does, because I know that it can be done, so why isn't it being done and why, what is this excuse 'that was an exception' that's an excuse d'you know? And it's crap! It really, really irritates me, you know the way that teams work. We all worked so well as a team and it's because everybody was willing to like give and take and acknowledge different things from within themselves....

It's really hard and because I think as well, I think, personalities can come out of culture so if the culture is such that this person is in the lead - and it's almost

encouraged that somebody who's like a real control freak should be in the lead then that's the culture isn't it? And then the personality fits the culture whereas if the culture would change maybe the personalities would change.

And it's so, d'you know what struck me as well within research is this thing d'you know, is it really about the people or is it about people getting stuff published and getting a name for themselves? That hurts a lot actually to be honest, because I went to this talk and I can't remember what it was, because it was, but it, it was about how stuff gets published and how many gets read and grey matter and all this sort of stuff and I was like [sigh] this is sick d'ya know? What is that about, is that about people always having their voices heard? Or people expressing what's right for them and what's not and d'you know, the street level?

7.3.11 While the academic and the intellectual aspects of involvement were a barrier for Phoebe, they were considered a benefit by some other participants. For Dorothy the lay reviewing of research proposals 'keeps the brain cells going'; Eva felt engaging with academics 'awakens a whole new sphere of understanding'; and Nicole felt good about 'just getting so involved with all the intellectual stimulation and the education and, and wanting to find out more and more and more about everything'.

7.3.12 In some ways Alan is almost the polar opposite to Phoebe. His concerns are not with being subsumed in the academic machine, but with being excluded from it, either figuratively or literally. He describes becoming increasingly involved in research 'through embarrassment'; after involvement in one project showed him that this was something he knew little about. Since that time he had attended courses on a range of related issues, including some that were specifically designed for people in roles that he did not occupy, but that he accessed through people he had come to know through his involvement in other health related groups and activities.

7.3.13 Alan is perhaps more akin to the 'wanderer' than Simmel's more rooted 'stranger'. During the interview he referred to fourteen different universities he had been involved with in some way, as well as research funders, regulatory bodies and service providers. He talked a lot about policy and governance structures; using a wide range of acronyms for organisations, programmes, treatments and conditions. Sometimes this made his stories hard to follow. He also named a large number of individual researchers and

prominent figures in policy and governance, often pausing to ask if I had also met them. He showed enormous curiosity about how policies, organisations and programmes are structured and had obviously spent time researching these issues. An image of the dogged police inspector in classic country house detective fiction, or the film noir detective, determinedly following up on every lead, was frequently brought to mind when listening to his interview.

#### **Box 28 Alan on feeling excluded**

How did I start? Through embarrassment, yeah! Mine was... I wouldn't say ignorance. [Researcher 1] was a member of staff where I was. I had a casual contract of employment with [university 1] With the NHS [involvement project] which came about in 2006 – I didn't really meet him that much, although the director of training and development was [researcher 2]. So I know all these guys from up there. And the NHS funding came to an end. But anyway, I was in the project bank but I covered the [region 1], so I would go to various places in the [region1], but this was active PPI engaging with NHS, trusts and PCTs – had nothing to do with research.

There was a call – you know, a general call across everybody that was on the bank, that there was gonna be, a systematic review, covering the [issue] covering the period of time 1998 to 2008, undertaken with [researcher 3] up at [university 2], [researcher 4] who was [university 1] [researcher 2] the [acronym for professional body], and they wanted two people, I applied. Okay, fair enough, I didn't quite understand. It used to meet at the [acronym for professional body] and then I realised what I've let myself in for – I'd never done research. So really, I wasn't really the right person but I wasn't gonna put my hands up and say maybe I've come into the wrong room, and when they started talking about: they'd identify a forensic librarian and do sort of like a literature review; started talking about all the other bits that go with it as you well understand; I thought I'm out of me depth here. I don't know that I can actually contribute anything towards it.

I think in the end there was only about four meetings. You know, we had limited amount of tasks to undertake – things that we could bring to the table but everything I'd been involved with was face-to-face with trust board, there was no looking back and comparing or anything that was sort of like – I'd heard the words qualitative/quantitative, multi-centre, three arm, I'd heard of these things, but I didn't know what they meant. So, really, out of sheer embarrassment of not really – Being paid, you know INVOLVE rate to be on this steering group, I thought I need to learn, so it was as a result of not knowing, I kind of like decided that I wanted to get involved 'cause I was kind of like put on the spot. It's nobody's fault! I was just, you know I was happy to be, I wouldn't say recruit

because I had a sort of like project manager or a programme manager and they just allocated people – I was more comfortable looking at, sort of like PPI in practise, but never really considered it in theory and some of the things around it. So that was about 2008, and the project which is published because it's moved on since then, is [study acronym 1] now that it's got [study acronym 2] which [researcher 2] supposed to – you probably know [researcher 2] You know how involved she is.

So what I did after that I thought I better get involved to get genned up, it seems that you know, NICE guidance is about system development and I had been on two previous NICE guidance development groups and I'm on another one which is almost concluding, and that's about grading the evidence, and ultimately, I'd love, I'd love it to be a legal requirement but it's only the technological appraisals that have to be implemented within three months, so you know, things like the guidelines for bipolar, schizophrenia you know, care pathway for cystic fibrosis, I'd love to see it being implemented because it would be very difficult for providers or commissioners of services to actually show that they've got some kind of research-based evidence that contradicts NICE.

So, anyway, what I found difficult, when I tried to get involved in research, is that if you're not already connected through a network, it was difficult and my first opportunity to get connected was with [region 2] RDS based at [Hospital], because that was a telephone conversation as result of an advertisement, wherever I'd seen it, by the time I'd got there, and they realised I was from [city 1] which was outside of their area, I think I only lasted two meetings 'cause the assistant director for the RDS felt that because I didn't live in [city 2] or [city 3] and stuff like that –

So you know, I attended two meetings, attended the regional [acronym for funder] conference in two o nine, that [researcher 5] attended before she is what she is now, director general or whatever, and then I started looking elsewhere. You know 'cause that had all concluded, I joined [acronym for service provider] but they didn't have a research network, because it was dysfunctional and it had been stopped – their service-user research forum.

I'm on – I'm on the [acronym for service provider] research and design – [Their service user panel] became dysfunctional because in terms of governance, unfortunately, [acronym for service provider] didn't ensure its integrity through terms of reference. I like things to be clear I love policy, practises and procedure – I love aims and objectives, I love outcomes I love things that are measureable – I don't like what the [acronym for university 3] does through their service user initiative, but it's convenient to the lecturers, the senior lecturers and researchers 'cause what they've actually got is a body of people that have been there too long, that can integrate within the curriculum

design, and assist researchers in the design of research – it's convenient; they don't have to advertise. What I'd like to see is to see that change – that you've got a tenantry for two years that may or may not be renewable.

So, in terms of getting involved with the [acronym for university 3], since two or eight, it hasn't happened for me. Yet I only live from here, about a mile and a half. And it's because mental health, learning difficulty, children's services or children nursing, adult nursing what have you, they hold to their own group of contributors – they don't replenish them or place them so what you might have is an individual that's only had one diagnosis in their life and each successive group of students would only ever hear the narrative of, maybe, mild depression rather than you know a cluster three or cluster two personality disorder. I'm not mocking – I'm not mocking it but, you know – I'd like to see it change but, at the end of the – and I'd like to work closer to home.

7.3.14 Alan elsewhere acknowledged that some people experienced his behaviour as challenging or even aggressive. However he did not connect this with his difficulty in engaging with his local group. Instead he saw this purely as a structural problem with the way his local university organises its patient and public involvement. Talking of geographically specific initiatives in other areas that he was not eligible to engage in he spoke of being 'postcode-lottery-ed out' of them.

7.3.15 At the outset of our interview Alan revealed that, prior to our meeting, he had read up on the regulations for PhD fellowships under a programme he thought might be funding my study. On the basis of that information he had prepared some 'hard questions' for me. Perhaps luckily for me, I was funded under a different programme and so avoided that ordeal. However this demonstrated to me how important it was for Alan to have some feeling of control. On the one hand acronyms and jargon, as well as references to policy initiatives and prominent individuals, were used to create the impression of a well-informed 'insider'. His narratives on the other hand were about exclusion; of being the 'outsider'.

## **7.4 The trouble with other people**

7.4.1 The sorting of people into 'insiders and outsiders' has been shown by social psychologists to be an important tactic for managing relationships. This is about building imagined allegiances by identifying shared characteristics. It can mean actively discriminating against those who do not share the identified

features, however trivial and even when the identity of both 'in-group' and 'out-group' members is unknown (Tajfel and Turner 1986). One way of claiming in-group membership is to use 'in-group jargon and local terminology' (Cutting 2002, p78). For Alan this tactic appeared to have, at best, a partial success. However, even more negatively, it can actively exclude those who do not share knowledge of these terms, making access to involvement more daunting. Kate describes her experiences in both service improvement and research involvement.

### **Box 29 Kate on jargon**

Meetings often remind me of that scene in Good Morning Vietnam, that bit where Robin Williams goes on about the V.P. is a V.I.P., so shouldn't we keep the P.C. on the Q.T. because if it leaks to the VC [laughs]. A lot of meetings are like that! I've been [to meetings] where they're dropping acronyms and initially you ask what they mean but after a couple hours you're fed up feeling like an idiot and feeling that you're looking like an idiot and holding proceedings up so you just shut up and then don't have a clue what's going on. And I think patient groups can be as guilty of that as professionals sometimes. I thought: 'Cut it out people, you know, makes you feel like you're an insider but it makes it incomprehensible and if you wonder why people interested in joining come to one meeting and don't come back, that's one of the reasons! Because they haven't a clue what you're talking about.'

I mean most people know that GP means, some people don't even know what PCT means. So there's, there's a sort of tension between creating a sort of group identity that shares some of these ideas and thoughts and excluding other people who find that incomprehensible and impenetrable. I don't think it's deliberate. I don't think it's an elitist thing, I think people do it without thinking but you know I'm more clued up than most but I get fed up saying: 'Sorry can and just stop you a minute, what exactly is the KEB?' But I know lots of people are just gonna sit there completely baffled and then slink away and not come back. Because they're going to think: 'Oh if I admit I don't know what they're talking about, you know people think I'm a twit.' It is actually a matter of undermining people's confidence when part of the point of this is to increase their confidence to engage... there's a way you could put it that other people could understand it without patronising your professionals. You might find they like it! [laughs] There must be some professionals out there whose heart sinks when they see a page just absolutely studded with jargon...

Very few people are aware that the possibility [to be involved] is even there and when they become aware they feel intimidated. And they think oh I couldn't do that you know, I'm not clever enough, I don't have enough knowledge. My

local LINK seems to be very good at giving people training and building their confidence and empowering them. Maybe they need to do a bit more of that, but yeah for a lot of people the NHS is a bit like Big Brother, you know they see it as you might like it, you might not like it but whatever it is you just have to put up with it – if you're not happy that's just your tough luck. They don't see that involvement is possible and I think that's why so many people are so frustrated if they're not happy with the treatment they've received, but they think it's a sort of like it or lump it system

7.4.2 Kate's emphasis on the importance of building people's confidence to contribute and to question is another recurring theme (e.g. see boxes 14 and 34). Harriet also felt that, before having experience of academic study, she would not have had the confidence to comment on research papers. She argued that going to university as a mature student 'and actually carrying out research myself gave me a voice if you like so I would feel confident enough to critique somebody else's research'.

7.4.3 Having confidence in your own skills and ability to engage is not, however, necessarily sufficient in itself to enable effective involvement. While for some participants involvement in health research provides an opportunity to create meaning from adversity or suffering, for others it may confront them with difficult and painful issues they do not want to dwell upon.

7.4.4 Both Georgina and Daisy are skilled and knowledgeable. Both have at least one academic degree, and both express themselves confidently. However unlike Kenneth (7.1.6) they did not experience involvement as evidence of recovery. Both are coping with conditions that have a poor prognosis. Georgina explained that involvement in one particular study of her husband's condition was experienced as increasingly bringing them 'face-to-face with what he couldn't do'. A similar issue seems to be implied in Daisy's description of herself as an 'ostrich'.

**Box 30 Daisy on reasons for leaving group**

I can see that the other members of [group] definitely get a huge amount out of it. I know that they seem to sort of build their lives around how fascinated they are with all the health questions and that was really nice to see. You know, people if they're involved in this. I guess felt that I wasn't as passionate as I should be, looking at the other members. [Laughs] I wasn't doing my homework and I felt like a dunce! The dunce of the class! [Laughs] – I guess I found that

everyone has got their own kind of coping mechanisms and, you know, I'm an ostrich and I stick my head in the sand. [Laughs]

I guess maybe for someone –particularly the [topic] workshop. I think it got very sort of personal and personal health. I guess I kinda had an idea in my head that it would be more general terms. Sort of there might be a research question and people would think about it, sort of using their experiences and own their health and interactions with the health service. Using that to sort of think about ways to take things forward in a positive direction for others. Maybe I found it sort of very focused on the individual and how awful their experiences were – which is all incredibly valid but I think that I felt that it didn't necessarily move anything forward. It just seemed to be a really kind of good sound box for people to get things off their chests, which is great, but I, I think I was expecting something more. Rather than it being a venting session, you know a more positive spin on things. Sort of how, how to use negative experiences to get a better environment when you go and see health professionals, or something. I'm not sure if I – I probably maybe misinterpreted it. So it wasn't such a great one. [Laughs]...

I guess I hadn't really anticipated quite how much sort of, homework there would be for some of the sessions there were a lot of papers to read and things like that so I guess I just felt a bit time pressured because I had other volunteering commitments at that time too. So I think I was just taking too much on and I guess I felt a bit like the dunce of the class. [Laughs] I think maybe, maybe I just wasn't really what the group needed so, so I wasn't prepared to do all the work for it. Like, the others were doing so much background reading and they, they were able to give a lot more.

7.4.5 Although she had been free to do as little or as much 'homework' as she chose; it is easy to see why Daisy might find the commitment of some other participants intimidating. A member of the same group as Daisy told me that, at that time, they were spending more time on their involvement activities than they had on their full time job, prior to retirement. In another region Hannah, one of the diarists for this project, described herself as spending 'vast amounts of time being a patient'. Indeed during the two and a half weeks that she recorded her activities she spent an average of almost forty hours a week on a combination of support group, service improvement and research involvement, this on top of being employed full time in the family business.

7.4.6 While Daisy also spoke of a range of genuine time pressures, from work (she had needed to use some annual leave to attend daytime



meetings), from family, and from other voluntary commitments; it was clear that the dynamics and focus of the particular project session she attended had influenced her decision to withdraw from involvement in health research. For some people, placing issues of health and social care at the centre of what they do can help them to cope with the distress of loss or illness, making public good from 'life's pains' (6.5.21). For others, the emotional work of coping is best achieved by keeping the impacts of illness on the periphery of thought. Sometimes people with chronic conditions just want to spend their time 'being like everybody else' (Asprey and Nash undated) not focusing on their condition.

7.4.7 Different tactics might be more personally appropriate at different times. This is one of the things that make it important that people feel able to disengage from their involvement, with the option to reengage, or engage differently at a more appropriate time for them. This can be a difficult process to manage. During a period of illness and family problems, John had negotiated cutting back his involvement activities with a patient group attached to a research organisation. However he was angered when the group secretary referred his offer to represent the patient group at a meeting of the research organisation's management board to the patient and public involvement facilitator for approval. He described this as being 'vetted'.

**Box 31 John on feeling 'vetted'**

I really, you know, was pissed off. [laugh] To be blunt. You know? With the amount of things that I've done and the involvement that I've had, and alright there was a concern but, you know, I'm a little bit better now than I was in February, you know I wasn't well in February and you know, I was suffering.

There was a lot happening January-February and I'd just gone a little bit overboard with what I was doing and the amount of times going up and down. And with being ill as well, another dose of the, the flu which was caught pretty quickly with antibiotics so I didn't end up being too ill but I was on antibiotics the busiest week. So I've had my review with [facilitator] and [researcher] and just said, you know I will decide what I want to do and I won't do too much. The reason I asked to [attend a meeting] was because I knew I was [already at the venue for an earlier event] and I would be doing nothing for two and a half hours, you know? And I, I felt that we needed to get representation there and somebody to support [another group member], because it was her first time of going. You know, so I was a little bit [sotto voce] pissed off.

7.4.8 John described this experience as a point at which his orientation to the group, and to the staff facilitating and administering its activities, had completely altered. It left him feeling deliberately marginalised and coloured how he interpreted other events. Instead of describing the group as a structure that empowered him and opened new possibilities, as he had done; he now talked of it as limiting his options and restricting his ability to make autonomous decisions about his own fitness to participate. His negative orientation led him to further negative judgements about some of the other group members and the research staff. This acted in a way similar to the fundamental attribution error; a ‘general tendency to overestimate the importance of personal or dispositional factors relative to environmental influences’ (Ross 1977, p184). It seemed to be set into a destructive spiral, in which each negative experience was seen as validating and reinforcing previous negative judgements of the people involved.

7.4.9 Jennifer was characteristically blunt about what she experiences as unrealistic expectations and undesirable group effects. For her it was important for involvement, particularly in research, to remain focused on being purposeful. She had little patience either for intergroup politics or for the kind of ‘venting session’ that Daisy described above.

**Box 32 Jennifer on negative group effects**

I’m not very good at, at consumer groups – they tend to turn into whinge fests... The only time [in health research] I’ve ever thought ‘oh, I wish I wasn’t here; I’m wasting my time’ has actually been at PPI meetings! [Laugh] Where everyone’s whinging about not being taken seriously! [Laugh] I bet you’ve found this – I know you can’t admit it, but I bet you have.

‘Oh whinge! Oh moan! Oh nobody listens to me! Nobody includes me, nobody treats me as a special case’

Well you shouldn’t be [treated as a special case]! If you can’t do it, you shouldn’t be there. There are other things to do. There are useful things to do with patient groups, with support groups, with all sorts of things.

7.4.10 I do have some sympathy for Jennifer’s obvious frustration as well as with Daisy’s expectation of something more productive than a ‘venting session’. However her use of this term also reminded me of an interview a colleague of mine conducted, some years ago, with Fr. Paul Butler (@RedRector), for the Joseph Rowntree Foundation project ‘Active

Governance' (Maguire and Truscott 2006). Fr. Paul described engaging with people who felt excluded and unheard as 'taking the lid off a kettle, you have to let the steam out before you can see what is in there'. This seems to me to be a very wise observation; explaining, as it does, why the same involvement activity can be experienced as a scalding by some while feeling like a release for others.

7.4.11 Here Cindy is talking about attending a group that was discussing the development of a research question about a particular surgical procedure that her husband had undergone. In addition to caring for her husband, and coping with her own chronic conditions, Cindy was also the main breadwinner for the family and cared for a school aged child. Her husband had suffered a number of adverse reactions and Cindy, as his carer, had an extremely stressful time helping him through this. They lived in a largely rural area several hundred miles from where the surgery had taken place. Cindy had to cope alone with a lot of the difficulties the family encountered at that time, because her husband had been unconscious or too ill to make decisions for himself. These things, together, meant that she had few opportunities to have her story, of what it had been like when things went wrong, heard by anyone.

**Box 33 Cindy on participating**

I went to a [surgical procedure] consultation group and it made me think of a lot of things that I hadn't – that I buried deep down and it's made me sort of face things that I need to do, or need to try to do and not, you know, not sort of push them away thinking 'oh, well', and it gave me a lot of information to think about. How perhaps that option is, not the answers for everybody. Because you, you know it, it, it causes its own problems. I'd be very interested to continue with this group and see how it develops.

I was able to give my experience as supporting somebody who's had this surgery and I've seen I think more negative parts to it than are positive so I was able to give, you know, the experiences that I went through, and hope by that, people who go forward to have the operation perhaps will think about or prepare themselves for the, for the fact that it's not all positive.

7.4.12 For Cindy this workshop was a valuable way to explore and validate her feelings about what she had felt was poor advice and care received by her husband. This was experienced by her as extremely encouraging and

empowering. Unfortunately for her, this group only met once and the hoped for on-going activities did not materialise.

## 7.5 Finding voice

7.5.1 One way of trying to make this 'venting' more productive is to turn it into a structured process of narrative reconstruction (6.5.4). This is something that has been done by the medical school that Linda works with extensively. Their patient group not only work with researchers on a range of projects they also teach, write training materials and mentor medical students. As part of their preparation for these roles members of the group undergo a three week course, telling their own stories and listening to those of others.

7.5.2 Linda had broad, and sometimes very negative, experiences of health and social care services both as the carer of a child with epilepsy and in dealing with her own painful chronic condition. After being made redundant from her career in childcare she had found it difficult to find work and had spent some time on income support before reaching retirement age. She had vocational qualifications but no academic background. She had become involved in research through a friend who asked Linda to go with her to a meeting.

7.5.3 For Linda the narrative process, undertaken with this group, not only made her feel better able to use her experiences of health and social care in her involvement activities, it also enabled her to communicate her needs better to healthcare professionals. For her that meant getting better treatment and having fewer return visits; so she no longer felt 'ticked as this frequent flyer'.

### **Box 34 Linda on group activity**

How do you describe a [group activity]? You go in with other people and you tell them your story and sometimes it's the first time anybody's ever listened to you And it's your journey.

And without understanding yourself – it's like a form of self-healing really. You don't realise it at the time but as you get more involved and you've realised it is the first time, you know? Over the years. I've been, done mine and I facilitate – co-facilitate on it. And you realise what a healing process it is. It sounds really weird, you know, people don't understand it: 'You sit there and you talk about yourselves?' but then you listen to other people and they tell their story and well they're all different. You can relate to 'Yeh, well I know where you are when

you're sitting up at three O'clock in the morning – on your own – or you're doing this or you're doing that or you're making phone calls and nobody's listening to you. You go into the doctors, you come out crying because you don't know what to say to the doctor – you think it's irrelevant'.

It's like a confidence building. And so now you see, as I've grown with the work and over my illness and things, I know exactly now when I go to the doctors what exactly I want to say and I can challenge him. And it's like, it's like my friend says – it's like you get the courage to challenge constructively and if you don't agree with whatever's been said or you don't like that you can say 'no' and this is what it's done for me. So, now, through that and over time it's a sort of counselling – you're counselling yourself. . And I know, so it does work – this [group activity] does work – maybe not for everybody but it worked for me.

Over the years that I've done these things people having been telling their stories and have said 'This is the first time I've ever said this' or 'I've never told anybody that this is what's been bothering me'. It just allows you to open up. You know it's not an exam and you can say as much and as little as you like and there's no pressure. You can do it three times – go to this class three time over three weeks And it's very laid-back, social and you make friends and some of the friends I made seven years ago, we're still friends. You might not see them regular, but you feel, you cross their paths and then remember. You remember them – but it's not, I don't think oh, I know that lady because she told me this story, that's not what it's about. It's so nice, this is how friendships grow. It's really weird how it works – it's not rocket science but it does work – I think it's because people listen.

It's like, when you start you're given a bag of jigsaw pieces and every time you come you can fit a piece in because you say 'oh yeh!' and you see this picture's building up – but you don't know what the picture is but it's building up. And that's how I, I see it. It's this, I have a bag of jigsaw pieces and I can. [gesture of putting pieces into puzzle] And this is how I think – 'oh yeh, I've learned that today'. I mean it's quite amazing really, the involvement has helped me so much it's unbelievable. I am a completely a different person – I am not this angry person any more. I'm not, I'm not angry any more. I mean, what happened's what happened. You like you carry all this rubbish on your back, but then you let it go because there's nothing you can do about it. Just get on with it, just get on with it you know, and if you do stumble across something there's always somebody around that'll say 'Right. Have you tried this, have you been here, have you done this?' When all the [public involvement group] is together you don't sit there and say 'Ohhh-oh!' you know, crying in us hands. You can tell by the face of somebody: 'You're not too good?' 'No, I'm not too good.' You understand – you don't go into detail, you know, it's just a phone call to say 'give

us a call' or whatever and that's all you need and you recognise it.

I think if you don't do this [group activity] how could you possibly – if you're still hurting and angry all you'll be passing on is the anger and negativity. And it's not what it's all about being involved,

7.5.4 What Linda is describing reminded me of what Dewey wrote about the educational value of communication for both the speaker and the listener. 'The experience has to be formulated in order to be communicated. To formulate requires getting outside of it, seeing it as another would see it, considering what points of contact it has with the life of another so that it may be got into such form that he can appreciate its meaning' (Dewey [1916] 2012, p6). However mapping this as a knowledge space, using the dimensions proposed by Gibson Britten and Lynch (section 3.6) gives a contradictory picture. It would appear to be a relatively weak public; it does not make decisions or allocate resources. It has a single mode of involvement, although multiple ways in which this may develop. It is both expressive and instrumental. Participants are explicitly invited to tell their own stories in their own way and to the extent they are comfortable to do so, but this is in order to prepare them to take part in specific tasks defined by the medical school.

7.5.5 In fact the group activity Linda is talking about can easily be described in terms of 'therapy'. However in this context it seems to me to be an error to see 'therapy', as Arnstein (1969) did, as being at the bottom of the ladder of participation; marginally above 'manipulation' but still within in the zone of 'non participation' (Appendix 9). The narrative process described here is not about diverting, dissipating and disarming protest. Nor is it about teaching patients to present their knowledge in a 'proper' clinical or academic form. It is about rehearsing, focusing and honing previously unformulated feelings, ideas and impressions into clearer arguments and tools which can then be used to effect change. During this process situated, emotionally bound, and experiential knowledge is transformed into something that can be accessed less painfully and can be used more purposively.

7.5.6 Through this group activity Linda was provided with a sympathetic 'looking glass' (7.1.3); giving her the space and the support to develop different ways of seeing and describing herself. This can help facilitate the translation of

emotional and embodied experiential knowledge, so that it can be used purposively. But, importantly, the development of this translational skill not only makes participants' knowledge useful to research and medicine. As Linda explained, it also provides her with tools she is able to use to extend her agency in personal encounters with health and social care systems.

7.5.7 This sort of process can, of course, take place in other ways. Some of the members of other groups spoke of the understanding and confidence that emanated from training or from social activities. For Lotte being part of a support group led her to hear other people's stories and encouraged her to speak out on her own behalf as well as theirs. For others, like Abigail, this process of validation, reinforcement and reflection has occurred through supportive relationships with academics and clinicians. The processes described by Linda and Lotte are reminiscent of the process of public opinion formation that Habermas has described as happening in the 'public sphere' (4.7). This is a process that rests on open discussions in which all participants have an equal opportunity to contribute, as well as to hear the contributions of others.

7.5.8 Nancy Fraser (1990) suggests, however, that what Habermas presents is an idealised vision of a single public sphere. She goes on to propose that there have always been different sorts of 'public spheres'. Fraser argues that it is impossible to 'bracket', that is ignore or exclude, the effects that social inequalities have on people's ability to take part in public debate and opinion making. Indeed trying to do that most often 'works to the advantage of dominant groups in society and to the disadvantage of subordinates' (1990, p64), excluding those who do not have what she calls 'participatory parity'. For Fraser the effect of this disadvantage leads to those excluded from equal involvement to form their own 'counter publics'. These may be more or less visible, depending on their access to cultural resources.

7.5.9 For Linda the value of having a space where she could rehearse her knowledge and build her confidence was vital to her ability to participate. She explained: 'Seven years ago I would never, ever have been able to stand up and say all these things. I didn't think I were interesting enough, I didn't think I were clever enough, but it's not to do with being clever or interesting – I just

didn't have the confidence to do it.' This feeling of not feeling 'clever enough' was often raised (e.g. see boxes 15 and 29),

7.5.10 This shows 'institutionalized value patterns that impede parity of participation' (Fraser 2000 p115). These value patterns can be seen as disadvantaging patients and carers when engaging in knowledge spaces with academics and health service professionals. Academic and professional knowledge is officially approved in a way that lay understandings are not, and therefore has a higher social status. Additionally, academic and professional knowledge comes from, and creates membership in, communities of practice and provides access to resources. This might include professional bodies, universities, research institutes, journals, hospitals the NHS etc. Being a patient or a carer on the other hand is not normally a shared experience. It is often experienced in isolation, or shared only with close family, as part of the private rather than the public sphere.

7.5.11 People involved in research as patients or members of the public may not only be acting as 'strangers' (7.3) to the research community they may also remain 'strange' to each other. This can not only feel lonely, lacking peer support; it also means that the opportunity to share and build upon useful information is lost. Elizabeth has an academic background and in her day job was used to being able to contact colleagues for information and advice. She felt a patient and public involvement group would be helpful, particularly when people were first involved.

**Box 35 Elizabeth on not quite belonging**

We don't have an actual support group as such, for the research partners at the moment – I mean there, there has been various training, for people, and introductory courses that sort of thing, and it tends to be a core of people that go so you gradually kind of meet with people that way but there's not a formal support group as such. You know I'd like there to be one – I think it's something that should come really.

Well because it's quite an isolated role being a research partner in a way, you're sort of drafted in to a thing and then you're sort of in the middle of it for a while and then you're out again and then you might be called. Like with [researcher's] one there might be nothing for several months because there's a phase going on that wouldn't involve me and then there be a flurry of emails;



can we help to edit a document or something so it's very in and out.

So I think when you first start, well I suppose it's a new field as well. You don't really know quite what's wanted and you never really know how you're measuring up, you know [laughs] presumably you're alright if you're called back! I mean obviously you manage without but it would have been a bit more comfortable from the beginning if there had been other research partners that I could have sort of called on or had a mentor or something like that and some kind of support you know? Sort of – 'oh they've asked me to do this and I'm a bit worried about this aspect of it' you know, 'Am I silly to worry, or is that an issue' you know? But I had to do it all by myself, so I mean you manage in the end – I wouldn't have a huge need for that type of information and sort of introductory support now, I mean and the lectures and the researchers are all very helpful and that, but they're so incredibly busy that you don't feel that you should always bother them, you know, and when you're new in a field you don't really know how relevant whatever question you've got is, you know whereas if you've got your colleagues, you know you can get more of a steer on what's the usual thing and what isn't, you know. So that would be the point for me.

Because you don't belong anywhere, you see, you don't belong to the research team, you don't belong to [university], you don't, you know I don't really belong to [condition specific research network] – again that's very isolating, I go there for meetings of standing committee's and that sort of thing but again you know, you're in and out so that's the nature of the beast really. [A support group] would be nice, it would be nice. And I suppose you could argue that it would make it more efficient but just to have a bit more support; it would just make it a bit easier really. Because also the other thing is, not so much of the smaller projects, but doing this kind of thing you know you sometimes have to go places you don't know, [where] you don't know anyone at all, you don't know where you are, you don't know where the hospital is, you know what I mean? You're in a new environment and I think most people find that quite challenging. So that would be another, if you knew someone had been to that particular one last year or something, you know? It's just a little bit of help really

7.5.12 While talking to Elizabeth I was strongly reminded of a presentation that had been given to the public involvement group in PenCLAHRC about eighteen months earlier by one of its members, Nigel Pyart.

## **7.6 Building communities**

7.6.1 The group, known as 'PenPIG', is where this study began. It was through discussions within PenPIG that the initial idea for this project arose. The membership of the group has transformed since then and only one of the

current members was there at the time of those initial discussions. However both past and present members of PenPIG have remained involved throughout the study in a range of different ways.

7.6.2 Nigel joined PenPIG during the first year of this study. He had been involved with some other research organisations and support groups and was interested in exploring what he found useful and congenial about PenPIG. He made a presentation to the group in which he raised the idea of viewing PenPIG as a community of practice. That is, a learning community which over time develops shared practices ‘by the sustained pursuit of a shared enterprise’ (Wenger 1999 p45). In this case the shared enterprise was improved quality and relevance of health research and care, from the perspectives of service users and the wider public. Yet the learning achieved by the group was experienced as transcending that purpose, and was opening unexpected knowledge landscapes. Nigel has given me permission to include here a summary of the points he made in that presentation.

**Box 36 Summary of ‘A snort from the sty’**

a presentation by Nigel Pyart

The aim of PenPIG is to make user involvement more effective. How PenPIG operates is also salient to this intention. Members bring expertise arising out of experience as a service user, and/or carer and a biography that adds to and complements the experience and skills of the whole team. Members do not represent a user group although they may act legitimately as advocates. Members are supported in assessing the level and appropriateness of their own participation in research.

My experience of PenPIG is that of a community as much as a team. I see myself as having become an established member of a relatively informal group through practice and participation (situated learning), against a personal backdrop of a constant and continuing tension between remaining involved and migrating to an imagined life trajectory that was occurring before I had a [condition] and became involved in research.

I freely belong in a community in which I experience for instance that the sharing of observations has value. It does not seem to me that we are a project team that is defined by its task, which on completion is disbanded. Nor is it membership solely of interest, but now goes beyond this as I experience it. I am being inducted into an identification with the practices of research involvement and critical thinking.

It has been enormously helpful to have confirmed that I can be included at different levels of participation; and that specific opportunities for continued dialogue with others is offered rather required. It is also valuable that my biography is taken into account and what I want from PenPIG is responded to. The regular rhythm of the community of PenPIG with its cycle of activities and events that allows us to regularly meet, reflect and evolve is something I find very congenial. My involvement includes widening my knowledge of concepts and the literature. It is exciting to participate in a variety of research user groups and forums, as well as balancing this participation with identifiable skill acquisition in evidence based research.

While PenPIG performs some specific tasks its team membership is not defined as yet by task. Its growth appears to have been something approaching organic and it fosters as many objectives as members. Because it functions as a community it is defined by the knowledge of its membership, mediated by group facilitators and the wider management and culture of PenCLAHRC. This enables the membership to change and members to take on new roles as interests and needs arise.

I would like to think it will exist so long as its members have something to contribute or to gain from it. It appears to be reaching a level of involvement that goes beyond interest toward active practice, accommodated by the acceptance of different levels of participation.

7.6.3 Nigel's arguments resonate with the earlier discussion of Mauss' 'Gift' (7.3). The meaningfulness of participation in this group arises from both what is contributed and what is gained. It does not only exist to fulfil a particular task, but also in order to create meaningful exchanges of knowledge, skills and understanding. This is an open ended, not a closed process.

7.6.4 In terms of the four dimensional mapping of knowledge spaces (3.6) Nigel describes a group that is able to move between being expressive and being instrumental. It has multiple ways of engaging; in some of these it acts as a 'weak public', discussing and formulating opinions, in others it acts as part of 'strong public' making decisions and allocating resources.

7.6.5 Some of the points Nigel makes towards the end of his piece indicate, however, that the practical reality, of a group of this sort, makes it dependent on the commitment of the fund holding organisation. Although PenPIG is involved in different ways across PenCLAHRC (appendix 14) a change in the 'culture of PenCLAHRC' or the withdrawal of funding from the

Department of Health would both remove practical support from the group and sever its direct connection to academic and clinical researchers, perhaps bursting its bubble.

7.6.6 While neither of these dangers may be imminent for PenPIG, the lack of genuine power and joint ownership, as Hollie discussed (box 26) can leave participants with the experience of being left hanging at the end of an involvement process. This was also described by Linda.

**Box 37 Linda on continuing engagement**

I think people want results; they want to see the end product, but you don't get the end product, not for a long time. And I think once that's over, although they've got involved in the thing, it may be dropped. I've just done a two year thing, talking about [health service improvement research topic] and now that's finished, the other people, they've come from all over the country – what happens to us now? Where do we go from here?' You've had a taste of it – you know, you can see it's done good. But that's it!

7.6.7 Linda went on to argue that researchers and research institutions were squandering a valuable resource by failing to share information about involvement opportunities more widely. She felt that people with genuine interest in research were put off further involvement because they felt abandoned at the end of an individual project.

7.6.8 Some participants, however, have resisted the dissolution of groups that funders or institutions have formed for a specific short term goal, taking control from the organisation that brought them together. Rosaline and her group had continued to undertake user led research projects for more than a decade after the short term project, in which their local university had involved them, was completed.

**Box 38 Rosaline on incorporation**

[University] advertised a course for older people on interviewing older people. It was a training course, and it was also funded by [charity] – which occasionally I still keep bumping into their name, they're still functioning. They got some funding from somewhere else, and this was one of the things that they were going to do with that money. They wanted to fund the course at [university] for a term, teaching interview techniques for interviewing older people. After that it would follow with actual research interviewing other older people. To answer

various questions about housing decisions in older age.

So we did a term's course on interviewing techniques and there were about seventeen or eighteen of us and then we did the research, which was eventually actually published with a paper on it. That was two terms and then some of us had got quite friendly together and we sort of felt, 'is that it? Is that the end? We'd done the course and right, what are we going to do next?' and we asked the university and they said: 'oh, well if you come in and do a course in watercolours painting – you don't to expect to continue it through the university.' We thought 'Well, It's not quite the same thing really. It's training people.'

We kicked up a lot of fuss and in fact in the end they called a meeting with all the various bodies and the university and they said well really, what you've got to do is form a research company. And we said 'okay, right', and then we thought 'well how are we going to do that?'

Anyway to cut a long story very, very short, we set up the research company with the help of the help of the Co-op because you know they are very involved in setting up companies. So we're a co-operative, it's called a Co-operative Consortium. So we're registered as a research company.

Actually from that we were asked to do a series research project by various bodies, through the [charity], the NHS, Local Authority here, [area] social services, and a university, a considerable number. So that, that, we've been doing that now for – Last year we did our final thing that we've done and we've got another thing programmed now, this time last year we finished with the research project that we did for the, Primary Care Trust in this area, on older people, their experiences in, hospital visiting – whether being visited or visiting. That was a research project and that's been published.

7.6.9 This group were able to resist their abolition through the withdrawal of institutional support. Through incorporation, they were able to prevent the bursting of their bubble. Clearly, taking this route requires access to a range of resources in terms of time, cultural and material assets. These might be out of reach for some participants, and are perhaps more achievable by the older, well-educated and relatively well off. A young person living in a bedsit or in shared accommodation, and needing to earn a living, might struggle to achieve incorporation in this way.

7.6.10 Rosaline admitted that it had been difficult, even for their already established collective co-operative, to continue to compete with traditional research institutions for commissions, as contracts became thinner during a

time of economic austerity. Also, because the university had not continued to run the methodology course that enabled the original group to form, it was also difficult for the collective to recruit new members. This meant that she was unsure how long they would be able to continue. In spite of their flexibility in transforming themselves, increasing external pressures were in danger of squeezing them out.

7.6.11 An alternative to the cooperative approach to independent involvement is the creation of a charity. This is the route that Beth and her group took, in order to pursue research that they felt was being neglected by established research institutions.

**Box 39 Beth on doing it for themselves**

We decided that we wanted to do our own study because we felt there was problems with the tests that they do for [condition]. We wanted to do something to test the tests. So, we decided to design and run our own study. So we were designers and controllers and then we found some other people to help us as well....

We found somebody who was a study coordinator for a hospital in [place], so she helped us and [we] sat down with her, had some meetings and designed the [study]. And then we did the funding for it. I wrote reports, telling our [condition specific charity] members what we wanted to do and why and then we asked for money to help pay for the study.

Initially it was driven by my own experience and the other lady – [name] – who helped me, her daughter’s experience. Then the other lady – the study coordinator – her experience, but by then the charity was getting a little bit bigger, and from the emails that we were getting and the phone calls that we were getting, there was a lot of people who were not being diagnosed, because their [tests] were normal. So that’s where it all came from.

We, we thought something’s wrong somewhere so we’ll start with the tests to see if the [other] test would be better. So we were comparing tests. We felt that it was you know, no good trying to get [doctors] to do anything because they didn’t think there was a problem. So we decided you know, we need to do something and there wasn’t research out there to do with [tests], to compare it to anything else...

We want to do another study again ourselves. But we wanted to try and get a [specialist] involved and our local Research Design Service were helping us. We couldn’t find a [specialist] willing to work with us. We were a little bit controversial...

I think that by doing it ourselves – it's research the academic research probably wouldn't touch with a barge pole.

7.6.12 While forming a charity to fund research might be accessible to more people than incorporation, achieving it still demands an enormous commitment of time, and a level of skill in negotiating regulations. To then go on to research this issue for themselves is a remarkable undertaking. As well as raising funds, Beth and her colleagues also had to gain access to skills and resources. They, further, had to negotiate research governance procedures from outside the structures through which these are normally facilitated. The sheer scale of obstacles Beth described as having found in their path was extraordinary.

7.6.13 Not only had they had to learn how to design and conduct a robust study, Beth's group also had to cope with institutional changes. At one point a reorganisation led to their local ethics committee losing their application so it had to be re-submitted. Another delay was caused when the hospital where the study was to take place scrapped machinery that was essential to their original study design. But overwhelmingly Beth felt that, because clinicians did not see a need to find a more accurate test for this condition, academic researchers were reluctant to support the group's efforts.

7.6.14 Part of this reluctance may also come from a concern for the academics' professional reputation. On a number of occasions during this study, in conversations with both academic and public contributors to research, I have heard the suggestion that, to work with a service user group to address a question they raised could be professionally damaging. Perhaps this has been made even more difficult following the behaviour of Andrew Wakefield (5.4.7) in the case of questions raised by some parents of children with autism.

7.6.15 Beth is quite realistic about this and continues to build relationships with professional researchers where she can. She tries to match the external pressures by building enthusiasm and energy within her organisation, matching internal and external forces. For instance, she admits that she personally found learning about potential research bias, and the techniques to overcome it, quite a challenge. Because of this she writes about the difficulties and challenges to help the supporters of her charity to

understand what the issues are and why researchers have to ensure robust study design. She feels that what is needed is for all research charities and funders to share information in this way. This could not only help the public shape their own research questions better, but also helps them to understand why research is important.

7.6.16 The group is also keen to improve channels for patients and members of the public to raise potential research questions and, when I spoke to her, Beth had been talking to the James Lind Alliance<sup>63</sup>. She was hoping to work with them to organise a priority setting partnership for the condition; a process that would include patients, clinicians and academic researchers. Beth's group also campaigns for improved research and treatment for the condition through publicity campaigns and by lobbying elected representatives.

7.6.17 This brings me back to the difference between Nancy Fraser's conception of a multiplicity of 'publics' as opposed to the Habermas' unified 'public sphere'. This group have created an arena for discussion and opinion formation, but they did so in response to the feeling that their views were being deliberately marginalised, and that they were unheard. This conforms to the definition of a 'subaltern counter public' as a parallel discursive arena 'where members of subordinated social groups invent and circulate counterdiscourse' (Fraser 1990, p67). Clearly this also links to the power of controlling what can be said, and thought, to be true discussed in chapter 5.

7.6.18 Fraser has also argued that these counter publics do not just rest between the spheres of private interests and the state; they are intimately connected into both. For her, one of the functions of counter publics may be to move issues between these spheres; she gives the example of feminism taking domestic abuse out of the sphere of private interests and making it an issue of public concern and policy. Some other medical examples of this have already been touched upon in this thesis, including the campaign to have homosexuality removed as a diagnosis (5.5.10) and campaigns to include new diagnoses or make treatments more available (6.3.4).

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<sup>63</sup> <http://www.lindalliance.org/> (accessed 03/05/14)



7.6.19 Through forming a group and working with others Beth has transformed a personal issue of her own delayed diagnosis into a public discussion about diagnostic testing and research. By taking the results of those deliberations to the political institutions of the state, through lobbying, they have further transformed them into issues of public policy. Finally, by undertaking research themselves, they have challenged the monopoly of experts in the creation of scientific knowledge. Through these actions this group has also transformed itself.

7.6.20 As discussed above, group activities like those described by Linda (box 34) could be described as the actions of a 'weak public'. However participants in that activity have been empowered to take on a range of other roles; roles that do include making decisions, empowering them to become more like 'strong publics'. Nigel's discussion of the membership of PenPIG not being defined by task (box 36) suggests that groups can move along the expressive and instrumental dimension of Gibson, Brittan and Lynch's cube (3.6), sometimes acting as an arena where views can be shared and opinions formed, at other times focussed on achieving particular goal. The achievements of the groups in the last two sections all suggest that, a space in which participants share experiences and understandings can enable personal meanings to be created, through this sense of community. These are prerequisites to the joint decision making and resource allocation of strong publics and collective action.

7.6.21 I would further argue that this can be nurtured in the environments described by Linda and Nigel. I have enormous personal admiration for both Beth and Rosaline, as well as for the achievements of their groups. I also find the role of professional academic and clinical researchers in their stories extremely sad. The inability of the professionals to be more supportive suggests that institutions, designed to produce knowledge, are sometimes acting to prevent it. Given the issue of the lack of participatory parity (7.5.8) this exclusion will be more effective in silencing some voices than others.

7.6.22 Hearing these different voices requires different ways of listening. These are needed because ignoring economic, social and cultural inequalities, in discussions and decision making processes, will keep some people excluded

and the inclusion of others may be experienced as tokenistic or as confrontational. The fact that a clinician or an academic researcher does not immediately recognise the problem that lies beneath what, for them, is an incorrectly phrased service user question, does not mean the problem is not genuine or important.

7.6.23 Similarly, established ways of working, within health service and academic institutions, privilege particular skills and forms of knowledge. Lay members of research teams, boards, ethics committees and funding panels might need some understanding of professional, management, clinical, or research cultures. For some people this is a preferred way of working. Someone working in that environment without a professional background, however, might find it difficult to be effective unless they have support. That same person might well contribute valuable insights, if they were given the opportunity engage in a way they found more comfortable, and that used language and techniques they were more familiar with.

7.6.24 It is also important for there to be opportunities for people to make contributions without feeling that they have to make a full time commitment. This might not only help people with other commitments to dip their toes into the water, but also enable people who do not want to focus on their illness to take part without feeling overwhelmed. The building of communities of practice, as proposed by Nigel, could make a range of different involvement activities accessible; enable different sorts of relationships to develop between researchers and the public, as well as providing research institutions with access to different sorts of knowledge.

## **8. Conclusion – so what?**

### **8.1 Question**

8.1.1 This study began with the question: ‘What motivates and sustains patient and public Involvement from the perspective of lay participants?’ and the intention to explore a conceptual framework that can enrich the understanding of involvement as it appears from the inside (2.1.2-3). An important influence on this was the Gibson, Britten and Lynch (2012) conceptualisation of patient and public involvement as ‘knowledge spaces’, metaphorical structures enabling people with different sorts of knowledge, experiences and understandings to come together and contribute to the social negotiation of knowledge, Jasanoff’s ‘civic epistemology’ (2000). In this final chapter I return to the knowledge space and the four dimensions outlined by Gibson Britten and Lynch and discuss how their model has been supported by data from this study, and how it has been problematised.

8.1.2 The central tenet of this thesis is that: patient and public involvement knowledge spaces, as they have been experienced by participants in this study, are not simple, easily outlined, structures within which people come together to achieve a shared goal; rather, they are complex often unstable and contested arenas in which varied experiences, theoretical approaches, and understandings are contributed to the processes of developing human knowledge. What have been described as effective, valuable and valued experiences of engagement in health and social care knowledge spaces, are where participants have been able to step outside the roles of ‘patient’, ‘carer’, ‘clinician’ or ‘academic’ and communicate with each other, both hearing and being heard, understanding and being understood.

8.1.3 At their best these spaces can connect individuals and their personal stories to the essentially human enterprise of knowing, supporting a sense of meaningfulness and self-worth. They also can enable a connection between what is known and who it is deemed to be known about, something that can both remind ‘knowers’ of their own humanity and ground their knowledge in the experience of living as a social animal. At their worst these spaces may be experienced as a cynical way for institutional actors to capture privileged information and insights, or to divert protest. So, on one hand, these

knowledge spaces create fields that can facilitate the development, articulation and communication of a broadly shared civic epistemology, legitimising and enabling health research and care, supporting the resolution of conflict. On the other hand, attempting to design and manage these spaces solely for the purpose of informing and legitimising existing structures, or to support institutional decisions that have already been made, can leave individual participants feeling alienated and undervalued; and leave the enterprises of health research and care seeming disconnected and dehumanised.

8.1.4 Patient and public involvement knowledge spaces were described by David (box 3) as 'liminal' spaces because they exist in between the worlds proper to familiar social roles: family, friends, taxpayers, patients, clinicians, and researchers. They exist between competing lifeworlds, systems and subsystems. Knowledge spaces are shaped, and squeezed, by the pressures exerted on them from these different worlds, particularly in the current context of economic retrenchment and political pressure to privatise social assets. Simultaneously the boundaries of knowledge spaces are being pushed in multiple directions by forces from within them.

8.1.5 A consequence of the complexity of these spaces, the social, economic and political forces acting upon them, the multiple orientations and understandings of participants within them, is that successful and valuable knowledge spaces are not necessarily sustainable or straightforwardly replicable. We cannot assume that, in describing a process that has been fruitful, we have a recipe which will continue to deliver the same results, or one which will be equally useful if replicated in different circumstances, with different people. Involvement 'toolkits' and methodologies, therefore, need to be used with care and with sensitivity, not as a blueprint of the 'right' way to do involvement. Toolkits must only be applied with attention both to the requirements of particular participants and of the broader context, and they need to be adapted as these things change. For instance, we can describe good practice in terms of enabling and supporting effective communication, what that means in any specific instance will differ. In order to be able to articulate their learning some, like Linda (box 34), require a preliminary space in which to vent their feelings, exploring and rehearsing their experiences in detail in order to choose what it is useful to highlight. Others, like Daisy (box 30)

prefer to background feelings, needing to be able to retreat from the emotional impact of their experiences, and those of others. One model of involvement knowledge space does not suit both approaches.

8.1.6 Equally, in mapping or describing patient and public involvement knowledge spaces it is vital to chart their environment and the internal forces that shape them. What boundaries do they press against; what freedoms do they have to break away; are the participants all moving in the same direction, what resources are they able to access? Stories like Hollie's (box 26) and Ellie's (4.6.3) describe how institutional changes, of staff or policy, can leave participants feeling abandoned by an incomplete process; their bubble burst and the results of their efforts vanished. Linda (box 37) described how even the conclusion of a successful project can be experienced in this way by lay participants. Rosaline (box 38), on the other hand described breaking free and creating a structure that enabled her group to continue undertaking and supporting research with other organisations, when the university that founded them withdrew support.

8.1.7 In focusing on the stories of 'lay' participants, this study has highlighted themes involving: different perspectives (chapter 4); language and understanding (chapter 5); transformations (chapter 6); and relationships (chapter 7). It also identified important cross cutting themes of: power, expertise, alienation and identity. In investigating these, it has shown that patient and public involvement knowledge spaces can be fruitfully explored in terms of the dimensions: expressive to instrumental; weak to strong publics; monism to pluralism; and conservation to change. It has not supported the Gibson Britten and Lynch cube as a framework with which to measure the dimensions of involvement.

8.1.8 Examples from this study have shown that, because of the different institutional allegiances, expertise and theoretical orientations of participants, these spaces can be simultaneously expressive and instrumental. Their setting between spheres and their orientation towards different sorts of power means they can act as weak publics in some fields of their activity and as strong publics in others. They can conserve some things while being transformative on another plane; an organisation may respond to the influence

of participants by conserving something rather than by transforming it. They can leave participants feeling alienated and objectified. They may also be important as vehicles of personal transformation or narrative reconstruction for participants, particularly those who have experienced life changing events. This can enable them to translate personal, often painful, experiences into socially useful knowledge, connecting their story to others and helping to give it meaning. Seeing these dimensions as a continuum along which knowledge spaces can be mapped, or assigning numerical values to them can therefore be misleading, masking contradictory or intrinsically paradoxical tensions, that are important features of these complex structures. The shape of these patient and public involvement knowledge spaces can be distorted and changed, they can become merged, divided, or obliterated by either, or both, the internal and external forces that are exerted on them.

8.1.9 Two major assumptions that were outlined in chapter two have underpinned the discussions throughout this thesis. The first is the ethical position that knowledge is a product of society and so is rightly owned by the public (2.3); the other is the epistemological understanding that the purpose of knowledge is to guide action (2.4). These have shaped the study and have led to a dynamic relationship between data, theory and analysis. Theoretical models and games were used to begin to investigate how participants might be supported to reflect on their own approaches to involvement, and where they differ from, or are similar to those of others.

8.1.10 The next section of this chapter will reflect on the conduct of the study. The following four sections will discuss the dimensions of a patient and public knowledge space outlined by Gibson, Britten and Lynch. I will argue that, while each dimension of this model identifies an important area for researchers designing and working with public involvement structures and processes to consider; linear scales can be misleading when describing these complex structures. Linear scales fail to capture the multiple and contradictory approaches participants may bring to involvement. It also misses the important role involvement plays in connecting personal narratives to the production of human knowledge. This connection may be particularly valuable when traumatic events, like life-changing illness, transformative treatments or major bereavements, have damaged someone's sense of self and of where they fit in

the world. Section seven will return to David's description of these as liminal spaces (4.6.12), ritual spaces, which can actively promote a civic epistemology that acknowledges and revitalises the public ownership of knowledge, exploring what an ideal space would look like in this light, and how real world spaces might differ from this. The final section argues that knowledge spaces are, rather than sharply outlined cubes, more like irregularly shaped bubbles. Mapping them needs to take into account, not only dimensions that might outline them, but also the dynamic external and internal forces that can cause them to change shape and direction, divide, combine or even burst.

## **8.2 Methodology**

8.2.1 An early difficulty I faced with the study design was how to reach potential participants. Using a survey to create a sample frame for the interviews was a useful tactic. A flyer was sent out through National Institute for Health Research (NIHR) networks, and the involvement leads in English 32 universities, included on Royal College of Nursing database. Leaflets about the study were also distributed, through contacts attending networking events held by patient groups. The number of responses to the survey was disappointing and, in retrospect, it would have been useful to have also targeted charity funders and support groups directly. Very few responses came through the university contacts database and it might have saved me a good deal of time if I had phoned the universities to check whether the details were up to date before emailing. Due to these issues, it is likely that people working nationally and particularly those involved with NIHR were over represented in my survey respondents, people working at regional hospitals and on small projects were likely to be underrepresented. While I did try to compensate for this in the purposive sampling of interview participants, inviting people to identify friends or colleagues with different sorts of involvement experience, it would have been helpful if the survey had produced a more diverse sample frame. Patient and public involvement networks have developed considerably over the past three years. A study beginning now would be likely to face less difficulty in contacting participants.

8.2.2 There was a lot of interest in being interviewed from survey respondents. It would have been good to have been able to offer to do all the interviews face to face. Practically this was not possible and telephone

interviews were the best available option in some cases. Participants in the face to face interview were able to choose where to meet. Five chose to meet in a public place; two of these turned out to be very noisy which made transcription slower and more difficult. In future, were time and funds available, I would visit the locations in advance and maybe offer a choice of a few venues to meet rather than relying on the participants' local knowledge.

8.2.3 While in some ways, for example by using narrative as well as thematic analysis, I was responsive to participant views; there were other issues I could have addressed better. Feedback from participants was that participant information literature was overly long and wordy. This could have been off-putting to some potential participants and, I suspect, some of those who signed to say they had read the sheets had, in fact, not done so. These documents were based on Peninsula College of Medicine and Dentistry templates, which were designed to be used in medical education and complementary medicine research, and were based on those used in clinical studies. In retrospect I would probably try harder to persuade the ethics committee to allow me to shorten them, given the nature of this study.

8.2.4 The NVivo 10 qualitative data management software provided a valuable way of collecting different types of data, transcripts, correspondence, survey responses etc. in one place so they could be interrogated together and compared. Had I begun to use it before completing data collection I could have made better use of it. A good deal of time could have been saved had I transcribed data directly, using the preferred formatting for that programme.

8.2.5 As well as formal data collection through the survey and interviews this study has involved a lot of time in 'conversations' to use David's term (box 3). These were vital in helping sort and prioritise issues arising from the data. In particular members of PenPIG have provided me with feedback throughout the study, confirming the importance of narratives, prioritising theoretical approaches, and guiding the development of models and games.

8.2.6 Exploring theoretical perspectives through the games and models formed the basis of many conversations, with both involvement and academic colleagues. These were central to addressing the questions: how might patient and public involvement in health research and care be explained or modelled



using a particular theoretical approach; and how would a participant's description of their activities be shaped by the implicit or explicit adoption of this perspective. Relatively simple models, like the structuralism marble maze, the structural Marxism tree, the biographical disruption/narrative reconstruction jigsaw and the Foucaultscope were easiest for people to engage with immediately. The more complicated board games, 'Structuration' and 'Capital as Resources', really needed to be played. This meant the simple models were more effective in a situation where they were being displayed, at a conference or during a presentation. The games were more effective in a workshop situation, where they could be played and discussed.

8.2.7 The 'Tall Tales', as a workshop activity, engaged the participants, provoked a lot of discussion and gave me a lot of feedback. As a poster display it was less useful, putting all the stories together made it look difficult and wordy. As a game it again worked much better, with the individual stories written on separate cards so that people could see them one at a time. Although equally wordy, the 'Involvement Zodiac' worked well both as part of a poster display and as a card game. This may be in part because the poster displayed only one segment at a time, it may also be because it closely resembled a horoscope, a culturally familiar form.

### **8.3 Expressive to instrumental – system/lifeworld**

8.3.1 The expressive to instrumental dimension has been highlighted as important by study participants. Communication and the quality of relationships in involvement has been an issue that reverberated through the survey and interview data. This comes through in David's insistence on the importance of 'conversation' as a means of avoiding 'objectification' (box 3). For Helen it was having her opinions 'valued' rather than just 'whinging' that was important; and Linda felt that going through a process of really listening to each other's stories enabled her group to use their experiences more productively, in education and research settings, as well in managing their own care.

8.3.2 Similarly, poor communication and unidirectional relationships were experienced as unsatisfactory. Ellie (box 2) disengaged, after clinical researchers failed to acknowledge her work or use the qualitative data she provided, identifying deficiencies in their research design. The instrumentalism

of their approach left her feeling undervalued. The tendency of some professionals to transmit the policy requirements that confront them, rather than listen to the people they are nominally consulting, was what discouraged Georgina (box 25); and Hollie (box 26) felt that her 'most poor experience' of involvement was as part of an award winning project, because the service users and professionals did not meet until on stage to receive their honours.

8.3.3 While these examples support the model of the patient and public perspective being rooted in the expressive mode of the lifeworld, this can be seen as having been directly contradicted in some of the interview data. For example, Ellie's criticism of the clinicians' behaviour was not that it was instrumental as such, but that the purposes they were pursuing were the wrong ones; the clinical researchers were overly focused on their personal professional advancement. This point was made by other participants, about both clinical and academic researchers, from this perspective the valid purpose of health service research, and of patient and public involvement in that research, is to bring about improvements in patient care, and to increase understanding; not to achieve a higher pay grade, publish in a prestigious journal or achieve a PhD.

8.3.4 In research, this focus on service improvement and better patient care implies a focus on how the results will be put into practice. This can give a different perspective on the endpoint of a project than that of even a selfless academic researcher. The researcher may be more focused on the results of a study than on the implementation of policy, or practice changes, following from those results. In fact, in an environment of short term contracts, the professional researcher may need to focus on particular tasks, rather than on the study as a whole. This can seriously impact the way service users feel about the value of their own involvement, or even the value of research as an activity. Ellie, Hollie and Phoebe all strongly emphasised this issue. The recognition that some forms of instrumentalism are inappropriate, however, is certainly no reason to forget where it is important, as Jennifer argued (box 4). She was particularly concerned that the purpose of improving healthcare should not be lost in the enthusiasm to improve or increase the levels of patient and public involvement: 'it's important that we're represented; let's do it properly - let's be helpful!'

8.3.5 As a result of this, while it can be useful to think about whether knowledge spaces enable good quality expressive communication and whether they have clear goals or objectives, an attempt to map them along this dimension can prove deceptive. That sort of linear measure may disguise disagreements about what the purposes of these spaces are, and whose purposes predominate.

8.3.6 A different difficulty with existing knowledge spaces, which also means they defy straightforward classification along this dimension, is that they can be both expressive and instrumental simultaneously. The group activity that was described by Linda (box 34) is rooted in the system of a medical school, with the specific purpose of delivering things required by that system. However its mode of action and its orientation are closer to those of the relationship focussed lifeworld. Participants engage in conversation, listening to each other and telling as much of their own story as they feel comfortable sharing. This is valuable because of the emotional work that is required to translate what Sue Lethbridge described as 'life's pains' into public goods (section 6.5.21). While, as Jennifer (box 4) argues, it is not possible to re-design research so there is never any risk of upsetting a participant; it is important to recognise that people contributing personal experiences of pain, loss and grief may need opportunities and support to deal with the feelings this provokes. The value of these structures, for research institutions, is that patient and public participants, who have the backing of an expressive group, may be better able to prioritise and articulate the most relevant issues for a particular purpose, without the need to revisit old ground. Linda described it as building a picture that enables her to access, and talk about, her experiences without becoming angry or upset.

8.3.7 In contrast to Linda's group, the charity that Beth started (box 39) arose from lifeworld experiences of personal healthcare. From there its members have chosen to take on board systematic research processes and methodologies. Yet, the group has found that adopting the methods and practices of the research establishment is not enough for them to be accepted by the institutions they need to work with. They remain 'controversial' outsiders, strangers who cannot fully belong because of their strange origins. This further means that professionals who engage with them may also risk becoming

estranged. Here the power disparity between the structure and the agent is starkly revealed.

8.3.8 As I argued in section 4.7, what Habermas has called ‘the paradoxical structure of juridification’ (1985, p372) has tended to lead to the institution of public involvement or engagement mechanisms, intended to legitimise the existing or planned organisation of health services or research. These mechanisms seek to tidy, and systemise the intrinsically messy and complex drivers of involvement. These, in contrast have arisen from the array of very different social movements outlined in section 5.5 and the social transformations discussed in sections 6.2-4. Because their function is limited, and regulated rigidly, mechanisms are frequently experienced by patients and the public as tokenistic and alienating; therefore their task of bridging democratic deficits fails and they are dissolved, shortly to be reinvented with a new acronym.

8.3.9 Therefore, as Gibson Britten and Lynch suggest, expressiveness and instrumentalism, and the relationship of knowledge spaces to the different imperatives that arise from the system and the lifeworld, are important issues from the perspectives of lay participants in knowledge spaces. These relationships are, however, unlikely to be experienced as straightforward or linear in the way suggested by the word dimension. It might be more useful to think in terms of, how effective knowledge spaces are at enabling communicative action (Habermas 1985); open and respectful exchanges between all participants, focussed on developing an understanding of their different approaches, needs and purposes. The strategic action, the system-focus on the instrumental use of knowledge, and on material reproduction, (Scambler 2002 p45), may be best achieved through the application of the understandings that emerge from these unpredictable spaces, rather than through attempting to tightly control or direct them.

## **8.4 Monism to pluralism – cultural capital**

8.4.1 The dimension of monism to pluralism is an extremely valuable concept. A fundamental misunderstanding, underlying the failure of involvement mechanisms, as discussed above (8.3.8-9), is the characterisation of patient and public involvement as a single activity. Involvement is an interesting field of

study precisely because of the diversity of experiences, activities, approaches and individuals. The diversity of contributions and understandings is also fundamental to the value that involvement can provide.

8.4.2 The number and types of involvement activities participants in this study had undertaken were very different. For example: Marina had not been involved, but was waiting until her retirement when she felt she would have more time and energy to contribute; Beth's charity had funded, designed, managed and undertaken their own trial; Elizabeth, Ellie, Hollie and others had worked as research partners or service user researchers on other people's studies; Dorothy and Hannah were among those who had provided lay reviews of research proposals; John and Jennifer both served on funding panels; Cindy and Daisy had been involved in generating research questions. Phoebe and Abigail worked as consultants and lecturers, both talking about their own experiences and supporting the involvement of others. Some participants were deeply involved in multiple ways. Occasionally this was because they belonged to a group which supported different sorts of involvement activities, for instance PenPIG invited and supported its members to become involved in: training, seminars, question generation, research prioritisation, governance bodies and in a range of different activities and roles within individual research projects. Most participants who were involved in a number of activities did so through membership of several groups and/or through association with a range of institutions, for instance Hannah: runs a condition specific support group; works with both national and international research governance bodies and funders; is secretary for her GP's patient participation group; is a member of her local hospital patient panel; and tweets hundreds of links to health information and news a week.

8.4.3 The background to the involvement of different participants was also varied. Some, like Thomas and Kenneth, had become involved in response to an overwhelmingly good experience of healthcare; some, like Lotte had been motivated by an experience of serious harm; most spoke of both good and bad experiences. These different experiences were often reflected in what they said motivated their involvement. As well as the desire to improve services for others, discussed above, statements about motivations have ranged from

‘repaying a debt for good service’ to ‘proving the doctors were wrong and I was right!’

8.4.4 In other ways participants in this study were less diverse. Only three of the survey respondents described themselves as an ethnicity that was not ‘white,’ and none of these were available for interview. There was also a high proportion of older people, of women and people with higher education and professional qualifications. These tendencies clearly could have been influenced by having to contact potential participants through third parties, something that, given improvements in patient and public involvement networking structures over the past three years, would be less of a hurdle for any future study. Nevertheless, the evidence from participants supports the suggestion that there are some ‘social groups’ who are poorly represented in patient and public involvement. While I have argued that this is a flawed way of framing lack of diversity, it is important to acknowledge that this issue was frequently mentioned, particularly in terms of ethnicity, class, age and gender.

8.4.5 As Jennifer (box 16) pointed out involving people of working age could be better achieved by developing a culture in which employers release people to take part. This would mean raising the public profile and the legal status of patient and public involvement in health research to the level of civic governance roles like local councillor or school governor. Oliver (box 18) was sure that his employers would have been sympathetic should he have needed to take time out for his involvement, but he was employed in a related professional field, was able to manage his hours flexibly and also had a fairly prestigious role in terms of involvement. While there is a perceived cachet, mentioned by several participants, in being in the position of advising what Grace termed as a ‘professor of something clever’ (7.2.8); this is not sufficient for most working people to be granted time off work. Daisy, for example, was told she would need to use some of her annual leave allocation in order to attend weekday meetings (7.4.5).

8.4.6 Some approaches to increasing diversity in involvement through a numerical spread across delineated groups appear to me, as I have argued in section 5.3, to lead towards involvement that may become tokenistic, divisive and self-defeating. By defining some distinctions as creating ‘groups’ that

should be 'represented' inevitably involves excluding others. The problem seems to be better approached by ensuring that involvement becomes more relevant and more accessible in order to engage and attract more and different people. A number of participants, including David, Phoebe and Edward (section 7.3.7), suggested different people could be involved if activities took place at different times and/or were held outside hospitals and universities. Jennifer argued that, people who are asked to review full research proposals do need a sufficient level of education or skill. John has shown that wider participation in these activities can be achieved by supporting training, although this demands a good deal of time and commitment. Another approach is to design involvement processes that take forms other than committee style meetings and written reviews.

8.4.7 As discussed above, for some participants a supportive environment, one that enables them to explore and rehearse their experiences, is vital to developing the confidence and clarity to present their views in other arenas. I have argued that, while these groups have a therapeutic function, it can be a far more empowering experience than the 'nonparticipation' diversionary activity suggested by Arnstein's model. In fact it is a powerful way to help address the lack of participatory parity in health research and service development. Conversely it is clear that for others, like Jennifer (box 32), these sorts of groups are both experienced as uncongenial and considered a waste of their time. Also, as Daisy (box 30) pointed out, they can undermine the tactics employed by some people to deal with chronic and intractable conditions, by confronting them with other people's negative experiences.

8.4.8 This supports the argument for different ways of listening in order to enable different voices to be heard, rather than attempting to achieve parity through some form of quota system. It also suggests to me that there is value in participants being encouraged to think about what sort of involvement best fits with their own approaches and values. This is about enabling people to make choices about what sort of involvement meets their needs, rather than researchers seeking participants that suit their requirements. Games and stories, like the 'Tall Tales' and the 'Involvement Zodiac' developed during this study have been shown to be promising reflective aids in this process. .

8.4.9 A separate, but related, issue is the need for ways to disengage as well as to engage. Although this process can provoke anxiety and may be difficult to manage, as John found (box 31), it is vital, particularly for people who have fragile health and/or complex lives, that they have opportunities to step back and reassess their level of commitment frequently, without feeling they need to give all or nothing. The fear of having to commit to frequent meetings, dozens of emails a week, or to a long term project, can be a barrier to becoming involved at all. For Daisy, witnessing the levels of involvement of some other group members left her feeling unable to keep up with them, feeling 'like a dunce'. She saw her own contribution in contrast as ineffective and pointless.

8.4.10 Monism to pluralism seems to be the most straightforward of the dimensions of a knowledge space proposed by Gibson Britten and Lynch. It is easier to see it as linear and to imagine it as measurable in terms of being able to count the ways people are able to be involved. This, however, could also be deceptive. For instance there may be different ways to be involved that all draw on the same skills, aptitudes or level of commitment. A qualitative approach is needed to explore what enables different people to be involved, what helps them to manage their level of involvement and what helps them to feel their contribution is of value.

## **8.5 Weak to strong publics**

8.5.1 An individual who feels able to influence the agenda of their group, project or organisation, who feels that their contribution has an effect on decisions that are made, and outputs that are produced, is likely to feel more engagement and ownership. As Elizabeth (box 1) argued 'when people volunteer their time people would prefer to have the results, have the feedback whether their contributions made any difference' and as she went on to say 'most people are practical aren't they?' Like Georgina (box 25) where people feel their involvement is tokenistic and unproductive, they are more likely to walk away. If Hannah did not feel that her contributions made any difference it is hard to see why she would put in the equivalent of a second working week on top of her full time job (section 7.4.5). Why would John (box 4) undertake a thirteen hour day to attend a two hour meeting if he did not see his presence there as valuable?



8.5.2 Yet, as discussed above (8.2.1), the quality of communication and relationships themselves have been central elements of value that people have attributed to their involvement. The expressive group process that Linda described (box 34) is not a forum where agendas are set or resources are allocated, decisions are not made there. It is a place where stories and feelings are shared. Where people talk things over, rather than plan or do things. It is through this process they are supported to reflect on their experiences, to formulate their impressions or understandings and to rehearse articulating them. This resonated with Nigel Pyart's, for me very moving, description of his involvement in PenPIG 'I freely belong in a community in which I experience for instance that the sharing of observations has value. It does not seem to me that we are a project team that is defined by its task, which on completion is disbanded. Nor is it membership solely of interest, but now goes beyond this as I experience it. I am being inducted into an identification with the practices of research involvement and critical thinking'.

8.5.3 In the use of the dimension of weak to strong publics, Gibson Britten and Lynch have identified a key distinction between different patient and public involvement knowledge spaces, or between different modes of action within them. Both Linda's group activity and Nigel's 'community' have been brought about in order to support people contributing to health research and education, but they achieve that by creating a space where people are able to share their experiences and observations; a space in which their contributions will be valued for themselves and not measured against required outputs or desired outcomes. They are weak publics in that they have no power beyond the self-empowerment of the participants that they enable.

8.5.4 That self-empowerment and self-confidence is then taken forward by group members into other spheres where they may be emboldened and better prepared to take part in stronger publics. In this way the weak public may have a role in addressing the problem of participatory parity. This may be particularly important in patient and public involvement where academics, clinicians and policy makers all have communities of practice and institutional settings in which their views, interests and approaches can be rehearsed and refined. Being a patient or service user is a more individual and potentially isolating situation and, as Linda pointed out, before becoming involved in health

research a patient or carer may never have told their story to anyone. Lotte also identified that it was through membership of a support group, where she shared stories with other patients, that she became a 'radical activist' campaigner for patient safety. This conforms with Fraser's (1990) description of a subordinated social group developing a counter discourse and becoming a counter public.

8.5.5 Beth's story (box 39) is iconically one of a counter public. This was a group that felt side-lined and unheard, and so came together to raise their concerns and influence both public policy and medical practice. The processes of establishing a charity, designing a research project and creating web based information resources are complex and so required the exercise of skills and resources. In doing this they not only created an arena of opinion formation but became a strong public, political campaigners and managers of their own resources. Yet this transformation is not absolute, conducting health research requires access to specific training, skills and resources.

8.5.6 Universities and hospitals contain and manage many of the socially owned resources that enable research. Those that manage these resources are accountable; in the case of publicly funded institution they are ultimately accountable to the public. There are processes to allocate the resources and to control access to them; these processes are designed to be accessed from within established research institutions, rather than by service user groups. The charity not only struggled to fulfil bureaucratic requirements but also to access information about what those requirements were. The difficulty they had in obtaining professional advice and help, in designing and conducting their study, suggests that members of the professional research community are frequently disinclined to be seen as enabling this sort of service user led research, in case it impacted on their own career. In this context Beth's organisation may still be seen as a rather weak public, supplicants rather than decision makers or opinion formers. They also still retain some of the softer social functions of a support group for people with that condition.

8.5.7 These stories depict the relationship between being a weak public, in which discussion takes place and experiences are shared, and a strong public that can make decisions and allocate resources, as complex and unstable. Sometimes a weak public provides a vital testing ground in which to

develop counter discourses and challenge existing understandings. Sometimes they can act as rehearsal spaces and support mechanisms for individuals who are participating in other arenas, with people from other spheres. A service user group may also act as a strong counter-public on some fronts, petitioning or campaigning, while having other more social and unfocused activities. These issues raise questions over the potential to map where a group sits along a continuum from weak to strong public.

## **8.6 Conservation and change**

8.6.1 The fourth dimension proposed by Gibson Britten and Lynch, conservation and change is intended to be applied across the other three dimensions of the model. This is about whether the knowledge space is focused on maintaining something that is currently valued, intended to transform it, or to create something new. Seen in terms of this dimension the knowledge spaces created by patient and public involvement in health research are diverse. Some work to monitor or sustain an organisation or process that is already in place, or explicitly to provide an opportunity to deepen understanding between people that organisation affects. Others are specifically formed to enable innovation, to improve current organisations, treatments or practices.

8.6.2 The research setting itself implies an orientation towards the creation of new knowledge. In health and social care research there is also, perhaps most particularly on the part of the patient and public participants as discussed above, an emphasis on implementation and service improvement. This may mean that, even where a group's explicit role is in the monitoring and maintenance of a research organisation, it is also involved in innovation and service improvement, because that is the purpose of the organisation.

8.6.3 Their focus on the system or organisational orientation towards knowledge spaces leads Gibson Britten and Lynch to ignore the implications of individual transformative and reconstructive processes that take place within patient and public involvement. Conservation and change are issues that deeply affect the orientation of individuals as well as organisations. Many of the stories I was told, following the question 'how did you become involved in health research?' began with a story about illness, about loss, or about healing. Rarely did an answer start with a description of recruitment or research. Frequently

these were narrative reconstructions of a sense of fractured selfhood. Sometimes the role of involvement in the reconstruction of a fragmented narrative was explicit, as when Abigail said: 'it healed a wound but also I thought "oh, my experience isn't wasted, it's educational."' This is about making sense of the past; it is also about reflexively validating transitions between fragmented selves. It can also be usefully explored in terms of a Gift relationship.

8.6.4 The importance of contributing, and of gaining recognition and respect from others in order to validate that contribution, has recurred throughout the study. This was demonstrated by appreciating thanks from a 'professor of something clever' (section 7.2.8), valuing an acknowledgement in a publication (box 22) or simply describing the difference between being listened to rather than lectured (box 25). In the case of the activity that Linda described (box 34) this need for validation was explicitly recognised and supported. For Nigel (box 36) it was implicit in the culture of the group he belonged to, and the organisation that hosted it.

8.6.5 Both Nicole (7.1) and David (boxes 3 and 23) also characterised good experiences of involvement in research as defined by the quality of relationships between participants, especially those coming from different backgrounds. David in particular (box 3), made a clear distinction between being engaged in a conversation, and being another object in the study. This speaks to changing roles within research and medicine. In the ideal relationships David describes, with researchers and with his GP, knowledge, diagnoses and treatments are being negotiated, rather than being given or prescribed to him. This is a more equalised 'sick role'.

8.6.6 For some participants, like Alan (5.3-5 and box 28), negotiating these relationships seemed quite a difficult process. He had moved between knowledge spaces, absorbing organisational terminologies and attending multiple training courses in order to amass the resources he felt he needed to achieve recognition and to make sense of his journey. Phoebe (box 27), by contrast, actively rejected transformation. She demands recognition for, and works to maintain, a self untouched by organisational imperatives. She resists any discussion of roles and refuses to apply the language of professionalism to

herself. In doing this, she recognises that this resistance is work that she needs undertake actively, in order for her to remain 'a mundane person', given that involvement in health research and education has become her career.

8.6.7 Participants frequently spoke of providing a 'patient', 'carer', 'service user', 'survivor' or even 'public' perspective that is distinct from an academic or clinical view, but it has been equally clear that there are enormous differences between the approaches of different participants. This diversity of approaches contributes to the complexity of involvement discourses; the different ways people talk and think about what involvement in health research and care is. This means important differences in approach can be obscured by using the same word to mean different things; while at other times using different words can make distinctions where there is little difference. This lack of a shared discourse means that, in order to enable effective communication, those of us engaging in knowledge spaces need to be open to the interrogation of our own understandings and theoretical approaches as well as examining each other's. This can help identify confusions and blind-spots that prevent us from communicating effectively. It is a matter of becoming aware of our theoretical baggage and leaving any that might get in the way of hearing others behind when we enter a knowledge space.

## **8.7 Liminality and equity**

8.7.1 David's description of patient and public involvement as a 'liminal space' was extremely useful in thinking about how the knowledge spaces it creates can be viewed. The concept of a space that exists between the lifeworld of being a patient or carer and the systems of health research and care resonated with an idealised version of Gibson, Britten and Lynch's framework. This ideal cube is perfectly poised between the worlds, so the roles pertaining to both are suspended. This space is equally owned by all participants, participants who have themselves been ritually cleansed of disparity, enabling both professionals and lay people to 'participate from a position of equality' (Gibson, Britten and Lynch 2012, p545). To achieve this, the professionals have removed their white coats or academic gowns; not only in order to equalise their relationship with lay participants but also to level out their hierarchical relationships to each other. Lay participants take responsibility for their own wellbeing and do not expect to be cared for as patients. Everyone there is able

to take responsibility for themselves, and remain mindful of the vulnerabilities of others. Each is an end-in-itself (Kant [1785] 2005, p30) to all. All views and perspectives are equally interrogated. All exchanges are honest and respectful. Everyone is sharing the risk Jennifer described (box4), that they might hear something they may wish they hadn't. Everyone has the possibility of achieving new understandings that they had not previously imagined. Within this space all are equally alien and equally at home. All are engaged in advancing human knowledge. There is plenty of time.

8.7.2 Toolkits, frameworks and models are, like narratives, partial and incomplete simplifications. The messiness and complexity involved in real knowledge spaces means they will not be like the ideal. They will be flawed. They will usually be embedded deeper into one of the worlds than the other, frequently the system world of institutions and policy makers. This means that some participants will have a greater ownership of them than others, however egalitarian their intentions. Some spaces will be more influential than others, some will be better attended, some will be better resourced. Some participants will be more forceful, some will lack confidence, some will be better communicators, some will be better motivated, some will not listen, and some will listen carefully and still not get it. Some people will insist on discussing issues that appear completely irrelevant however you look at them. There will be tricky moments, confusions, wounded pride and hurt feelings. Some people will be really annoying. Funding will usually be insecure. There will never be enough time.

8.7.3 People will enter these spaces speaking different languages and carrying old theoretical baggage that can trip them up or blinker them. There will be conflicts. Even so, this is not to characterise these imperfect spaces as populated by the piratical, drunken sailors of Plato's ship (3.5, 3.5.2). They are more often closer to the alternate version (3.5.4), where the captain, navigator and assistant cook try to pool their different sorts of knowledge, in order to enable them to surpass their individual understandings, and travel beyond the edge of the map. This model rejects Plato's concept of justice as orderliness (3.1.6), acknowledging that untidy, unconventional thinking may sometimes be what leads us to find new, fairer and more genuinely functional, destinations.

8.7.4 Rather than rejecting spaces that fail to live up to an idealised blueprint, we should embrace their imperfections and the learning these provide. If there are enough different flawed spaces, in which people are encouraged and supported to articulate and elaborate their own understandings, and see them in relation to those of others, they may get better at it. People (here that word intentionally includes clinical, academic and lay participants) may become better able to reflect on the knowledge they have, and better able to learn from each other, developing Abigail's 'dual perspective' (4.6.26), looking, Janus like, into both worlds. This is what can provide access to adjacent possibles (3.1.8), possibilities that may not otherwise exist.

8.7.5 A multiplicity of untidy and imperfect spaces, catering for different people, with different needs and different experiences, can provide much better involvement than the clumsy mechanisms that seek to tidy, and systemise it. When clinical, academic and lay participants are able to reflect upon and share their motivations and values, uncovering the complexity of involvement, by openly discussing their multiple orientations and sorting through their pre-existing theoretical baggage, new understandings and adjacent possibles are brought into existence.

8.7.6 Knowledge spaces are arenas where conversations can be held and ideas can be interrogated, but also where messages can be left and stories posted. The structures of knowledge spaces need to be varied in order to enable different styles of communication and different lives, enabling more and different people to contribute. Equally they will be structured, and restructured, by what takes place in and around them. Positive experiences of contributions being acknowledged and accepted build participants' confidence and skills. Showing a willingness to listen, ensuring that all perspectives are interrogated and explored, helps to build translational skills between different discourses, both academic and lay. This can help everyone to connect their own stories to the enterprise of creating knowledge, and supports the development of a relationship between different forms of understanding that enhance each other, rather than ranking them hierarchically (Tritter and McCallum 2006). By opening up and exploring the theoretical approaches participants bring with them into knowledge spaces, better communication and more useful conversations are facilitated.

8.7.7 Participating in flawed spaces can enable more people to validate their own, and each other's, roles in the co-production of knowledge; becoming both contributors to and beneficiaries from involvement. This can also enable a more open and well informed process through which to negotiate 'civic epistemology' (Jasanoff 2000). A sign of this would be that, when a health issue rose into the public consciousness and more people would ask: 'what evidence do we have on this subject?' 'how good is that evidence?' and 'how can we find out more?' than sign petitions asking the government to screen everyone for cancer or to shoot any animals that could possibly carry TB

## **8.8 Mapping imperfect spaces**

8.8.1 While participants' stories supported the importance of the four dimensions, outlined in the Gibson Britten and Lynch 'cube' model of a patient and public involvement knowledge space (appendix 15); what they also identified was the instability of these dimensions. They described the possibility for knowledge spaces to bend and buckle along these proposed continua. The dimensions are unstable, like those of giant soap bubbles distorting and flexing in the wind. The contours of these spaces can contort and change shape or direction in response to the varying pressures from both around and within them. Spaces may be attached to an institution or to a single project; or they can become free floating, connecting with a range of institutions, like Rosaline's cooperative (box 38). One space may divide, with the parts taking off in different directions and engaging in different activities, like Linda's group (box 34) or Nigel's 'community of practice' (box36); spaces may conjoin or merge completely. In some conditions these spaces can be durable but, when the external and internal pressures are too imbalanced, the bubble may burst and vanish, dropping and scattering participants, as described by Hollie (box 26) or Linda (box 37).

8.8.2 Where involvement knowledge spaces are dependent, for support, access to training or resources, on external institutions that do not wholly own them; participants may be required to do significant amounts of work to both to build bridges and to maintain boundaries, as described by Beth (box 39). The mutability and complexity of involvement knowledge spaces makes them intrinsically difficult to map or measure with any accuracy. They are best



described qualitatively, by defining: the forces acting around them; the pressures created within them; where they sit within wider landscapes; and the degree to which their membranes are yielding or inelastic, permeable or hermetically sealed.

8.8.3 Chapter four described some of what can be seen as the external pressures on knowledge spaces. These spaces not only connect different worlds, different ways of thinking and being, they have often come into existence, like blisters, where these worlds rub against each other, or like bruises, where they have collided. Public involvement may be the result of active campaigns; like feminism, gay rights and the disability movement (5.5.5-11), creating 'counter publics' that force issues into the arena of public debate (7.6.17-18). Involvement may be instigated, by professionals and policy makers, to cushion these knocks, to legitimate processes, evade conflict, and to exert control over the terms of an encounter (4.7, 6.4). Although, when these goals are explicitly pursued, they may become self-defeating, experienced as dishonest objectification (box 3), or tokenism (boxes 2 and 25). The pursuit of strategic aims may require the suspension of those aims and the adoption of a genuine engagement with communicative action in these arenas (8.3.9).

8.8.4 The shape of knowledge spaces is affected by that which is around them, and which exerts pressure upon them. This means that, in order to map a knowledge space, it is, first of all, important to place it in context of the social, political, economic and cultural landscapes that have brought it about. It is only with reference to that information that we can understand the difference between a blood sample and a baby's heart, between making health data available to NHS researchers and selling it to private companies. Only with that contextual understanding is it possible to begin to understand to what extent a knowledge space functions as an observation post (3.6.3), and to what extent it is, in effect, a colonial outpost. Does it look more like a vehicle for space-exploration (3.6.3), or a troopship (3.6.6)? Vitaly, does that perception still hold true if you look at it from a different perspective?

8.8.5 Other pressures that shape a knowledge space come from within. What can be known and what can be said are linked together within political and social relationships, relationships that are themselves shaped by power and access to resources. Knowledge spaces are, then, arenas within which power and the access to resources are implicitly or explicitly contested. It may be possible to imagine a public involvement knowledge space in which all participants have identical interests and approaches, but it is unlikely. In fact, as described in chapter five, trying to eliminate or disguise conflicts, by the imposition of an approved language or definition of terms, can lead us to miss the point all together, neutralising the very discussions that are most pertinent. Of particular concern in this is that it may lead to the exclusion of those who have not achieved 'participatory parity' (7.5.8) in the approved format, except, perhaps, where their views are useful to those with the power to set terms. There are as many ways that people can be defined as 'unrepresentative', justifying their exclusion, as there are ways for them to represent (5.2-5.3).

8.8.6 In order for more people to feel that they contribute to knowledge, are able to play a part in the development of civic epistemology and human understanding, we need to develop better ways of listening to these diverse voices, and better ways of acknowledging their contributions. This cannot be done by ensuring we have one delegate from 'race' and one from 'sex' on each formal governance structure. What is needed are many flexible spaces, spaces that are accessible and made with more permeable membranes; spaces that people can easily enter and effortlessly leave. Accessibility is about where spaces are placed in the wider landscape, for instance, a knowledge space that is built on a mountain may become populated only by goats. Permeability is not only about having an intention to let people move freely in and out; this needs to be demonstrated by design. A knowledge space that is built to resemble a prison may only look inviting to gaolers, even if it has many doors wedged open.

8.8.7 Open and inviting spaces can provide places for people contribute their stories and leave messages, for themselves as well as for others; 'I offer this, and in doing so I recognise your contribution'. These messages support our personal narrative notations: 'I was there, now I am here, I am heading in

this direction' (6.6.3). They can act as corrective lenses through which to reassess self-images, distorted through alienation and distress, reconnecting us with others in the social production and ownership of knowledge (2.3).

8.8.8 The participants in this study were overwhelmingly enthusiastic about involvement, often in spite of some bruising experiences in imperfect processes. None reported having experienced the ideal liminal knowledge space described above (8.7.1). Motivations for involvement were diverse, though facilitating practical improvements in healthcare, getting their views or stories heard, and achieving recognition as contributors to knowledge development, even in a small way, were extremely important to many participants. This was often explicitly described as supporting the reconstruction of a damaged sense of self or as contributing to the resolution of an alienating experience of feeling objectified.

8.8.9 In order to craft and prioritise their stories and messages, some people require, or just prefer, the help of a support group or a 'community of practice' (boxes 34, 35 and 36). Others prefer to make their contribution independently (boxes 30 and 32). This can be a self-defence in the face of a poor prognosis, or a way of avoiding what Fr. Paul described as the sometimes scalding process of letting the 'steam' out of the kettle, which often occurs when people have been previously excluded or unheard (7.4.10). Opportunities to engage in both ways of would seem to be required, in order to approach participatory parity (7.5.8).

8.8.10 Yet, within the processes taking place in patient and public involvement spaces, there seems to be little cost and enormous potential benefit in ensuring that time is allowed for participants from different fields to be able to reflect on, and share, their theoretical approaches, values, understandings and motivations for involvement. In this way, everyone taking part can become clearer about what internal and external pressures are shaping their space. Even flawed knowledge spaces can provide us with an opportunity to orientate ourselves towards understanding. If we wish to travel beyond the scope of our present maps, it must be useful to pause and discuss

where we all have come from and where we hope to be going, before we start to deliberate about which is the best route to take us there.

## APPENDICES:

### Appendix 1. Interview Participant summaries

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<b>Abigail</b>	Female	Unmarried	40-49	White British
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Lives in a small city that has easy access to several universities and teaching hospitals.

Abigail works as an advisor and collaborative researcher to researcher teams working in several universities and hospitals. She lectures medical students about patient experiences of healthcare and has an honorary contract with one university. She also is a self-employed trainer and consultant, sometimes speaking at biotechnology industry conferences.

Abigail became involved fundraising for research following life changing surgery. Through this she built a network of contacts and was invited to become involved in other ways. She describes herself as a natural researcher and came up with a number of innovative ways of coping with her own condition and the procedures it necessitated. One of these is being evaluated through a research project. She says that, as a researcher who has been a long term patient, observing health care and getting better from on physical disability, she is able to use these multiple perspectives to effect changes in health care.

Abigail's day to day activities are still limited a little by her condition.

At the time of the interview Abigail had some vocational training but no academic qualifications. She had returned to education as a mature student.

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<b>Alan</b>	Male	Married	Over 40	Other White Background
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Lives in a medium sized city with easy access to several universities and teaching hospitals

Alan has been involved in a number of service improvement patient involvement groups and in health service governance. Through this he became part of the steering group on a research project looking at patient and public involvement. Since then he has been involved in a number of other studies as an advisory group member and as a lay reviewer of research proposals for NIHR funding streams and the Research Design Service.

When Alan first attended a research steering group meeting he realised that it was something he knew little about. He therefore determined to find out about the structures and processes of research and has become involved in conferences, training and projects across England. He would really like to work nearer home but feels the structures of involvement within the institutions in the city where he lives are inaccessible. He believes that clearer constitutions and policy documents would bring about better, more accessible involvement.

Alan has a condition that limits his day to day activities a little he also gives care or support to someone with ill health or a disability for between twenty and forty-nine hours a week.

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He has undertaken a great deal of vocational training and is educated to degree level.

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<b>Amy</b>	Female	Not given	Not Given	Not given
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Lives in a small city with easy access to a university and teaching hospital

Amy undertook research in education before becoming a carer. As a carer Amy was active in a number of service user groups locally and nationally. She also worked as a carer support worker. As a member of a group that supported service user led research Amy had the opportunity to design and conduct a study about the experiences of carers.

For Amy it is important for carers to be heard

Amy is educated to degree or higher degree level.

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<b>Beth</b>	Female	Married	50-60	White British
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Lives in a coastal town with fairly good access to a university and teaching hospital.

Beth co-founded a condition specific charity following her own poor experiences of diagnosis and treatment. She found many people with similar stories. Her group found clinicians and researchers unsympathetic to their requests for better diagnostic tests and so decided to fund and undertake research on this topic for themselves.

Beth argues that patients being involved in studies can ensure the right questions are asked in the first place, and that better protocols are put in place from their perspective. She feels that research funders should do more to help patients and the public to understand how research is done, explaining issues like bias and sampling.

Beth gives care or support to someone with ill health or a disability for between one and nineteen hours a week.

Beth has professional and vocational qualifications.

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<b>Cindy</b>	Female	Married	40-49	White British
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Lives in remote coastal town very distant from both universities and hospital.

Cindy became involved in a support group in order to better understand her condition. She has supported her husband's multiple involvements in research. She would like to be more involved herself but finds it difficult because of the distance from research centres as well as her caring and work responsibilities.

Cindy feels it is important for people to be involved both so that they become better informed about their conditions and so that clinical researchers can better understand the difficulties faced by patients and carers. She would really like it if more research were taking place nearer to where she lives and at times that enabled her to attend.

Cindy cares for someone with a long term condition for more than 50 hours a week.

Cindy works full time in a family business.

Cindy is educated to the level of five or more GCSEs or an A level.

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<b>Daisy</b>	Female	Married	30-39	White British
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Lives in small city with easy access to a university and teaching hospital.

Daisy is not currently involved but was previously a member of a public involvement in research group.

Daisy became involved through a relative who introduced her first to a specific research project and then to a public involvement in research group.

Daisy finds it interesting to have an input on research having been a user of the healthcare service for many years. She feels it is nice to think that patients can have a say on how their treatment is managed.

When Daisy first signed up to the group she was off work and it was easy to fit the meetings in, but once she went back to work it was really difficult to fit in day or half day meetings into the working week. She had to book a holiday to attend.

Daisy's day-to-day activities are limited a little because of a health problem or disability which has lasted, or is expected to last, at least 12 months

Daisy gives care or support to someone with ill health or a disability for between one and nineteen hours a week.

Daisy was looking after her home/family at this time.

Daisy is educated to higher degree level.

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<b>David</b>	Male	Married	70-79	White British
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Lives in a rural location on the edge of a small city with a university and teaching hospital.

David attended an information day and a subsequent meeting organised by a condition specific research network. Another service user he met there invited him to apply for a vacancy on the Working Party. He contributed to a number of projects, edited and wrote articles for the newsletter, also becoming a member of an NIHR CLAHRC public involvement in research group, attending training and seminars and contributing to the prioritisation of research topics and the governance of research.

David describes his involvement as a 'substitute for a particular personal loss' and says that he finds it intellectually challenging.

As well as his own day to day activity being limited a little by a long term condition David also provided support to someone else for between 1 and 19 hours per week.

David is retired.

David is educated to degree or higher degree level and has professional qualifications.

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<b>Dorothy</b>	Female	Widowed	70-79	White British
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Lives in a rural location near to small city with a university and teaching hospital.

Dorothy became involved in a condition specific research network following an

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information day. From there she became involved in an NIHR CLAHRC public involvement in research group and as a lay reviewer for the regional NIHR Research Design Service.

Through her involvement Dorothy has realised that researchers need information and advice from service users and survivors. As well as adding her own views she has enjoyed hearing those of others, and learning about other conditions..

Being retired, Dorothy values the intellectual stimulation she gets from involvement and particularly enjoys reviewing the lay summaries of research projects

Dorothy is educated to degree or higher degree level.

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<b>Edward</b>	Male	Married	60-69	White British
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Lives close to a medium sized city with easy access to universities and a teaching hospital

Edward sits on an NIHR funding panel. He is involved with a condition specific research network and a condition specific Research Hub. He is also a member of an NIHR CLAHRC public involvement in research group and is involved in a number of patient involvement and support groups both nationally and locally.

Edward initially became involved in service improvements through a community health facility he attended. Through that he received invitations to take part in research projects and then research governance.

Edward is strongly motivated to help others, this means he is sometimes frustrated by forums where researchers inform patients about research, he would rather be 'doing'. He wishes he had more time for all his activities.

Edward gives full time care and support to someone with ill health or a disability.

Edward is retired.

Edward studied to GSCE/CSE level

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<b>Elizabeth</b>	Female	Married	Over 60	White British
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Lives in a medium sized city with easy access to several universities and teaching hospitals

Elizabeth is involved in a university based involvement network, she has acted as service user researcher on several projects, She is also a member of condition specific service-user involvement group

After being a hospital patient Elizabeth got involved with a service-user group.

Through this she met a lecturer/researcher and was invited to become involved in teaching and research activities.

Elizabeth is fascinated by the learning involved, feels validated by her involvement in health research and wants to make a difference. Elizabeth believes in the value of PPI as a principle

Elizabeth would like to be offered regular, weekly or fortnightly sessions of work where experiences and learning could be swapped. (Admits this is highly unlikely scenario.)



Elizabeth's day-to-day activities are limited a little because of a health problem or disability

Elizabeth has retired from a professional career that involved research relevant skills

Elizabeth is educated to degree or higher degree level and also holds professional qualifications

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<b>Ellie</b>	Female	Not given	50-59	Not given
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Lives in a small city with easy access to a university and teaching hospital.

Ellie became involved in research as a service user researcher on a project aimed at developing and improving a specific NHS service. She has since been involved in a number of ways, supporting and assessing research proposals, conducting research and prioritising research topics. While remaining committed to service improvement, Ellie has become disillusioned with the timescale of research, the instrumentality and lack of patient focus of some clinical researchers and what she sees as a lack of commitment to implementation of research findings.

Ellie's day to day activities are limited a little by a long term condition.

Ellie did not state her educational background.

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<b>Eva</b>	Female	Not given	60-69	Not given
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Lives in a coastal town near to a university and teaching hospital.

Eva became involved in research through a friend in a local support group. She is a member of a CLAHRC involvement group and has undertaken a range of activities with them.

For Eva involvement gives a real-world perspective. She believes that clinicians and health service researchers can forget how alien the hospital and university can seem to many people.

Eva is retired.and her day to day activities are limited a little by a long term condition.

Eva did not state her educational background.

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<b>Georgina</b>	Female	Married	50-59	White British
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Lives in small city with easy access to a university and teaching hospital.

Georgina has been involved as a service-user researcher, service improvement advisor and as a service improvement focus group participant.

Georgina became involved in research through a close friend who devised a service user led research project and invited her to take part in it. She became involved in service improvement through contact with the professionals supporting the care of her husband.

Georgina identifies herself as an educator and mentor and wants to continue to make things better for people. She particularly wants to improve the understanding of and experiences for carers and people coping with similar conditions to her husband's.

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Georgina says she has particularly valued the opportunities that involvement has afforded her to give her views without having the responsibility to make the changes she identifies happen in reality.

Georgina is the full time carer for her disabled husband, providing over 50 of care hours per week.

Georgina took early retirement in order to take on this role.

Georgina is educated to degree or higher degree level and also holds professional qualifications

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<b>Grace</b>	Female	Unmarried	60-69	White British
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Lives in a coastal town near to a university and teaching hospital.

Through involvement in an expert patient programme and a condition specific support group Grace became involved with teaching and research in a nearby university. Through attending a research prioritisation workshop she also became involved in an NIHR CLAHRC public involvement in research group. Through this she also became involved in other research projects and governance structures.

Making a contribution is something that helps Grace to feel good about herself. She is also keen to address issues of stigma that are attached to some conditions.

The institutional landscape of research involvement is something that Grace has also found difficult to navigate. She feels it is unnecessarily complex, leading to both duplication of effort and unfilled gaps.

The condition Grace suffers from does limit her day to day activities a little.

Grace has retired.

Grace is educated to degree or higher degree level.

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<b>Hannah</b>	Female	Married	Not given	White British
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Lives in a medium sized city with easy access to universities and a teaching hospital

Hannah first became involved in a local support group, later running it. Through that she joined a NICE Guideline Development Group and from that came to hear of other opportunities. She has since become involved in another Guideline Development Group, a number of research projects, a funding panel, local, national and international patient groups and involvement initiatives. She also uses social media to inform patients and carers of research evidence.

Hannah's primary motivation is to ensure the best possible outcomes for patients. She identifies lack of access to scientific journals and background papers as an obstacle to full involvement. She also acknowledges that full payment for the time service users contribute would make involvement easier.

Hannah is employed full time.

Hannah is educated to degree or higher degree level.

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<b>Harriet</b>	Female	Divorced	60-69	White British
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Lives in a small city with easy access to universities and a teaching hospital.

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Harriet has discussed involvement in funding panels and as a lay reviewer since a friend began undertaking these activities. She is actively considering pursuing these activities following her retirement. She also feels that she would not have had the confidence to take on these tasks before completing her degree as a mature student.

Harriet feels that it is vital for patients and public to play a role in prioritising and steering research agendas. Her experience as an administrator in an academic institution has led her to feel that academic researchers can sometimes be out of touch with the priorities of the majority of the public, and the needs of potential study participants.

However she feels that while she is working full time it would not be viable for her to take on extra roles.

Harriet has a long term condition that limits her day to day activities a little.

Harriet is educated to degree level.

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<b>Helen</b>	Female	Married	40-49	White British
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Lives in a small city with easy access to a university and teaching hospital.

Helen has been a participant in studies herself, and through her children. She is now a member of an NIHR CLAHRC public involvement in research group.

She feels it is important to include patient and carer views in research design and prioritisation. She also feels that there needs to be a better focus on the support people require so they can become involved, addressing issues like transport, childcare and other care support.

The condition Helen has limits her day to day activities a little, and she also cares for someone else with a long term condition for over 50 hours a week.

Helen is in full time employment

Helen is educated to degree or higher degree level

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<b>Hollie</b>	Female	Unmarried	Not given	White British
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Now lives in a large city where she works at a university supporting research.

Previously Hollie lived in a more rural area but fairly close to a small city with universities and a teaching hospital. There she was involved as a service user researcher and she remained in touch with the group, contributing by email, after her move. She was actively seeking new opportunities for involvement in her new location.

Hollie became involved through a service user support group and service improvement initiatives. This led to a number of collaborative research projects, Hollie believes it is important that lay members of the public have a real input to shaping health service delivery. She argues that the people who are/will be receiving care bring vital understandings to the process of service improvements. In spite of some poor experiences of tokenistic and unproductive engagement she remains convinced of its value. She thinks the institution of posts like User & Carer

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Involvement in R & D Manager can improve involvement by ensuring participants and researchers have channels to communicate opportunities and ideas.

Hollie's daily activities are limited a little due to illness or disability.

Hollie works full time and she is educated to degree or higher degree level

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**Isobel**      Female      Married      80-89      White British

Living in a rural area near as small town strategically placed between two centres of medical education and research, leading it to being used as the base for the regions NIHR Research Design Service.

As a former nurse Isobel was the lead on health matters in a voluntary sector group in which Isobel was an active member. This led her to be part of the Community Health Council and then the Patient and Public Forum as well as a patient representative in a number of committees associated with her local hospital. Through this she became a member of the NIHR Research Design Service scientific committee and also began to write lay reviews for NIHR funding programmes.

Being able to put forward the views of the lay person and giving the public a voice in decisions being made concerning them are important issues for Isobel. She feels that more feedback, both positive and negative could help improve the contribution of those involved.

Isobel is retired

Isobel has professional nursing qualifications.

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**Jennifer**      Female      Married      Over 50      White British

Lives in a large city with access to a wide range of hospitals and research institutions.

Jennifer first became involved in the consumer group attached to a medical Royal College. Through this she heard about and became interested in involvement in research. She has acted as patient representative on a number of studies, including one she designed and conducted herself, with help from an academic. She has also served on an NIHR funding panel and acted as lay reviewer on a number of proposals.

Jennifer relishes the intellectual challenge and the chance to learn something new. She likes working with clever people and learning from them, She describes involvement as having 'the bonus that I can feel noble because it's in a good cause.'

On the whole Jennifer finds involvement fairly easy and agreeable. However she dislikes having to review documents that are presented as protected PDF documents as this means she has to laboriously take notes while reading them on screen, re-writing/typing the content she is commenting on. Something she finds repetitive and dull.

Jennifer has retired.

Jennifer is educated to degree or higher degree level.

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<b>John</b>	Male	Married	50-59	White British
<p>Lives in remote costal town very distant from both universities and hospital</p> <p>John is involved in a condition specific research network, research governance, charity funding panel, providing lay reviews for NIHR funding streams, he is a member of an NIHR CLAHRC public involvement in research group and several health service service-user groups.</p> <p>Through his involvement in service-user support group he was invited by a service-user representative on a condition specific research network to 'buddy' or 'shadow' that role. Later he took over that role and from the contacts he made there found out about other opportunities for involvement and training.</p> <p>John feels that getting his voice and views heard by decision makers is important. John has had largely positive experiences of involvement, though has sometimes felt that the processes are unclear and so do not provide equal access to all participants.</p> <p>John's day-to-day activities are limited a lot because of a health problem or disability</p> <p>John gives care or support to someone with ill health or a disability for between twenty and forty-nine hours a week.</p> <p>John is long-term sick or disabled.</p> <p>John has no academic qualifications but some occupational qualifications.</p>				
<b>Kate</b>	Female	Unmarried	50-59	Not given
<p>Lives in a large city with access to a wide range of hospitals and research institutions.</p> <p>When first approached Kate was heavily involved in the Expert Patient Programme through a national condition specific charity but was not involved in research. When interviewed she had become the service user representative on a research proposal being prepared for funding, a role she had been asked to take up in behalf of the charity.</p> <p>It is really important to Kate that people have access to the information and resources they need to be as healthy as they can.</p> <p>Her long term condition limits Kate's day to day activities a little and she is long-term sick or disabled.</p> <p>Kate is educated to degree or higher degree level</p>				
<b>Kenneth</b>	Male	Married	50-59	White British
<p>Lives in a large city with easy access to hospitals and universities.</p> <p>Kenneth became involved as a participant in a trial. Since then he has been involved in a number of other projects, a condition specific research network, support groups, healthcare learning programmes, has made a video about involvement and has spoken at national conferences.</p> <p>For Kenneth involvement is important because it gives a patient perspective to</p>				

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health research and healthcare management, helping to target resources in a more appropriate patient centred way.

He has found most people he works with are very accommodating of his support needs, but feels that there could be a greater focus in research on the needs of patients and service users. He is also critical of the Londoncentric approach that he identifies in many organisations.

As well as coping with his own condition, which at the time of the interview limited his day to day activity a lot, Kenneth also provided support for between 1 and 19 hours per week to someone else with a long term condition.

Kenneth took early retirement due to ill health.

Kenneth is educated to degree level and also has professional qualifications.

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<b>Linda</b>	Female	Divorced	60-69	White British
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Lives in a large city with easy access to hospitals and universities.

Linda describes becoming involved 'by accident' when she attended what she thought was health training. Instead she became part of a patient and carer involvement community. Since then she has been involved in several research projects but her main interest is involvement in medical and healthcare training. She has written articles and training scenarios, acted as simulated patient, given lectures, mentored medical students, co-facilitated training sessions for other participants and written articles about these experiences.

Linda feels she has really benefitted from people having faith in her and giving her encouragement. She sees having one person participants can go to who is able to give them time, treat them as individuals, understanding the difficulties participants face and not victimising those with challenging personal circumstance, as important to successful involvement. She loves having a variety of different work, with working times that are appropriate for people with disabilities and caring duties. Training and briefing before involvement and debriefing afterwards are also things she sees as vital. She is also frustrated with the structural and institutional barriers to paying participants for their work.

As well as having a condition that limited her own day to day activities a little, Linda also cared for someone else for between 20 and 49 hours a week.

Linda had just retired at the time of the interview.

Linda has had vocational training to NVQ level 4.

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<b>Lotte</b>	Female	Divorced	Over 70	White British
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Lives in a rural area fairly distant from universities and hospitals.

Lotte is very active in a range of service improvement, campaigning, governance and research groups. Following a an experience of personal harm due to poor care Lotte felt 'driven' to speak out. As a counsellor and member of a patient support group she felt there was so much wrong and 'no-one dared complain'. She therefor felt a need to seek justice for patients. She describes herself as a 'radical patient activist'. Through this activism she has: advised funders, service providers, national

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government and professional bodies; served on ethics committees and review panels; as well as writing letters, articles and books.

Having a voice that can influence improvements in care is vitally important to Lotte. Lotte feels that healthcare has been constructed as an hierarchical structure with patients at the bottom. She argues that there is still a lot of work to be done to get 'the establishment' to accept the importance of involvement and to train staff on how to work with people effectively.

Although officially retired Lotte says she could get a lot more work done if her day to day activities were not limited a lot by her illness. She also suggests that having more administrative support would help her achieve more.

Lotte is educated to degree or higher degree level.

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<b>Nicole</b>	Female	Married	50-59	White British
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Lives in a rural location near to small city with a university and teaching hospital. Nichole attended a self-management course through which she met a researcher who invited her to become involved in a research project. From there she became involved in a bio-bank project, two research networks, a number of other individual projects and an NIHR CLAHRC public involvement in research group.

Having her views heard, influencing medical practice and research, meeting and engaging with people, hearing others' views and experiences, learning new skills and intellectual stimulation, are all aspects of involvement that Nicole identifies as important to her. She believed that involvement would be more accessible if it reached out into local communities, being held at local venues rather than in universities.

Nicole describes her condition as limiting her day to day activities a little. Nichole is educated to degree level and has professional qualifications.

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<b>Oliver</b>	Male	Unmarried	40-49	White British
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Lives in a medium sized city with easy access to universities and a teaching hospital

Oliver chairs the lay group for a medical college.

An advertisement for lay members appeared in the Guardian and his initial appointment to the lay group came through responding to that.

Oliver describes involvement as being 'worth doing in the widest (Kantian) sense, voice of reason among a group of doctors'. He also suggests that proper remuneration for the work involved would help make these posts more accessible.

Though Oliver works full time he acknowledges that his employer (an education institution) values this sort of activity and so is willing to allow him to attend meetings during normal working hours.

Oliver is educated to higher degree level and also holds professional qualifications

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<b>Phoebe</b>	Female	Not given	40-49 check	Not given
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Lives in a small city with easy access to a university and teaching hospital.

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Phoebe became involved through research projects that took place with the supportive community to which she belonged. She has since worked as a trainer, facilitator and service user researcher. She is also a member of an NIHR CLAHRC public involvement in research group.

Phoebe sees it as important for researchers to hear the voices of people who use services. She is deeply frustrated by research institutions and sees the pressure on researchers to publish as sometimes getting in the way of good involvement, and good research practices.

Phoebe is self-employed as a trainer and facilitator in health research and care.

Phoebe did not state her educational background.

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<b>Rosaline</b>	Female	Married	70-79	White British
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Lives in a rural location near to small city with a university and teaching hospital. Rosaline became involved as a service user researcher following a course at the university that trained and supported service users to run a research project. The group decided that they wanted to continue and became incorporated as a cooperative, undertaking research for local authorities, charities and the NHS. She has also been active in research forums and has worked with the NIHR Research Design Service.

Rosaline sees it as essential for patients and members of the public to be part of research from the very beginning of a research project. She feels they need to be involved and engaged in all research, inputting directly throughout the process.

Rosaline's day to day activities are limited a little due to a long term condition. Rosaline is retired.

Rosaline is educated to degree or higher degree level and has professional qualifications.

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<b>Ross</b>	Male	Unmarried	16-19	Not given
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Lives in remote costal town very distant from both universities and hospital. Ross has thought about being involved in research, he has attended some events with a family member, but not joined a group or become part of any project as yet. Although he sees involvement as an important and interesting thing to do, he feels that there are too many other activities competing for his time. He feels that if there were more opportunities to become involved through school or college or more available online, then more young people might become involved. He feels that currently what is offered in school is aimed at recruiting pupils who might be interested in becoming medical students rather than involving young people as patients or members of the public.

Ross is currently an A level student in an FE college

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<b>Thomas</b>	Male	Widowed	Over 50	White British
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Lives in a medium sized city with easy access to universities and a teaching hospital

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Thomas first became involved in research when approached by a healthcare professional who had provided him with support and who was undertaking a PhD study assessing that service. Initially he served on the steering group for that study, later taking on data input. He has since been involved in other studies, including developing proposals and acting as co-applicant. He has become a lay reviewer for NIHR funding streams and is also a member of an NIHR CLAHRC public involvement in research group.

Thomas identifies three things that motivate him to be involved. 1. He enjoys it, finding the insights into the world of healthcare research very interesting. 2. He strongly believes in the value of researching how healthcare services can bring benefit to patients and carers, then using findings to influence service to NHS patients. 3. He is particularly passionate to see the high quality support he received being extended to others.

Thomas admits that he has struggled to navigate the institutions of health research. He strongly believes that, in order to make involvement more accessible there needs to be better signposting and task specific training made available.

Thomas's day to day activities are limited a little by his health problems, took early retirement, though this was in part with the intention of devoting more time to socially useful activities.

Thomas is educated to degree or higher degree level and also has professional qualifications.

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## **Appendix 2. Survey Questions**

\*Name. Address, \*Postcode. Phone. Mobile. Email. (\*Minimum requirements)

How would you prefer to be contacted? Post/Phone/ Mobile/email/ only want to take part in the survey and prefer not to be contacted

I am interested in taking part in other parts of this study. Yes/No

(please tick) Interviews/PPI Activity Diary/Workshops/Online Discussion Forum/I would like to receive updates about the study

These five questions are about your Public and Patient Involvement (PPI)

1. What PPI role(s) are you currently involved in? (e.g. groups, organisations or activities)
2. What other PPI roles have you been involved in?
3. How did you get involved in PPI? (briefly)
4. What is important about PPI for you?
5. What would make involvement easier for you?

The next seven questions are based on the 2011 census.

6. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Yes, limited a lot/Yes, limited a little/No
7. Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health /

disability? problems related to old age? No/Yes, 1-19 hours a week /Yes, 20-49 hours a week /Yes, 50 or more hours a week

8. Last week, were you: Working as an employee? On a government sponsored training scheme? Self-employed or freelance? Working paid or unpaid for your own or your family's business? Away from work ill, on maternity leave, on holiday or temporarily laid off? Doing any other kind of paid work? Retired (whether receiving a pension or not)? A student? Looking after home or family? Long-term sick or disabled? None of the above

9. Which of these qualifications do you have? No qualifications 1 - 4 O levels/ CSEs/ GCSEs (any grades), Entry Level, Foundation Diploma NVQ Level 1, Foundation GNVQ, Basic Skills NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma 5+ O levels (passes)/ CSEs (grade 1)/ GCSEs (grades A\*- C), School Certificate, 1 A level/ 2 - 3 AS levels/ VCEs, Higher Diploma Apprenticeship 2+ A levels/ VCEs, 4+ AS levels, Higher School Certificate, Progression/ Advanced Diploma NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE) NVQ Level 4 - 5, HNC, HND, RSA Higher Diploma, BTEC Higher Level Professional qualifications (for example teaching, nursing, accountancy) Other vocational / work-related qualifications Foreign qualifications

10. Marital Status Never married and never registered a same-sex civil partnership /Married/Separated, but still legally married/Divorced/Widowed/In a registered same-sex civil partnership/Separated, but still legally in a same-sex civil partnership/Formerly in a same-sex civil partnership which is now legally dissolved/Surviving partner from a same-sex civil partnership

11. How would describe yourself (please tick) Male/Female/Transgender

12. How would you describe your ethnic group (please tick)

A. White. English/Welsh/Scottish/Northern Irish/Cornish/British: Irish: Gypsy or Irish Traveller: Any other White background (please write below)

B. Mixed/ multiple ethnic groups. White and Black Caribbean: White and Black African: White and Asian: Other Mixed/multiple ethnic background (please write below)

C. Asian / Asian British: Indian: Pakistani: Bangladeshi: Chinese: Other Asian background (please write below)

D. Black/ African/ Caribbean/ Black British. African: Caribbean: Other Black /African /Caribbean background (please write below)

E. Other ethnic group, Arab: Any other ethnic group (please write below)

I prefer not to identify with an ethnic group

### **Appendix 3. Interview topic guide**

How you have been involved in a PPI role in health research

How long you have been involved

How you were recruited /became involved

Why you agreed to become involved

Whether you intend to continue to be involved

What the benefits your PPI involvement have been

What the dis-benefits or costs have been

Whether your involvement has changed how you feel about research

Whether your involvement has changed how you feel about yourself

What you think could make involvement easier/better

Any learning you feel you have gained from your involvement

Is there anything about your PPI experience that I have not asked about and that you wish to add?

## Appendix 4. Sample Log and Diary

Log: Please note all PPI activities

date/time	duration	activity (e.g. phone, email, meeting etc.)	who for (e.g. group, project etc)	Comments (e.g. agreed/turned down further involvement)

### Diary page

PPI activity sheet	
please complete this as soon after the activity as practical, while it is still fresh in your mind	
Date	Time
10.00 - 12.00	10.00 - 12.00
Description of involvement	(what you were asked to do, who with, who/what it was for, why did you decide to do it)
Meeting to discuss participation in [redacted] panel. Read paper, formulate decision. [redacted] panel. Found it interesting, & possibly good - breakfast, walk. Could mean PPI will be involved in [redacted] panel in future.	
How did it go?	(How did you feel about it? Was it a good experience? Why do you think it felt like that?)
Went very well. Excellent guidance & facilitation from [redacted], as always. Very careful & precise. Good explanation of what to expect, discussion of our roles & how to [redacted] in the future planned meetings & [redacted]. [redacted] note-taking - her notes are always excellent, & save me trying to remember.	
What could have made it easier?	(How could it have fitted better with your needs?)
Nothing else needed to have been done & it fitted very well with my needs - clarity, skill of lead, record-taking, & even my favourite decaff coffee! Good lunch - keep it too.	
Feedback you received	(formal or informal)
Thanked for time & input, at end of informal meeting.	

## Appendix 5. Alienation

### **Karl Marx – Paris notebooks – 1844 – Estranged Labour** (excerpt)

<https://www.marxists.org/archive/marx/works/1844/manuscripts/labour.htm>

We proceed from an actual economic fact.

The worker becomes all the poorer the more wealth he produces, the more his production increases in power and size. The worker becomes an ever cheaper commodity the more commodities he creates. The devaluation of the world of men is in direct proportion to the increasing value of the world of things. Labour produces not only commodities; it produces itself and the worker as a commodity – and this at the same rate at which it produces commodities in general.

This fact expresses merely that the object which labour produces – labour's product – confronts it as something alien, as a power independent of the producer. The product of labour is labour which has been embodied in an object, which has become material: it is the objectification of labour. Labour's realization is its objectification. Under these economic conditions this realization of labour appears as loss of realization for the workers; objectification as loss of the object and bondage to it; appropriation as estrangement, as alienation.

So much does the labour's realization appear as loss of realization that the worker loses realization to the point of starving to death. So much does objectification appear as loss of the object that the worker is robbed of the objects most necessary not only for his life but for his work. Indeed, labour itself becomes an object which he can obtain only with the greatest effort and with the most irregular interruptions. So much does the appropriation of the object appear as estrangement that the more objects the worker produces the less he can possess and the more he falls under the sway of his product, capital.

All these consequences are implied in the statement that the worker is related to the product of labour as to an alien object. For on this premise it is clear that the more the worker spends himself, the more powerful becomes the alien world of objects which he creates over and against himself, the poorer he himself – his inner world – becomes, the less belongs to him as his own. It is the same in religion. The more man puts into God, the less he retains in himself. The worker puts his life into the object; but now his life no longer belongs to him but to the object. Hence, the greater this activity, the more the worker lacks objects. Whatever the product of his labour is, he is not. Therefore, the greater this product, the less is he himself. The alienation of the worker in his product means not only that his labour becomes an object, an external existence, but that it exists outside him, independently, as something alien to him, and that it becomes a power on its own confronting him. It means that the life which he has conferred on the object confronts him as something hostile and alien.

### **Alienation and medicalization.**

We proceed from an actual medical fact.

The patient becomes all the sicker the more healthcare she consumes, the more her consumption increases in power and size. The patient becomes an ever more valuable commodity the more symptoms she creates. The devaluation of the world of people is in direct proportion to the increasing value of the world of medicine. Healthcare produces not only treatments; it produces itself and the patient as a commodity – and this at the same rate at which it produces commodities in general.

This fact expresses merely that the object which healthcare produces – the patient's treatment – confronts her as something alien, as a power independent of the patient. The product of healthcare is health which has been embodied in institutions, which has become material: it is the objectification of health. Healthcare's realization is health's

objectification. Under these medical conditions this realization of healthcare appears as loss of realization for the patients; objectification as loss of the object and bondage to it; appropriation as estrangement, as alienation.

So much does the health's realization appear as loss of realization that the patient loses realization to the point of death. So much does objectification appear as loss of the object that the patient is robbed of the objects most necessary not only for her life but for her health. Indeed, health itself becomes an object which she can obtain only with the greatest effort and with the most irregular interruptions. So much does the appropriation of health appear as estrangement that the more symptoms the patient produces the more she falls under the sway of medicine.

All these consequences are implied in the statement that the patient is related to the product of healthcare as to an alien object. For on this premise it is clear that the more the patient spends herself, the more powerful becomes the alien world of objects which she creates over and against herself, the poorer she herself – her inner world – becomes, the less belongs to her as her own. It is the same in religion. The more man puts into God, the less he retains in himself. The patient puts her life into healthcare; but now her life no longer belongs to her but to medicine. Hence, the greater this activity, the more the patient lacks health. Whatever the product of her healthcare is, she is not. Therefore, the greater her healthcare, the less is she herself. The alienation of the patient in her care means not only that her health becomes an object, an external existence, but that it exists outside her, independently, as something alien to her, and that it becomes a power on its own confronting her. It means that the life which she has conferred on the object confronts her as something hostile and alien.

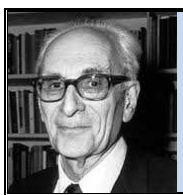
## Appendix 6 Tall Tales vignettes

Fred



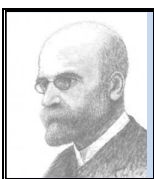
Fred wonders if there is something indecent in researchers trying to capture the essentials of his experience in a system, and the extent to which he colludes in this. He finds identifying his role and differentiating that from researchers' requirements important. In spite of concerns he flourishes when genuinely engaged in health research, transcending felt intellectual limits. He looks forward to richer experimentation in PPI and thinks this experimentation made explicit will prove an adventure

Claude



For Claude PPI is exciting because it brings together different sorts of knowledge: trained and untrained; theoretical and practical. Service users bring their practical lived experience; clinicians bring medical knowledge and clinical expertise; while academics provide a theoretical framework and methodological rigour.

Emile



Emile finds engaging with health research means fitting in with the way things are organised. Universities and medical schools all have their own ways of doing things and he has to navigate a way to become involved. Sometimes he feels research is mostly about publishing papers and advancing (other people's) careers within the academic hierarchy

Emilia



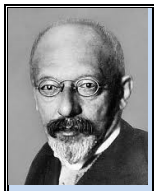
Emilia became involved in health research because she wanted to do something useful, something that could contribute to the wellbeing of others in the future. However over time she realised that this motive has become less important to her than the social support she receives from being part of a group and the intellectual stimulation she gets from looking at research proposals.

Gareth



Gareth was an active and outgoing man until a serious illness left him with mobility and communication difficulties. For a while he felt lost, but as a member of a service user involvement group Gareth is re-inventing himself as a useful and energetic member of the community

Georg



Georg sees his role as a PPI member of a funding panel as that of a 'stranger'. Because he is not part of an academic or clinical community he has the freedom to ask the naïve or 'stupid' questions and he has the objectivity of an outsider.

Jurgen



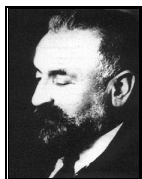
Jurgen sees lay members as grounding clinicians and researchers in the real life world of participants. Panels include experts and specialist; Jurgen doesn't need to worry about checking sample size calculations or detailed pharmacological data, his focus is on down to earth issues: could a new treatment plan work in a small flat with a kitchenette; or what problems could be faced by participants asked to attend an extra clinic appointment each week.

Karla



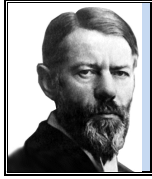
Karla was very enthusiastic when she was asked to become part of her local service user research group. However, over time, she began to feel dissatisfied with researchers coming and asking for her help to answer their questions. When she tried to raise questions of her own she felt unsupported and sidelined. The final straw came when she saw a poster display for a project she had worked hard to develop. Many of her ideas had been included, but she was not credited. Karla felt as if her stories had

Marcel



Marcel has had a lot of help and support from the NHS and his local community to overcome some of the problems caused by his long term health problems. Being involved in his local PPI group is, for Marcel, a chance to give something back and help others.

Max



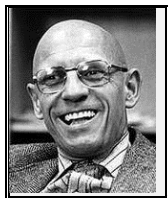
For Max it is important that policy is based on scientific evidence. He sees public involvement as having two purposes: to ensure research that is undertaken has legitimate legal authority, and to widen public understanding of the importance of scientific evidence in the allocation of resources.

Michelle



Michelle has worked on funding panels and on ethics committees. She sees her involvement as keeping a weathered eye on what researchers do and keeping them honest.

Mick



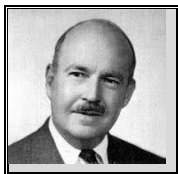
Mick is passionate about getting the voice of the ordinary patient represented in health research. For him it is important that academics and clinicians are made to speak and more importantly to listen to the people who have to live with the conditions they are researching and who undergo the treatments they prescribe. He believes that only when there is a shared language can research come up with answers that people are able to implement in their own lives.

Nancy



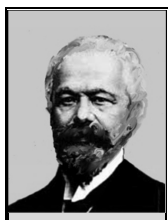
Nancy feels that there is a big difference between a group that can make decisions and influence policy and one that just comes together for coffee and a chat. Sometimes service user involvement has to be about challenging the way things are done and a campaign group can be far more effective than lone voices. However having a group where you just talk about your experiences can also help develop your ideas and confidence to get involved.

Talcott



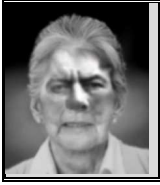
Talcott feels that the doctors he has been to have often treated him like a child. Sometimes this has left him feeling angry and frustrated. He feels that working with researchers will not only improve health research but also improve his knowledge and put him in a much better position to make informed and adult decisions about his own health care.

Karl



As far as Karl can see, at the end of the day it is the money that really matters. Academics want to keep funding coming into universities, clinicians want to keep it for health services and drug companies want us all to take more drugs. When it comes down to it the interests of everyone (except the patients) seem dependent on inventing new illnesses and diagnosing them in as many people as possible. For him public and patient involvement is an important check on how public money is spent.

Maxine



Maxine feels that the bureaucracy involved in health research is a good thing in that it helps to ensure fairness and good governance. However she also feels it can lead to things becoming too distanced from the real lives and concerns of individual service users. Public and patient involvement makes sure that real human experience of health, illness and participating in research are central to the process.

Roberta



Roberta finds the social side of involvement really valuable. Not only does she find the company of other service users enjoyable, she also gets useful information valuable support from members of the group that make a difference to her life and health.

Topal



Topal sees the knowledge of clinicians and academics as being mostly second or third hand. Their learning about diseases comes from books or the traces left on other people's bodies and behaviour. Topal feels that only the patients have real knowledge of the disease in itself and he feels that they have a responsibility to try and explain what it really is as best they can.

Ivana



Ivana just feels that medicine has gone too far. It defines more and more of our lives. It is seen as normal to be born in hospital and to die in hospital. People are encouraged by advertisements to pop pills for everything, including feeling less happy than they are told they should, or to have surgery to make them look like air-brushed magazines photos. She thinks it is time for academics and clinicians to move over and let service users create and validate definitions of health that are more grounded

#### Tall Tales Key

- Fred based on Friedrich Nietzsche's ideas about active self creation. By exerting our power on the world and taking responsibility for our actions we are made real.
- Claude based on Claude Lévi Strauss' use of binary opposites to create a model of social and cultural phenomena.
- Emile based on Emile Durkheim's Structuralism. Seeing social structures as facts that can be studied like things. These things can limit our options.
- Emilia based on Emile Durkheim and the Functionalist concept that the stated purpose of something may not be the same as its underlying social function.



- Gareth based on Gareth Williams' ideas about narrative reconstruction of social identity. We need a good story about who we are and how we fit into society.
- Georg based on Georg Simmel's essay on 'The Stranger' someone who is within a group but not of it. Someone who can take on tasks the group finds unacceptable.
- Ivana based on Ivan Illich's 'Limits to Medicine' which argues that more and more life events are defined by medicine and that this should be resisted.
- Jurgen based on Jurgen Habermass' concept of a difference between rules applying to 'lifeworld' personal relationships and 'system' legal, rational social relations.
- Karl based on Marxist economic theory. This sees the economic system as the base on which the social structure rests.
- Karla based on Karl Marx's theories about Alienation. Lack of recognition for what we create in the world does us harm.
- Marcel based on Marcel Mauss' ideas of Asynchronous Reciprocity, 'The Gift'. We need to both give and receive to belong.
- Max based on Max Weber's ideal types of legitimate authority. Decisions are seen as legitimate because they are based on rational scientifically sanctioned evidence.
- Maxine based on Max Weber's analysis of bureaucracy as a structure intended to limit favouritism and partiality, but a structure that can become too rigid.
- Michelle based on Michel Foucault's ideas about discipline and surveillance. Being watched, or the possibility of being watched, changes how people behave.
- Mick based on Michel Foucault's ideas about the relationship between knowledge, power and language. What we can say and what we can know and do are linked.
- Nancy based on Nancy Fraser's identification of different sorts of public discussions. 'Strong publics' making decisions, 'weak publics' share ideas and information.
- Roberta based on Robert Putnam's work on Social Capital. This emphasises the importance of social networks in providing access to support and resources.
- Talcott based on Talcott Parsons' concept of the 'sick role'. This sees doctors sanctioning time out from normal social duties if patients comply with treatment.

Topol based on Plato's distinction between direct perception and representation of things, between things as they really are and images of those things.

## **Appendix 7. Involvement Zodiac**

**Aries** – the spring lamb.

Recovering from a traumatic injury, adapting to life with a chronic condition or bereavement can be like starting a new life. It involves reassessing what you can do and who you are in relation to the world around you. Involvement in health research can be part of this exploration, giving access to a new world of ideas and opportunities. The Arian participant can get really fired up and start scampering after these ideas like an excited puppy trying to chase all the rabbits on the downs at the same time. This can mean the reading piles up and the calendar fills with meetings to an overwhelming extent. But, in their calmer moments, they realise they only want to commit to things that support their own exploration so start to pick which groups and projects to be involved in with their personal journey in mind.

**Taurus** – the resource.

Ill health, disability and caring responsibilities can be expensive in terms of both economic and social resources. However for the Taurean participant the phrase 'a wealth of experience' becomes real; a way of turning what could be seen as a burden into a resource. As experts through experience they are a real asset to researchers because of the richness of their knowledge about coping with issues and services. Being valued in this way is also useful to them, building their own sense of self-worth. However they can sometimes be seen by others as pushy, because they volunteer for every committee and panel.

**Gemini** – the communicator.

In health and social care there are some good stories, but there are also things that go wrong and some people have very bad experiences. When this happens the Gemini participant does not see the point of moaning about it, but nor do they want to keep it to themselves. They question the value of holding pain for private consumption and are skilled at seeing how to share good and bad experiences usefully. However if they are not listened to, don't expect them to stick around. They are not just there to tick the researchers' 'patient involvement' box and are bored by circular discussions. They have better things to do with their time.

**Cancer** – the supporter.

Being the recipient of care can become debilitating, especially if there is no opportunity to care in return. The loss of a primary caring role through bereavement or changed circumstance can also leave a big hole. The Cancerian participant enjoys being able to support others through their involvement, including researchers and other participants. They are keen to please others and the group, team or project can become very important to them. They may be hurt if they do not get timely feedback or feel researchers are more interested in career development than in the benefits that the research will deliver to patients.

**Leo** – the promoter.

Service users sometimes need strong advocates to promote their interests and to get attention for improvements that can be made, sometimes researchers need that too. The Leonine participant is made for the job. They are happy to get up on stage and talk about the work of their team, have their story told on the website, chair a meeting, or to put up a hand and ask awkward questions from the audience if that is what is needed. They enjoy the limelight and public recognition of their achievements. However it can be difficult for them step aside and let others speak for themselves, sitting quietly in the background does not feel natural to them.

**Virgo** – the refiner.

The difference between quite interesting research and research that is really useful often lies in the fine detail. The Virgoan participant is particularly interested in this. They are committed to making sure that what is asked of participants is clear and realistic. They are very good at refining protocols and critiquing information sheets. Their attention to detail is impressive, and it is usually clear that their strong motivation is to make sure that the research is really effective and successful. However their desire to make things perfect can sometimes lead researchers to experience them as hypercritical.

**Libra** – relating.

Health and social care research is, for the most part, a social process in itself. Whatever attracted the Libran participant to research involvement in the first place, it is that social process that keeps them coming back. The quality of the relationships and communication within the group and the research team are therefore really vital for them. If the team is able to build an attractive social environment the Libran participant will be happy to put themselves out and contribute whole heartedly. However if the social experience of research is not a good one, then they will soon drift away.

**Scorpio** – delving deep.

From the outside academic health research can look like a different planet, with its own language, rules and ways of being. For people who feel powerless and vulnerable it can seem deliberately secretive and obscure. For the Scorpionic participant this presents a challenge. They are natural detectives; their mission becomes understanding how health research and care are structured, funded and governed. They want to discover how they and others can influence and shape the system so that it is better focused on the needs of patients. However their style can sometimes seem a bit confrontational to researchers, who may then try to avoid working with Scorpionic participants - unfortunately reinforcing the appearance of a powerful closed shop.

**Sagittarius** – aiming high.

Academic research involves developing ideas and expanding human knowledge. This is what makes the Sagittarian participant engaged and enthusiastic. They are excited by being a part of great and inspiring projects aimed at the scientific understanding of disease and suffering as well as the promotion of health and wellbeing. They enjoy the intellectual stimulation and have high hopes for what can be achieved through the endeavours of human ingenuity and intellect. However this means they can find the

laboured pace at which a lot of research projects move slow and many of the frustratingly actual outcomes can seem mundane and disappointing.

**Capricorn** – holding firm.

Research needs to be done systematically and thoroughly, according to agreed and validated methods. This means it can take a long time and require a lot of patience. This suits the Capricorn participant. They are there to invest their past, sometimes difficult or painful, experience in the future. They are patient and practical; taking a long view, they are happy to devote their time to creating benefits that may not bear fruit for many years, perhaps for generations. However some other participants might experience the Capricorn as identifying too closely with the research establishment, becoming part of the mechanism that holds the break on patient benefit rather than the engine promoting it.

**Aquarius** – campaigning.

Health and social care research is intended to provide benefits that reach beyond personal interests and help others, often unknown to those who are directly involved. This humanitarian purpose particularly appeals to the Aquarian participant. They feel strongly that there is a need to tackle health and care inequalities and they campaign energetically for people to be treated with compassion and respect. However sometimes they are better at being compassionate about Humanity in theory than with actual human researchers or group members who in turn may find it difficult to live up to the Aquarians' high ideals.

**Pisces** – empathising.

Involvement in health and social care research is often about enabling a wider range of perspectives to be included and ensuring that different voices are heard. The Pisces participant feels passionate about their part in accomplishing this. They can have a real empathy with the emotions and understandings of others, particularly those who find it difficult to express themselves in the sort of language used by academics and clinicians, so they can be extremely effective translators or representatives. However they can sometimes be experienced as over sentimental and seen as overcomplicating things in a way that is frustrating for their more practical colleagues.

**Post script: Where these ideas comes from:**

From sociology this zodiac draws on the work of Max Weber. He argued that, to simplify scientific analysis of why people behave as they do in society, it was useful to measure actual behaviour against a model of how this behaviour might be expected to look if it was based on rational choices, unclouded by contradictory feelings. He called these models 'pure' or 'ideal' types. One of his most famous uses of this technique is in his work on authority.

In this he described 'Three Pure Types of Legitimate Authority':

- Traditional, based on established customs, beliefs and status;
- Rational, based on shared rules and a legal structure that enforces those rules;

- and Charismatic, based on belief in a particular leader and their ability to persuade others to follow them.

If you think about actual authorities you are familiar with, from national government to social club committees, you can probably see that they might each have a different blend of Weber's 'pure types', but having those types outlined can make the similarities and differences easier to identify and describe. This seemed a useful exercise to apply to people's motives for involvement.

However, in our society being 'rational', 'pure' and 'ideal' are all seen as 'good' things. I felt this might mislead some people into thinking that it is somehow better to fit exactly into one of these categories, even though most of us are likely to be an untidy blend of several 'types'. I was also concerned that the language social scientists often use to discuss motives can be equally loaded with value judgements, for instance 'altruism' is usually seen as a good thing and 'egoism' as bad.

In order to get away from the ideas that one motive is better than a mix of motives or that some motives are better than others I have tried to find a way of categorising them that sidesteps these traps. From psychology and literature I have drawn the idea of using archetypes, that is, symbols or models of behaviour which are widely recognisable and often linked with mythology or fairytales.

However the archetype does not describe a whole real person, it is a shorthand way of indicating particular social relationships and roles, or aspects of those roles. For instance the 'wicked step mother' and the 'fairy godmother' are easily recognisable archetypes of adult women in relation to children and young adults; one limits freedom while the other enables and empowers. Most women who have had responsibility for the care of young people would recognise that, at different times and while performing different aspects of their role, they may be characterised by one of these archetypes, possibly both on the same day. The archetypes can be useful in the same way as the pure or ideal types, to explain and discuss what is happening in a social relationship.

### **Why a Zodiac?**

Astrological signs are a system of archetypes that will be widely recognised. They were chosen for this reason and also because they help avoid some of the value judgements implied by the sociological language. Many people will also be familiar with the idea that people have more than one 'star sign' through astrological concepts like 'rising signs' and 'moon signs'. This helps to support understanding of the blending of different motives for involvement that we find in real life.

Another reason for choosing a zodiac is the potential to display these ideas in a way that is attractive and accessible to participants who may not be interested in reading

sociology textbooks or journal articles. This is part of trying to ensure that this study results some things that can be used by people involved in research rather than just a document that sits on a shelf.

## Appendix 8. Models and Games



Foucaultscope



Functionalism



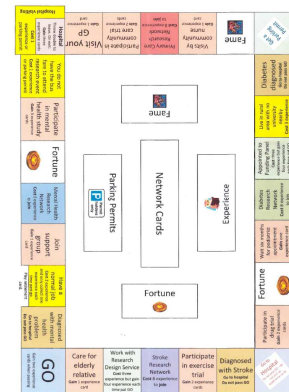
The Gift



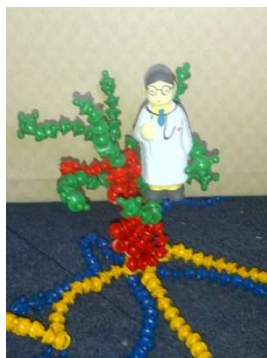
Structuralism



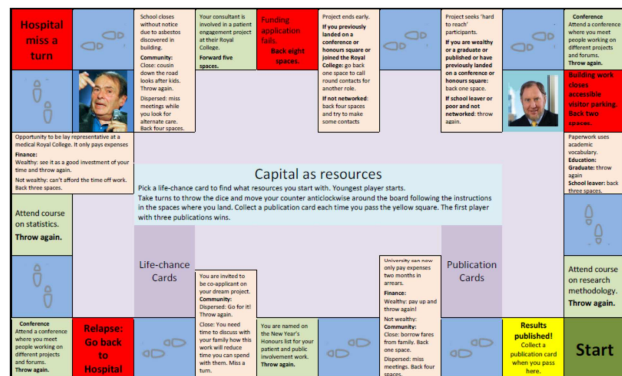
Biographical Disruption/  
Narrative Reconstruction



Structuration



Structural Marxism



Capital as resources

## The Structuration Game (for two to six players)

### RULES

To play the game you will need: the 'Structuration Game' board; two dice; a counter to represent each player; pack of 'Experience' cards; pack of 'Fame' cards, pack of 'Fortune' cards; pack of 'Parking Permits'; four packs of 'Network' cards. Counters begin on the 'Go' square.

'Network' cards are placed in the centre of the board.

'Parking Permits' and well shuffled 'Fame' and 'Fortune' cards are placed in the marked rectangles.

Each player begins with two 'Experience' cards dealt from the shuffled pack. The pack is then placed in the marked rectangle.

Players take turn to throw the dice. They must throw a double to begin. Players then move their counter around the board in a clockwise direction according to the number of squares indicated on the dice.

They should follow the instructions in the square where they land.

Each time they pass 'GO' a player may take two 'Experience' cards from the top of the pack.

If a player lands on a square marked 'Fame' or 'Fortune' they must take the top card from the appropriate pack and follow the directions on the card. The card must then be returned to the bottom of the pack unless it states that it may be retained.

When a player lands on a 'Network' square they may join that network by returning cards worth eight experiences to the bottom of the experience card pack. They then take a membership card for that network. No change is given if a player does not have the exact denominations of 'Experience' cards.

They may join a network more than once if they choose. Membership cards may be traded between players or sold back to the network for two experience cards taken from the top of the pack.

If a player lands on a yellow penalty square they must forfeit the designated experience. No change is given if a player does not have the exact denominations of 'Experience' cards. If they do not have resources to pay they must go directly to hospital, unless another player is willing to pay the penalty for them.

A player who lands on the 'Have a normal job' square may avoid the penalty by playing a 'retirement card'. Once the card has been played, it must be returned to the bottom of the 'Fame' or 'Fortune' pack.

If the number on the dice leads a player to land on the Hospital square they are deemed to be 'visiting' and must pay for parking with a permit or experience. No change is given if a player does not have the exact denomination of 'Experience' cards. If they do not have resources to pay they are deemed to have been hospitalised and must throw a double on their subsequent go in order to leave. However when they do so they will be awarded three experience cards.

Landing on a 'Diagnosis' square means that a player must go directly to Hospital, without collecting two experience cards for passing 'Go'. They must throw a double on their subsequent go in order to leave. However, when they do so they will be awarded three experience cards.

There are also two opportunity squares that enable players to purchase future benefits by investing currently held experience.

A 'Parking Permit' is awarded when a player lands on the 'get a Parking Permit' square. However, there is a limited supply of 'Parking Permits', should a player be entitled to a 'Parking Permit' when none remain, that is deemed to be 'though luck'.

**The object of the game** is to join all four research networks.

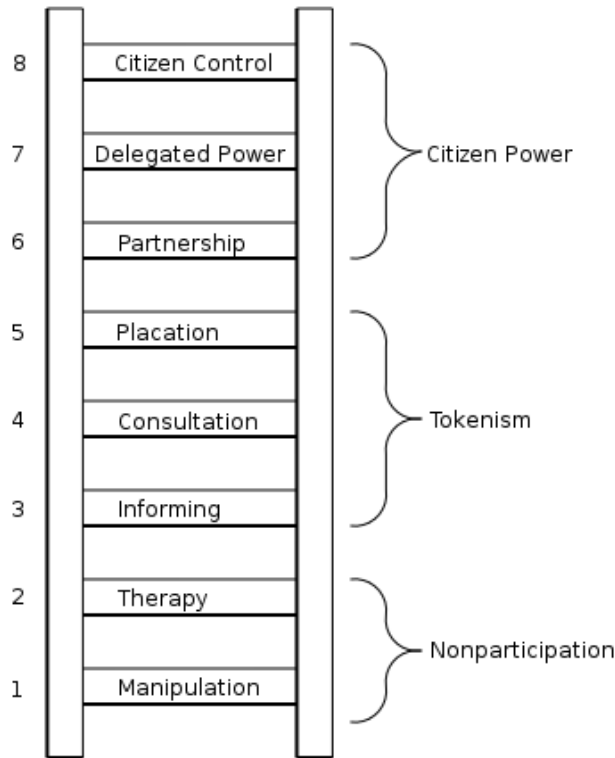
**The game will end** when any player has membership of all four networks.

**The winner will be** the player holding the most experience when the game ends.

**All rules must be strictly adhered to at all times.**

Unless the players or any individual player should agree or decide that any or all the rules should be adapted, re-drafted or disregarded. However this may lead to the objectives becoming unachievable and the game unplayable.

**Appendix 9. Arnstein’s Ladder of Participation (1969)**



**Appendix 10. Participant references to distinct perspectives**

Abigail	<ul style="list-style-type: none"> <li>• I come from the pure perspective of having, also of living with a disability</li> <li>• I've been sort of able to sort of impart the patient experience</li> <li>• That dual perspective because I've been through it myself but I also understand the clinical side of it</li> <li>• The industry point of view.</li> <li>• looking at it from all perspectives really</li> <li>• understand the kind of researcher perspective</li> <li>• from a scientific point of view.</li> <li>• I understand it from that dual perspective as well</li> <li>• pure design point of view</li> <li>• actually they do need to get the view of the patient</li> <li>• so I'm kind of giving them that perspective</li> </ul>
Alan	<ul style="list-style-type: none"> <li>• board I sit on as a public contributor</li> <li>• I will go and research it, I will go on the various websites and learn,</li> </ul>



	<p>and just give a public... I can't talk about a personal perspective, but I look to see what NICE guidance is or best care pathway, and how services are configured. Those figure... those services that are part of the definitions of the national specialised services group. It's not commissioned locally – it's commissioned regionally. So I look to see what their evidence is</p> <ul style="list-style-type: none"> <li>• if you become chronic then the CBT didn't work then you move on, er, and the medication's different. So their perspective won't necessarily be the same as a certain group of people</li> <li>• the first you know, lay review application I did, they thought I'd gone further and beyond the PPI remit... You know, I was looking at the robustness and the vigour and they sent me some guidance and I thought they're scaling me down but hey, when they're paying me £50 without an attendance, or £150 for the day, if all they want is a real public, you know, perspective yeah, I can, I can do that, I can keep it in plain, simple language</li> <li>• I'm trying to get the nursing and midwifery council, and healthcare professional council covers all the others to include the patient perspective</li> </ul>
Amy	<ul style="list-style-type: none"> <li>• giving people who use services and their carers a voice</li> <li>• carers voice ought to be heard</li> <li>• I felt that it was very important the carers voice was part of that</li> <li>• does seem to be keen to get er, a patient voice</li> <li>• public engagement point of view</li> </ul>
Dorothy	<ul style="list-style-type: none"> <li>• the [public involvement group] point of view where I've learned about lots of other conditions.</li> </ul>
Edward	<ul style="list-style-type: none"> <li>• it's getting the public involved which is always a fresh look at things, it's a new glance</li> <li>• I think it brings a different perspective</li> </ul>
Elizabeth	<ul style="list-style-type: none"> <li>• so she actually wanted help from just, you know a lay person's view on the questions to be asked and that sort of stuff.</li> <li>• there are always issues that are important to the public</li> <li>• involving the mo... I say the mob, but involving people outside the NHS you know, is a, is a challenge, you know. They aren't employed, erm, they haven't got the same attitudes to things that – that's the whole point, they have got a different point of view, you know erm, and they're not worried about their careers, and this that and the other, in the same ways, so it is a challenge to positively engage such people</li> </ul>
Ellie	<ul style="list-style-type: none"> <li>• the workers had their own perspectives on it as workers</li> <li>• they [academic researchers] analysed everything but they analysed it themselves, so there was no perspective in the analysis of people using services, or carers, or even front line commissioners!</li> </ul>

	<ul style="list-style-type: none"> <li>• the research department at one point, the doctor er, who was running it and still is really erm, would send me out research proposals on a regular basis – unpaid – for me to read...Feedback my service user perspective which he would then incorporate into his funding applications</li> <li>• it [acting as a researcher] gave me a perspective from being on the other side of the fence</li> <li>• it's better to keep all of the perspectives on board</li> <li>• you need to look at the participants' erm, perspective</li> </ul>
Eva	<ul style="list-style-type: none"> <li>• From my point of view it was different to er, academics point of view to someone... a specialists point of view</li> </ul>
Grace	<ul style="list-style-type: none"> <li>• obviously you know we'd be looking at it from a, from a totally different viewpoint.</li> <li>• [public involvement group] point of view</li> <li>• the researchers were looking at one thing whereas the patients wanted something else</li> <li>• managers' point of view,</li> </ul>
Hannah	<ul style="list-style-type: none"> <li>• talking from a general patients...point of view, not from you know, a sufferer of whatever the problem</li> </ul>
Harriet	<ul style="list-style-type: none"> <li>• it's important that lay people have input</li> <li>• but it's important that er a la... a light is shone from a different angle</li> </ul>
Isobel	<ul style="list-style-type: none"> <li>• And gives the patients point of view and the public's point of view,</li> <li>• And they were not – to my mind – actually giving a voice to the people.</li> <li>• it's not too medically orientated for the public</li> <li>• that they can put their voice to and say what they feel and how they feel</li> </ul>
Jennifer	<ul style="list-style-type: none"> <li>• I mean I know from my own experience at work and you forget what it's like to be a real person you know?</li> <li>• And you do! Erm, and when somebody say 'Hey, but ...' you're sort of 'Oh yes, I never thought of that....'</li> <li>• I mean you're putting forward the point of view of other people, you're putting yourself in somebody else's shoes</li> </ul>
Kenneth	<ul style="list-style-type: none"> <li>• on my experience of good and bad leadership and management in the health service from a lay perspective.</li> </ul>
Linda	<ul style="list-style-type: none"> <li>• giving it from our perspective</li> <li>• It makes them think outside the box</li> <li>• we talk to the students they're taught by academic types - they're taught by tutors and then we come in and we're the grey area you see</li> <li>• we, as patients, as carers, we go in and tell them this</li> </ul>
Oliver	<ul style="list-style-type: none"> <li>• non-clinical advice and input</li> <li>• lay group differ from the views the College as a Medical College</li> <li>• officers of the College absolutely want a lay group to provide</li> </ul>

	<p>different perspectives</p> <ul style="list-style-type: none"> <li>• non-medical input</li> <li>• is that me speaking as patient or is that me speaking as qualitative researcher/sociologist</li> <li>• in my experience they're comparatively more open to alternative perspectives</li> <li>• kinds of professional groups have a kind of narrowing view</li> <li>• how it looks from the perspective of the department</li> </ul>
Rosaline	<ul style="list-style-type: none"> <li>• it may be that we can do something to put our voice forward.'</li> </ul>
Ross	<ul style="list-style-type: none"> <li>• I think certainly changing the structure of things to better fit in a, a patient voice that's actually erm, oh, what's the word I'm looking for? That's actually regarded, is quite important</li> <li>• I think there's a severe underestimation of lay knowledge which is endemic to the medical community and it's a very serious problem that... 'because this person doesn't know all of the medical knowledge and have a piece of paper from a prestigious university to prove it that their opinions are moot!' And I, I think that there's a lot of very deep contemplation that needs to be done in, in the erm, in the command structure of health provision as to the other fields of knowledge that can be useful in public... in erm, in medicine i.e. Public and Patient Involvement and in general a sort of wider acceptance of knowledge that isn't strictly academic.</li> </ul>
Thomas	<ul style="list-style-type: none"> <li>• looking primarily at those applications from a PPI perspective.</li> <li>• I'm allowed to comment on the study as well, and I do, but none the less this [public involvement] is my prime angle</li> <li>• reviewing that from, these studies from the same perspective</li> <li>• from the psychological perspective.</li> <li>• put the patient view to them</li> </ul>
<p>Survey: What PPI role(s) are you currently involved in? (e.g. groups, organisations or activities) What other PPI roles have you been involved in</p>	<ul style="list-style-type: none"> <li>• a social science perspective</li> <li>• a public/patients perspective</li> <li>• carers perspective</li> <li>• carers perspective</li> </ul>
<p>Survey: What is important about PPI for you?</p>	<ul style="list-style-type: none"> <li>• the patients' and carers' perspective is represented</li> <li>• Sometimes patients/carers might have a clearer view</li> <li>• important that the patient perspective - the expertise of the person</li> <li>• Lay involvement gives researchers more knowledge of what it is like to actually live with the conditions.</li> </ul>

	<ul style="list-style-type: none"> <li>• Patient and carer, etc. voice can make a difference</li> <li>• Ensuring that the voice of the patient / parent is heard when research professionals identify research</li> <li>• Giving a different angle on health</li> <li>• To try to ensure the Patient and carer voice is heard by decision makers.</li> <li>• a patient perspective</li> <li>• not restricted to the views of researchers</li> <li>• patient to carer perspectives, both are important.</li> <li>• Being able to put forward the views of the lay person thereby giving the public a voice in decisions being made concerning them</li> <li>• The voice of the user is equal to the voice of the provider</li> <li>• ensuring patient perspective is clearly stated</li> <li>• making sure patients priorities are included</li> <li>• Getting the patient's view into focus</li> </ul>
Survey: How did you get involved in PPI?	<ul style="list-style-type: none"> <li>• was able to use both perspectives for change in health care</li> <li>• representing the user voice.</li> </ul>

## Appendix 11. Participant references to representation

Interviews	
Abigail	<ul style="list-style-type: none"> <li>• I don't do very much actual <b>patient representation</b> because I've kind of moved beyond my experience</li> <li>• we also had a <b>patient representative</b> who sat on our own [service user generated study] group.</li> <li>• It's better in a way because in a way now I'm sort of working, I'm truly integrated, as a member of a high level team that is multidiscipline, I'm not thought of as a <b>patient representative</b>, they don't sort of edge round me carefully.</li> </ul>
Alan	<ul style="list-style-type: none"> <li>• I've got a code of conduct that I have to adhere to, with any organisation and I wouldn't <b>represent an organisation</b> if I wanted to be challenging</li> </ul>
Amy	<ul style="list-style-type: none"> <li>• that was a good example really of erm volunteers i.e. carers or <b>carers representatives</b> and professional staff sitting down, working together 'cause carers on their own couldn't, couldn't change much unless you took the staff with you</li> <li>• I became the <b>LINK representative</b> on the [local hospital patient group]</li> <li>• [professional body] asked for a <b>[national service users'</b></li> </ul>

	<p><b>organisation] representative</b> on its board and they nominated me</p>
Dorothy	<ul style="list-style-type: none"> <li>• [It is difficult] remembering, sometimes, who I'm <b>representing!</b></li> </ul>
Edward	<ul style="list-style-type: none"> <li>• the most <b>unrepresented</b> person in this whole country is the white, working man... 'cause they're never involved in things 'cause they're always at work ... There were down holes, they were driving lorries; they never come to any of these things. They never get <b>represented</b>.</li> <li>• the white working man's got no bodies, now with the demise of trade unions and things; they've got nobody <b>representing</b> them, not one. So there's none of them get involved in PPI, 'cause most things are in the daytime.</li> </ul>
Hannah	<ul style="list-style-type: none"> <li>• you get out what you put in to a large extent, and I've never been, never been a passenger. Er, and I'm sure that must be the same with any <b>patient representative</b></li> <li>• we – me and the other girl that are <b>patient representatives</b> – ask them to do it [diarise meetings well in advance] every time and they just don't seem to get their act together.</li> </ul>
Harriet	<ul style="list-style-type: none"> <li>• [patient and public members of a health research funding panel] I assume it's one person or one <b>representative</b> [Interviewer: often it's now at least two] Well that I think that's helpful</li> </ul>
Isobel	<ul style="list-style-type: none"> <li>• [Involvement forums] were not – to my mind – actually giving a voice to the people. Totally unrepresentative in fact.</li> </ul>
Jennifer	<ul style="list-style-type: none"> <li>• I first got involved in patient <b>representation</b> although not in research ... there was erm, an advertisement in The Guardian, for members of the [Medical specialism college]</li> <li>• by that time I was quite heavily involved in being the patient <b>representation</b> on quite a lot of studies</li> <li>• I suspect it [negative feedback on patient involvement plans from a funding panel] was probably the PPI <b>representative</b>....Which is a bit worrying</li> <li>• I mean I recognise the arguments, and I agree with the arguments that say it is essential that the <b>people who are going to be participating in this research have somebody to represent them</b> all the way along. I think it's a giant step forward, but it can become dysfunctional , it becomes... among <b>PPI representatives</b>, it becomes regarded as an entitlement somehow, as the only thing that matters</li> <li>• you find the <b>PPI representative</b> arguing for it [poorly designed study] on the grounds that it's an important subject and it's got a lot of PPI in it</li> <li>• It's important that we're here, it's important that we're represented; let's do it properly... let's be helpful.</li> </ul>

	<ul style="list-style-type: none"> <li>• before I got involved in <b>patient representation</b></li> <li>• I get uneasy about the demands of erm of <b>PPI representatives</b> to be treated differently, in, in the sense that erm.... Well I, I was once present at a meeting where there were two researchers who were discussing ... whether it should be the case that protocols that were or applications or whatever that were going to be shared with <b>PPI representatives</b> and lay people, should be written in a way that would avoid them being upset by anything that was in it. Because they'd recently been involved in a situation where there had been two <b>PPI representatives</b> erm, present at a meeting and one of the had got desperately upset reading through the protocol, because erm, it revealed that the condition that she herself was suffering from did not have a particularly good prognosis and she'd freaked out and gone... and you know the meeting stopped and they had to get everybody out of the room because they couldn't go on... and I thought no! If you can't stand the heat you just can't be allowed in the kitchen, you really really can't, ... And you cannot having people wasting time by re-writing these... I mean they're long, long documents.... In order to avoid upsetting the <b>PPI representative</b>... you can't. It's so counter-productive. ...</li> <li>• it may even be a good idea to say to people who are interested in becoming <b>PPI representatives</b> erm, that you will hear things that you may... you may wish you hadn't heard</li> <li>• real life is that there are people that are good at, at, at being <b>PPI representatives</b>, there are people that are good at, at running support groups, there are people who are good at providing helpline information and, and they're not necessarily the same people</li> <li>• You're <b>representing</b> other people and you cannot <b>represent</b> other people if... I mean you're putting forward the point of view of other people, you're putting yourself in somebody else's shoes and saying: 'if I were this person in this piece of research what is it going to mean to me, how would I want to be treated, what do I need to understand?' and all those things and if you simply cannot stand the reality of the research in relation to yourself... you can't do that.</li> <li>• I've often noticed that in meetings where there are several <b>PPI representatives</b>, that it becomes almost a duty to find something wrong 'cause what are you there for if you can't find anything wrong? You know. And that, that is counterproductive I think.</li> </ul>
John	<ul style="list-style-type: none"> <li>• [I was invited to become involved] via a friend of mine called [name] who had been invited onto the [condition specific research network] and he felt that you should have a buddy</li> </ul>

	<p>system so if he couldn't make it then I would take his place so that there was continuous involvement from <b>patient representatives</b> at all times.</p> <ul style="list-style-type: none"> <li>• If I hadn't have gone [research organisation board meeting], there'd have been no <b>representation from [patient and public involvement group]</b>, which I think, you know, we've got to have the <b>representation</b> there.</li> <li>• I felt that we needed to get <b>representation</b> there and somebody to support [name of fellow patient and public involvement group member], because it was her first time of going.</li> <li>• I think there's five people now who've got [condition] within the group. So there's five people who can go to <b>represent people</b>.</li> </ul>
Kenneth	<ul style="list-style-type: none"> <li>• I think erm, I have an advantage [over professional researchers when challenging policy makers] as I say, because I'm a, erm, <b>lay representative</b> erm, and to be fair I know my stuff now</li> <li>• [on the value of a supportive network] given the people that I can call on to <b>represent me</b>...Who've offered their help and support at both regional and national levels erm, people I would've never have believed I would have come in contact with</li> </ul>
Oliver	<ul style="list-style-type: none"> <li>• [Medical specialism college] it kind of <b>represents the specialism</b>.</li> <li>• ultimately they [medical specialism college] are a professional body and they are there to <b>represent a particular professional group</b> and that's what those institutions do, and you shouldn't be unrealistic</li> <li>• I kind of think 'oh right; so I'm sitting here <b>representing 20 million patients</b>', [Specialism] see roughly 20 million patients a year. Erm, and I kind of, [laugh] but, you know actually, that, that just becomes sort of paralysing, if you kind of think that</li> <li>• it kind of serves to illustrate how er, for all the rhetoric there's been about PPI, across the whole of the National Health Service, it's kind of me <b>representing 20 million people</b>, in a room of 25 professionals. So, the balance has shifted a little bit</li> <li>• again, I always worry about that, well I'm not exactly representative. But then how can anybody be <b>representative</b> for those kind of people? And I, you know kind of, and I'm absolutely the sort of person who is consulted 'cause I'm, you know, appallingly well educated – far more education than anyone could sensibly er, need or use, and middle-class and white and male and all of those kinds, which - but again I, I said to somebody on the phone, I'm entirely aware of all of those things, and at the same time I think if I wasn't all of those things I wouldn't really get in the door of the Department of Health, so</li> </ul>

	<p>what, what you gonna do? Come and say, well no you should be talking to some old people, when that means they wouldn't even do it at all, so I, I kind of continue to struggle with that one, but I kind of figure better to try and do something than to erm, yeah, to try and bring about change that isn't gonna happen in the short term.</p>
Thomas	<ul style="list-style-type: none"> <li>• PPI so called reference group which was meeting from time to time but that one rather petered out because although it was bringing together <b>patient representatives</b> involved with [research organisation], in fact not many other than myself was actually involved in a study and let's face it that's where the rubber hits the road. If you're not involved in one of these 15, 16 studies, why are you there?</li> <li>• there were several people, such as myself getting their sleeves rolled up, but not many of us and frankly we couldn't possibly be acting as <b>patient reps</b> on 16 projects.</li> <li>• one of the [research organisation]'s themes is [condition] rehabilitation which are mostly run by this lady called [name] and they actually source <b>PPI reps</b> from their own group so that theme's reasonably well taken care of but the in the other themes I think it is a bit patchy.</li> <li>• He [new facilitator] has now got the bones of a section on the [research organisation] website which tells potential erm, <b>representatives</b> what it's all about signposting them to places like INVOLVE</li> <li>• there don't seem to actually be any new <b>reps</b> coming through</li> <li>• this particular study, which I'm on the [research organisation]'s portfolio, was looking for <b>patient representatives</b> and actually came and asked for a <b>rep</b>.</li> <li>• I will not be the only patient <b>rep</b> this time, now there are one or two others also</li> <li>• One of the bits of feedback was I look a little bit too close to a, a '<b>professional</b>' <b>PPI rep</b>. I almost took that as a backhanded compliment, but I am aware of this danger, that if you get too involved you can start to go native as it were. Erm, I'm very much aware that as I'm doing this data input work, which I've been doing for a few months now, on the erm, return to work study, I can start to think like one of the team a bit too much. Erm: 'Oh, flipping heck, they haven't even read the question properly!' you know? I can, yet actually, when I see it as a <b>patient rep</b> I can see that some of the questions that I'm typing the answers to have been so confusing that really...</li> <li>• project management type skills which might well be new to many <b>PPI reps</b> getting involved, were not new to me.</li> <li>• there is a need to ensure that academics fully appreciate why,</li> </ul>



	<p>why they need patient involvement and therefore need to be inviting <b>patient representation</b> into their study.</p> <ul style="list-style-type: none"> <li>the researchers then need at the very least to be able to point the people they have got involved to a central point of reference that we can then go to, we the patient <b>reps</b>. Your patient <b>reps</b> can then go to to get the knowledge, to get the training</li> </ul>
Correspondence and diaries	
John	<ul style="list-style-type: none"> <li>Attending lay panel meeting for the [condition specific] research network for the [region] as a lay member. I had two spots on the agenda which were to ask for a patient <b>representative</b> to apply for a position on the [study] project trial steering group. And to advertise the PPI conference next year</li> </ul>
Lotte correspondence	<ul style="list-style-type: none"> <li>The day before the seminar, <b>an ambulance trust representative</b> came to college where I was doing a course, and asked me what I was going to say.</li> <li>User involvement – past: [National Government organisation] [condition specific] Reference Panel, <b>user representative</b>.</li> </ul>
Nicole	<ul style="list-style-type: none"> <li>Future: [I intend to become a m]ember of [group] through introduction by <b>another PPI representative</b></li> </ul>
Survey data	
David	<ul style="list-style-type: none"> <li>Activities include... where invited to <b>represent</b> such groups [research networks and institutions] to stakeholders albeit in disadvantaging power relationship</li> </ul>
Jennifer	<ul style="list-style-type: none"> <li><b>PPI representative</b> on studies with [research institutions] Former <b>PPI representative</b> on studies with [three named] Universities;</li> </ul>
John	<ul style="list-style-type: none"> <li>Was invited by the [condition specific] research network to be a patient <b>rep</b> on their steering group</li> </ul>
Lotte	<ul style="list-style-type: none"> <li>[central government body] [condition] Reference Panel, <b>user representative</b>.</li> </ul>
007	<ul style="list-style-type: none"> <li>[what would make PPI better] Connections with other <b>PPI representatives</b> who can advise or share experiences.</li> <li>[PPI is important because:] It ensures that the <b>patients' and carers' perspective is represented</b> in discussions about public funding of research.</li> </ul>
016	<ul style="list-style-type: none"> <li>Patient <b>rep</b> at my local GP commissioning group</li> </ul>
023	<ul style="list-style-type: none"> <li><b>Patient Rep</b> for Type 1 Diabetes @ [local] NHS</li> </ul>
026	<ul style="list-style-type: none"> <li>Diabetes Research Network's Clinical Studies Advisory Group, <b>patient rep</b></li> </ul>
036	<ul style="list-style-type: none"> <li>Patient <b>representative</b> in Informatics trials... Patient representative for [local condition specific research network] PPI strategy group</li> </ul>
052	<ul style="list-style-type: none"> <li>[Local] General Hospital found it had no <b>patient representative</b> for an external [specific field] peer review and I was hastily</li> </ul>

	recruited, being literate
058	<ul style="list-style-type: none"> <li>• Patient <b>Representative</b> on the [local institute for health research] Innovations Group at [local hospital]</li> </ul>
084	<ul style="list-style-type: none"> <li>• Lay Representative on the Steering Committee of [condition] biobank</li> </ul>
085	<ul style="list-style-type: none"> <li>• I became the <b>Governor Representative</b> on the newly formed Patient Panel because I have some [condition] myself and am particularly interested in the work being carried out</li> </ul>
093	<ul style="list-style-type: none"> <li>• User <b>rep</b> in [local health] Services Liaison Committee. ...Carer <b>rep</b> on Learning Disabilities Partnership Board</li> </ul>

## Appendix 12. Participant's references to lay

Correspondence	
David	<ul style="list-style-type: none"> <li>• service user /<b>lay</b> member roles</li> <li>• Might support both facilitators and <b>lay</b> members</li> </ul>
Nicole	<ul style="list-style-type: none"> <li>• reviewing proposal, abstract, <b>lay</b> summary</li> <li>• review of [project] <b>lay</b> summary and patient consent form</li> </ul>
Lotte	<ul style="list-style-type: none"> <li>• Peer Review Team – <b>lay</b> input.</li> <li>• <b>Lay</b> Advisory Committee</li> <li>• The <b>Lay</b> Advisory Committee</li> <li>• <b>Lay</b> Advisory Committee (LAC) Symposium</li> <li>• workshop <b>lay</b> perspective</li> </ul>
John	<ul style="list-style-type: none"> <li>• the position for a <b>lay</b> panel member</li> <li>• I was a <b>lay</b> panel member within health research</li> <li>• my story of being a <b>Lay</b> Panel member</li> <li>• Attending <b>Lay</b> Panel meeting</li> <li>• as a <b>lay</b> member</li> </ul>
Hannah	<ul style="list-style-type: none"> <li>• Suggest <b>lay</b> member</li> </ul>
Interviews	
Elizabeth	<ul style="list-style-type: none"> <li>• a <b>lay</b> person participant</li> <li>• having <b>lay</b> people in at the beginning</li> <li>• but they were <b>lay</b> people like myself ex, ex [condition] sufferers</li> <li>• I was just er, a <b>lay</b> person helping a researcher</li> <li>• from just, you know a <b>lay</b> person's view on the questions</li> <li>• they had this policy of paying people, you know, <b>lay</b> people</li> </ul>
Ross	<ul style="list-style-type: none"> <li>• I think there's a severe underestimation of <b>lay</b> knowledge which is endemic to the medical community and it's a very serious problem</li> </ul>
Alan	<ul style="list-style-type: none"> <li>• it's really difficult to understand some researchers because what I <b>lay</b> review I take... you know, I follow [facilitator]'s method – I've done the erm, down at the [medical school] –</li> </ul>

	<p>the training that they did for generating research questionnaire and the PICO and all that, and I always remember that</p> <ul style="list-style-type: none"> <li>• I'm not with some of these networks but I'm a <b>lay</b> reviewer or contributor</li> <li>• if you didn't get us... you know, 'cause we're <b>lay</b> reviewing, you know you get the qualitative reviewer but you don't know who he or she is, and eventually you get a meridian score – if you did get past that, you go on to a B list, and the A list would be invited to submit a full proposal.</li> <li>• You know, they don't demonstrate the PPI bit and they've got a PPI <b>lay</b> reviewer, they're gonna pick up on that; it's gonna feed in to the board meeting, you know, everybody's got their electronic button to press between one and 6, yeah, and suddenly it doesn't go beyond 3.5, so it can't be considered for an invitation</li> <li>• I'd like to be able to phone up that researcher on a one off, on the basis that there's no payment, but you get to <b>lay</b> review, and should they be successful, then you be a part of that particular team. And to me, I think that's right – that's okay</li> <li>• all I needed to do is attend a few of their meetings to understand and they kind of like stunted me because the first you know, <b>lay</b> review application I did, they thought I'd gone further and beyond the PPI remit</li> <li>• I'll learn you know, vascular dementia or sort of like about stroke rehabilitation or whatever it is, but I'm not the expert 'cause I've not got that experience, but if somebody wants somebody to quickly do a <b>lay</b> review, you know I can do that q- I can do that quickly</li> </ul>
Helen	<ul style="list-style-type: none"> <li>• I've just done a <b>lay</b> review recently for something.</li> </ul>
Ellie	<ul style="list-style-type: none"> <li>• So actually just pulling a group of people and saying: 'Right this is a <b>lay</b> review' I think you need to be quite clear what you mean by <b>lay</b> review because erm, you're not, you know you're not coming in an informed way</li> <li>• So I do think, you know in terms of reviewing proposals for funding and stuff then actually having people who have the related experience is more valuable than just having a group of so called '<b>lay</b> people'</li> </ul>
John	<ul style="list-style-type: none"> <li>• for 2 and a half years I have been on the steering group of [condition] Research Network which in February of this year erm, made it erm, a <b>Lay</b> Panel so I'm currently the vice chair of the <b>Lay</b> Panel...</li> <li>• as we now have a <b>lay</b> panel group</li> <li>• [involvement would be easier if] when we're looking at documents [there were] more <b>lay</b> panel reviews done. As I</li> </ul>

	<p>was speaking to another [involvement group] member on Friday and, and she also said, erm, could do with a few more <b>lay</b> panel reviews</p> <ul style="list-style-type: none"> <li>• I'm now on their panel as a <b>lay</b> reviewer.</li> <li>• they looked at my CV of what other things I've been involved in erm, they sort of snatched my hand off as being a <b>lay</b> member</li> <li>• they sent it out to 15 erm <b>Lay</b> Panel members and I applied to them</li> <li>• Generally there's a <b>lay</b>, a <b>Lay Panel</b> erm a <b>lay</b> review – that's it, so I generally read that, most of the time, 'cause that's got most of the information on.</li> <li>• it seems to be getting bigger and bigger, it seems to be that I'll probably be a full-time research <b>lay</b>... <b>lay</b> person, [laughs]I mean doing more hours than I would do in a full-time job</li> <li>• but I'm just sort of there as a <b>lay</b> member, there's no pressures on me and I quite enjoy just going to the meetings and listening to it.</li> <li>• so I'm going up in the car on that one and er, yeah, it's a <b>lay</b> meeting and there's just two a year for those so I'm quite happy with that</li> <li>• to the [condition specific research network] it's all about the numbers of <b>lay</b> people that they get involved in other projects that are to do with research</li> <li>• Because I just think, feel that [clinicians/former clinicians on a lay panel] you know, they're trying to get in their clinical goal, you know sort of thing and they're not really for the actual <b>Lay</b> Panel</li> <li>• that's when I thought you know that they weren't getting the feedback from the organisations that they were advertising you know, for <b>Lay</b> Panel members? And I think that's a must because it's all about numbers to these organisations.</li> </ul>
David	<ul style="list-style-type: none"> <li>• my name went on the [condition] Network register, er, to be available for forums, to have <b>lay</b> reviews and so on</li> </ul>
Grace	<ul style="list-style-type: none"> <li>• I'm afraid I sort of tore it apart. Which, they were very pleased about you know, because they wanted to, something that erm, that a <b>lay</b> person could understand and, and also that the ethics committee would allow.</li> </ul>
Dorothy	<ul style="list-style-type: none"> <li>• they had erm vacancies for <b>lay</b> members on the [condition] research management thing. So I thought why not, learn a bit more, erm so I applied had an interview and got in and from there I did erm the <b>lay</b> members on the [condiyion] research management meeting</li> <li>• I was discussing this on the way to a research committee – a</li> </ul>

	<p>[condition] research meeting, last Thursday with a new <b>lay</b> member</p> <ul style="list-style-type: none"> <li>• I have also, a bit stupidly, taken on em being a <b>lay</b> member of the [research advisory service]. But that is very complicated</li> <li>• but you review somebody's complete thing, not just the <b>lay</b> members' part of it</li> <li>• though they've put me on the bottom as a co-applicant which is nice. As a <b>lay</b> member, [condition] survivor</li> <li>• we had a <b>lay</b> members' meeting the night before</li> </ul>
Oliver	<ul style="list-style-type: none"> <li>• I'm chairman of what's called the <b>lay</b> advisory group for the [medical specialism] college</li> <li>• The College has what it calls a <b>lay</b> group, and the, the choice of the term <b>lay</b> group is quite specific that the College, and I think to a degree we agree with them; didn't want this to be specifically a patient group, is what they were looking for was non-medical, non-clinical advice and input, and I think they conceded that as being a bit broader than just patients. So the people that are on the group are all we're people who aren't, we don't belong to any of the healthcare professions, but we've all had erm, quite a lot of experience in relationship with the NHS.</li> <li>• what they wanted from a <b>lay</b> group – they wanted people who were interested in health care and have some understanding but also had an expertise which they as doctors didn't feel that they particularly had.</li> <li>• there's obviously stuff where I and we as a <b>lay</b> group differ from the views the College as a Medical College</li> <li>• I've always found both the current and the previous president and the office, officers of the College absolutely want a <b>lay</b> group to provide different perspectives from the ones, I think they take the view, we can hear from doctors any time, erm, and they want people who will- who are prepared to differ from them</li> <li>• It was in the Guardian public appointments, which has advertisements for voluntary role er and it was one of those, and they erm, they advertised it – it was an application form, and then invited us for an interview and we were interviewed by the then kind of senior administrator within the college and original chair of the <b>lay</b> group. I mean the appointments all notionally have to be approved by the College's council in the same way that any role within the college has to be. But I'd be very surprised if anyone ever objected</li> <li>• we'd like to broaden who's on the <b>lay</b> group and whatever that consists of I think, think we'd like to be more diverse than we are just now And erm, you know, about the only way we are</li> </ul>

	<p>balanced is in terms of gender.</p> <ul style="list-style-type: none"> <li>• I was the <b>lay</b>, you know the non-medical member of the research publications committee, up until this year I became chair of the <b>lay</b> group and I just can't do sort of 18 or 20 meetings a year</li> <li>• I think they were quite keen on the idea that I'm sociologists, I'm a qualitative researcher. Because I think they, they've got all the scientists they need. So, it was a kind of, you know, again where the, where does, does -the boundaries- where do you draw it? And I think "Am I there as a <b>lay</b> person or am I there as someone who's actually kind of an expert?" But it's an expertise that they've not got. I think it's important to say you know, when you're this thing, or that thing; you're advising because of that, and not because of- I don't know.</li> <li>• I'm a part of the panel within the college that looks at the applications and again that was a deliberate choice on the part of the previous president who said he wanted <b>lay</b>, non-medical input on that process</li> <li>• the previous chair of the <b>lay</b> group erm, has been invited to speak a couple of times</li> <li>• I think one of the reasons why they have the <b>lay</b> group that they do and it works the way they do, is that because ... they have a very strong sense of wanting to be different from the other medical Royal Colleges</li> <li>• one of my colleagues from the <b>lay</b> group has been working with.. well actually it's kind of an intercollegiate inter-professional group, on guidelines</li> <li>• I kind of say: "you know I worry [president of college] that we're, we're kind of as a <b>lay</b> group we're kind of captured by the profession and the professionals" and he goes "It doesn't feel like that to me!"</li> <li>• we as the <b>lay</b> group were really critical of what the department originally came up with</li> <li>• we could be much broader in who and how we're involved than - what we probably need, need to have, you know, I think, - this is us at the <b>lay</b> group and also much more globally - is a much sort of richer menu of what involvement could conceivably be.</li> </ul>
Thomas	<ul style="list-style-type: none"> <li>• <b>lay</b> reviewer of research funding applications</li> <li>• initially they were going to all be vetted by a <b>lay</b> panel who again would be looking for what patient involvement have they really got.</li> </ul>
Jennifer	<ul style="list-style-type: none"> <li>• the thought that there are going to be <b>lay</b> people involved erm, and they will be looking out for the way patients are being</li> </ul>

	<p>treated and I think that may make a difference; I think it does make a difference in some cases. Erm, and partly because When you're very focused on work you, you lose sight of the things that matter outside, I mean I know from my own experience at work and you forget what it's like to be a real person you know?</p> <ul style="list-style-type: none"> <li>• I've done things like write the patient information leaflets... write the <b>lay</b> summaries and things like that. Erm, the patient information leaflets might have made a difference to patients; might have been more user friendly the <b>lay</b> summaries are an aid to researchers. I mean I think there's two things that PPI does to help and one is help researchers [Laugh] the other is help patients.</li> <li>• I would resent it in, in my professional life if outsiders – <b>lay</b> people as it were – had come in and started telling me how to do my job and I would have been mad as hell</li> <li>• Where even a <b>lay</b> person can see that this is really, really crap.</li> <li>• whether it should be the case that protocols that were or applications or whatever that were going to be shared with PPI representatives and <b>lay</b> people, should be written in a way that would avoid them being upset by anything that was in it.</li> </ul>
Kate	<ul style="list-style-type: none"> <li>• Self-management course for people with long-term conditions on how to basically self-manage the condition, but it's a condition of [copyright holder] that it's <b>lay</b> led.</li> <li>• I think it's the '<b>lay</b>-led' that gets up their [some clinicians] nose. You know, they think "What can 'they' possibly tell them I couldn't tell them?" and the point is you don't have time to tell them! Overall I'm giving them 15 hours of my time and you'll be lucky if you can give them 15 minutes!</li> </ul>
Beth	<ul style="list-style-type: none"> <li>• Yeah, one person [from an ethics committee] tells us one thing, and then we went back to find out what was going on, and then they said no they shouldn't have asked you to do that, that's wrong, you've got to do this. So it seems that they're not really up to scratch with what should be done. So I mean that might be a legacy of PPI, I don't know. I don't know if he was a <b>lay</b> member or not.</li> <li>• I find bias very complicated. And that's me, and I know a bit about research so I think <b>lay</b> people might find it complicated. So, yes so I think probably some training on different aspects might have made it easier for me in some ways, 'cause I've done it all myself, I've just done a lot of reading.</li> </ul>
Harriet	<ul style="list-style-type: none"> <li>• But of course I'm only a <b>lay</b> person so I wouldn't know. [laugh] Well the internet helps.</li> <li>• If you're expecting somebody to walk a tightrope, it is</li> </ul>

	<p>ridiculous to not give them some training on how to balance [laughs] you're setting them up to fail and they are going to fail in rather a spectacular way. I think it's not unreasonable to, not train them what questions to ask but how to ask them, and what things that they might want to explore – how to get their message across. I think we do that all the time don't we? That doesn't mean I don't know, I can't think of an example. Erm, passing a driving test or having erm, training to drive a car or a child to erm, ride a bike doesn't make them any less a car driver or a cyclist it just makes them more proficient on the road As long as you're... well I don't know how you could - I think that's a bit patronizing to be honest. <b>Lay</b>-ness, what's that supposed to mean? So "somebody who isn't in the know" we're talking about ... it's not a matter of training it's a matter of giving them confidence in that situation and I would have thought the more confident they were, the more articulate they'll be and my experience with academics is that you have to be pretty damn articulate and you need to be quite assertive erm, for them to listen to you! .... and it means that you are not just relying on having the '<b>lay</b> person' inverted commas [gesture] erm, who have those traits to begin with, so you're excluding a lot of people who might have something useful to contribute</p> <ul style="list-style-type: none"> <li>• I think it's quite revealing actually that the professionals want the <b>lay</b> people to preserve their lay-ness, because I think they would not admit it and they're probably not conscious of it. But unconsciously their <b>lay</b>-ness is erm, a contribution to the power differential. And it ain't in the <b>lay</b> persons benefit.</li> <li>• Health research affects all of us, and it can affect people in a very detrimental way and it's important that <b>lay</b> people have input</li> </ul>
Kenneth	<ul style="list-style-type: none"> <li>• [film I made] encouraged 2 people who had had [condition] to er, apply post on the national <b>lay</b> panel which I sit on, the [organisation] national lay panel</li> <li>• I've got nothing to lose which is quite nice, you know - as long as I'm polite, as a volunteer they can't sack me... I have an advantage as I say, because I'm a, erm, <b>lay</b> representative, and to be fair I know my stuff now</li> <li>• I felt confident to be one of the er, lead speakers and on my experience of good and bad leadership and management in the health service from a <b>lay</b> perspective.</li> <li>• That was far more challenging you know, to make sure you don't dumb things down to annoy people who can understand you but, but on the other hand you've still got to be able to communicate with members of the <b>lay</b> community who</li> </ul>



	<p>perhaps have only got sort of erm, reading age of a Sun reader</p> <ul style="list-style-type: none"> <li>• Going back to those, those <b>lay</b> people in an inner ring area with very limited educational background you know, to try and convince them that they could take part as true partners in erm, some academic research is a real challenge, but actually the reward could be huge for everybody.</li> </ul>
Survey	
Roles	<ul style="list-style-type: none"> <li>• <b>Lay</b> reviewing</li> <li>• <b>lay</b> reviewer</li> <li>• <b>lay</b> visiting</li> <li>• Chair, <b>lay</b> Group</li> <li>• member, <b>lay</b> group</li> <li>• <b>lay</b> reviewer</li> <li>• developed training for <b>lay</b> people</li> <li>• <b>Lay</b> Chairs Group</li> <li>• <b>Lay</b> member</li> <li>• <b>Lay</b> Reviewer on Education/training programmes</li> <li>• <b>Lay</b> Member</li> <li>• <b>Lay</b> Member</li> <li>• advisor on studies <b>lay</b> and patient experience</li> <li>• <b>lay</b> member to patient partner</li> <li>• <b>Lay</b> membership Ethics Committee</li> <li>• <b>LAY</b> MEMBER OF MY LOCAL HOSPITAL</li> <li>• <b>LAY</b> MEMBER OF [condition] INCIDENTS PANEL</li> <li>• <b>Lay</b> member of Scientific Committee</li> <li>• <b>Lay</b> Reviewer/Referee</li> <li>• <b>lay</b> input</li> <li>• <b>Lay</b> Advisory Committee</li> <li>• <b>lay</b> reviewer</li> <li>• <b>Lay</b> reviewer</li> <li>• <b>lay</b> member/service user</li> <li>• Lay member</li> <li>• "embedded <b>lay</b> membership"</li> <li>• <b>Lay</b> tutor in Self Management Programme</li> <li>• <b>lay</b> member</li> <li>• <b>lay</b> member</li> <li>• <b>lay</b> member</li> <li>• funding panel <b>lay</b> member</li> <li>• <b>lay</b> reviews</li> <li>• (Chair) <b>Lay</b> panel</li> <li>• <b>Lay</b> Panel Member</li> <li>• <b>Lay</b> Advisory Panel</li> </ul>

	<ul style="list-style-type: none"> <li>• Chair <b>Lay</b> Advisory Panel</li> <li>• <b>Lay</b> Representative on the Steering Committee</li> <li>• <b>Lay</b> Member of a Research Ethics Committee</li> <li>• <b>Lay</b> Member of research [advisory organisation]</li> <li>• <b>Lay</b> Member of a Research Ethics Committee</li> <li>• <b>Lay</b> member of another Research Ethics Committee</li> <li>• <b>Lay</b> Associate [professional body.</li> <li>• <b>Lay</b> reviewer</li> <li>• <b>Lay</b> member of Clinical Ethics Committee</li> <li>• <b>Lay</b> Non-Executive Director</li> <li>• <b>Lay</b> Partner</li> <li>• <b>Lay</b> member</li> <li>• <b>Lay</b> review for funding panel</li> <li>•</li> </ul>
How to improve involvement	<ul style="list-style-type: none"> <li>• I ask researchers to provide <b>lay</b> summaries for our group</li> <li>• better liaison and communication between researchers and <b>lay</b> members [would improve involvement] but I realise this is difficult</li> <li>• It would be a great help if there were a single website which listed every PPI Group, <b>Lay</b> Panel, Working Party, Conference etc</li> <li>• A proper system of support and training of <b>lay</b> people</li> <li>• Things that can help that include: Clarity in the organisation about their values and reasons for <b>lay</b> members being part of the team. Appropriate training and guidelines for specific role. Committee chair with genuine commitment to PPI. Brief ‘SMART’ feedback to inform personal development (rarely happens). On [funder] reviews and panels, not being ‘boxed in’ to only commenting on PPI arrangements, especially if the research question and/or design have significant problems from patient perspective. Not losing option for hard copy – way easier to work with for a lot of reasons. N.B. PPI is difficult for any organisation, for a whole host of reasons. Evaluation of impact is really important – but very wary of the pressure to “measure” impact – what’s needed is qualitative evaluation.</li> </ul>
Why it is important	<ul style="list-style-type: none"> <li>• <b>Lay</b> involvement gives researchers more knowledge</li> <li>• That <b>lay</b> members of the public have a real input to shaping health service delivery - important understandings are brought to the process of changing/improving care by people who are/will actually be receiving it.</li> <li>• One of my most enjoyable tasks is reviewing possible research <b>lay</b> summaries tasks is reviewing possible research lay summaries</li> <li>• <b>Lay</b> people should be involved so that they can advise medics</li> </ul>

	<p>and researchers how they think their ideas will be received by the public so the public will understand them</p> <ul style="list-style-type: none"> <li>• Being able to put forward the views of the <b>lay</b> person thereby giving the public a voice in decisions being made concerning them</li> </ul>
How recruited	<ul style="list-style-type: none"> <li>• Invited onto an RCT steering group as <b>lay</b> member via a patient support group</li> <li>• saw an advert to become a <b>lay</b> member of [college] Patient Partnership Group and bingo!</li> <li>• I was approached by [organisation] to become a <b>lay</b> member</li> <li>• The lecturer said that she was looking for people who might be interested in starting a group of <b>lay</b> people interested in research so I went along and got involved.</li> <li>• Attending a [condition] Information day about June 2008 when <b>Lay</b> members were wanted on the [network] management group. I applied and the rest is history</li> </ul>

### Appendix 13. Protected characteristics: definitions<sup>64</sup>

**Age:** Where this is referred to, it refers to a person belonging to a particular age (e.g. 32 year olds) or range of ages (e.g. 18 - 30 year olds).

**Disability:** A person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.

**Gender reassignment:** The process of transitioning from one gender to another.

**Marriage and civil partnership:** Marriage is defined as a 'union between a man and a woman'. Same-sex couples can have their relationships legally recognised as 'civil partnerships'. Civil partners must be treated the same as married couples on a wide range of legal matters.

**Pregnancy and maternity:** Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.

**Race:** Refers to the protected characteristic of Race. It refers to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.

**Religion and belief:** Religion has the meaning usually given to it but belief includes religious and philosophical beliefs including lack of belief (e.g. Atheism). Generally, a belief should affect your life choices or the way you live for it to be included in the definition.

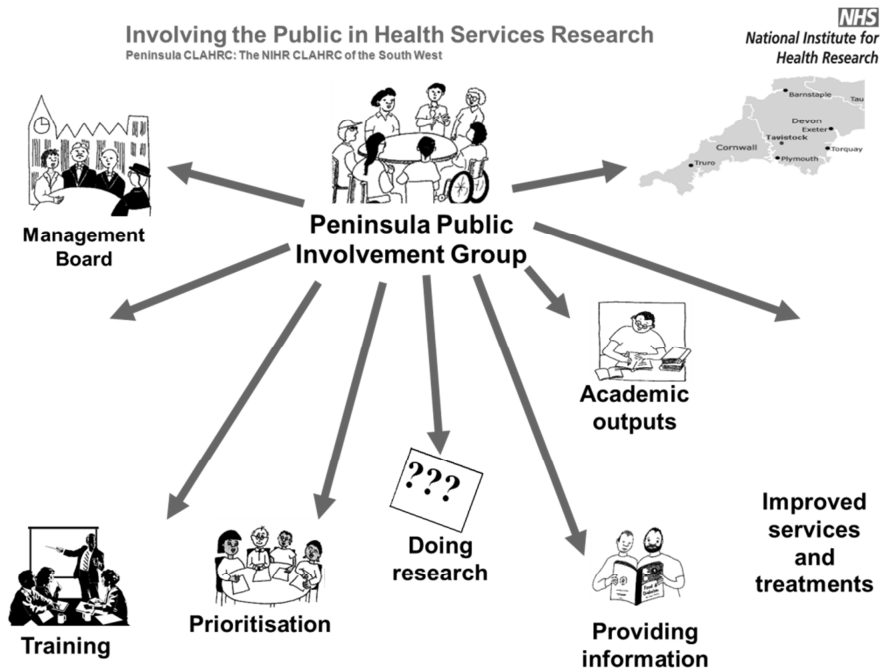
**Sex:** A man or a woman.

**Sexual orientation:** Whether a person's sexual attraction is towards their own sex, the opposite sex or to both sexes.

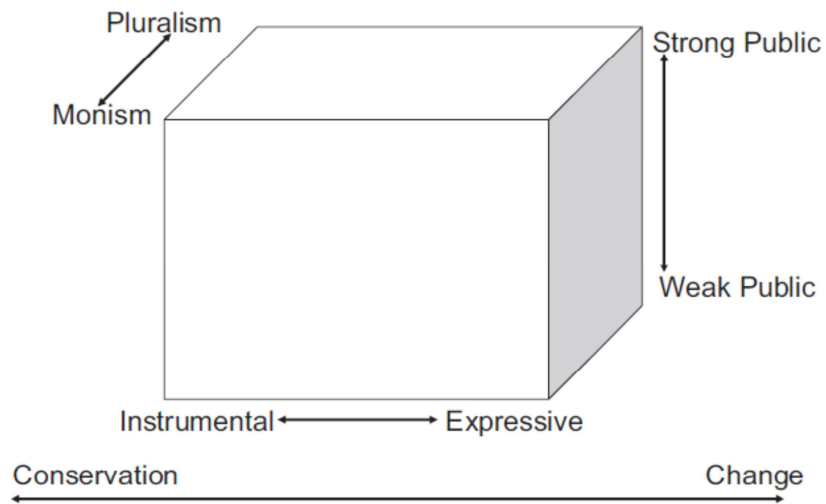
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<sup>64</sup> <http://www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance/protected-characteristics-definitions/> (accessed 03/05/14)

## Appendix 14 PenPIG



## Appendix 15 The Gibson, Britten and Lynch 'Cube'



**Figure 1.** A four dimensional view of knowledge spaces

(Gibson, Britten and Lynch 2012, p543)

## BIBLIOGRAPHY

- The Aberdeen Magazine (1832) The destruction of the anatomical Theatre. The Aberdeen Magazine. 2:13-24, [ebook] pp54-55. Aberdeen: Lewis Smith  
<http://books.google.co.uk/books?id=MHIBAAAAYAAJ&pg=PA607&dq=The+Aberdeen+Magazine,+1832&hl=en&sa=X&ei=xllkU4PSO4yhOsiigOgG&ved=0CD8Q6AEwAA#v=onepage&q=theatre&f=false> (accessed 03/0514)
- Allen R. E. (ed) (1990) The Concise Oxford Dictionary of Current English (eighth edition). Oxford: Clarendon Press
- Allen, P. (2006) New localism in the English National Health Service: What is it for? Health Policy. 79:2–3, December 2006, pp244–252
- Alvelo, P. J. (2009) The Politics of Madness: The Mental Patients' Liberation Movement in the 1970s. Sarah Lawrence College. Available on  
<http://gradworks.umi.com/14/66/1466470.html> (accessed 03/0514)
- Alvesson, M. and Sköldbberg, K. (2009) Reflexive Methodology: New Vistas for Qualitative Research (Second Edition) London: SAGE
- Aristotle [c330BC] (1955) Ethics. Thompson (trans) Harmondsworth: Penguin
- Aristotle [c330BC] (1996a) The Politics. in The Politics and The Constitution of Athens. Everson (ed) Cambridge: Cambridge University Press
- Aristotle [c330BC] (1996b) The Constitution of Athens. in The Politics and The Constitution of Athens. Everson (ed) Cambridge: Cambridge University Press
- Armstrong, D. (1989) An Outline of Sociology as Applied to Medicine. London and Boston: Wright
- Arnstein, S. R. (1969) A ladder of citizen participation, Journal of the American Institute of Planners. 35, pp216–224
- Asch, S. E. (1956) Studies of Independence and Conformity: I. A Minority of One Against a Unanimous Majority. Psychological Monographs, 70, Whole No.9
- Asprey, A. & Nash, P.T.S. (undated) Including young people with cystic fibrosis in mainstream education. Based on findings from the Being Like Everybody Else Project. Barnstaple: Children's Hospice South West.
- Atkinson, P. (1997). Narrative turn or blind alley? Qualitative Health Research. 7:3, pp325-344.
- Baert, P. (1998) Social Theory in the Twentieth Century. Cambridge: Polity

- Barnes, M. Harrison, S. Mort, M., and Shardlow, E (1999). *Unequal partners: User groups and community care*. Bristol: Polity Press
- Barnes, M. (1999) *From paternalism to partnership: Changing relationships in health and health services*. Policy Futures for UK Health Technical Series No 10 Public Expectations  
<http://www.health.jbs.cam.ac.uk/research/cuhresearch/downloads/reports/expectations.pdf> (accessed 03/05/14)
- Bauman, Z. (1992) *Intimations of Postmodernity*. London: Routledge
- Baggott, R., Allsop, J. and Jones, K. (2005) *Speaking for Patients and Carers: Health consumer groups and the policy process*. Basingstoke: Palgrave Macmillan.
- BBC News (1999a) Bristol heart probe sets out inquiry terms.  
[http://news.bbc.co.uk/1/hi/health/background\\_briefings/the\\_bristol\\_heart\\_babies/257853.stm](http://news.bbc.co.uk/1/hi/health/background_briefings/the_bristol_heart_babies/257853.stm) (accessed 03/05/14)
- BBC News (1999b) Tabloids slammed over missing children's hearts.  
<http://news.bbc.co.uk/1/hi/health/277676.stm> (accessed 03/05/14)
- BBC News (1999c) Government protects NHS whistleblowers.  
<http://news.bbc.co.uk/1/hi/health/434789.stm> (accessed 03/05/14)
- BBC News (2011a) Everyone 'to be research patient', says David Cameron.  
<http://www.bbc.co.uk/news/uk-16026827> (accessed 03/05/14)
- BBC News (2011b) Four arrests after patient abuse caught on film.  
<http://www.bbc.co.uk/news/uk-13548222> (accessed 03/05/14)
- BBC News (2013) Tamiflu drug bill 'shocking waste of taxpayers' money'.  
<http://www.bbc.co.uk/news/health-22608671> (accessed 03/05/14)
- BBC On This Day (1991) Citizen's charter promises better services.  
[http://news.bbc.co.uk/onthisday/hi/dates/stories/july/22/newsid\\_2516000/2516139.stm](http://news.bbc.co.uk/onthisday/hi/dates/stories/july/22/newsid_2516000/2516139.stm)  
 (accesses 03/05/14)
- Beck, U. (1992) *Risk Society: Towards a new Modernity*. London: Sage
- Beck, U. (2006) *Living in the world risk society: A Hobhouse Memorial Public Lecture given on Wednesday 15 February 2006 at the London School of Economics*. *Economy and Society*. 35:3, August 2006, pp 329-345
- Beresford, P. and Branfield, F. (2012) *Building solidarity, ensuring diversity: lessons from service users' and disabled people's movements*. in Barnes and Cotterell (eds) *Critical perspectives on user involvement*. Bristol: The Policy Press. Kindle Edition. (accessed 03/05/14)

- Boote J, Telford R, Cooper C (2002) Consumer involvement in health research: a review and research agenda. *Health Policy* 61:2, pp213-236.
- Borges, J. L. [1942] (1999) *The Analytical Language of John Wilkins*. Vázquez (trans) Solem, Davidsen and Andersen(eds).  
<http://www.alamut.com/subj/artiface/language/johnWilkins.html> (accessed 03/05/14)
- Bourdieu, P. (1986) The forms of capital. in J. Richardson (ed.) *Handbook of Theory and Research for the Sociology of Education* pp241-258. New York: Greenwood Also available at: <http://www.marxists.org/reference/subject/philosophy/works/fr/bourdieu-forms-capital.htm> (accessed 03/05/14)
- Bourdieu, P. (1990) *The Logic of Practice*. Cambridge: Polity Press.
- Bourdieu, P. (1991) *Language and Symbolic Power*. Cambridge: Polity
- Bourdieu, P. (1992) *The Practice of Reflexive Sociology (The Paris Workshop)*. in Bourdieu and Wacquant. *An Invitation to Reflexive Sociology*. Cambridge: Polity Press
- Bourdieu, P. (1999) *The Weight of the World: Social Suffering in Contemporary Society*. Cambridge: Polity
- Braslow, J. (1999) Therapeutic effectiveness and social context: the case of lobotomy in a California state hospital, 1947-1954. *Western Journal of Medicine*. 170:5, pp293–296.
- Brett, J. Staniszevska, S. Mockford, C. Seers, K. Herron-Marx, S. and Bayliss, H. (2010) *The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research*. UKCRC <http://www.ukcrc.org/wp-content/uploads/2014/03/Piricom+Review+Final+2010.pdf> (accessed 03/05/14)
- Brinckman, D. (2000). The regulation of rBST: the European case. *AgBioForum*, 3(2&3), 164-172. <http://www.agbioforum.org> (accessed 15/08/14)
- Bristol Royal Infirmary Inquiry (undated) *The Inquiry into the management of care of children receiving complex heart surgery at The Bristol Royal Infirmary, Interim Report*. Annex A.  
[http://webarchive.nationalarchives.gov.uk/20090811143745/http://www.bristol-inquiry.org.uk/interim\\_report/pdf/annexa.pdf](http://webarchive.nationalarchives.gov.uk/20090811143745/http://www.bristol-inquiry.org.uk/interim_report/pdf/annexa.pdf) (accessed 03/05/14)
- Bury, M. (1982), Chronic illness as biographical disruption. *Sociology of Health & Illness*. 4. pp167–182.

Burrell, S. and Gill, G. (2005) The Liverpool Cholera Epidemic of 1832 and Anatomical Dissection—Medical Mistrust and Civil Unrest. *Journal of the History of Medicine and Allied Sciences*. 60:4, pp478-498.

Burrell, W. G., and G. Morgan (1979) *Sociological paradigms and organizational analysis*. London: Heinemann.

Bunyan, N. (2001) Alder Hey sold tissue from live children. *The Telegraph*  
<http://www.telegraph.co.uk/news/uknews/1319600/Alder-Hey-sold-tissue-from-live-children.html> (accessed 03/05/14)

Cameron, D. (2011) Transcript of Speech on Big Society delivered on Monday 14th February. 2011 <https://www.gov.uk/government/speeches/pms-speech-on-big-society> (accessed 03/05/14)

The Campaign For Safer Medicine (2013) Big Pharma Taken To Task About Their Underhand Tactics. September 17, 2013  
<http://www.campaignforsafermedicine.com/big-pharma-taken-to-task-about-their-underhand-tactics/> (accessed 03/05/14)

Cartwright, J. Crowe, S (2011) *Patient and Public Involvement Toolkit*, Chichester: Wiley-Blackwell

Champagne, P. (1999a) A View from the Media. in Bourdieu et al: *The Weight of the World*. Cambridge: Polity

Champagne, P. (1999b) A View from the State. in Bourdieu et al: *The Weight of the World*. Cambridge: Polity

Charlton, J. (2000) *Nothing About Us Without Us*, Berkeley and Los Angeles: University of California Press

Charmaz, K. (1997) *Good Days Bad Days*. New Brunswick NJ: Rutgers University Press.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage

Charmaz, K. (2012) BSA MedSoc 2012 - Professor Kathy Charmaz presents 'The Power and Potential of Grounded Theory'.  
<http://www.youtube.com/watch?v=zY1h3387txo> (accessed 03/05/14)

Chomsky, N. (2013) in Žižek vs Chomsky: Is a pointless spat becoming a meaningful debate? By *Sociological Imagination* July 28, 2013  
[http://sociologicalimagination.org/archives/13725?utm\\_content=buffer4d51e&utm\\_sour](http://sociologicalimagination.org/archives/13725?utm_content=buffer4d51e&utm_sour)



ce=buffer&utm\_medium=twitter&utm\_campaign=Buffer#sthash.zuhEBVVV.dpuf  
(accessed 03/05/14)

CMS Cameron McKenna (1999) The Bristol Inquiry; Removal, Retention and Use of Human Tissue Following Post Mortem Examination(INQ0023). available at National Archive: pp1-20

[http://webarchive.nationalarchives.gov.uk/20090811143746/http://www.bristol-inquiry.org.uk/images/inq/0023/INQ0023%20\(0001-0020\).pdf](http://webarchive.nationalarchives.gov.uk/20090811143746/http://www.bristol-inquiry.org.uk/images/inq/0023/INQ0023%20(0001-0020).pdf) (accessed 07/05/14)  
pp21-40 [http://webarchive.nationalarchives.gov.uk/20090811143746/http://www.bristol-inquiry.org.uk/images/inq/0023/INQ0023%20\(0021-0040\).pdf](http://webarchive.nationalarchives.gov.uk/20090811143746/http://www.bristol-inquiry.org.uk/images/inq/0023/INQ0023%20(0021-0040).pdf) (accessed 07/05/14)

Collins, H.M. and Evans R. (2002) The Third Wave of Science Studies: Studies of Expertise and Experience Social Studies of Science 2002. 32, pp235-296

Colombo, C. Mosconi, P. Villani, W. Garattini, S. (2012) Patient Organizations' Funding from Pharmaceutical Companies: Is Disclosure Clear, Complete and Accessible to the Public? An Italian Survey. Plos One. May 09, 2012

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0034974>  
(accessed 03/05/14)

Comte, A. [1825] (1998) Plan of Scientific Work Necessary for a Reorganization of Society. in Jones (ed) Comte: Early Political Writings. Cambridge: Cambridge University Press

Conrad, P. and Angell, A. (2004) Homosexuality and remedicalization. Society. 41:5, pp32-39

Constant, B. [1819] (1988) The Liberty of the Ancients Compared with that of the Moderns. in Fontan (ed) Political Writings. Cambridge: Cambridge University Press

Cooley, Charles Horton [1902] (2007). Human nature and the social order. [ebook]. The internet archive <https://archive.org/details/humannaturesocia00cooluoft> (accessed 03/05/14)

Cooper, L. (1995) Voices Off: Tackling the Democratic Deficit in Health. London: IPPR

Cutting, J. (2002) The In-Group Code Lexis. Hermes, Journal of Linguistics. 28-2002 pp59-80

Davies, R. (2012) Becoming Them. presentation at the 2012 INVOLVE conference. See Becoming 'them' and remaining 'us' ... or the road to ruin? Davies and Maguire <http://www.invo.org.uk/becoming-them-and-remaining-us-or-the-road-to-ruin/>

Deagle, J. (2001) Administering antibiotic therapy at home, *Nursing Times*. 97:38, p62  
<http://www.nursingtimes.net/administering-antibiotic-therapy-at-home/200737.article>  
(accessed 03/05/14)

Denegri, S. (2013) Leadership, and a strategy transplant from NHSBT would do the patient data debate no harm. Simon Denegri's Lay Review: The public and health research <http://simondenegri.com/2013/07/11/leadership-and-a-strategy-transplant-from-nhsbt-would-do-the-patient-data-debate-no-harm/> (accessed 03/05/14)

Denhardt, J. V. Denhardt R. B. (2011) *New Public Service, Serving not Steering*, New York: M. E. Sharp

Department for Business, Innovation and Skills (2011) *Investing in UK Health and Life Sciences*, London: HMSO  
[http://webarchive.nationalarchives.gov.uk/20130109092234/http://www.number10.gov.uk/wp-content/uploads/2011/12/8971-BIS-Life-Sciences-Prospectus-BMK\\_Spreads.pdf](http://webarchive.nationalarchives.gov.uk/20130109092234/http://www.number10.gov.uk/wp-content/uploads/2011/12/8971-BIS-Life-Sciences-Prospectus-BMK_Spreads.pdf)  
(accessed 03/05/14)

Department of Health (1992) *The Patient's Charter. Raising the Standard*. London: HMSO

Department of Health (1999) *Saving Lives: Our Healthier Nation*. London: HMSO

Department of Health (2001) *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*. London: HMSO

Department of Health (2010) *Equity and excellence: Liberating the NHS*. London: HMSO  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213823/dh\\_117794.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf) (accessed 03/05/14)

Derrida, J. (1976) *Of Grammatology*. Baltimore: Johns Hopkins University Press

Dewey, J. [1916] (2012). *Democracy and Education*. [ebook] Start Publishing LLC. Start Publishing Ebook Edition. (accessed 03/05/14)

Doyal, L. (1991) *The Political Economy of Health*. London: Pluto

Dunk-West, P. and Verity F. (2013) *Sociological Social Work*. Farnham and Burlington: Ashgate

Durie, R. and Wyatt, K. (2007) New communities, new relations: The impact of community organization on health outcomes. *Social Science & Medicine*. 65:9, November 2007, pp1928–1941

- Durkheim, E. [1895] (1982) *The Rules of the Sociological Method*. in Lukes (ed) *The Rules of the Sociological Method and Selected Texts on Sociology and its Method*. London and Basingstoke: Macmillan
- Durkheim, E [1915] (1976) *The Elementary Forms of the Religious Life*. Old Woking: George Allen and Unwin
- Durkheim, E. [1903] (1982) *Sociology and the Social Sciences*. in Lukes (ed) *The Rules of the Sociological Method and Selected Texts on Sociology and its Method*. London and Basingstoke: Macmillan
- Dwyer, P. (2002) Making sense of social citizenship: Some user views on welfare rights and responsibilities. *Critical Social Policy*. 22:2, pp273-29
- Easton, P.M. Marwick, C.A. Williams, F.L.R. Stringer, K (2009 ) A survey on public knowledge and perceptions of methicillin-resistant *Staphylococcus aureus*. *Journal of Antimicrobial Chemotherapy*. 63:1, pp209-214
- Ehrenreich, B. and English D. (2005) *For Her Own Good: Two Centuries of the Experts' Advice to Women*. New York: Anchor Books
- Elliott, E. and Williams, G. (2008) Developing public sociology through health impact assessment. *Sociology of Health & Illness*. 30:7, p1101-16
- Elston, M. A. (1991) *The Politics of Professional Power: Medicine in a Changing Health Service*. in Gabe Calnan and Bury (eds) *The Sociology of the Health Service*. London and New York: Routledge
- Epstein, S. (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkley and Los Angeles: University of California press
- Faulkner, A. (2004) *The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Bristol: The Policy Press
- Finucane, M. L. (2002) Mad cows, mad corn and mad communities: the role of socio-cultural factors in the perceived risk of genetically-modified food. *Proceedings of the Nutrition Society*. 61:01 pp 31-37
- Fraser, N. (1995) From Redistribution to Recognition? Dilemmas of Justice in a 'Post-Socialist' Age. *New Left Review*. 212, pp68-93.
- Fraser, N. (1990) Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy. *Social Text* 25:26, pp56–80,

- Fraser, N. (2000) Rethinking Recognition. *New Left Review*. 3 May-Jun 2000, pp107-120 <http://newleftreview.org/II/3/nancy-fraser-rethinking-recognition> (accessed 03/05/14)
- Frazer, E. (2000) Citizenship and Culture; in Dunleavy. In Gamble, Holiday, and Peele (eds) *Developments in British Politics 6*, Basingstoke: Macmillan Press
- Freidson, E [1970] (1988) *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. Chicago: University of Chicago Press
- Foucault, M. [1971] (1981) *The Order of Discourse*. in Young, R. (ed) *Untying the Text a Poststructuralist Reader* (pp 48-78). Boston Mass: Routledge and Kegan Paul
- Foucault, M. (1982) *The Subject and Power*. *Critical Inquiry*. 8: 4 Summer 1982, pp777-795
- Foucault, M. [1975] (1995) *Discipline and Punish: The Birth of the Prison*. New York: Random House
- Foucault, M [1976] (1998) *The History of Sexuality I: The Will to Knowledge*. London: Penguin
- Foucault, M. [1973] (2003). *The Birth of the Clinic*. Abingdon: Routledge Classics
- Foucault, M. [1970] (2007). *The Order of Things: An Archaeology of the Human Sciences* [ebook] London: Taylor & Francis. Kindle Edition. (accessed 03/05/14)
- Gibson, A., Britten, N., Lynch, J. (2012). Theoretical directions for an emancipatory concept of patient and public involvement. *Health*. (london), 16:5 pp531-547
- Giddens, A. (1986) *The Constitution of Society: Outline of the Theory of Structuration*. Cambridge: Polity
- Giddens, A. [1991] (2013) *Modernity and Self-Identity: Self and Society in the Late Modern Age* [ebook] Cambridge: Polity. Kindle Edition. (accessed 03/05/14)
- Gilligan, C. [1987] (1995) *Moral Orientation and Moral Development*; in Held, V (ed) *Justice and Care: Essential Readings in Feminist Ethics* Boulder Co. Westview press <http://www.scribd.com/doc/16034158/Justice-and-Care-by-Carol-Gilligan> (accessed 03/05/14)
- Glaser, B. (1978) *Theoretical Sensitivity*. Mill Valley CA: Sociology Press
- Glaser, B.G. and Straus A. L. (2012) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. (seventh paperback edition) Piscataway NJ: Transaction Publishers

- Glendinning, C. Challis, D. Fernández, J. Jacobs, S. Jones, K. Knapp, M. Manthorpe, J. Moran, N. Netten, A. Stevens, M. Wilberforce, M.(2008) Evaluation of the Individual Budgets Pilot Programme Final Report. York: Social Policy Research Unit
- Greene, L (1994) Mythic Astrology. London: Simon & Schuster
- GMC (2009) GMC establishes Reference Community. Press release 4<sup>th</sup> September <http://www.gmc-uk.org/news/3267.asp> (accessed 03/05/14)
- GMC (2012) The state of medical education and practice in the UK. London: General Medical Council
- Goffman, E. (1961), Asylums: Essays on the social situation of mental patients and other inmates. Garden City NY: Anchor Books, Doubleday & Co.
- Goldacre, B. (2009) Bad Science. London: Fourth Estate
- Goldsmith P. (2008). Citizenship: Our Common Bond. London: HMSO
- Gosling, J. (2010) The Ethos of Involvement as the Route to Recovery. in Weinstein (ed) Mental Health, Service User Involvement and Recovery [ebook] London and Philadelphia: Jessica Kingsley Publishers. Kindle Edition (accessed 03/05/14)
- Green, D. G. (1985) Working Class Patients and the Medical Establishment, Aldershot: Gower/Maurice Temple Smith
- Habermas, J. Lennox, S. and Lennox, F. (1974) The Public Sphere: An Encyclopedia Article (1964). New German Critique. 3, Autumn, 1974, pp49-55.
- Habermas, J. (1985) The Theory of Communicative Action: volume 2, Lifeworld and System: a critique of functionalist reason. 3<sup>rd</sup> corrected edition. McCarthy (trans) Boston Mass: Beacon Press
- Habermas J (1992) The Structural Transformation of the Public Sphere. Cambridge: Polity
- Habermas J (1998) On the Pragmatics of Communication. Cambridge MA: MIT Press.
- Hansard (1994) <http://hansard.millbanksystems.com/commons/1994/feb/11/beverly-allitt-report> (accessed 03/05/14)
- Harrison, S. and Mort, M (1998) Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation Social Policy and Administration. 32:1, pp60-70
- Haskell, T.L. (1981) Are Professionals Professional? Journal of Social History. 14:3, pp.485-493

- Heaney, S. [1999] (2009). *Beowulf: A New Translation* [ebook] London: Faber & Faber. Kindle Edition. (accessed 03/05/14)
- Hegel, G. W. F. [1820] (1991) *Elements of the Philosophy of Right*. Wood (ed) Cambridge: Cambridge University Press
- Helman, C. G. (2000) *Culture Health and Illness* (fourth edition) Oxford: Butterworth Heinemann
- Henwood, K. and Pidgeon, N. (2003) *Grounded Theory in Psychological Research*. in *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design*, edited by P.M. Camic, J.E. Rhodes and L. Yardley. Washington, DC: American Psychological Association, pp131-155
- Herxheimer, A. (2003) Relationships between the pharmaceutical industry and patients' organisations. *BMJ* (online) 06/2003; 326(7400):1208-10.  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1126060/> (accessed 03/05/14)
- Hess, M [1843] (1997) *The recent Philosophers*. In Lawrence S. Stepelevich (ed) *The Young Hegelians: An Anthology*. [ebook] New Jersey: Humanities Press. Kindle Edition. (accessed 03/05/14)
- Hibbert, C. [1998] (2010). *Wellington: A Personal History*. [ebook] London: Harper Collins Publishers. Kindle Edition. (accessed 03/05/14)
- Hince T. A. and McVie J. G. (1991) *Obituary: Professor T. J. McElwain*. *Annals of Oncology* 1:80
- HM Government (2007) *Trust Assurance and Safety: The Regulation of Health Professions in the 21st Century*. London: Crown
- HM Government (2011) *Government response to the Communities and Local Government Select Committee's Report: Localism*. London: Crown  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/6277/1993667.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6277/1993667.pdf) (accessed 03/05/14)
- HM Government (2012) *Caring for our future: reforming care and support*. London: Crown
- Hobbes, T. [1651] (1996) *Leviathan*. Cambridge, Cambridge University Press
- Holman, H. Lorig, K. (2000) *BMJ*. Patients as partners in managing chronic disease: Partnership is a prerequisite for effective and efficient health care. *British Medical Journal*. 320:7234, February 26, pp526–527.
- Hosking, P. (2013) £800m pensions black hole could scupper Premier rights issue. *The Times* December 23 2013,

<http://www.thetimes.co.uk/tto/business/industries/consumer/article3957014.ece>  
(accessed 03/05/14)

House of Commons (1828) Report from the Select Committee on Anatomy. [ebook]  
London: House of Commons Available on:

<https://archive.org/details/reportfromselect00grea> (accessed 03/05/14)

Hughes, B. McKie, L. Hopkins, D. and Watson, N. (2005) Love's Labours Lost?  
Feminism, the Disabled People's Movement and an Ethic of Care. *Sociology*. 39:2  
pp259-275

Hunt, L. (1993) News of death greatly exaggerated: The report on the Bristol Cancer  
Help Centre was damning, it was also highly inaccurate. *The Independent*, Monday 15  
November 1993. <http://www.independent.co.uk/life-style/news-of-death-greatly-exaggerated-the-report-on-the-bristol-cancer-help-centre-was-damning-it-was-also-highly-inaccurate-these-expatrients-want-the-world-to-be-told-and-they-are-tired-of-waiting-liz-hunt-reports-1504475.html> (accessed 03/05/14)

Hurren, E. T. (2002) Patients' rights: from Alder Hey to the Nuremberg Code History  
and Policy <http://www.historyandpolicy.org/papers/policy-paper-03.html> (accessed  
03/05/14)

Illich, I (2002) *Limits to Medicine medical nemesis: The expropriation of Health*. London  
and New York: Marion Boyars

Ipsos MORI (2013) Trust Poll [http://www.ipsos-mori.com/Assets/Docs/Polls/Feb2013\\_Trust\\_Topline.PDF](http://www.ipsos-mori.com/Assets/Docs/Polls/Feb2013_Trust_Topline.PDF) (accessed 03/05/14)

Irigaray, L (1985) *The Speculum of the Other Woman*. New York: Cornell University  
Press.

Ives, J. Damery, S. Redwood, S. (2012) PPI, paradoxes and Plato: who's sailing the  
ship? *Journal of Medical Ethics*. 39:3, pp181-185

James, W. [1890] (2007). *The Principles of Psychology, Vol.1*. New York: Cosimo  
Classics. Kindle Edition. (accessed 03/05/14)

Jasanoff, S. (2000) *Designs on Nature: Science and Democracy in Europe and the  
United States*. Princeton NJ: Princeton University Press

Jonson, A. R. (2000) *A Short History of Medical Ethics*. Oxford and New York: Oxford  
University Press

Jung, C. (1964) *Approaching the Unconscious*. Jung and von Franz (eds) In *Man and  
His Symbols* pp18-103. New York: Anchor.

- Kafka, F. [1915] (2012) *The Metamorphosis*. In Appelbaum (trans) *The Metamorphosis and Other Stories*. [ebook] Dover Thrift Editions. New York: Dover Publications. Kindle Edition. (accessed 03/05/14)
- Kant, I. [1785] (2005) *Groundwork of the Metaphysics of Morals*. In Bennett (trans) <http://www.earlymoderntexts.com/pdfs/kant1785.pdf> (accessed 03/05/14)
- Kemp P. (2010) *Introduction to Mental Health, Service User Involvement*. in Weinstein, J. *Mental Health, Service User Involvement and Recovery*. [ebook] London and Philadelphia: Jessica Kingsley Publishers. Kindle Edition (accessed 03/05/14)
- Kennedy, A. Gately, C. Rogers, A. (2004) *National Evaluation of Expert Patients Programme: Assessing the Process of Embedding EPP in the NHS, Preliminary Survey of PCT Pilot Sites*. National Primary Care Research and Development Centre <http://www.population-health.manchester.ac.uk/primarycare/npcrdc-archive/Publications/EPP%20Report%202004.pdf> (accessed 03/05/14)
- Kennedy, I (2001) *The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995 Learning from Bristol*. Norwich: The Stationary Office Ltd  
[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.bristol-inquiry.org.uk/final\\_report/the\\_report.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.bristol-inquiry.org.uk/final_report/the_report.pdf) (accessed 03/05/14)
- Kierkegaard, S. ([1843] 2003) *Fear and Trembling*. London: Penguin
- Kittay, E. F. Schriempf, A. Silvers, A. Wendell, S. (2001) *Introduction Hypatia*. 16:4, Fall 2001, Published by Indiana University Press, ppvii-xii
- Kittay E. F. (2001) *A Feminist Public Ethic of Care Meets the New Communitarian Family Policy*; *Ethics*. 111, 3, April 2001, pp 523-547 Published by: The University of Chicago Press Stable URL: <http://www.jstor.org/stable/10.1086/233525> (accessed 03/05/14)
- Kittay E. F. (2005) *At the Margins of Moral Personhood*. *Ethics*. 116, October 2005, pp100–131
- Kittay E. F. Jennings, B. Wasunna A.A. (2005) *Dependency, Difference and the Global Ethic of Longterm Care*, *The Journal of Political Philosophy*. 13: 4, pp443–469
- Krieger, J. Takaro, T. Allen, C. Song, L. Weaver, M. Chai, S. & Dickey, P. (2002) *The Seattle-King County healthy homes project: Implementation of a comprehensive approach to improving indoor environmental quality for low-income children with asthma*. *Environmental Health Perspectives*. 110:2, pp311-322



The Lancet (1831a) Destruction of a Theatre of Anatomy. 31st December 1831. pp478-485 in The Lancet, Volume 1 [ebook] London: Mills Jowett and Mills

<http://books.google.co.uk/books?id=-7A1AQAAMAAJ&pg=PR8&dq=The+Lancet,+MDCCCXXXI&hl=en&sa=X&ei=We5kU97cF43VPJvvqOAO&ved=0CDgQ6AEwAQ#v=onepage&q&f=false> (accessed 03/05/14)

The Lancet (1831b) The Murders by Bishop and Williams, 10th December 1831. pp373-376 in The Lancet, Volume 1 [ebook] London: Mills Jowett and Mills

<http://books.google.co.uk/books?id=-7A1AQAAMAAJ&pg=PR8&dq=The+Lancet,+MDCCCXXXI&hl=en&sa=X&ei=We5kU97cF43VPJvvqOAO&ved=0CDgQ6AEwAQ#v=onepage&q&f=false> (accessed 03/05/14)

Lather, P. (1991) Getting Smart: Feminist Research and Pedagogy with/in the Postmodern. New York and London: Routledge

Lawrence. C. (2002) Alder Hey The taken for granted and professional practice. Journal of Epidemiology and Community Health. 56:1

<http://jech.bmj.com/content/56/1/4.full> (accessed 03/05/14)

Lévi-Strauss, C (2009) Le triangle culinaire. Le Noinel Observateur Hors-Série, Noveivibre-Déceivibre, pp14-17

Lévy, P. (1999) Collective Intelligenc: Mankind's Emerging World in Cyberspace. trans Bononno, R. Cambridge Mas: Perseus Books

Liddell, H. D. and Scott, R. (1940) A Greek-English Lexicon. (ninth edition) Oxford: ClarendonPress

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J. and Morgan, K. (2002) 'The public is too subjective': public involvement at different levels of health-care decision making, Social Science and Medicine. 54:12, pp1825–37.

Locke, J [1689] (1823) Two Treatises of Government. [ebook] London. Thomas Tegg; W. Sharpe and Son. Available from:

<http://www.efm.bris.ac.uk/het/locke/government.pdf> (accessed 03/05/14)

Lorig, K. R. Sobel, D. S. Ritter, P.L. Hobbs, M. (2001) Effect of a Self-Management Program on Patients with Chronic Disease. Effective Clinical Practice. 4:6 November/December 2001 pp256-262

Lupton, C. Buckland, S. amd Moon, G. (1995) Consumer Involvement in Health Care Purchasing: the role and influence of the community health councils. Health and Social Care in the Community. 3:4 pp215-216.

- Lyotard, J-F. (1984) *The Postmodern Condition: A Report on Knowledge*. Manchester: Manchester University Press
- Maguire, K. and Truscott, F. (2006), *Active Governance: The Value Added by Community Involvement in Governance through Local Strategic Partnerships*, York: Joseph Rowntree Foundation
- Maguire, K. (unpublished) *From Civic Duty to Active Citizenship: what are community empowerment and citizen engagement for?* University of Exeter
- Mandel, E. (1968) *Marxist Economic Theory*. London: Merlin
- Martin, G.P. (2008) "Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health & Illness*. 30:1 pp35-54
- Mauss, M [1925] (1966) *The Gift: forms and functions of exchange in archaic societies*. Cunnison (trans). London: Cohen & West
- McAllister, J. W. (2001) *Relativism*. In Newton-Smith (ed) *A Companion to the Philosophy of Science*. Oxford: Blackwell
- McLaren, A. (1999) *Twentieth Century Sexuality: a history*. Oxford: Blackwell
- Marx, K. [1844] (1994) *From the Paris Notebooks: Self Estrangement*. in Marx *Early Political Writings*. O'Malley (ed) Cambridge: Cambridge University Press
- Marx, K [1858] (1996) *Introduction to the Gründrisse*. in Marx *Later Political Writings*. Carver (ed) Cambridge: Cambridge University Press
- Merton, R. K. (2001) *Science, Technology and Society in Seventeenth-Century England*. New York, Howard Fertig
- Mihill, C. (1990a) 'Doubled risk' at cancer unit. *The Guardian*, Sep 6 1990, p 1
- Mihill, C. (1990b) Cancer help study team admits errors. *The Guardian*, Nov 9 1990, p2
- Mihill, C. (1990c) Strain led to suicide of cancer expert. *The Guardian*, Dec 13 1990, p5
- Miller, G. (1997) *Building bridges: the possibility of analytic dialogue between ethnography, conversation analysis and Foucault*. in Silverman (ed.) *Qualitative research—theory, method and practice*. pp.24-44. London: Sage
- Mills, C. Wright [1959] (2000). *The Sociological Imagination*. Oxford and New York: Oxford University Press. Kindle Edition (accessed 03/05/14)
- Ministry of Health and Department of Health for Scotland (1944) *A National Health Service*. London: His Majesty's Stationary Office Available on <http://www.sochealth.co.uk/national-health-service/the-sma-and-the-foundation-of-the->

[national-health-service-dr-leslie-hilliard-1980/a-national-health-service/](#) (accessed 03/05/14)

Morris (undated) Removing the barriers to community participation: A report by the National Community Forum Commissioned by the Neighbourhood Renewal Unit

[http://www.centreforcities.org/assets/files/pdfs/Removing\\_the\\_barriers\\_to\\_Community\\_Participation.pdf](http://www.centreforcities.org/assets/files/pdfs/Removing_the_barriers_to_Community_Participation.pdf) (accessed 03/05/14)

Morrow, E. Boraz, A. Brearley, S. Ross, F. (2012) The Handbook of Service User Involvement in Nursing and Healthcare Research. Chichester: Wiley-Blackwell

Moynihan, R. Heath, I. and Henry, D. (2002) Selling sickness: the pharmaceutical industry and disease mongering. BMJ. 324:7342, April 13, pp886–891.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1122833/>

Mulgan, G. and Bury, F. (2006) double devolution: the renewal of local government.

London, the Smith Institute <http://www.smith-institute.org.uk/file/DoubleDevolution.pdf>

(accessed 03/05/14)

National Archives a. (undated) The Cabinet Papers 1914-1984: Policy and inauguration. The National Health Service Bill.

<http://www.nationalarchives.gov.uk/cabinetpapers/themes/national-health-service.htm>

(accessed 03/05/14)

National Archives b. (2002) The Shipman Inquiry

<http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/firstreport.asp> (accessed 03/05/14)

NHS Choices (2013) Advantages and disadvantages of the different types of dialysis.

<http://www.nhs.uk/Conditions/Dialysis/Pages/Advantages-and-disadvantages.aspx>

(accessed 03/05/14)

NHS Executive (1996) Patient Partnership: Building a collaborative strategy, Leeds: Department of Health.

NHS Management Executive (1992) Local Voices: The views of local people in purchasing for health London: NHS Management Executive

NICE (2008) Quick Reference Guide: Community Engagement

<http://www.nice.org.uk/nicemedia/live/11929/39565/39565.pdf> (accessed 03/05/14)

Nisbet, M. C. and Myers, T (2007) Twenty Years of Public Opinion about Global Warming. Public Opinion Quarterly Volume 71:3, pp444-470.

Nietzsche, F. [1881] (1994) Daybreak. in On the Genealogy of Morality. Ansell-Pearson (ed) Cambridge: Cambridge University Press

- Nietzsche, F. [1887] (1994) *On the Genealogy of Morality*. Ansell-Pearson (ed) Cambridge: Cambridge University Press
- Oliver, M. (1983) *Social Work with Disabled People*, Basingstoke; Macmillan
- Oliver, M (1992) Changing the Social Relations of Research Production, *Disability Handicap and Society*, 7:2, pp101-115
- Oliver, S., Rees, R., Clarke-Jones, L., Milne, R., Oakley, A., Gabbay, J., Stein, K., Buchanan, P. and Gyte, G. (2008) A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations*, 11:1, pp72-84.
- Parliament (1946) *National Health Service Act*. London: HMSO. Available from <http://old.post-gazette.com/pg/10119/1054305-114.stm> (accessed 03/05/14)
- Papagianni, K. (2008) Participation and State Legitimation. in *Building States to Build Peace*. Call and Wyeth (eds) Colorado: Lynne Reinner Publishers
- Parsons, T. (1951), *Illness and the Role of the Physician: A Sociological Perspective*. *American Journal of Orthopsychiatry*. 2, pp452–460
- Parsons, T. (1975) *The Sick Role and the Role of the Physician Reconsidered*. *The Milbank Memorial Fund Quarterly*. Health and Society. 53:3, pp257-278
- Phillips, A. (1995) *The Politics of Presence*. Oxford: Oxford University Press
- Phillips, A. Rakusen, J. (1978) *Our Bodies Ourselves*, Harmondsworth: Penguin
- Pitkin, H. F. (1972) *The Concept of Representation*. Berkley, Los Angeles and London: University of California Press
- Plato [c380BC] (1955) *The Republic*. Harmondsworth: Penguin
- Popay, J. Williams G. (1996) Public health research and lay knowledge. *Social Science & Medicine*. 42: 5, pp759–768
- Popay, J., Williams, G., Thomas, C. and Gatrell, T. (1998), *Theorising Inequalities in Health: The Place of Lay Knowledge*. *Sociology of Health & Illness*. 20, pp619–644
- Porter, M. and Porter, R, (1993) *Doctors, Politics and Society: Historical Essays*. Amsterdam-Atlanta Ga: Editions Rodopi B, A
- Pratchett, L and Wingfield, M. (1996) *The demise of the Public Service Ethos*. in Pratchett and Wilson (eds) *Local Democracy and Local Government*, Basingstoke: Macmillan
- Prior, L. (2003) Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health & Illness*. 25:3, pp41–57

- Propper, C. Burgess, S. Abraham, D. (2002) *Competition and Quality: Evidence from the NHS Internal Market 1991-1999*. Bristol, University of Bristol, <http://www.bristol.ac.uk/cmppo/events/2002/health-care/propper.pdf> (accessed 03/05/14)
- Purtell, R. Gibson, A. (2012) *How to Make Health and Social Care Research Really Really Useful*. in Lloyd and Heller (eds) *Long Term Conditions, Challenges in Health and Social Care*. London: Sage
- Rabe, B. G. and Borick, C. P. (2011) *Fracking for Natural Gas: Public Opinion on State Policy Options*. Center for Local, State, and Urban Policy (CLOSUP), 'Survey Report: Fracking'. <http://ssrn.com/abstract=2313288>
- Ramesh, R. (2012) *Formal complaints about National Health Service rise by 8%*. The Guardian <http://www.guardian.co.uk/society/2012/aug/29/nhs-formal-complaints-rise-health> (accessed 03/05/14)
- Rawls, J. [1971] (1999) *A Theory of Justice*, Revised edition. Oxford; Oxford University Press
- Redfern, M. (2001) *The Royal Liverpool Children's Inquiry*. London: House of Commons
- Richardson, R. (1989) *Death, Dissection and Destitution*. London: Penguin
- Roberts, W. (1843) *Mr Warburton's Anatomy Bill: Thoughts on its Mischievous Tendencies, With Suggestions for an Entirely New One, Founded Upon an Available Anti-Septic Process*. [ebook] London: J Olliver <https://archive.org/details/mrwarburtonsanat00robe> (accessed 03/05/14)
- Rogers, A. Bower, P. Gardner, C. Gately, C. Kennedy, A. Lee, V. Middleton, E. Reeves, D. Richardson, G. (2006) *The National Evaluation of the Pilot Phase of the Expert Patients Programme Final Report*, Manchester: National Primary Care Research & Development Centre <http://www.population-health.manchester.ac.uk/primarycare/npcrdc-archive/Publications/EPP%20FINAL%20REPORT%202007.pdf> (accessed 03/05/14)
- Ross, L. (1977) *The intuitive psychologist and his shortcomings: Distortions in the attribution process*. in Berkowitz, L. *Advances in experimental social psychology*. 10, pp173–220
- Rousseau, J-J. [1762] (2008) *Du contrat social ou Principes du droit politique*. Edited by Sálvio M. Soares. MetaLibri, v1.0p [http://www.ibiblio.org/ml/libri/r/RousseauJJ\\_ContratSocial\\_p.pdf](http://www.ibiblio.org/ml/libri/r/RousseauJJ_ContratSocial_p.pdf) (accessed 03/05/14)

- Runciman, D. (2007) The Paradox of Political Representation. *The Journal of Political Philosophy*. 15:1, pp93–114
- Sage, D. (2013) The big society: Rediscovery of 'the social' or rhetorical fig-leaf for neo-liberalism? *Critical Social Policy*. 33, August 1, pp451-472
- Sample, I (2013) Big pharma mobilising patients in battle over drugs trials data: Leaked memo from industry bodies reveals strategy to combat calls by regulators to force companies to publish results. *The Guardian*, Sunday 21 July 2013  
<http://www.theguardian.com/business/2013/jul/21/big-pharma-secret-drugs-trials>  
 (accessed 03/05/14)
- Sartre, J-P. (1989a) *Existentialism and Humanism*. Mairet (trans) London: Methuen
- Sartre, J-P. (1989b) *No Exit, and Three Other Plays*. New York: Vintage International
- Seale, C. Cavers, D. and Dixon-Woods, M. (2006) Commodification of Body Parts: By Medicine or by Media? *Body & Society*. 12, March pp25-42
- Serres, M. (1995) *The Natural Contract*. Ann Arbor: University of Michigan Press
- Scambler, G. (2002) *Health and social change: A critical theory*. Buckingham and Philadelphia: Open University Press
- Scambler, G. and Scambler, S. (2010) Introduction. in Scambler and Scambler (eds) *New Directions in the Sociology of Chronic and Disabling Conditions: Assaults on the Lifeworld*. Basingstoke: Macmillan Palgrave
- Shapin, S. and Shaffer, S. (1989) *Leviathan and the Air Pump: Hobbes, Boyle and the Experimental Life*. Princeton NJ: Princeton University Press
- Shaw, J. Baker, M. (2004) "Expert patient"—dream or nightmare? *BMJ*, 328:7442, March 27; pp 723–724.
- Shelly M. (1818) *Frankenstein; or, a Modern Prometheus*. London: Lackington, Hughes, Mavor and Jones
- Sherif, M., & Sherif, C. W.. (1969) *Social Psychology*. New York: Harper and Row
- Shortt, S. E. D. (1983) Physicians, science, and status: issues in the professionalization of Anglo-American medicine in the nineteenth century. *Medical History*. 27:01, January 1983, pp51-68
- Simmel, G. [1908] (1950) *The Stranger*. in Wolff (ed.) *The Sociology Of Georg Simmel* [ebook] Glencoe, Illinois: The Free Press  
<https://archive.org/details/sociologyofgeorg030082mbp> (accessed 03/05/14)

- Smith, G. Bartlett A. and King, M. (2004) Treatments of homosexuality in Britain since the 1950s—an oral history: the experience of patients. *British Medical Journal*. 328:427, 19 February, <http://www.bmj.com/content/328/7437/427> (accessed 03/05/14)
- Smith, R. (1994) Charity Commission censures British cancer charities. In *British Medical Journal*. 308:2, 15 January 1994 <http://www.bmj.com/content/308/6922/155.2> (accessed 03/05/14)
- Snape D, Kirkham J, Preston J, Popay J, Britten N, Collins M, Froggatt K, Gibson A, Lobban F, Wyatt K, Jacoby A. (2014) Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: a modified Delphi study. *BMJ Open* 2014;4:e004217  
<http://bmjopen.bmj.com/content/4/1/e004217.full> (accessed 03/05/14)
- Sociological Imagination (2013) Žižek vs Chomsky: Is a pointless spat becoming a meaningful debate? By Sociological Imagination July 28, 2013  
<http://sociologicalimagination.org/archives/13725> (accessed 03/05/14)
- Stacey, M. (1998) *The Sociology of Health and Healing*. New York: Routledge
- Staley, K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE
- Staniszewska, S. Mockford, C. Gibson, A. Herron-Marx, S. Putz, R (2012) Moving forward: understanding the negative experiences and impacts of patient and public involvement in health service planning, development and evaluation, in Barnes and Cotterell (eds) *Critical perspectives on user involvement* [ebook] Bristol: Policy Press. Kindle Edition (accessed 03/05/14)
- Starr, P. (1982) *The Social Transformation of American Medicine*. New York: Basic Books
- Stewart, M. Brown, J. B. Donner, A. McWhinney, I.R. Oates, J. Weston, W. W. Jordan, J. (2000) The Impact of Patient-Centered Care on Outcomes. *Journal of Family Practice*. 49:9, September, pp796-804
- Strauss, A. L. (1987) *Qualitative Analysis for Social Scientists*. New York: Cambridge University Press
- Strauss, A. L. Fagerhaugh, S. Suczek, B. and Wiener, C. (1997) *Social Organization of Medical Work*. New Brunswick NJ: Transaction Publishers.
- Stroud L. (2005) MMR--public policy in crisis: whose tragedy? *Journal of Health Organisation and Management*. 19:3, pp252-60.
- Swift, J. ([1726] 2001) *Gulliver's Travels*. Penguin: London

- Szasz T. S. (1960) The Myth of Mental Illness. *American Psychologist*. 15, pp113-118
- Tajfel, H. and Turner, J. C. (1986). The social identity theory of inter-group behavior. in S. Worchel and L. W. Austin (eds.), *Psychology of Intergroup Relations*. Chigago: Nelson-Hall
- Timmermans, S. Tavory, I. (2012) Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. *Sociological Theory*. 30:3, September, pp167-186
- Torjesen, K. J. (2008) Clergy and Laiety. In Harvey and Hunter (eds) *The Oxford Handbook of Early Christian Studies*. Oxford: Oxford University Press
- Tritter J. Q. and McCallum A. (2006) The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*. 76, pp156–168
- Tritter, J.Q. (2009) Revolution or evolution: The challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*. 12, pp275–287
- Tritter, J. Q. and Koivusalo, M. (2013) Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement. *Health Expectations*. 16:2, June 2013, pp115–118
- Turner, B. S. (1992) *Regulating Bodies*. London/New York: Routledge
- Turner, B. S. (1995) *Medical Power and Social Knowledge*. London: Sage
- Turner, V.W. (1964) Betwixt and between: The Liminal Period in Rites de Passage. *The Proceedings of the American Ethnological Society* 1964 pp4-20
- Ulicsak, M. and Wright, M. (2010) *Games in Education: Serious Games*. Futurelab [http://media.futurelab.org.uk/resources/documents/lit\\_reviews/Serious-Games\\_Review.pdf](http://media.futurelab.org.uk/resources/documents/lit_reviews/Serious-Games_Review.pdf) (accessed 28/02/14)
- Ursu, I. Cowl J. (2010) Community membership of NICE groups producing public health guidance - Report of an evaluation study, NICE
- Verity, A (2013) University pensions black hole 'even worse than thought'. *BBC News* 25 October 2013 <http://www.bbc.co.uk/news/education-24657049> (accessed 03/05/14)
- Wagner, E. H. Austin, B. T. Davis, C. Hindmarsh, M. Schaefer J. and Bonomi A. (2001) Improving Chronic Illness Care: Translating Evidence into Action. *Health Affairs*. 20:6, pp64-78



- Wagner, E. H. and Groves, T. (2002) The efficacy of coordinated and patient centred care is established, but now is the time to test its effectiveness. *British Medical Journal*. 325:7370, October 26, pp913–914
- Wakefield AJ, Murch SH, Anthony A, Linnell J, Casson DM, Malik M, Berelowitz M, Dhillon AP, Thomson MA, Harvey P, Valentine A, Davies SE, Walker-Smith JA (1998) Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet*. 351:9103, pp637–41 (Retracted)
- Wakefield AJ, Anthony A, Murch SH, Thomson M, Montgomery SM, Davies S, O'Leary JJ, Berelowitz M, Walker-Smith JA (2000) Enterocolitis in children with developmental disorders. *American Journal of Gastroenterology*. 95:9, pp2285–95 (Retracted)
- Walker, D. Myrick, F. *Grounded Theory: An Exploration of Process and Procedure. Qualitative Health Research*. 16:4, April 2006 pp547-559
- Wallerstein, N, (2006) What is the evidence on effectiveness of empowerment to improve health? Copenhagen: WHO Regional Office for Europe
- Weber, M. [1922] (1964) *The Theory Of Social And Economic Organization*. New York, Free Press
- Weber, M. [1917] (1994) *Suffrage and Democracy in Germany*. in *Political Writings*. Lassman and Speirs (eds) Cambridge: Cambridge University Press
- Wegwarth, O. Schwartz, L. M. Woloshin, S. Gaissmaier, W. and Gigerenzer, G. (2012) Do Physicians Understand Cancer Screening Statistics? A National Survey of Primary Care Physicians in the United States. *Annals of Internal Medicine*. 156:5, pp340-349.
- Weinstein, J.(2010) Introduction. in Weinstein (ed) *Mental Health, Service User Involvement and Recovery*. [ebook] London and Philadelphia: Jessica Kingsley Publishers. Kindle Edition (accessed 03/05/14)
- Weinstein, J with service user colleagues (2010) *User Involvement in their Own Treatment and Care*. in Weinstein (ed) *Mental Health, Service User Involvement and Recovery*. [ebook] London and Philadelphia: Jessica Kingsley Publishers. Kindle Edition (accessed 03/05/14)
- Wenger, E. (1999) *Communities of Practice: Learning, Meaning, and Identity*. Cambridge: Cambridge University Press.
- Wilks-Heeg, S. Blick, A. Crone, S. (2012) *How Democratic is the UK? The 2012 Audit*. Liverpool; Democratic Audit

<http://democraticaudituk.files.wordpress.com/2013/06/auditing-the-uk-democracy-the-framework-13.pdf> (accessed 03/05/14)

Williams, C. (2000) Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health & Illness*. 22:2, pp254–272.

Williams, G. (1984) The genesis of chronic illness: narrative re-construction. *Sociology of Health & Illness*. 6, pp175–200

Williamson, C. (2010) *Towards the emancipation of patients*. [ebook] Bristol: The Policy Press. Kindle Edition (accessed 03/05/14)

Wittgenstein, L. [1953] (1998) *Philosophical Investigations*. Oxford, Blackwell

Wynne, B. (1989) Sheep Farming after Chernobyl: a case study in communicating scientific information. *Environmental Magazine*. 2, pp33-39

Žižek, S. (2013) in *Žižek vs Chomsky: Is a pointless spat becoming a meaningful debate?* By Sociological Imagination July 28, 2013

[http://sociologicalimagination.org/archives/13725?utm\\_content=buffer4d51e&utm\\_source=buffer&utm\\_medium=twitter&utm\\_campaign=Buffer#sthash.zuhEBVVV.dpuf](http://sociologicalimagination.org/archives/13725?utm_content=buffer4d51e&utm_source=buffer&utm_medium=twitter&utm_campaign=Buffer#sthash.zuhEBVVV.dpuf)  
(accessed 03/05/14)