Structured abstract

INTRODUCTION: Reporting data from a case study of a collaborative systematic review, this paper discusses the impact service user involvement might have on research, and how research might benefit from this. METHODS: This was a qualitative case study. The researcher analysed process data on the collaboration in the form of meeting transcripts and minutes, reflective interviews and the researchers’ own field diary. The review was also compared with two systematic reviews on a similar topic, using the AMSTAR checklist. RESULTS: The young people had influence at all stages of the review, but most importantly shifted its focus from healthcare to education, emphasising education as an important determinant of health. CONCLUSION: Young people involved in this review influenced the researcher’s reviewing as well as the review, which shows that involving service users in research is important in order to reduce researcher bias in social care research.

Background

Service user involvement in research is increasingly becoming an integral part of publicly funded research, across disciplines and research designs. As a ‘movement’ service user involvement has evolved from a range of developments within social care policy, research and practice. Some of these have been academic, and some have been partisan and political. For example, AIDS activists in the 1980s pushed for both a change in biomedical research practices and for the political rights and identities of those affected by HIV (Epstein 1995). So as well as being viewed as having the potential to improve research, reduce biases, and open up research to a wider range of expertise and knowledge, service user
involvement has also been about certain groups’ fight for their identity, to change society’s image of them as a group.

The latter is important because research is one of many influences on identity formation within and perception of a group; for instance the HIV research showed that transmission happened through unprotected sex, which could support judgemental views on gay men’s promiscuity, real or imagined. Research itself is also informed by the dominating images of a particular group, and research questions will inevitably reflect these. Thus, many activist groups have seen research as one of many tools for changing ruling paradigms, concepts and what they see as society’s (mis)conceptions about what it means to be gay, disabled, female, or poor (Graham, 1993; Fleming, 2010).

The terms used to describe ‘service user involvement’ vary across disciplines, yet the central point remains: that knowledge is multidimensional and a widening of perspectives can improve the validity of research and enhance our understanding of the social world. This corresponds to seminal sociological papers which have asked whether and how our research questions and analyses capture people’s lives and experiences, whether research should take on a partisan role and support those with less power to influence policy, and whether research addresses what communities and individuals see as critical to their well-being (Becker, 1967; Collins and Evans, 2002; Gouldner, 1968; Graham, 1993; Oakley, 2000; Wright Mills, 1959): “What passes as scientific knowledge in Britain has been built up through a set of data-collection methods where minority voices can go unheard.” (Graham 1993: 198)
Outside of academia, interest groups and individuals themselves have fought against what they perceive as discriminatory paradigms for researching their lives. People with disabilities and mental health patients especially have questioned the validity of research conducted within the frameworks and perspectives of medical practitioners rather than those of patients and disabled people themselves (Beresford and Evans, 1999; Oliver, 1992).

At first sight, there is a gap between sociological work on the ‘partisan’ role of research and interest groups’ demands for people’s lived experience to be reflected in academic and policy research. The first is proposed in academic articles and conventions, with an academic audience, and relates to a debate about epistemology and the science of knowledge. It prompts questions about what knowledge is, and whether it can be trusted. The latter comes from activist groups and has often been framed in colloquial language, and where research is equated with power (Oliver, 1992; Beresford, 2005).

However, these arguments meet in that they are not instrumental in nature: they are not asking about outcomes or theories of change, they are asking fundamental questions about the perceptions underpinning the frameworks within which research is conducted. For example, when we conduct a study on social care: what do we mean by ‘care’, whose ‘needs’ are we measuring, from what perspective are we approaching our field? Becker argues that we will always take sides and so it is a question of whose side we want to be on (Becker, 1967). Oliver (Oliver, 1992) and Beresford (Beresford, 2005) are examples of service user researchers who have argued similarly: that the lack of lived expertise perspectives threatens the validity of research. Both traditions, then, have suggested that there is a need
to reduce the bias inherent in all research, by considering how to incorporate the perspectives of those excluded from mainstream understanding of society.

**Impact of involvement**

As ‘service user involvement’ has gained ground in health and social care research, much has been written about how to involve people (Alderson and Morrow, 2004; Barber et al., 2007; Braye and Preston-Shoot, 2005; Telford et al., 2004), and why (Braye and Preston-Shoot, 2005; Telford et al., 2004). As the rationale for service user involvement has been adapted across academic disciplines, and by funding organisations and policy makers, questions have increasingly been asked about what influence such involvement might have on research studies themselves (Staley, 2009; Oliver et al., 2004). A considerable part of the literature is very positive about involvement, citing people’s rights (including children’s rights) to participation and citizens’ responsibility. Critiques of patient and public involvement in research have raised concerns about bias (David, 2002), the problematic notion of ‘empowerment’ (Pease, 2002; Carey, 2011), and how involvement does not guarantee research quality (Brownlie, 2009; McCarry, 2012).

Overall, there is a question about whether service user involvement is important in terms of changing research. Considering the rationales outlined earlier, this question seems like a logical extension of these arguments. Will service user involvement in research help achieve wider perspectives on services and challenge stereotypes? Will this in turn produce research that is more externally valid and implementable? Is it possible to achieve this within the constraints of a systematic review?
A narrative of and reflection on ‘impact’

Drawing on findings from a 4-year study where I collaborated with a group of care leavers on a systematic review, this paper discusses the notion of ‘impact’ from public and service user involvement in research. I here present my findings on the young people’s influence on the review in terms of its focus, form and relevance. From my position as researcher-collaborator I argue that to ask for measurable outcomes and hard evidence of change from ‘service user involvement’ is to miss the most important rationale for this endeavour: involvement of service users or the public is about change, but it is primarily about change in researchers’ focus and approach to their field. It is about changing the relations between the researched and the researcher. It is about questioning how studies are positioned within a highly politicised funding-agenda. It is about wider aims which are not measurable in terms of hard outcomes.

To evidence these points, this paper provides a narrative and in-depth reflection on the journey travelled, from the researcher’s perspective, when collaborating with a group of people who had not previously done any systematic reviewing. As a starting point, I was interested in how the subjectivities introduced by participation interact with the rigid framework of a systematic review. While the notion of a systematic review as favouring randomised-controlled trials (RCTs) is fading as a result of ground-breaking methodological work in this field (Harden, 2006; Thomas et al., 2004; Gough et al., 2012; Petticrew and Roberts, 2003), systematic reviews remain associated with being a priori, protocol-driven and aiming to reduce bias. Systematic reviews remain an important method for identifying patterns of research and gaps in knowledge. The involvement of service user perspectives in
reviews is therefore especially important since their influence may further enhance the review’s ability to expose existing literature.

Rather than seeing service user involvement in research in contradiction to research rigour, this study addresses how to widen our knowledge base, and expand the research focus to include the priorities and views of the people we research. Within an objective reality, as we collectively experience it, the project of social research is to derive knowledge in a systematic and replicable fashion. Drawing on Collins and Evans (2002), this paper argues that service user involvement in research, as the inclusion of experience-based experts in knowledge production, is key to developing useful, relevant and valid research, including so-called positivist studies, such as systematic reviews and randomised controlled trials.

**Ethics, consent and permission: Care Leavers’ Involvement in a Systematic Review**

In 2008 I asked a group of young people with residential or foster care experience if they wanted to be part of a systematic review group. They would decide the review topic and question, and be involved in all stages of the reviewing, should they wish to. This participative reviewing process formed the case study of my qualitative investigation into how researchers might involve young people, and how that might impact on their research. The setting of the review question had as a parameter that it should be relevant to looked after children’s health.
Two distinct sets of findings were expected to derive from this research; first a systematic review, and second a case study of the service user involvement in this review. This was therefore a two-pronged study: 1. we jointly chose a question for the systematic review; 2. the collaborative work on the review formed the basis of a qualitative case study. This paper focuses on the analysis of the case study data on how the involvement impacted on the quality and relevance of the systematic review, considering the question “Will service user involvement in research have the desired impact on research such that it becomes ‘better’ and more valid?”

Ethical approval for the study was granted by the research institution hosting the study and they commented particularly on the dual nature of the research. They were concerned that I ensured young people’s awareness of their participation in the case study, as well as the systematic review, to as far as possible avoid covert research. To address this, the information and consent forms emphasised the duality of the study, written consent was sought from each participating young person, and ongoing verbal consent was sought throughout to remind them of the ethnographic aspect of the meetings. Consent was sought for collecting data at research meetings, and for use of this in reporting the research.

Methods

Research Methods
Two types of research methods were employed simultaneously: the systematic reviewing and the ethnographic case study of the collaboration on the review. This meant that the young people were both collaborators on the systematic reviews and research participants providing data to the case study. The same was true for me, as the researcher, with the additional roles of co-ordinating the systematic review and analysing the case study data.

The data underpinning this article are my fieldwork journal (Hammersley & Atkinson 2007), meeting minutes and reflections, transcripts of audio-recorded research meetings, one-to-one interviews between young people 3 months into the study, and two focus groups with young people at the end of the study. This paper draws on three analyses of this data from the case study.

First, analysis of all qualitative data collected through meeting minutes and reflections, audio recording, interviews and focus groups (Pope et al., 2000). I developed an index chart displaying the main coding areas corresponding to the case study’s research objectives and questions. Within each coding area, my approach was similar to thematic conceptual analysis (Miles and Huberman, 1994). When the initial coding was completed I ran several network analyses, exploring the relationship between the sub-codes and the main coding areas. Main themes from the initial analysis were brought back to the young people for their views, which in turn informed the final fine-tuning of categories. A critical incident chart, in the form of a table, was collated. In this paper I focus on my coding areas around impact, which captured how the young people influenced the review and when.
Second, I appraised the review in terms of its topic and question, the protocol, search strategy, screening of search hits, study analysis and synthesis. I then considered which aspects of the review clearly came from the young people’s involvement, and which had been ‘off limits’ to young people’s influence.

Third, our review was assessed by an experienced systematic reviewer not involved in this study and compared with two other systematic reviews, using the AMSTAR checklist (Shea et al., 2007). One review was called “Improving the educational outcomes for looked-after children and young people” (Brodie et al., 2009). The other review was “Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth” (Wilson et al., 2011). The two reviews are briefly described in Table 2.

[Table 2: Abstracts of the two comparison reviews on education support]

<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(From website of the Campbell Collaboration) A new Campbell Review suggests that most dropout prevention and intervention programs are effective in decreasing school dropout when implemented well and adjusted to local context.</td>
</tr>
</tbody>
</table>

The review suggests that no single prevention or intervention strategy stands out as better than any other. The results suggest that the particular program strategy chosen makes less of a difference in eventual outcome than selecting a strategy that can be implemented successfully by the school or agency. Therefore, the authors recommend that policy-makers and practitioners consider cost-effectiveness, adaptation to local needs and a good strategy for implementation when choosing a dropout prevention or intervention program.
Involvement Methods

The systematic review was initially introduced as a research summary, rather than going into the intricacies of systematic reviewing methods. The information leaflet said:

“In this project we will make a summary of research done on a chosen topic. Making a summary of research includes looking for information, and deciding if the information is of good enough quality.”

I provided training on systematic reviewing at each stage of the review.

The initiating group first said they wanted to keep the review group closed to new members, but then welcomed new people on an ongoing basis. Twenty care leavers aged 16-24 attended at least one meeting, eight young men and twelve young women. Three were from the UK and the rest were unaccompanied asylum seekers from Central and East Africa (13), Eastern Europe (3), and Central Asia (1).

There were 20 meetings over two years. Five of the young people attended four meetings or more, and two of them were involved in every stage of the review, in addition to conference
attendance and presentation. The core group were four young women and one young man.

Most of the young people had mainly experienced foster care, or a combination of foster and residential care, but one of the core group’s members had mainly experienced residential care.

The review itself is published elsewhere (Liabo et al., 2012), but for reference a summary of findings is provided in Table 1.

[Table 1: Summary of review findings]

| The systematic review evaluated the impact of interventions to support looked-after children in school. Included interventions aimed to improve attainment, prevent drop-out or exclusions, and reduce absenteeism in the care population. The review concluded that the development of programmes is still in its early stages, in spite of the education of looked after children being a concern of researchers, policy makers and practitioners for years, and that the leap from correlation studies to outcome evaluations of interventions has yet to be made. In the absence of clear findings on impact, studies were appraised in terms of their conceptual clarity, theoretical approaches, and policy aims: Studies provided only brief descriptions of the problem of education and looked after children, and with a focus on system failings, rather than more complex analyses including early life and family circumstances. While most interventions were adequately described, policy evaluations focused more on process than intervention components. There was large heterogeneity of outcomes across the studies but none of the studies provided a rationale for their chosen outcomes. Only two studies provided in-depth description for how the intervention would produce change. Finally, there appeared to be a dissonance between policy makers’, researchers’ and practitioners’ expectations of programmes. While some studies have included the views of young people in care on broad concerns in education, we did not find any that had asked young people’s views on specific interventions. |

The young people were encouraged to take on active roles within the review and be involved in both the reviewing and the practicalities of meeting. Following findings by Oliver et al (Oliver et al., 2004) I aimed for an overall collaborative way of working, where through
deliberation we would make joint decisions. I considered everyone’s contribution with regard to their unique expertise (Collins and Evans, 2002). Young people brought experience-based expertise on the topic of looked after children, and I brought technical expertise on the topic of systematic reviewing (Stewart and Liabo, 2012). Within the collaboration the young people would have a stronger say on topic-related decisions, whereas I would have a stronger say on the technical reviewing decisions.

Systematic reviewing involves technical skills in database searching, reference screening, critical appraisal and research analysis, and research training was essential. To maintain flexibility for involvement, I provided ongoing research training. When the review question was set, the young people were introduced to the specific methods of the kinds of studies which could be used to address the question. Once the review was under way they were at each stage introduced to the main aspects of that research stage, what tasks were required and why. Training was provided at each meeting, sometimes alongside the information-sharing and decision-making.

Figure 1 provides an overview of how young people were involved in each stage of the review. ‘Consultation’ refers to when I prepared information about research and discussed this with the young people who commented on and presented their views in response.

‘Collaboration’ refers to when the young people were involved in doing the research as well as setting priorities and making decisions. For example, the review protocol developed through a series of discussions on inclusion and exclusion criteria, outcomes and interventions. I presented them with the key components of a review protocol, and
explained what each referred to. The young people then made decisions in relation to each, for example on the characteristics of the population we would include.
[Figure 1: Young people’s level of involvement at each stage of the review]
Results

As the review progressed the young people took a more active role in driving the review forward as well as responding to my initiatives. Their influence was therefore both on the review and on the organisation of the research. They would invite other young people to come to the meetings, suggest meeting dates and initiate dissemination activities. This paper focuses on the impact of their involvement on the research, not on research organisation.

Impact of involvement refers to how these decisions shaped the final systematic review, and how the interaction with young people influenced my reviewing. The framework for the discussions was developed and facilitated by me, and so I had a direct influence on these discussions. Young people were new to systematic reviewing and needed a structure for inputting their perspectives. Considering my technical expertise in systematic reviewing, I took leadership in driving the study forward. These results therefore reflect young people’s input, in response to my initiative.

Impact on Review Scope and Focus

Review topic and question

Denzel [exasperated]: I’m just saying I don’t want the topic to be alcohol and illegal drugs but that’s my personal view. [interruption, all at once]
Carla: why? [all at once]
Denzel: ‘cause I don’t want to, don’t want to tarnish young people with a brush with alcohol and illegal drugs
Mart [on top of Denzel]: fair enough, fair enough

(2nd research topic prioritisation meeting)

My funding application stated that the review would be relevant to looked after children’s health. Through fierce debates across three meetings, the group discussed various topics, most of which were topics often associated with looked after children in a negative way. Included in these debates were therefore concerns about avoiding stigmatising language or angles to the review. At the third meeting the group decided to focus the review on education, arguing that education is the most important thing in a person’s life, and that it is imperative to health.

The young people also decided that the review would focus on solutions or support interventions rather than understanding the nature of the problem. This resulted in a final review title ‘Interventions to support looked after children to stay in school’. This was based on young people’s decisions that the review would focus on: education, how to solve a problem, ‘support’, and ‘staying in’ rather than ‘dropping out’:

Ermad: ... ‘cause we can’t, can’t just produce findings with just negative, that’s not gonna motivate anyone
Mart: exactly [unclear] constantly thinking about the negative. If we’re constantly talking about the negative I mean ...
The suggestion for using the term ‘staying in school’ was directly from a young person at the second protocol writing meeting (not recorded due to consent not given\(^1\)). Comparing our published review with Brodie et al 2009, and Wilson et al 2011, the review questions differed both in scope and language used. Wilson et al (2011) used the term ‘drop-out prevention’. Brodie et al (2009) focused on achievement, again the outcome most commonly measured in identified research evaluations, but not prioritised by our group.

**Review Protocol**

Beth: … if you’re having a child that’s left their parents live with an aunt and uncle they still have that family support, they still have their kind of, I don’t know what it’s called, you know that family support, whereas you know, if the kid’s taken to a foster, foster carer or a home, they’ve lost all of that family support, so it’s two completely different...

(Discussing population section in fourth protocol meeting)

We followed the established structure for systematic review protocols, but the young people made several decisions which went against my expectations: we excluded studies on kinship care and disabled children. As indicated by the quotation above, the young people argued that kinship care is inherently different from other foster and residential care

\(^1\) At this meeting one participant consented to participation in the research but rejected to audio recording of the meeting. I did not probe this young person as to why recording was rejected.
because you are moved in to live with someone you already know. In terms of looked after children with disabilities they were concerned about the validity of drawing conclusions from studies where the population would have a second factor impacting on their education:

Beth: but then as you said about the specialised schools, those specialised schools give them a different, a whole, completely different education, so then that’s why I didn’t think it would be an accurate account, because they’re not getting the same education

Kristin: yeah. So what we could say is that we will only include studies in mainstream schools.

Beth: yeah

Kristin: shall we say that?

Beth: yeah

Maria: yeah

(Discussing population section in fourth protocol meeting)

Finally, they wanted the review to exclusively focus on interventions for mainstream children in care rather than including all sub-groups of this population. Again, this could be seen to reflect their desire to avoid stigmatisation.

Finding relevant studies for inclusion in the review

Young people took part in the searching for studies, but since this requires technical knowledge of searching bibliographic databases their impact was limited. At a searching
workshop at the university’s computer lab they came up with some search terms which were not used by other reviews on the same population:


Kristin: Care leavers?
Noor: Yeah.
Kristin: And?
Noor: Accommodated children.
Kristin: Accommodated children, okay, has anybody else thought about the population, anything to add?
Maria: ‘Children asylum team’

(First searching workshop)

Including these terms did not yield a higher number of hits, however, or appear to identify any other studies, than when using researcher-devised terms.

Screening of studies

Young people’s involvement in the screening of study abstracts was more extensive than I anticipated. Four young people contributed extensively to the screening of papers, and two of them screened 817 abstracts between them (12.5% of the total number of hits).

The testing of the screening tool resulted in the study inclusion criteria being changed to include studies on interventions to improve attainment as well as attendance. This decision
was made in discussions between the topic experts (young people) and technical expert (me, as the systematic reviewer), and was recorded explicitly in the review’s methods section.

The involvement in screening further exposed how looked after children are often, in the language of research, associated with other groups such as those with behaviour difficulties and offending behaviour. While the young people did not deny that this was a significant subgroup of looked after children, they objected to being automatically incorporated within these groups.

Kristin: .... The other one that we decided on the last meeting that you couldn’t come to, Denzel, was about offending, and that’s another tricky one, because I was tempted to include offending, but you guys were saying absolutely not, and we decided not to include it and, yeah...

Beth: It was all three of us, like.

(Fourth screening meeting)

Systematic reviews are especially good for exposing gaps in the research literature and when involving members of the public this extends to exposing bias in research language. In the quotation above, the young people had objected to the broader inclusion of young offenders as well as looked after children, whereas much of the research in our database did not. Further, this was also an illustration of how the young people pushed through decisions which may have gone the other way if the team had consisted only of researchers.
Young people found the research abstracts during screening hard to decipher, and decided not to read the full reports of the included studies. To account for this I ‘translated’ the reports into summaries and graphic descriptions of the interventions and the results. While this can be seen as problematic because the young people got my interpretation of studies rather than making a decision on the original reports, they would not have participated in this stage without them. Based on these summaries their discussion informed the analysis and conclusion of the review. Young people organised the included studies into intervention categories:

Denzel: I’ve got one here that I think goes with the Virtual School Head.

Mahad: And that one, it goes with that one.

Kristin: Sorry. Oh yeah, okay so you’ve got a Catch Up...

Mahad: Yeah a Catch Up with this one... It says Catch Up starts with assessing individual’s strengths and weaknesses in each child. Then uses this to set literacy targets and to identify the most appropriate Catch Up book level, book that individual can read without a problem.

(First analysis meeting)

Discussing the studies’ outcome measures we found that these differed from young people’s priorities. This in turn informed the review’s consideration of outcomes in the included studies, and also highlighted the lack of connection in most studies between the intervention and expected outcomes. For example, few studies provided in-depth
description of the rationale for how the intervention would produce change. Some studies concluded that the initial expectations of the intervention’s outcomes were unrealistic. This underpinned the review’s argument that education for looked after children is a poorly conceptualised area with unclear aims for what it is that these interventions are trying to achieve.

Beth: I’m not bothered by attainment to be honest, I’m not that bothered ‘cos I don’t think it should... as long as a child tries their best, then that’s all that you can ask for, whereas if their... I think to me, the most important thing is attending, not being excluded or expelled.

Kristin: It’s really interesting that you say that because, like I said, all the studies, bar one, so ten studies...

Denzel: I think attainment is important but I wouldn’t say it’s the be all and end of our... I think attainment has its part to play because I think... look, for me, you’ve got staying in school, motivation to go to school, attainment, and again, it starts from the bottom that I think if you’re doing well at school, you’re gonna be motivated to go to school, which is, in turn, gonna mean you stay in school.

(Third analysis meeting)

Impact on Review Quality

The AMSTAR checklist (Shea et al., 2007) was used to compare our review with two other systematic reviews on similar topics. This comparison found that the review by Wilson et al
(2011) was a high quality systematic review and that our review did not match up to their transparency and reporting standards. The AMSTAR assessment indicated that our review was more transparent than the review by Brodie et al (2009). None of the other reviews identified additional studies to the ones we found, which indicates that our search strategy and inclusion criteria were sound.

Our review originally aimed for an *a priori* design, but the review question and protocol were changed during screening and critical appraisal, as described earlier. It can be difficult to conduct *a priori* systematic reviews with people who have little or no research experience, because they may not fully appreciate the later consequences of decisions made early on in the research cycle. It is the role of the professional researcher to highlight this, but it can be difficult to do so in a collaborative spirit when incorporating people’s views is part of the overall project. Research teams will also often have to revisit their review protocols and original plans, and it has been acknowledged that judgements made at later stages are often not transparent in reviews (Boaz *et al* 2006).

Our review shows that the involvement of lay groups can highlight these often hidden judgements and thereby improve review transparency. This is partly due to the ongoing dialogue within the co-production of the review, between people who have different types of expertise, or belong to different ‘communities of practice’ (Wenger, 1998). This means that a co-produced research study will need to revisit the meanings of certain words, as well as the focus of the research, to a larger extent than research teams embedded in the same ‘community of practice’ where certain assumptions are taken for granted. One example is the young people’s decision to use the phrase ‘stay in school’ rather than ‘dropping out’.
Another example is their critique of the identified studies’ focus on achievement outcomes, described above. So while our review did not score fully on AMSTAR transparency, it did expose other aspects of the reviewing which were not picked up by the AMSTAR checklist.

It can further be argued that the idea of an *a priori* review is itself flawed because focusing effort on an answerable question requires some familiarity with the existing literature. An ‘empty’ review offers little learning (Yaffe et al., 2012). Deciding to focus on a particular question, developing the question, and writing the protocol are all iterative processes that involve interpreting knowledge (Hammersley, 2001). Further interpretation and deliberation occur at each stage of the review. As such, the involvement process exposed the systematic reviewing as a process in which knowledge is socially constructed.

I also found that the involvement of young people had a considerable impact on my own work on the review. First, it changed my knowledge and perspectives on looked after young people and their situation. Second, working with a stigmatised and vulnerabilised group made me reflect in-depth about my own writing and that of the identified studies and policy frameworks. Looked after children are sometimes placed under an overall category of ‘vulnerable children’, which is the kind of negative label that the young people had tried to avoid with our work. When screening I became more aware of whether I thought a study would chime with young people’s views on what is important, or their self-perceptions.

The young people’s views on study quality also required me to consider a wider range of studies than I would have chosen alone, and to be open to how these studies could contribute to furthering knowledge in this field. Many reviews which set out to aggregate
knowledge would discard studies of inferior design, whereas ours became more configurable due to the wider range of study designs included and the lack of adequate effectiveness research in this area. Rather than presenting an empty review, this enabled us to point to future research directions in relation to evaluation theory.

In comparison to Wilson et al (2011) and Brodie et al (2009) our review showed how a review can set out to address a specific question about effectiveness and through deliberation within the review group and by the nature of the studies found, inform theoretical consideration of the research question. This process was directly informed and motivated by the young people’s involvement because of their novice status, because of their expert knowledge, and because this required me to re-think processes and terms often taken for granted within review groups consisting only of researchers and technical experts.

**Barriers to Impact and Negative Impact**

Of course, young people’s impact on the review was also conditioned by the context of the involvement. The review was funded due to its involvement of young people and I was accountable to them. I had to make sure I included their views and completed a review with them, and I needed to show that I had done so. However, the funding was provided to me, and I initiated the project with certain aims in mind. In addition, while I subscribe to the arguments put forward by Mayall and others (Christensen, 2004; Mayall, 2002) on the generational order of power in society, I cannot evade the replication of some of these
power relations in a study where the researcher is an adult and the collaborating public are young people.

Particular aspects of the involvement methods presented barriers to young people’s impact on the review. Most notably, the first voting on the review topic was fraught because of the decision-making method, which was a show of hands, leaving people’s votes open to the influence of other members of the collaboration. Some young people felt that I influenced the votes when I helped one group write down their arguments when they expressed reluctance to do so.

Systematic reviewing is still a fairly unknown research design outside of academia. Much time was spent on introducing young people to the particularities of type of research. This hindered young people’s impact on at least two levels. First, many young people preferred to drop in on the study at convenient times but the various stages of the review required knowledge of the technicalities involved to do research at that particular stage. As a result, many young people dropped out after one or two meetings. Second, their involvement was founded on my particular stance on systematic reviewing. While I aimed to encourage their agency on the review, to support their ‘free’ involvement, I had to recognise that their introduction to systematic reviewing and therefore knowledge on the topic was framed by my own training and convictions in relation to this study design and methods. This is a conundrum all researchers will face when involving novices in research: involvement without structure is meaningless, yet the structure will shape their growing research knowledge, how they engage and what they contribute. Of course, the more research
knowledge people gain, the more they will be able to challenge existing conventions (Epstein, 1995).

Discussion

The question of whether involvement of members of the public in research impacts on the quality of the research is important because the future expansion of involvement relies on it. If involvement has a negative impact on academic research, this is likely to weigh heavier than the relevance argument which has so far been evidenced in involvement evaluations (Oliver et al., 2004).

This qualitative evaluation found that the young people’s impact on the review was substantial on the review’s focus and quality. In choosing education as topic they challenged the review to go beyond obvious health-related topics, focusing instead on fundamental opportunities for optimising health in the long term (Lleras-Muney, 2005). The young people also wanted to use this review to fight against the marginalising discourse dominating the literature on looked after children. Considering the overwhelming bias of middle-class perspectives in published research, this shows how essential it is to increase impact from socially excluded groups on the questions asked in research, and the analysis of findings.

This impact was both limited and enabled by the structure I set up for their participation, and by established conventions for systematic reviewing. Some proponents of service user involvement in research might see the process described here as being too constrictive in
terms of involvement. I argue that this trade-off between agency and structure is necessary. The young people contributed with their unique expertise, I with mine. During our interaction, I convinced the young people to limit the scope of the review, for practical and technical reasons. The young people convinced me to alter the scope as a result of the initial screening. Both these decisions aided the process of producing a high quality, practice-relevant, systematic review.

The collaboration challenged my own research training, unwritten assumptions about research and implicit prejudices about young people. Sitting face to face with young people when talking about study characteristics influences how study relevance is seen, because the topic is brought onto the table not just by the study but by people in the room. Particularly in the screening of studies, comparing the language and focus of the abstracts with that of the young people highlighted differences between research perspectives and service user experiences and characteristics, which in turn influenced how the review was shaped.

This enhanced the transparency of the review, brought about by our ongoing and active reflection of what we were doing and the qualitative evaluation of the collaboration. Also, because of our differing skills and expertise we were more aware of what each of us brought to the research, and we had to justify our viewpoints to each other. This was particularly relevant for me, as the researcher. We were not a group of colleagues making decisions where much of the conversation contains implicit meaning which is understood within an established community of practice. We were from different communities of
practice and therefore had to use different words and communicate clearly to each other
the anticipated implications of our decisions.

This study therefore adds to research which has exposed the social nature of science, how it
is created in social interaction, influenced by the relationships between those driving the
study forward. Involvement makes research more relevant to its field, to the real world, but
it also exposes the research process and thereby enhances its transparency. This is
beneficial to science, and to those wanting to use the results. This study found that
involvement improves the internal validity of a study by making research decisions more
transparent and accountable, and it improves the external validity because it makes the
research more relevant to the field.

This study found strong arguments for why public involvement is beneficial to research, but
it does not suggest that it is necessarily so, nor does it downgrade researchers’ essential
contribution to high quality research. Instead, with others I argue that the benefit of service
user involvement comes about when their expertise is paired with academic skills (Collins
and Evans, 2002). The craft of research, thinking critically about external and internal input
to a study, and balancing internal and external validity issues, remains an essential part of
any study. As well as an open attitude by the researcher to include the views of lay expert
groups, there is a need for research leadership to ensure that the study remains a research
study, based on established criteria for research. While these criteria should be open for
critical assessment by the public, the responsibility for ensuring academic rigour ultimately
lies with the researcher.
Conclusions

Political motivations for service user involvement in research come from rights, empowerment and consumerist arguments. This study shows how public involvement may benefit research itself. No matter what methods they apply, researchers are prone to bias due to factors such as their personal, educational and social class backgrounds, ethnic group, and so on. Involving experience-based experts in setting research priorities has the potential to introduce other perspectives to the research, and highlight problems which would otherwise have been overlooked by academia (Entwistle et al., 1998; Epstein, 1995).

As evidenced in this narrative on a research collaboration with a group of young people with experience of being in care, their input into the study challenged existing stereotyping of this population. For example, young people insisted that we focused on ‘staying in school’ rather than ‘dropping out’, and they objected to studies which in their view had conflated looked after children with young offenders.

In this study the young people’s influence functioned as a counter-balance to the researcher bias. I was accountable to them, not just my supervisors and my academic colleagues. This improved my reviewing and the review. The young people pushed the boundaries of my research framework and this resulted in a broader but no less rigorous review. In fact, their involvement in the screening process meant that we were successful in reaching our double screening target. Ultimately, however, the involvement rested on my willingness to include young people’s views, and my insistence on academic rigour. This paper argues that
research can benefit substantially, and epistemologically, from collaborating with people with different perspectives of the topic being researched.

The story of how this systematic review developed, and the collaboration between the young people and myself, also illustrate how participation is not an A-B intervention from which a set of pre-defined outcomes can be measured. Involvement in research is a give and take relationship based on ongoing deliberations, decision-making and discussions, and includes a whole variety of forms, rationales and stakeholders (Oliver et al., 2015). Values are central to all forms of involvement, whether these relate to ontological and epistemological questions in research, or whether they relate to participation as a right. Introducing an instrumental concept of ‘impact’ to an inherently value-infused enterprise seems contradictory.

At the beginning of this article I asked the question “Will service user involvement in research have the desired impact on research such that it becomes ‘better’ and more ‘valid’? My account of working with a group of care leavers on a systematic review indicates that the answer to this is ‘possibly’, and that the result rests on those involved in the collaboration. Researchers who involve service users need to be open to influence from those who are new to research, and people involved need to be willing to engage with the sometimes difficult notions and methods used in research. Involvement in research brings people together to discuss topics of importance: outcomes are reached through dialogue, joint learning, and deliberation. Impact in this context relates to whether people engaged, whether the process was meaningful, whether it inspired further action and engagement –
not in terms of quantifiable outcomes. As such, if involvement is truly participatory, it will always influence the research.

Acknowledgement: This research was funded by the National Institute for Health Research Fellowship Programme RDA/02/06/065. Kristin Liabo's time for writing this paper was supported by the NIHR Collaboration for Leadership in Applied Health Research and Care South West Peninsula. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health

References


