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Kath Maguire, Nicky Britten

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"How can anybody be representative for those kind of people?" Forms of patient representation in health research, and why it is always contestable.

Kath Maguire
University of Exeter

Nicky Britten
University of Exeter

Corresponding Author:
Kath Maguire
European Centre for the Environment and Human Health
University of Exeter Medical School,
Knowledge Spa,
Royal Cornwall Hospital,
Truro
TR1 3HD

K.Maguire@exeter.ac.uk

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1 **Abstract**

2 Different discourses that co-exist within the world of patient and public involvement in health and

3 social care mirror a tangle of historical, social, political and theoretical roots. These range from the

4 radical activism, born of civil rights movements, to a more passive model in which patients are the

5 recipients of information. This paper explores the concept of 'representation' and the ways the

6 concept is used by people serving as 'patient' or 'lay' representatives in a range of roles within

7 research projects, funding bodies and academic institutions. We address the issue of why the

8 representativeness of those involved is contestable. Drawing on qualitative research and engaged

9 practice as well as on literature from social and political sciences we question how people

10 conceptualise their own and their fellows' acts of representation. In doing this we identify nine

11 different conceptualisations of what it is to represent and use these to explore how judgements are

12 made about what can count as legitimate forms of representation.

13 **Key words:** England; Representation; Patient and Public Involvement; Service User Involvement;

14 Public Engagement

15 **Why representation?**

16 In 'The Order of Things' (Foucault, 2007) Foucault describes Velázquez's painting 'Las Meninas' and

17 the way this represents the social relations of the Spanish Court of Philip IV. Using position,

18 orientation, lighting and reflection the painting underlines and explores what the child at its centre

19 represented within that society. Foucault acknowledges that his descriptions and the naming of

20 protagonists gives additional information, but points out that he cannot tell us the same things we

21 see in the picture. He argues this is not because either the words or the picture are more 'true' but

22 because they are different, and not reducible one into to the other. What we see can never be

1

1   identical to what we say. By the same token, what we feel ourselves to be and how we imagine

2   ourselves to represent others in concrete social situations cannot be fully captured in the language

3   we use to describe it.

4   Within patient and public involvement (PPI) in health research the word 'representative' is often an

5   important role descriptor. Yet the role it is used to describe may vary enormously. Being a

6   patient/service user/PPI/community 'representative' can suggest taking on a role in which an

7   individual represents a broad section of the population, i.e. patients, service users, tax payers or the

8   lay public. More narrowly an individual may act as a representative of a specific group or

9   organisation, for example a community based support group or a charity. In contrast organisations

10   like these might be said to represent individuals, a whole community, a profession or a more

11   abstract idea like 'cancer research' or 'the environment'.

12   Given these different substantive acts covered by the word 'representative' the reason that the role

13   of a patient or public representative in health and social care research can feel vulnerable to

14   challenge (Beresford & Branfield, 2012) starts to become clear. While some argue that patient and

15   public involvement promotes civil society and democratic renewal, the counter argument, that those

16   involved are an unrepresentative minority, is also commonly heard; a debate that was discussed in

17   some detail by Tritter (2010).

18   Political science literature has described a paradox at the heart of these concepts of representation:

19   that being a representative is to make present someone or something which may not be there,

20   making them both absent and present. This is what Pitkin has described as a 'fundamental dualism'

21   (Pitkin, 1967, p9) around which our ideas of representation are constructed. One way that theorists

22   have attempted to resolve this paradox is by imagining representation as the manufacture of an

23   artificial presence. In this way representation, like a prosthetic limb, can be described as both

24   'artificial' and 'real' (Runciman, 2007).

1   This paper maps ideas and experiences that patient, public and lay members have of providing a

2   group or an interest with this artificial presence, and how this paradox influences the ways their

3   activities may be viewed by others

4   **Perspectives on Patient and Public Involvement**

5   What it means to be a patient, public or lay representative in health research and care is made

6   complex by an array of different concrete activities that are referred to under that heading. This

7   point was made in the UK House of Commons Health Committee report on involvement in the NHS,

8   which also argued for a clear distinction between patient involvement and public involvement

9   (House of Commons Health Committee, 2007).

10 Involvement and engagement in research may mean including people as members of steering

11 groups, committees and funding panels or asking for their comments on information leaflets. Patient

12 and public involvement also includes consulting patients, carers and the wider community about

13 research priorities or particular trial proposals. People may be involved throughout research as co-

14 producers (Cameron 2015); they may be asked to collect or analyse large data sets, as 'citizen

15 scientists' (e.g. www.zooniverse.org and ecsa.citizen-science.net). People are often involved in more

16 than one activity, with multiple organisations and they may act tactically in connecting and shaping

17 their different involvement opportunities (Renedo & Marston, 2015).

18 Researchers might choose to involve people in order to help ground their research design in the

19 reality of patient experience, to improve recruitment to a trial or to support dissemination. For some

20 researchers it is a matter of principle that publicly funded research should include patient and public

21 representation. There has also been support for patient and public involvement and engagement

22 from funders who highlight its potential to provide insights and information which can enhance

23 relevance, implementation and impact or because it can improve governance and support

24 legitimation (e.g. see NIHR, undated and RCUK, 2010). 'Engagement' is sometimes seen as more

1   passive than 'involvement', the former being a model in which patients or the public receive

2   information or education rather than actively contributing (INVOLVE, 2017).

3   Many active patient or carer campaigners tell of a more contested history of struggle for voice and

4   recognition. Patient safety campaigners are now part of a recognised social movement (Williamson,

5   2010), one that has learned from other civil rights movements highlighting inequality and power.

6   Social movements have often challenged boundaries between the personal and the political.

7   Feminism targeted medicine for treating women's bodies and behaviour as abnormal, because they

8   were not the same as those of men (Ehrenreich & English, 2005). Other paradigms of normality were

9   challenged by the disability rights movement, through the social model of disability (Oliver, 1983)

10 and the mental patients' liberation movement (Alvelo, 2009) with antipsychiatry (Cooper, 1967).

11 The gay rights movement also had a profound impact on involvement in health. There was a

12 prolonged and colourful international campaign for the removal of homosexuality from the World

13 Health Organisation's International Classification of Diseases and the US Diagnostic and Statistical

14 Manual of Mental Disorders (King et al., 2004; McLaren, 1999). This campaign can be seen as an

15 important landmark which demonstrated that definitions of 'illness' can be challenged by political

16 action, and therefore that scientific 'truth' can be altered by public protest. The model of direct

17 action and established networks of gay rights activists empowered people affected by HIV AIDS to

18 challenge medical research they felt was not addressing issues of vital importance to them. This

19 campaign made significant contributions to research methodology in that field (Epstein, 1996).

20 So, rather than a clearly defined phenomenon, patient and public involvement can be seen as a

21 collection of practices which take place as part of political and administrative processes, often in a

22 context in which the distribution of power is being contested (Contandriopoulos, 2004). In this paper

23 we use empirical data from a study looking at theoretical approaches to participants' experiences of

24 patient and public involvement in health research (Maguire, 2014) to address two serious questions

25 at the heart of the idea of patient and public involvement:

1 • in what ways do people understand their roles or actions as representation?

2 • how can these understandings help us to assess the legitimacy of representation in health

3 research and care?

4 **Study methods**

5 The overarching research question for the study was "What motivates and sustains patient and

6 public involvement from the perspective of lay participants?" The study was undertaken as a

7 doctoral study by a service user researcher and, as well as data from in depth interviews the study

8 included autoethnographical reflections and continuous engagement with a patient and public

9 involvement group (The Peninsula Public Involvement Group, PenPIG) throughout the study

10 (Maguire, 2014). Ethical approval for the study was granted by the Peninsula College of Medicine

11 and Dentistry Ethics Committee in 2011.

12 A sampling frame for interviews was constructed from respondents to a questionnaire, available

13 online or as a hard copy and circulated through networks maintained by the National Institute for

14 Health Research and through the patient and public involvement leads in 32 universities in England,

15 from a list obtained from the Royal College of Nursing. The survey received 105 responses; 30

16 respondents did not wish to participate in further parts of the study; two did not live or work in

17 England and five were eliminated as they were academics or clinical researchers managing or

18 working with lay participants. This produced a sampling frame of 68.

19 Invitations to take part in interviews were sent to 34 people from this frame. These were chosen in

20 order to maximise variation in terms of involvement experience, activities undertaken, and

21 organisational structures. Four invitations did not elicit any response, two people initially agreed to

22 be interviewed but did not respond to subsequent communications, three were unable to set a

23 mutually convenient appointment, two had to cancel and one did not attend on the day. Ten people,

1 identified by other interviewees as key informants, were contacted directly; eight of these agreed to

2 be interviewed.

3 A total of thirty one participants were interviewed, 23 female and 8 male. Three interviewees had

4 not been actively involved in health research at the time of contact. One of these became involved in

5 a project advisory board during the study. Two interviewees had been members of a patient

6 research group previously but were no longer involved in research. One of these had specifically

7 withdrawn from research involvement to focus on service improvement and governance. Most

8 interviewees, had been involved in a number of roles in health research, health service

9 development/governance, and/or patient/carer support groups.

10 Interviews took place, either face to face or over the telephone, between summer 2012 and early

11 2013. Interviewees were sent an information sheet, consent form and a topic guide in advance.

12 Signed consent forms were returned by post, email or in person. The topic guide explained that we

13 wanted to discuss the duration and scope of participants' involvement; their motivations and

14 aspirations for these activities; perceived costs and benefits; learning gained from involvement; and

15 feelings about research. This was not a questionnaire and participants were invited to tell their own

16 story about involvement rather than responding directly to questions. All interviews were audio

17 recorded, with permission, and transcribed. All interviewees were offered an opportunity to edit or

18 comment on either a verbatim transcript or a version edited to remove repetitions and stumbles, to

19 make text more readable (Bourdieu, 1999).

20 Analysis took place alongside data collection. Analytic codes and categories were constructed from

21 the data (B. Glaser, 1978; B. G. Glaser & Straus, 2012; Strauss, 1987). Some transcripts were

22 independently coded by members of the supervisory team and discussed to reach a consensus on

23 coding. Emerging themes and anonymised illustrations from the data were also shared with the

24 public involvement group for comment and discussion. 'Representation' was identified as a major

25 theme early on, arising from both survey and interview data, and drawing on Pitkin (1967)

1 representative acts and roles were categorised as either 'acting for' or 'standing for'. On this basis

2 we identified sub categories through which these activities and roles were claimed to be legitimate,

3 or sometimes were challenged. 'Acting for' included the sub categories of: defending interests either

4 by petitioning authority in a particular cause or by consciously imagining yourself in the role of those

5 being represented and arguing from that perspective; being authorised by the organisation through

6 a formal appointment process; being authorised by those represented, either through election or

7 nomination; and being accountable or answerable to those being represented, either formally or

8 informally. 'Standing for' included: symbolising or personifying a group or entity; sharing a particular

9 experience, characteristic, illness or disability with the represented group; or being statistically

10 similar to the represented population. These are shown in table 1.

11 This study began from the perspectives of the people involved. The focus was on how their personal

12 motivations, goals and experiences might shape their involvement. This meant that the rigid

13 conceptual distinction between involvement in health research and involvement in health services

14 became incoherent. This distinction between research and care is an important element of good

15 governance, and so is rightly of vital concern to professionals and institutions. But the boundary

16 between health service research and the provision of services is often not seen as important from a

17 patient perspective. Many of the patient and public roles in research focus on improving safety and

18 care. As one interviewee, who we will call 'Elizabeth', said 'most people are practical aren't they?'

19 In order to safeguard confidentiality all the interviewee names used in this paper are pseudonyms.

20 Also the names of the organisations they are involved with and any specific medical diagnoses they

21 revealed have been removed.

22 **Results**

23 The terms 'representative' or 'rep' were widely used by interview participants, with some using

24 them frequently throughout their interview, to describe themselves and/or others. Most used the

25 term in a way which implied a role description they found comfortable and self-explanatory. For

1   others representation was experienced as a complicated and knotty concept, something that they

2   may be challenged about, or that they feared they might fail to fulfil.

3   One participant who explicitly used multiple concepts of representation was Oliver, a member of the

4   lay advisory group for one of the Medical Royal Colleges which deal with standards of care and

5   medical education for particular specialisms. Oliver was also an academic sociologist. During his

6   interview Oliver not only spoke of his role as representing patients, he also described the College

7   both as representing the abstract construct of the specialism and as representing a particular

8   professional group. These roles may often coincide, but potentially they could conflict. For example,

9   a move to shift decision making from doctors to nurses or managers, or from professionals to service

10   users, could be in the interest of the specialism, but may not be welcomed by the doctors. These

11   issues of who is representing and who or what is being represented add to the layers of complexity

12   when analysing what people say about their roles and activities.

13   The following sections will describe the categories of representation in more detail with illustrations

14   from the data.

15   **Acting for**

16   *Defending interests*

17   Representation as defence of a particular interest or group was identified in two different forms. The

18   first is in the sense of 'making representations'. Specifically this refers to formal statements or

19   petitions made to a body or individual in a position of authority.

20   Oliver provided one example of this when he described how, in his role as a member the lay panel of

21   a Medical Royal College, he accompanied the president of that College to the Department of Health

22   for meetings during consultations about the Health and Social Care Act. In attending these meetings

23   Oliver talked about making representations to the minister as "someone who's not a physician" but

8

1   who was capable of presenting a case about why the College "didn't think [the Act] was a terribly

2   good idea." [Interview]

3   At a more local level Phoebe, as a service user co-applicant, accompanied research staff to a meeting

4   of their regional Research Ethics Committee to explain why the team were resisting some protocol

5   changes that had been suggested.

6   "I just knew that this project should… you know, should get past the Ethics, there was no way that it

7   should be changed at all and that it was them that didn't understand, so I was going to go and say

8   whatever I felt was relevant." [Interview]

9   Phoebe had been supporting the development of a research protocol looking at a service for

10   patients who were both vulnerable and poorly connected to health services. She saw the Research

11   Ethics Committee as very distanced from this group and as lacking understanding of their needs. She

12   saw her role as persuading them that that a particular approach was necessary to support

13   participants, rather than the complex pro forma paperwork that was being requested. In this Phoebe

14   was defending both the interests of the research participants and those of the research team.

15   The second form of representation as defending interests is described here by Jennifer, an

16   interviewee with wide experience of different involvement roles. For her patient and public

17   representation is an imaginative act of:

18   "Putting yourself in somebody else's shoes and saying: 'if I were this person in this piece of research

19   what is it going to mean to me, how would I want to be treated, what do I need to understand?' and

20   all those things." [Interview]

21   This concept of representation requires the capacity to go beyond personal testimony or the ability

22   to present a case for a particular group with whom you are familiar. Wearing "somebody else's

23   shoes" may not draw upon individual health care or research experience. In fact, rather than calling

24   on your own feelings or preferences, this form of representation could mean overcoming or masking

1 your feelings in order to present a case for someone in a very different position from yourself.

2 Therefore, Jennifer argues, representation in health research is a role that requires particular skills

3 and aptitudes.

4 "There are people that are good at, at, at being PPI representatives, there are people that are good

5 at, at, at, running support groups, there are people who are good at providing helpline information

6 and - they're not necessarily the same people." [Interview]

7 In identifying different concepts and activities that can be described as representation, it is worth

8 also questioning whether people who are good at acting as a representative in one capacity, may

9 lack the skills or aptitude for another, and vice versa. Even within this category of defending

10 interests the specific roles and activities described differ significantly.

11 *Authorised representation*

12 How people were selected to these or other representative roles was often talked about as an

13 important factor. A formal mechanism through which people were chosen and given authority to

14 act, where this existed, was important in legitimising the role of a representative. One way of

15 obtaining authority to act was through an appointment system that was recognised as legitimate.

16 Some had responded to an open advertisement, posted either locally or nationally, for at least one

17 of their involvement roles. Some of these also described a formal process of application and

18 interview. This process was seen as providing legitimacy through the authority of the organisation

19 they were involved with, in a similar way to the authorisation given to the organisation's employees.

20 Both Oliver and Jennifer suggested that this sort of process often failed to reach broadly enough

21 across society, by privileging those with professional or academic backgrounds and failing to address

22 the marginalisation of some communities. Another critic of formal interviews was David, although

23 that was how he had initially become involved. Since then, his experience of different recruitment

24 processes had led him to become a champion for informal open invitations.

1 "Interviews are bloody silly… and anyway you're choosing people, you want to balance and so on

2 and so forth and you choose them when you can find them, which I think is perfectly valid."

3 [Interview]

4 Few participants spoke of any formal elective process. Amy described being "voted in" as trustee on

5 the board of a national service users' charity, a body which included both representatives elected

6 from the membership and external co-optees. Both Amy and John also talked about elections to

7 posts like chair, vice-chair and treasurer within patient groups.

8 Another mechanism by which people became representatives was through being nominated by one

9 group to represent the organisation or their membership in a different body or project. Amy was

10 asked, as elected trustee of the charity, to act as service user representative on the governing body

11 of an organisation representing service providers. Kate was nominated by a charity with which she

12 acted as an Expert Patient tutor, to represent them on a research project steering group.

13 *Accountable representation*

14 Few formal mechanisms for accountability or feedback from patient and public representatives to

15 others were identified. Some involvement groups which met regularly had a standing agenda item

16 that enabled members to speak about projects or activities they had been involved in. People also

17 fed back informally, often by email and some were very active on social media.

18 Most interviewees had been invited or co-opted by researchers or clinicians into at least one of the

19 groups or projects they were involved with. This made some reluctant to describe their role in terms

20 of representation. An extreme of this was Alan, someone involved in a wide range of patient forums

21 and panels as well as research projects. He deliberately chose to describe his role as a 'public

22 contributor'. He argued that this role was fundamentally different from acting as a representative.

23 Acknowledging his behaviour was sometimes perceived as difficult and challenging by both

24 professionals and other patient and public contributors Alan argued:

1 "I've got a code of conduct that I have to adhere to with any organisation and I wouldn't represent

2 an organisation if I wanted to be challenging." [Interview]

3 So by using the term 'contributor' rather than a 'representative' Alan saw himself as legitimating his

4 ability to behave in a way that sometimes upset or caused offence to others. This was not a view

5 expressed by any other interviewees, although taking the appellation of representative frequently

6 suggested an acceptance of some level of responsibility or accountability.

7 Co-option, self-nomination or volunteering, was sometimes seen as legitimate, where the process

8 was undertaken in a way that was open to challenge or contestation. In this way the representative

9 could be seen as being accountable to those represented. For example John suggested that his

10 representation of a patient group at meetings of their host research organisation's governing body

11 was legitimated by copying in the whole group when he sent an email putting himself forwards. He

12 saw this as giving others the opportunity to object to him taking that role and to hold him to account

13 for how he fulfilled it. A related claim of representation was also identified in a study of community

14 representatives working with local government and service providers in Local Strategic Partnerships

15 (Maguire and Truscott, 2006). In that study a priest who sat on the partnership as a community

16 representative argued that this role was legitimated by the informal connection he gained with local

17 people through 'walking the streets'. He saw this as giving him an insight into their views and needs

18 as well as giving local people an opportunity to question or challenge him. This is clearly a model

19 more applicable in a small geographical community than dispersed patient/carer groups or the wider

20 public.

21 Both these models of accountability rely on what Runciman has called the 'non-objection criteria'

22 (Runciman, 2007, p95) in which those represented are assumed by their silence to have assented to

23 the act of representation. This non-objection seems a poor measure of accountability. People like

24 John, feel quite comfortable putting themselves forward to represent a group of patients or service

25 users in another arena. Once they occupy that role, other group members can find it difficult to

12

1 challenge them or hold them to account. In the same way not all parishioners may feel able to accost

2 a priest in the streets to question his contributions to a local planning meeting.

3 Similarly those represented may struggle to hold elected or nominated representatives to account

4 effectively. Perhaps it is not always possible, or necessary, for there to be explicit "mechanisms

5 through which lay members can act as representatives of broader constituencies" (Barnes, 1999,

6 p25). Yet discomfort with Alan's claim, that a lack of affiliation to a particular group relieved him of

7 any accountability for his views and actions as a 'public contributor', leads us to see such

8 mechanisms as desirable. This raises questions about who should be responsible for creating and

9 maintaining these mechanisms and networks. Is accountability the responsibility of patient or public

10 representatives themselves, or of the organisations involving them? And how could we ensure such

11 mechanisms have a representative reach?

12 **Standing for**

13 *Symbolic representation*

14 The value of a patient or public representative attending meetings with professionals, politicians or

15 other authorities may not just be in what they say. Locock et al (2016) have highlighted the

16 importance of symbolic capital in patient and public involvement, as the status of being a patient or

17 a member of the public carries significant symbolic meaning. Simply by attending in that

18 representative role they may change the nature of the proceedings. This was Oliver's understanding

19 of his role in the ministerial meetings:

20 "I had a kind of symbolic role - I was sort of decorative erm, [laugh] perhaps decorative is the wrong

21 word to describe me but I think it, it helped them make a political point." [Interview]

22 In accepting the invitation Oliver saw that this was not just based on his knowledge and ability as an

23 individual. He was also acting in some way as a banner or totem of the public as users of the health

24 service. This explicitly evokes Pitkin's (1967) concept of symbolic representation, representation that

13

1 does not necessarily require the representative to resemble those represented, but to act as a place

2 marker, reminding negotiators to include their interests.

3 This representation of patients and the public in arenas previously exclusively occupied by

4 professionals (policy makers, researchers, clinicians and/or managers) creates artificial presence of

5 those previously excluded. Their interests are conjured, almost metaphysically into presence within

6 those bodies, like Banquo's ghost in Shakespeare's play Macbeth shaking their 'gory locks' at tables

7 from which they have been completely absent in the past.

8 A similar conjuring of artificial presence was observed during a research prioritisation meeting

9 involving NHS and academic institutions. A service user gave powerful personal testimony about the

10 need to research treatments for a particular population. This had the effect of shifting the focus of

11 the meeting from clean, impersonal deliberations to the frequently messy personal impacts that

12 illness and treatments have on people's lives. What could have been a discussion about numbers

13 became one about people. In this way a patient, through the act of representation, enabled 'those

14 who are literally absent nevertheless to make their presence genuinely felt' (Runciman, 2007 p95).

15 *Shared experience/characteristic*

16 As well as the symbolic role of his presence in that arena, the representative described above also

17 introduced the personal into a research arena dominated by the impersonal, professional and

18 scientific. This was seen as an important aspect of patient representation, explicitly drawing on

19 personal experience as a way of illustrating and informing the development of health research and

20 care.

21 This is demonstrated in the way Abigail describes her changing role. As she became more integrated

22 into an interdisciplinary research team as a service user researcher she felt she was outgrowing

23 'patient representation'.

1   "I don't do very much actual patient representation because I've kind of moved beyond my

2   experience." [Interview]

3   She went on to describe how this altered her relationship with the research team.

4   "I'm not thought of as a patient representative, they don't sort of edge round me carefully. I'm sort

5   of treated as one of the team." [Interview]

6   Another service user researcher who saw the use of life experience as a central focus of patient

7   representation was Ellie. She had done a lot of work on NHS mental health service improvement,

8   governance and research, and was very comfortable with that role. But Ellie found involvement as a

9   patient representative in a broader research prioritisation process took her beyond her experience

10   in a way that caused her concern.

11   "Having people who have the related experience is more valuable than just having a group of so

12   called 'lay people'… I thought actually, I'm probably not the right person to be doing this."

13   [Interview]

14   The concept of sharing a condition as a qualification for patient representation was used by John, a

15   member of a patient and public involvement group attached to a research body. This group included

16   people with a range of different health and social care issues, including patients and carers. When

17   discussing researchers seeking patient and public representatives for their projects, he identified

18   people within the group who share a particular condition as qualifying.

19   "Five people now who've got [condition] within the group. So there's five people who can go to

20   represent people." [Interview]

21   This suggests that legitimate representation within these research studies was, for John, based on

22   sharing a particular diagnosis. He did not, for instance, include group members who have experience

23   of the condition as carers or family members.

24   *Statistically representative*

15

1 John's ideas of legitimate representation chime with the concept of having a study sample

2 statistically representative of the study population. Clearly this is not a measure that is completely

3 appropriate for patient and public involvement. In terms of scale and cost a statistically

4 representative group would often be unmanageable and prohibitively expensive

5 Yet for some patient and public representatives, the role did imply that they should be similar to the

6 wider population they served. Oliver most clearly articulated the burden that this interpretation of

7 representation implied for him. He spoke of the realisation, at meetings he attended between the

8 Medical Royal College and the Department of Health, that he was the sole representative of the

9 specialism's 20 million patients as "sort of paralysing". This led him to express concerns about what

10 it means for him to be in this role.

11 "I always worry about that, well I'm not exactly representative. But then how can anybody be

12 representative for those kind of people? I'm absolutely the sort of person who is consulted 'cause

13 I'm, you know, appallingly well-educated and middle-class and white and male at the same time I

14 think if I wasn't all of those things I wouldn't really get in the door of the Department of Health, so

15 what you gonna do?" [Interview]

16 Lack of diversity in patient and public involvement groups in terms of class, age, education, gender

17 and/or ethnicity was a concern frequently raised. In terms of gender, the imbalance was most often

18 seen as a predominance of women in patient and public involvement groups and forums. Alan felt it

19 was important for more men to be appointed to posts supporting patient and public involvement in

20 order to address this imbalance.

21 "If you wanna demonstrate that you can walk the walk after you've talked the talk, you only have to

22 look, the whole staffing complement [of patient and public involvement support team] are female."

23 [Interview]

1   Lack of diversity was an issue Jennifer had had tried to address in one of her patient representative

2   roles, as lay chair of the patient liaison committee for another Medical Royal College. Her aim had

3   been to recruit: "a) a man, b) somebody young, and c) somebody from one of the ethnic minority

4   groups" [Interview]

5   Practical barriers to involvement were seen as important in limiting access to some groups. People in

6   employment had difficulties getting time off to attend meetings. People on low incomes sometimes

7   found often protracted waits for the reimbursement of out of pocket expenses unaffordable and

8   people on benefits had anxieties about payments leading to them being sanctioned. Transport and

9   travel were also mentioned as barriers, particularly for people in more rural or marginal

10   communities. All these issues were seen as structurally disadvantaging some groups.

11   Another way that Alan believed that he and others were excluded from opportunities to contribute

12   was through the uneven geographical distribution of research and research funding. He spoke of

13   being "postcode-lotteried out" of some groups and projects.

14   For Abigail the emphasis on patients in patient and public involvement in itself led to a skewing of

15   those involved, when compared to the general population.

16   "You don't actually necessarily have to be a patient to be involved in research… Sometimes I think

17   you can lose sight of what's normal." [Interview]

18   This raises the issue of the purpose and nature of any individual involvement activities. In some roles

19   in health studies or service development projects members of the public might not have much to

20   contribute, unless they had some specific and relevant health, care, or cultural experience.

21   It is telling that 'representative' in this statistical sense was most often used to describe something

22   that a group, organisation or individual lacked. It can be hard enough to recruit a statistically

23   representative sample from a population for a trial. Having a statistically representative public

24   involvement group, particularly in terms of the general population rather than patients with a

1 specific condition or using a particular service, is unrealistic because of the number of people that

2 would be required.

3 **Discussion**

4 The questions we sought to address in this paper are:

5 In what ways do people understand their roles or actions as representation?

6 and

7 How can these understandings help us to assess the legitimacy of representation in health research

8 and care?

9 With regard to the first question, we have identified a range of different concepts and

10 understandings; both acting for others and standing for an idea, an institution or a population. Some

11 participants described multiple forms of representation in their involvement activities. Often the

12 potential for their legitimacy as representatives to be challenged was implicit in their discussion of

13 the role. Sometimes this was explicitly discussed.

14 INVOLVE has argued the importance of making involvement opportunities accessible as broadly and

15 as fairly as possible (INVOLVE, 2012). If health research and service development systematically

16 excludes some groups their needs may remain unrecognised and unmet. Yet avoiding the castigation

17 or exclusion of those who are involved for failing to be sufficiently diverse may be equally important.

18 Refusing to value and nurture those currently contributing is unlikely to encourage more or different

19 people to be attracted to these roles. Addressing shortfalls in the structures in place to enable and

20 support involvement might be a better approach.

21 In order to demonstrate a commitment to diversity, some organisations (Maguire, 2014) have tried

22 to recruit patient and public representatives from 'groups' they have defined by the nine protected

23 characteristics outlined in the 2010 Equality Act (see Equality and Human Rights Commission). Only a

24 very brief imagining of the qualification for membership of such groups is necessary to make the

1 absurdity of this concept apparent. For instance you would need to include: somebody who has an

2 age or age range; someone who is either a man or a woman; someone who has a religion or a

3 philosophical belief; someone who has a race, colour, nationality, ethnic or national origin etc. This

4 conflation of diverse characteristics with group membership creates an unachievable illusion of ideal

5 representation and disguises the criteria actually used to select representatives. A 'protected

6 characteristic group' would not be representable, i.e. 'would not exist fully as a represented group if

7 [the representative] were not there to incarnate it' (Bourdieu, 1991, p204). The 'protected

8 characteristic group' for 'race' can only exist, as a 'group' through the choices of those appointing its

9 representative. These choices might be most visible from the outside by noting who is excluded. Any

10 actual involvement based on this sort of construct is open to the accusation of being

11 'unrepresentative', either because an alternately defined 'group' has not been included or because

12 the boundaries defining represented 'groups' are contested.

13 The range of different definitions of what it means to represent, or to be a representative, helps to

14 explain why the legitimacy of almost any actual act of patient, public or community representation is

15 so easy to challenge. While an act may be perfectly representative using one or more of these

16 definitions, that same act is very likely to fail to meet the criteria of some others. It is possible for an

17 individual acting in a single role to demonstrate a range of different 'representations' and yet a

18 broad and inclusive group may be 'unrepresentative' in at least one dimension or sense. A lack of

19 some form of 'representativeness' can probably be used to delegitimise any involvement that takes

20 place in practice.

21 Representation as it is enacted seems to be far too complex to be contained mechanistically within

22 any one of these definitions. Those acting as a patient or lay representative move between roles and

23 relationships. In championing individual studies, taking part in the assessment of research proposals,

24 contributing to governance processes etc., public, patient or lay representatives might need to

25 consider different conditions, individuals and interests. They may act as conduits of information

1 between different groups and constituencies. In doing this they may frequently have to look beyond

2 their own experience of a condition or a service, perhaps drawing on their family's experiences, on

3 professional expertise, life skills, imagination and understandings of their communities. They are

4 also likely to need to draw on these sources of personal knowledge and skills in roles they have been

5 elected or nominated, creating a complex web of accountability and connections.

6 This may lead us to conclude, with Runciman that while "there is no single answer to what is to

7 count as 'genuine' representation" (2007, p113), the important question to ask is when are we

8 justified in identifying an act of representation as 'bogus'? Avoiding the use of the word

9 'representative' does not help us escape this task. Alan's decision to call himself a 'public

10 contributor' rather than a 'representative' did not prevent both patient and professional colleagues

11 having concerns about his actions and lack of accountability. His behaviour was still experienced as

12 'standing for' in some arenas and sometimes seen as a damaging 'bogus' representation of patients.

13 Representation, as a paradoxical and artificial presence of someone or something also absent, will

14 always be imperfect. Pitkin's argument that people, ideas and things can be represented in a lot of

15 different ways, depending on what they are and the context of their representation "but not

16 everything can be made present in every way." (1967, p226) resonates with Foucault's (2007)

17 differentiation between what is conveyed by Velazquez' painting and what words can communicate.

18 In that case it becomes important to match the type of representation enacted to the nature of that

19 which is being represented and to the arena of that representation.

20 Organisations wishing to involve people normally set the rules by which people are involved and

21 often the criteria used to judge whether or not the actions performed by those people are

22 representative. In trying to codify a single requirement for patient and public representation

23 organisations can end up asking for people with what Graham Martin has described as a 'strange mix

24 of representativeness, diversity, ordinariness, knowledge and expertise' (Martin, 2008, p46).

1 Professionals have both a responsibility and an interest in shaping spaces for patient and public

2 representation within their organisations and activities in a way that is purposeful and appropriate.

3 It is fruitless to blame patient groups for failing to live up to criteria of representativeness which are,

4 at best, nebulous and shifting. Professionals need to support activities and structures which enable

5 patient and public representation to take place in different ways if they wish them to be more

6 widely accessible. Mechanisms of feedback and accountability can be co-produced with patient and

7 public representatives, but the resources to enable that generally sit within organisations they work

8 with. Organisations also need to support members of those groups to identify and challenge 'bogus'

9 representation, both their own and that of others.

10 Before we criticise a group, an individual or a process for being unrepresentative, it is important to

11 be clear what we mean by that, and to look and see if there are any other ways in which they are

12 representative. Then we are more able to judge the appropriateness or falsity of that

13 representation. There is a real danger of miscommunication and misunderstanding when we

14 become preoccupied with a particular word someone may have used to describe a role or activity, if

15 in doing so we fail to engage with meanings they are trying to convey to us.

16

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Table 1 Examples of different concepts of 'representation' as legitimation

Table 1 Examples of different concepts of 'representation' as legitimation in interview data			
Acting for	Defending interests	Petitioning	Pheobe: 'it was them [Research Ethics Committee] that didn't understand, so I was going to go and say whatever I felt was relevant.'
		Walking in their shoes	Jennifer: 'if I were this person in this piece of research what is it going to mean to me?'
	Authorised by	Appointed by	David: 'I went for an interview… and went on the working party and that really began the story of further involvements.'
		Elected by	Amy: 'the trustees of [national organisation representing service users] are voted for by the membership. '
		Nominated by	Kate: '[Researchers] approached [charity] and [charity] volunteered me.'
	Accountable to		John: 'I sent the answer back to everybody - you know to 'all' so that everybody knew that I was putting meself forward.'
Standing for	Symbolising		Oliver: 'I had a kind of symbolic role… it helped them make a political point.'
	Sharing experience/ condition		Ellie: 'Having people who have the related experience is more valuable than just having a group of so called 'lay people'.'
	Statistical		Abigail: 'Sometimes I think you can lose sight of what's normal.'

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