

**Service user involvement in research:
Collaborating on a systematic review with
young people who have experience of
being in care**

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Abstract of thesis

This study was conducted as an inquiry into the involvement of service users in research. It was informed by theories of the social construction of science, which argue that knowledge is dependent on those who frame, prioritise and conduct research. People with experiential knowledge as opposed to those with professional training have traditionally been excluded from these processes, although their experiences may differ considerably from the professional judgement of it, resulting in research which is removed from the realities of those whose lives it describes. This study was also informed by an argument that involvement of people with experience in the field of investigation can highlight areas neglected by previous research.

To investigate the nature of involvement and its potential, the study set up a collaborative working group with young people who had all experienced being looked after by the state. The young people were invited to be involved in setting the question for a systematic review on a health-related topic, and to participate in all stages of the research. Qualitative data was collected throughout this process, to inform a qualitative evaluation of the collaboration between the researcher and the young people.

This thesis first provides an overview of the literature on involvement in research and a description of the epistemological framework for the investigation. After presenting the study design and data analysis methods of the study, it describes how the young people were involved the research and presents the findings of the resulting systematic review. Based on in-depth analysis of the qualitative data collected during the collaboration, it considers the negative and positive impact of the involvement, on the review and on those involved. Finally, it considers the quality of the systematic review and discusses how consumer involvement may be optimised without compromising on the review quality.

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I hereby declare that, except when explicit attribution is made, the work presented in this thesis is entirely my own.

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A handwritten signature in black ink, appearing to read "K. Sturges".

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Title: Service user involvement in research: Collaborating on a systematic review with young people who have experience of being in care

Chapter 1: Introduction

The aim of this study was to add to the evidence-base on ways in which members of the public may be actively involved in the research process. I did this by setting up a collaboration with young people with experience of being in care, and worked with them on a systematic review on a topic of their choice. In this chapter I introduce the main readings that inspired this research. Drawing on seminal works in sociology and studies on activism I argue that involvement in health and social care research has derived from several strands of work which have rarely been consolidated in one study. I also describe my understanding of involvement in terms of its general nature and aims and key concepts.

Chapter 2: Service user involvement in research

There has been an increasing democratisation of decision-making processes in policy making, practice development and research, inspired by activism by people at the receiving end of services, as well as a shift towards consumerism in public policy. Several models for considering involvement have derived from this and are described in this chapter, which argues that these models suffer from a hierarchical concept of different levels of involvement. This hierarchical view ignores the fact that the mode of involvement does not necessarily determine the level of input service users may have on the final product. Rather than focus on the extent of the involvement, this chapter suggests that analytical work focus more on the concept of expertise and how service users' knowledge might best be incorporated into the research process.

Chapter 3: The UK care system and looked after children

The young people involved in this study all had experience of being in care. To contextualise the work I therefore provide a brief introduction to the UK care system and characteristics

of children in care as identified in research. While social care researchers have highlighted how looked after children are often protected from taking part in research, children's rights activists have pointed out that this is a group for which their right to protection tends to overrule their right to participation. Although this study primarily involved care leavers rather than those still in care, it is a step towards working with this population.

Chapter 4: The research questions and theoretical framework

This study first worked with a group of young people on a systematic review and then qualitatively analysed this process and its research products. The study investigated: 1) how young people can be involved in planning and conducting a systematic review, 2) whether a systematic review can be conducted in collaboration with young people and at the same time maintain quality standards in systematic reviewing, 3) the obstacles and facilitators to involvement at each stage of the research process, 4) how the involvement was experienced by those involved. While systematic reviewing has been accused of being 'positivist' and too narrowly focused on certain research designs, involvement has been seen as threatening the principles of scientific objectivity and rigour. This chapter presents the philosophical underpinnings of the two approaches, and argues that combining the two is likely to unlock further methodological potential rather than threatening research validity.

Chapter 5: Study design

This study aimed to produce a systematic review and simultaneously research the process of doing so. This chapter describes the overall study design, and the methods for each research component. The young people were recruited from the Participation Advocacy Service (PAS), which is an involvement initiative run by an inner-city children's services department. Considerations were made in relation to ethical aspects of the research such as confidentiality and my role as both a participant in the collaborative research team with young people and researcher of the process of involving them in the review. This chapter describes these ethical considerations, the planning of the involvement, and how I aimed to support young people's continuing participation. The chapter also describes how the systematic review plan followed established quality standards and procedures for

systematic reviewing. The involvement process was analysed using framework analysis, where the research questions informed the first readings of data, while also looking for themes emerging from the data itself.

Chapter 6: Involvement in the systematic review

This is the first findings chapter which addresses the question 'How can young people be involved in planning and conducting a systematic review?' It provides an overview of the levels of involvement across the review and key characteristics of the young people who participated. It then describes how the involvement panned out in each stage of the review and how it affected practical decisions about the organisation of the collaboration. An initial evaluation of the involvement process is considered in relation to a framework developed by Rowe and Frewer (2000) who suggest that involvement is best evaluated according to principles and standards rather than outcomes. Considering the process against their criteria shows that while the young people were involved to a high degree, the process itself suffered from lack of a formal framework and established frames of reference. This chapter nevertheless shows how young people can be involved in each stage of a review, but that the earlier stages may be more conducive to collaboration than the later stages. Involvement in the earlier stages of a study also enhances influence on later stages if service users influence the research framework and questions.

Chapter 7: A systematic review of interventions to support looked after children in school

The young people chose to focus the review on the poor educational outcomes for looked after children in the UK. The initial review question was 'What is the effectiveness of interventions to support looked after children to stay in school?', and the importance of this question was confirmed by relevant research literature and official statistics showing how looked after children under-perform in comparison with their peers and also have higher levels of truancy, exclusions and school drop-out. The systematic review initially sought studies that had evaluated interventions to reduce drop-out and exclusions, but during screening this was widened to also include studies that had assessed the impact of supporting looked after children to improve their literacy, numeracy or grades as much of

the literature focused mainly on these outcomes. As a result, the final review was titled 'Interventions to support looked after children in school'.

Chapter 8: What were the obstacles and facilitators to involvement?

This chapter presents findings from the analysis of obstacles and facilitators to the young people's involvement and discusses these with respect to four components of the collaboration: systematic reviewing, the people, the environment and the methods used for engaging young people in the reviewing. This analysis indicates that efforts to facilitate the involvement did not always achieve the intended outcome, and that systematic reviewing represents particular challenges to involvement which are unique to this research methodology. The chapter argues that successful involvement ultimately hinges on the attitudes of those involved, in particular those who are gatekeepers of the research.

Chapter 9: How did the involvement influence the systematic review?

This chapter returns to the involvement process described in Chapter 6 and contextualises it in relation to the obstacles and facilitators identified, and the extent to which young people had influenced the process of systematic reviewing and on the final review. It compares our review with two systematic reviews on education support programmes and considers the methodological quality of our review compared to these.

Chapter 10: What were the negative and positive experiences of the involvement?

The final findings chapter examines the views of the young people and the researcher on their experiences of being involved in the systematic review, what worked well and what did not work so well. This chapter also presents an analysis of the ongoing mutual learning between the researcher and the two young people who remained involved in the review from start to finish.

Chapter 11: Conclusion

Using an adapted version of an evaluation framework for involvement developed by Oliver et al (2011) this chapter presents an overview of the findings in this study, plotting them

against key aspects of involvement. This chapter provides a summary of the findings in relation to each study question and considers the ethical implications of involving young people with care experience in a systematic review. This chapter also considers the strengths and weaknesses of this study and sets out some implications for further research.

Chapter 1 INTRODUCTION

“What passes as scientific knowledge in Britain has been built up through a set of data-collection methods where minority voices can go unheard. ... Measures of social class, ‘race’ and sexuality, like those that tap into the experience of being disabled and non-disabled, can mask what women are most concerned about. They can simultaneously leave out what is most valued and what is most oppressive about being working class and Black, lesbian and disabled.” (Graham 1993: 198)

This thesis is inspired by sociological works which have recognised knowledge as multidimensional, and how a widening of perspectives can improve the validity of research and enhance our understanding of the social world (Becker 1967; Collins & Evans 2002; Gouldner 1968; Graham 1993; Oakley 2000; Wright Mills 1959). These works 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 (Becker 1967; Gouldner 1968), and whether health and social studies address what communities and people see as critical to their well-being:

“The broad subject-divisions current in modern sociology appear, at first sight, to be eminently logical and non-sexist. Social stratification, political institutions, religion, education, deviance, the sociology of industry and work, the family and marriage, and so on: these are, surely, just descriptions of different areas of human social life. To examine whether or not this is so one needs to ask three questions. First, to what extent are the experiences of women actually represented in the study of these life-areas; secondly, how does this representation compare with the empirical role of women in social life; and, lastly, do the subject categorizations themselves make sense from the perspective of women’s particular situation?” (Oakley 1974, p. 3-4).

Sociologists of deviance and feminism have provided critiques of academic frameworks and established ‘truths’. They argue that knowledge, and in particular knowledge about our

social world, alters according to the perspective and social position of the viewer (Becker 1967; Gouldner 1968). This social constructivist view of science does not mean subscribing to relativism or postmodernism. Rather, it is an acknowledgement that all research contains a degree of bias, and that some biases are inherent in researchers themselves, because we are all influenced by our own social situation: “Whether he knows it or not, the line-up of a man’s problems – how he states them and what priority he assigns to each – rests upon methods, theories, and values” (Wright Mills 1959, p. 143). This, Collins and Evans (2002) have argued, shows “that it is necessary to draw on ‘extra-scientific factors’ to bring about the closure of scientific and technical debates – scientific method, experiments, observations, and theories are not enough” (p. 239). In addition to technical and professional expertise, research needs to be informed by experiential expertise which traditionally has been ignored and treated as non-expert, or ‘lay’.

Outside of academia, interest groups and individuals themselves have also fought against what they perceive as discriminatory paradigms for researching their lives. Disabled people 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 & Evans 1999; Oliver 1992). In this vein, politics is central to knowledge production, and their arguments mirror those of sociologists of deviance, such as Becker (1967) who stated that because all research is political, researchers should take the side of marginalised groups.

The sociology of childhood stands both close to and aside from this. On the one hand it is a field of research where those who are the subject of inquiry have traditionally been seen as future members of society and culture, rather than active and valuable participants here and now (Prout & James 1997). The changing perspectives on childhood have largely been led by adult researchers who have argued for children’s rights and children’s value in society on their own merits, rather than as future adults. On the other hand, childhood research has been strongly rights-based, championing the rights of street children (Freire 1998), children in care (Winter 2006a), and all children as active and important contributors to society (Alderson 2008; Mayall 2002). As a result, children have been involved in research projects

and have also run their own studies, showing how their perspectives produce unique research questions and investigations within strong study designs (Kellett et al. 2004).

INVOLVEMENT OF SERVICE USERS IN RESEARCH

A range of terms have been used for initiatives which open up the planning of research or research tasks to the influence and input from people who have life experiences that are relevant to the topic of the research inquiry. 'Service user involvement in research', 'participatory action research' and 'community action research' aim to widen the basis for our research questions and framework, by tapping into experiential knowledge which researchers may or may not have themselves. Experiential expertise is seen as essential to developing relevant questions, using accurate tools and measuring outcomes that are important to end users of services. This thesis is an investigation into this kind of endeavour.

The main characteristics of such research are that people outside the research community have some degree of influence on the decisions made on a study or a research programme. Rather than acting as mere respondents to researchers' pre-set questions, people who are not researchers, but have relevant topical experience, are invited to influence the research funding, planning and priority setting, or to take an active part in the research study, including collecting and analysing data, and disseminating findings. People who are involved may be patients, members of the public, service users, or any person who has experience that is of relevance to the research questions.

Motivations for involvement in research derive from a variety of histories and rationales. Underlying all of these is the belief that research informed by the perspectives of people using services, will be more relevant to policy, practice and service users themselves. This argument sees patients and service users as experts, from living with an illness or facing social problems, and by having accessed, or failed to access, available services. It is argued that this kind of knowledge is accessible only through lived experiences and therefore if

research is to be relevant to patients and service users, studies must tap into their expertise and respond to their views (Beresford 2005).

This implies that service user involvement in research can be beneficial to enhancing study validity. Within science, ideas and initiatives for what to investigate and how are based on certain perspectives and views held by researchers and research funding organisations. The findings of health and social care research, and the conceptual frameworks within which they operate, have implications for how people and services are understood. Furthermore, research tools themselves may introduce bias to a study. Poor response rates to a questionnaire may be due to unintelligible phrasing of questions, or because the questions were felt to be irrelevant by the respondents. Service users may highlight where a trial recruitment strategy can be improved, because they are closer to patients' particular needs and behaviours, both in the clinic and at home.

Much of the research conducted in this vein has been rights-based, growing out of activist movements for enhancing the voice of service users in policy and practice (Wallcraft et al. 2003). Elsewhere the term 'community-based research' is used for the same purpose; "a recognized tool for addressing issues of power and exclusion within researcher/community relationships by inviting the community's equitable involvement as research partners" (Greene et al. 2009). Service user involvement in research and participatory research overlap, and both have been initiated by researchers, policy makers or service users and communities. This thesis is interested in how researchers can engage with service users and draw them in on the research decision-making. While it is based on a view of the importance of opening up research to the influence of a range of voices it was not initiated as a direct response to activism from young people.

INVOLVEMENT OF DIFFERENT GROUPS OF SERVICE USERS

A range of terms has been used to describe members of the public who are involved in planning or conducting research, including 'lay people', 'patients', 'consumers', 'citizens',

'stakeholders', 'survivors' and 'service users'. What they are called tends to reflect the role they are given, or take, within the research, and whether it is based on specific experiences of an illness or a treatment, or whether it is done to ensure a generally 'lay' perspective on the study. The language adopted by a research project or publication will reflect not just how the project approached the involvement, but also the underlying assumptions and biases of those controlling the work (Bastian 1998; Boote et al. 2002). A commonly used term like 'consumers', for example, has been criticised for its emphasis on choice and for ignoring the wider value of citizenship and public participation; "true citizens do more than consume" (Plamping & Delamothe 1991, p. 203). Similarly, the use of the term 'lay' indicates that those involved are not experts, when in fact they are asked to contribute their knowledge in relation to a specific experience. Collins and Evans (2002) therefore call them 'experience-based experts' as opposed to 'certified experts', which include researchers and professionals whose expertise is valued by examination certificates and membership in professional organisations.

Another criticism raised is that people involved are often referred to as what they are not, for example non-professionals or non-researchers, or that the terms define their relationship with services rather than emphasise their capacities. The UK organisation INVOLVE now uses the term 'public involvement in research', however, this does not capture the fact that people are usually involved owing to their experiential knowledge of the topic under investigation, rather than representing the general public. More than anything, discussions about these terms illustrate how poorly conceptualised this field of research is.

This study examines the involvement of young people with experience of being in care. When referring to them, I will use the term 'young people', and when referring to involvement in general I will use the terms 'users', 'service users', or 'the public'. I will use the term involvement rather than participation, although these two terms are largely overlapping. Primarily, my investigation is into how researchers can initiate the participation, or involvement, of service users in their research.

INVOLVEMENT ACROSS RESEARCH METHODOLOGIES AND STUDY DESIGNS

Qualitative research is often used as a method of inquiry into people's experiences, which explains why much service user involvement in research has been initiated within qualitative research designs (McNeish 1999). For example, in childhood research, methods have been developed to facilitate a flexible approach where respondents' views on the data-collection methods feed directly into how the study progresses (Christensen 2004). This is changing, and there are now examples of service user involvement across study designs and topic areas. One review has identified clinical trials and qualitative studies as particularly conducive to such involvement (Staley 2009). Many research designs build on the same principles and ideas as service user involvement, such as participatory research, action research and participatory rural appraisal. What distinguishes these participatory approaches is that involvement is built into their study design, whereas 'involvement in research' refers mainly to the drawing of experience-based expertise into traditional and established research designs, such as clinical trials, surveys, ethnographies or systematic reviews.

It is likely that the nature and methods of involvement need to vary across research designs and topic areas, although little has been written about this. All research designs are guided by frameworks and established criteria for methodological rigour. Participatory action research aims to facilitate change in practice as part of the research, which means that the study design by default is sensitive and responsive to external and internal views on the research process and findings, particularly by those directly affected by subsequent changes resulting from the research findings. Clinical trials are led by pre-designed protocols and scientific standards which are designed to reduce influence from respondents and enhance the objectivity of findings. This kind of study design does not have a long tradition of service user involvement, and established good research practice principles will in some cases even conflict with involvement.

The focus of this thesis is involvement in systematic reviewing. Systematic reviewing is a way of systematising and facilitating the flow of information from research and is a research method particularly well placed to bringing research findings closer to policy making and

practice (Chalmers 2003). Reviews' closeness to policy making means that they are important to advocates of service user involvement in research. Successful knowledge transfer requires research that can practically be made into interventions within existing policy and practice frameworks. This then raises the question as to whether the synthesised research is relevant to those who may use its findings (Stevens et al. 2005). Involving members of the public in prioritising and planning reviews may be one way of improving the relevance and usefulness of reviews. Involvement may also highlight convergences or gaps between researchers' priorities and frameworks and those of people who have traditionally been research objects only.

Chapter 2 SERVICE USER INVOLVEMENT IN RESEARCH

Service user involvement in research has evolved from many different movements and theories within policy, research and practice. Some of these have been political, some have been scientific, and some have been partisan movements with multiple aims. For example, the AIDS activist movement of 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 science, reduce biases, and open up science to a wider range of expertise and knowledge, service user involvement in research has also been about certain groups' fight for their identity, or for society's image of them as a group. The latter is important because science can add to such changes in images; for instance the HIV example showed that transmission happened through unprotected sex, which could support judgemental views on gay men's promiscuity, real or imagined. Science 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 misconceptions about what it means to be gay, disabled, female, or suffering from a particular illness.

This chapter unpacks the varying motivations for involving in research people with experience-based expertise. Building on the introductory chapter, it defines such involvement and presents the context and rationales underpinning such initiatives. Research is conducted in a political and cultural context, and so the push for participation and involvement in research is mirrored in politics, practice and culture, with museums and galleries having public engagement strategies and higher education institutions wider participation teams. Consultation exercises are standard components of UK policy making, exemplified in the development of Every Child Matters (Every Child Matters 2004), and in the emphasis on public participation among knowledge organisations such as the Social Care Institute for Excellence (SCIE) and the National Institute for Clinical Excellence (NICE).

This chapter also describes different models used to analyse public involvement. Although social activism in research, and academic works arguing for participation and involvement, appeared in the 1960s onwards, the involvement field is still lacking in theoretical frameworks for analysis. This, in turn, has meant that there has been little work on the impact of service user involvement on research, discussed in this chapter.

THE CONTEXT OF INVOLVEMENT IN RESEARCH

Citizen, public, patient, consumer or service user involvement in research, policy and practice is about crossing the boundaries between professionally acquired knowledge and experience-based knowledge, attempting to facilitate dialogue, collaboration and learning between the two, and making joint decisions. In research, this means that people are involved not just as research subjects, but in influencing decisions in regards to the research topic and how the research is carried out and disseminated. Traditionally, service users have taken part in studies which are initiated, designed and managed by researchers or funders of research. Service user involvement in research, however, facilitates service users' input into the planning and running of the research study. Since the early 1990s such involvement has increasingly become a priority within the NHS and other publicly funded services in the UK (O'Donnell & Entwistle 2004b).

In some models of such research, involving service users means that they are not just respondents to a pre-set agenda developed by the researcher, but take an active part in shaping that agenda. Their experiences as service users may mean that they have in-depth knowledge about particular aspects of the study, and from a different perspective than someone who has not received such services or experienced the condition. The aim is to develop research that reflect the priorities of people who are experiencing the problems, rather than the priorities of professionals who may only know the problems from a clinical, scientific or general 'outsiders' point of view. In other words, it means tapping into people's unique 'been there, done that' expertise. In health, concepts such as illness and well-being relate to individuals' subjective experience of disease. Incorporating the views of

patients contributes to a fuller understanding of how to provide services and treatment within the social model of health (Boote et al. 2002; Callaghan & Wistow 2006).

In research concerning children and young people, it is equally important to gain their perspectives, and develop methods that will enable us to do so, although in the past this is a group that has often been excluded from participation in matters that concern them (Prout 2003). In childhood research, participation often goes hand-in-hand with children's rights, and the UN Convention on the Rights of the Child (CRC) refers directly to children's participation, including their right to have their views heard in matters that affect them, and to participate "freely in cultural life and the arts" (United Nations 1990). Like all UN Conventions the CRC does not guarantee or demand that children's views are acted on.

There has also been a strong current of work on perspectives in social science. In his works on the sociology of knowledge, Merton discussed what he called the 'insider doctrine', which is based on the assumption that only people from within a group can understand other people within this group (Merton 1973). Merton's conclusion was that the insider perspective is necessary, but that it needs to be included in terms of scholarly work, rather than the assumption that lay insider knowledge is more valuable than scholarly outsider knowledge. This is similar to Collins and Evans, who argue that experience-based experts (for example service users) need to tap into knowledge production conducted by certified experts (for example researchers), but likewise "sociologists of knowledge should not be afraid of their expertise" (Collins & Evans 2002, p. 239, authors' emphasis). Researchers are experts on research, while experienced-based experts can provide important knowledge about the field.

More recently, the lay perspective has been increasingly emphasised as important to scholarly work. An examination of articles in the academic journal 'Sociology of Health & Illness', published between 1979 and 2002, found a change in the perception of the 'lay voice' during those years, "from a focus on lay health *beliefs and understandings* to a focus on lay *knowledge and expertise*" (Prior 2003, p. 42, my emphasis). As argued by Collin and Evans (2002) the use of the term 'lay' is redundant in this context because "'lay experts' are

just plain 'experts' – albeit their expertise has not been recognized by certification” (Collins & Evans 2002, p. 238).

In its mainstream form, service user involvement in research represents one strand of a wider push for citizen participation in publicly funded activities seen from the 1990s onwards. UK government departments have involved the public in the development of policies, and opinion polls are regularly used to assess the public's attitude to government initiatives. This is also true for children and young people's participation, which increased across the board from the early 1980s onwards (Prout 2003). Young people's views have been sought by a number of policy and practice initiatives in the UK, for example by the Children and Young People's Unit within the then Department for Education and Skills (Children and Young People's Unit 2002).

At the same time, organisations of patients, carers and parents of sick children have worked inside and outside the system to promote particular research, policy and service interests. Interest groups, often user-led, have played an important role in driving forward the rights of vulnerable groups, as well as their participation in research, policy and practice. For instance, patients have contributed to primary research findings in several areas including cancer research (Chalmers 1995). This has resulted in some important methodological and conceptual work on the relationship between researchers and the researched, as well as primary research findings. For example, research methods and consent forms have been developed to fit with children's ages and abilities (Curtis et al. 2004a; Prout 2003).

Lay involvement initiatives have shaped and been shaped by professional, national and international policies. As well as an increased awareness of rights amongst patients, the concept of patient-centred care has established itself in medical and nursing practices (Dawood 2005). Internationally, the UN conventions on the rights of specific groups, such as women (1979), children (1989) and disabled people (2007), have inspired and been inspired by advocacy movements both outside and within research. Increased participation supports citizens' rights as users of services, but policy makers and politicians have also used it to legitimise services in the face of declining participation in general elections, loss of public confidence in government funded services, and a perceived need to strengthen citizens'

responsibilities in a modern democracy (Barnes 1999; McNeish & Newman 2002). In the early 1990s there was an increased recognition of the potential value of enhancing public participation in the running of the modern welfare state. 'Consumers' and 'consultation' gave way to 'partners' and 'public engagement', reflecting a change from supply to demand driven services (Barnes 1999; Caron-Flinterman et al. 2006).

RATIONALES FOR INVOLVEMENT IN RESEARCH

The underlying reasons for involving service users in a research project will influence its aims and objectives, and in turn impact on how decisions are made and how the project is designed. Beresford (2002) suggests that two conceptual models of involvement have dominated discussions since the 1990s; consumerist and democratic approaches to participation. In childhood research, Sinclair (2004) suggests three main drivers; the consumer movement, the rights agenda and our understanding of the active role children can play in shaping their environment, related to our changed understanding of children's competencies (Sinclair 2004). Brownlie (2009) argues that the two underpinning rationales for participation are 'empowerment' and 'efficiency', and that these tend to "morph into what can be termed the 'participation versus rigour' debate" (Brownlie 2009:701). This suggests that there is a tension between research which is acceptable to research participants in terms of its relevance and ability to promote social change, and research which is seen as rigorous science. It has been maintained that "the existence of multiple rationales for public involvement itself suggests the absence of a clearly defined and accepted role for it" (Callaghan & Wistow 2006, p. 2293). Being clear about the underpinning rationales for the involvement is crucial in gaining understanding about the purpose of involvement and its intended outcomes for research and those involved.

I argue that impetus for involvement may be usefully considered along four strands. First, consumerist arguments for public involvement arose in the 1980s, when many countries privatised services previously funded by the government, and introduced market terminologies and management systems to those that remained in public ownership. This

was supported by the Organisation for Economic Co-operation and Development (OECD), which promoted a form of performance management in the public sector, also known as New Public Management. In the UK for example, the 1983 Griffiths Report suggested that the NHS utilise market research and consumer satisfaction surveys (Barnes 1999). The Citizen's Charter, introduced in 1991, was a continuation of this idea, that public services have customers, not just recipients, and that these customers have rights and thereby should be able to influence the quality of the services they are offered.

The consumer model emphasises the accountability required of public service management, and it is suggested that this accountability encourages patients and service users to exercise their rights. Public services should be effective, customer-focused and cost efficient (McGuire 2002). While these aims are commendable, the model fails to take into account the particular nature of public services, which make them substantially different from private initiatives. The market model is based on the assumption that customers have a complete overview of available options. However, the inequality of information means that active participation, making informed decisions and demanding more choice when need be, is more open to certain segments of 'consumers', such as the most advantaged in terms of resources to obtain information (Hyman & Shingler 1999).

Second, the UK the consumer focus from the late 1980s was carried forward in policies developed under the Labour government after 1997, but accompanied by a discourse of partnership and community participation (Barnes 1999). Democratic arguments for participation go beyond choice, to include people's rights and responsibilities to participate, and emphasise the importance of making the involvement meaningful (Starkey 2003). On the one hand individuals and interest groups have a right to be heard in decisions that will impact on their lives. On the other, through tax payment, we 'own' our public services and should therefore have a say in how they are run (Boote *et al.* 2002). To facilitate these rights, participation and public consultation is now systematically included in many policy developments, in a 'system of representation' (Cooke & Kothari 2001).

The arguments for involving children and young people in research often fall within the democratic category, but this group is particularly vulnerable to being used for tokenistic or

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decoration purposes, rather than engaging in true participation. Although young people's rights to participation in decisions that concern them are outlined in the UN Convention on the Rights of the Child, the Convention has been criticized for being too protectionist, and relying too much on the family as protector and guarantor of children's rights (Hart 1997). Studies on childhood have emphasised that children operate independently outside their family, at school and in the community (Davis & Hill 2006). However, like many other vulnerable groups, children and young people are in danger of being used to highlight agendas set by the more powerful, in this case adults, rather than expressing their own views. Although children's competencies are increasingly being recognised by adults, their views are still often "consulted but not heard" (Curtis *et al.* 2004a).

The third line of rationales for involvement has come from social activist groups who see true participation as having the ability to empower socially excluded groups and promote social change (Barton 2005; Beresford 2002; Boote *et al.* 2002; Starkey 2003). By participating in collective decision-making in research, policy or practice, marginalised groups have the opportunity to enhance their position in society. They learn about how democratic consultation processes work, and how to lobby, thus potentially gaining individual power as well as improving conditions for people in the same situation. One example is how disabled people were involved in changing terminology and pushing forward the social model of disability (Tregaskis 2002).

The empowerment model challenges notions of research objectivity, and argues that researchers themselves operate within ruling paradigms which are coercive to certain groups. The extent to which empowerment processes can be aided by others has been debated. There are practice theories within health and welfare professions which aim to empower service users to improve their own lives. A critique of these points out that there are risks associated with such models, because the practice can end up regulating as well as liberating vulnerable groups (Pease 2002). Empowerment practices have been criticised for aiming to socialise people into the values and standards of more dominant groups (Colley 2003; Henkel & Stirrat 2001; Kothari 2001).

Aside from the problems with the concept of empowerment itself, the role of liberation in research is not straightforward. Empowerment arguments are often linked with user-controlled research, where decisions on how the research is conducted are made by people who have a direct stake in the findings. Academic research is primarily concerned with the production of knowledge (Hammersley 2000) and the empowerment agenda therefore presents a challenge in terms of how we maintain the integrity and validity of research while opening up for the expertise and knowledge of those outside of academia (Becker 1967; Boote *et al.* 2002; David 2002). User led research therefore sits less comfortably with involvement in research as I have defined it here: because involvement in research is about input into established research designs, its decision-making needs to be balanced between research experts and experience-based experts. Of course, activist groups can learn about scientific methods and use this knowledge to challenge established research principles, as happened with the HIV activists' influence on trial design in the USA. In this example, activists' arguments were grounded in academic concerns with pragmatism in trials, as well as HIV patients' desire to be eligible for trial participation (Epstein 1995).

In addition to the political motivations for involvement described above, a fourth and final set of rationales are concerned with how public involvement may benefit research itself. As well as influencing the analysis of data, researchers' individual beliefs and world views also inform the questions driving our research and the outcomes we chose to measure. The view that scientific activities do not operate in a vacuum sheltered from society's values and political trends became prominent in the 1960s (Becker 1967; Berger & Luckmann 1991; Gouldner 1968). No matter what methods they apply, academic researchers' ideas are prone to bias on the basis of factors such as their personal, educational and social class backgrounds, ethnic group, and so on. Involving service users in setting research priorities has the potential to make research informed by views outside of academia, as well as identifying areas in need of further research. Service user involvement may highlight problems which would otherwise have been overlooked by research (Entwistle *et al.* 1998).

In other words, such involvement may improve research validity, and make it more relevant to subsequent decisions. Uptake of research findings in policy and practice has the potential

to improve outcomes for service users and patients, by stopping programmes that have been shown to produce detrimental effects, or helping to implement programmes that have produced positive outcomes (Chalmers 2003; Grimshaw *et al.* 2004). User involvement is therefore important because uptake of research depends on research being relevant and acceptable to users of services and treatments. One example is how lay women's views on smoking helped shape a systematic review of smoking cessation programmes for pregnant women (Oliver 2001). Expertise comes in both certified and experience-based forms, and science should tap into both of these (Collins & Evans 2002). Such outcome-focused arguments emphasise the instrumental impact public involvement can have, in making research more relevant and more effective.

DIMENSIONS OF INVOLVEMENT

Service user involvement in research can happen at a range of different points in the research life cycle, with different levels of influence and through different channels of participation. One of the most well-known models of participation is Arnstein's eight-rung 'ladder of participation', originally developed for community planning (Arnstein 1969). Her starting point is that involvement without power is meaningless. The bottom rungs of the ladder consist of non-participation dressed up as involvement. The next rungs up (3-5) are labelled tokenism. These consist of informing people of their rights, but without opportunities to exercise these. Citizen power is only achieved in levels 6-8, and takes the shape of partnership, delegated power or citizen control.

Hart (1992) has developed a children's version of Arnstein's ladder with manipulation and decoration at the bottom, which is particularly relevant to children. Further up there are degrees of participation ranging from tokenism to adult-initiated but shared decisions with children, and finally on the top are child-initiated projects (Hart 1992). Franklin (Boyden & Ennew 1997) developed Hart's 8-rung ladder into 10 levels of participation, defining the roles of adults and children on all levels (Table 2-1):

Participation		
Level 10	Children in charge	Children decide what to do. Adults get involved only if children ask for their help.
Level 9	Children lead, adults help	Children take the lead in deciding, with help from adults.
Level 8	Joint decision	Adults and children decide together on a basis of equality.
Level 7	Consultation	Adults consult children and consider their opinion carefully; then adults decide, taking all opinions in account.
Level 6	Invitation	Adults invite children's ideas but make the decisions themselves, on their own terms.
Pre-participation		
Level 5	Tokenism	Adults decide what to do. Afterwards, children are allowed to decide some minor aspects.
Level 4	Decoration	Adults decide what to do. Children take part by singing, dancing, and performing ceremonial functions.
Level 3	Manipulation	Adults decide what to do and ask children if they agree. Children must agree.
Level 2	Adults rule kindly	Adults make all the decisions. Children are told what to do and are given reasons and explanations.
Non-participation		
Level 1	Adults rule	Adults make all decisions. Children are told nothing except what they must do.
Level 0	No consideration	Children are not given any help or consideration at all. They are ignored.

Table 2-1: "The ladder of participation in matters concerning children" by Franklin 1997 (presented by Boyden and Ennew 1997, p. 53)

A revision of Hart's ladder is also provided by Shier (2001). He suggests five levels of participation in relation to children's involvement:

Children are listened to

Children are supported in expressing their views

Children's views are taken into account

Children are involved in decision-making processes

Children share power and responsibility for decision-making

In addition, Shier suggests three stages of commitment at each level: openings, opportunities and obligations. At the 'opening', an adult makes a personal commitment to working with children at that level. The 'opportunity' arises when practical needs are met, which makes the initiative possible, for example by the release of funds or development of new procedures. At the 'obligation' stage the initiative is integrated in the project, organisation or policy (Shier 2001).

The image of a ladder has been highly influential in analyses of involvement in research. At the 'top' levels of these models, service users have full control over decisions made, which is seen as more desirable than lower levels, where they have little or no decision-making powers. The ladders developed by Arnstein, Hart and Franklin make political points by emphasising situations which may be labelled participation by those in charge, but where people have no influence and are simply being used to sell an agenda set by the more powerful. This is a recognised problem not just in one-off policy consultations, but also in participation initiatives which are based on a deeper understanding of involvement, including participative rural research and empowerment practices (Mosse 2001; Pease 2002).

INVOLVE's 3-level model for public involvement in research resembles the taller ladders of participation and consists of: 1. consultation, 2. collaboration and 3. consumer control (Hanley et al. 2004a). Because INVOLVE (www.invo.org.uk) is part of the National Institute for Health Research and was specifically set up to support the involvement in NHS, public health and social care research, this model has been widely cited and used. This model also

categorises each level according to the level of decision-making. Oliver et al (2004) provide the following definition of these different levels:

Consultation: asking consumers for their views and using these views to inform decision-making. For example, funders of research have held one-off meetings with consumers to ask them about their priorities for research, or write to consumers in accessible terms to invite their views. Consumers' views were not necessarily adopted, although they may inform decisions.

Collaboration: active, on-going partnership with consumers. For example, consumers have been committee members or collaborated less formally to complete a task.

Consumer-controlled research: consumers designing, undertaking and disseminating the results of a research project. 'Professionals' were only involved at the invitation of the consumers.

This model does not contain a value judgement as to which level is most desirable, but recognises that the appropriateness of each level will vary depending on the research project and its context (Hanley et al. 2004a). Using this 3-level model, Boote et al (2002) have suggested that the level of involvement employed by a research project will indicate the extent to which it will empower the service users involved. The bottom level of involvement (and thereby the lowest empowerment) is consultation, moving up to collaboration, with user-led research at the top (Figure 2-1).

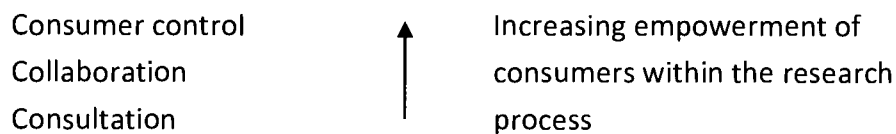


Figure 2-1: Levels of consumer involvement and empowerment (Boote et al 2002)

The image of a ladder has been criticised for its focus on decision-making, for seeing other forms of participation as less valuable and for not taking into account the fact that people's capacity for participation varies (ECPAT International 1999; Tritter & McCallum 2006).

Service user involvement does not in itself necessarily overcome the unequal relationship between researchers and consumers, and may even reinforce it. The ladders' differentiation between those with and those without power is seen as too simplistic and fails to reflect that lay knowledge, like other forms of knowledge, is constructed culturally, socially and politically (Kothari 2001).

'Community', as a concept, conceals power relations and covers up differences in interests within communities such as class, gender, ethnicity and age (Cooke & Kothari 2001). This point questions the suggestion made by Boote et al (2004); that increased involvement in decision-making will result in increased empowerment. Research on participative behaviour indicates that there is inequality in the level of engagement within the population, and that this tends to mirror other inequalities, such as education and income distribution (Hyman & Shingler 1999; Warland et al. 1984). Unequal power relationships may also exist within the service user group involved (Smith et al. 2002), and this may or may not be successfully addressed by those in charge of the study, whether they are researchers or lay service users.

Tritter and McCallum (2006) argue that Arnstein's ladder fails to recognise that participation may mean differing things to people. For example, young people who work as peer-researchers on a study may influence the way in which their lives are represented, even if they are not involved in making decisions about the focus of the study and the methods used. Information-sharing is therefore an essential part of involvement, not fully recognised within a ladder model. Instead of a hierarchical ladder, Tritter and McCallum (2006) use the image of a mosaic to illustrate the complex relationships in user involvement initiatives. Rather than a simple hierarchy, various people come together and complement each other's knowledge and skills. People's level of involvement and control will depend on the aims and objectives of the project as well as people's willingness or ability to be involved (Tritter & McCallum 2006).

In a framework for analysing service user involvement in health research Oliver et al (2004) have outlined eight different models, according to both service users' and researchers' level of engagement in the project. They categorise service users' degree of engagement as control, collaboration, consultation or minimal. Researchers' engagement is categorised according to whether they invite consumer groups or individual consumers to their project, respond to consumer action, are minor partners or completely absent (Table 2-2).

Researchers' degree of engagement	Consumers' degree of engagement			
	Consumer control	Collaboration	Consultation	Minimal
Inviting consumer groups		X	X	
Inviting individual consumers		X	X	
Responding to consumer action		X	X	X
Minor partner/absent	X			

Table 2-2: Levels of consumer involvement (Oliver et al 2004)

The crosses in Table 2-2 indicate eight types of involvement in research. The blank squares indicate unlikely scenarios, such as minimal engagement by service users in a project where researchers have invited them to participate (column 2, row 2). The levels in this model are less hierarchical than the ladders, and emphasise the distinction, also suggested elsewhere, between reactive, proactive or initiator involvement (Mullen et al. 1984).

A participation model developed specifically for the health policy context by Charles and DeMaio (1993) presents three variables that impact on involvement; a) the decision-making context or domain, b) the perspective adopted by the service users involved, and c) the level of participation. By adding context and perspectives to the levels of involvement, they make the point that participation is likely to vary accordingly. Service users' views may be based on personal experiences, or underpinned by policy concerns such as cost and prioritisation.

Their views will vary with their personal backgrounds, their reasons for being involved (context) and the level at which they are involved (Charles & DeMaio 1993).

All these levels may operate within a single research project, at different stages of the research. INVOLVE has suggested nine stages of research in which service users may be involved: 1) identifying topics for research; 2) prioritising topics for research; 3) commissioning research; 4) designing research; 5) managing research; 6) undertaking research; 7) analysing and interpreting the results of research; 8) disseminating the results of research; 9) evaluating the research process (Hanley et al. 2004b). Considering these across the levels of involvement, within one study, service users may have veto on the research question, but no impact on the research methods chosen to address this, yet participate in collecting data, be consulted on the data analysis and take a leading role in dissemination.

The nature of the involvement also depends on the experiences and personalities of the service users and researchers, and people may be involved as individuals or as members of an organised group (Oliver et al. 2004). In turn, the characteristics of the people involved will also influence how the involvement is facilitated, including the choice of methods for encouraging people to express their views. Qualitative methods used in decision-making include interviews, focus groups, Delphi surveys and citizen juries. Quantitative methods include surveys using ranking or rating to set priorities (Oliver et al. 2004).

How the involvement pans out in practice depends on people's motivations for engaging in a consultation or collaboration. From a decision-theory point of view, service users may be altruistic in their approach. They may participate in research because they believe that if everyone did it, it would produce better research. Or they may be utilitarians who will take part in order to promote the common good. This means that they would not take part if somebody else is already doing it, but they would if it was required. The utilitarian focuses on the common good for their group. People may also co-operate to achieve whatever is seen as being fair. They will take part if other people do, and they will contribute if other people do, but they will not, like the altruists, contribute irrespective of this. If other people do not contribute they are not going to either (Elster 1989). Finally, people may make a

rational choice about their involvement, in terms of considering what they personally would achieve by participating. A mixture of motivations is likely to be the case for many.

A research project may operate with a high formal level of participation, but if service users feel alienated or excluded, they are unlikely to participate actively in information-sharing and decisions. Furthermore, some researchers may not operate with formal models of involvement, but still employ participatory techniques which cater for a reciprocal dialogue in the research process. For example, in her ethnographic work in a primary school, Christensen (2004) adapted her research methods to suit the children's needs. When the children expressed discontent with her "silly questions", she shifted her approach "to find a way that better corresponded with the children's own practices and strategies" (169). Her research was not conducted in the vein of service user involvement, but was shaped in dialogue with her research subjects, and by listening to them (Christensen 2004). Formal models are useful for planning research which involve service users, and for analysing the involvement, but they do not guarantee a shift in power, in terms of influence on decision-making.

As Foucault argued, power is not something that individuals hold, but something that exists in social relations (Barker & Roberts 1993; Foucault 1980). Practically, it may be claimed that the powerful in involvement initiatives is the researcher, because she holds the budget control, has the research experience and may be more highly educated. This claim ignores the social relationships that occur in these initiatives. Some service users may be in a position to block the researcher's access to the field, or emphasise that without their co-operation the research will not get funded. In the latter example, the service users are in possession of something the researcher has not (in-depth knowledge, link to the field), and they may use this to control parts of the relationship with the researcher.

Ultimately, the level of influence service users have on the research in which they are involved, depends largely on the different dimensions outlined here, but also on how they are implemented. A study open for input from research participants is arguably more involving than one which does not do so, even if the influence is ad-hoc and informal. Furthermore, a well-conducted consultation exercise may in reality give more voice to

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service users than a poorly conducted user-led research project. The extent to which involvement is meaningful does not only depend on the levels at which people participate, but whether their views are heard and integrated into the study framework. Rather than a hierarchical model, involvement may be considered along a five-stage process, as illustrated in Figure 2-2:

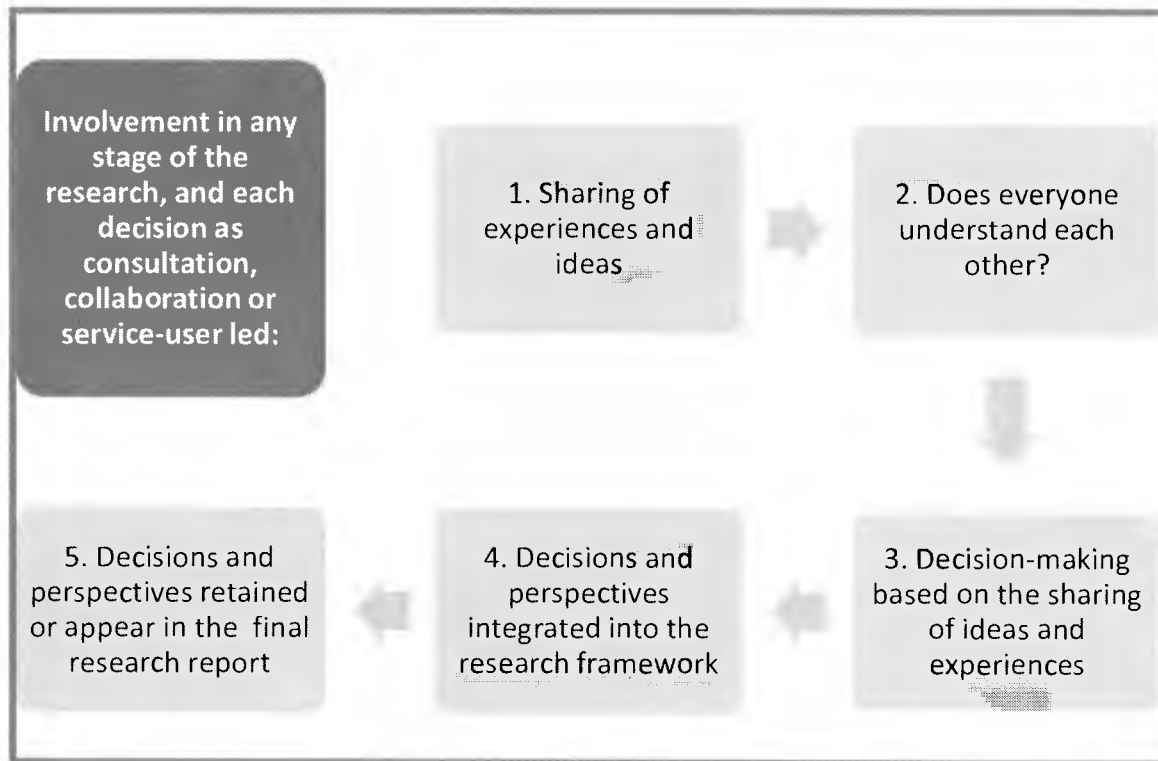


Figure 2-2: the involvement process' key stages adapted from Oliver et al (2011)

In Figure 2-2 the key stages of the involvement process are emphasised, especially information-sharing and decision-making. This figure includes the stages of whether people's perspectives and decisions were integrated into the research, and whether they were evident in the final research report. Each decision can be collaborative, consultative, or led by service-users, and this process will be repeated, or not, at each stage of the research lifecycle, depending on where in the research the involvement is sought. At each stage, people's expertise is central to their contribution, following on from Collin and Evans' (2002) notion of experience-based experts. People are involved due to their experiences, not simply by being 'lay' or 'members of the public', as illustrated in Figure 2-3, taken from Stewart and Liabo (2012):

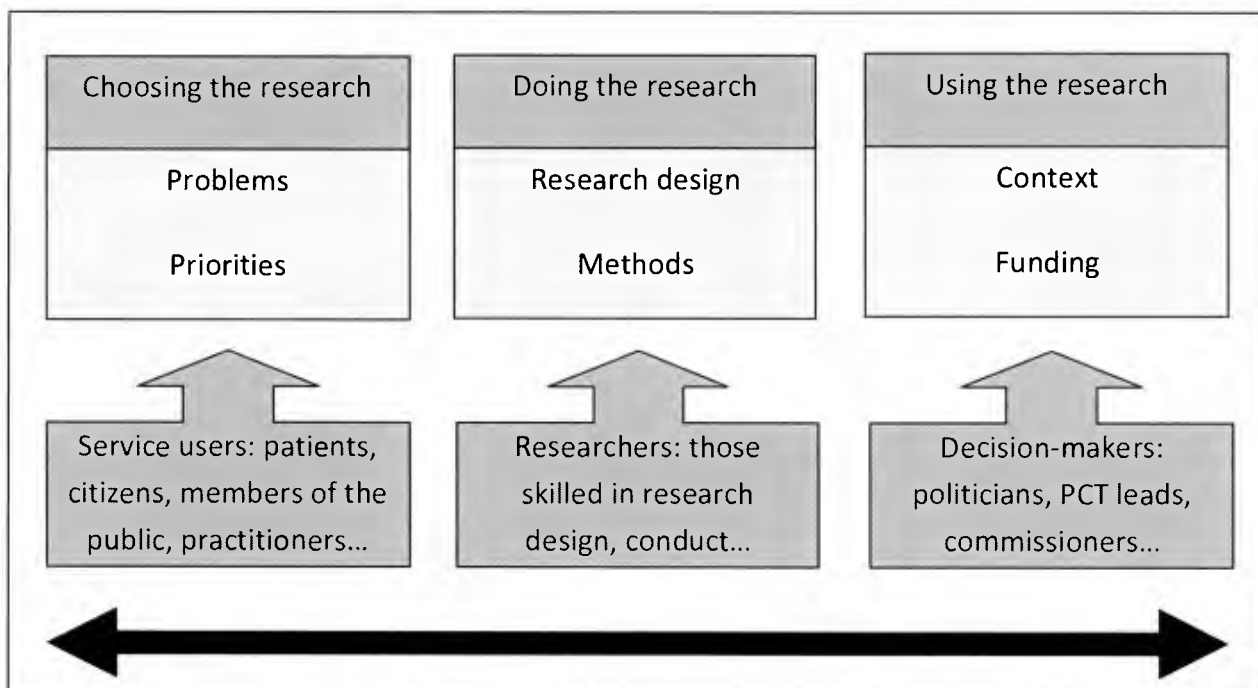


Figure 2-3: Experience relevant to research (Stewart & Liabo 2012)

Central to this model is the emphasis on why patients, service users, children or other groups are or should be involved as experts in research studies. It does not exclude researchers from prioritisation, nor service users from doing the research, but it emphasises that people’s expertise varies, and that certain experts ought to have more influence at different stages of the research lifecycle (Stewart & Liabo 2012).

CHAPTER CONCLUSION

The participation of service users in the research endeavour is not new. Participative action research, community-based participatory research and participative rural appraisal are examples of research methods where professional researchers collaborate with community representatives on research projects relevant to their lives (Mosse 2001; Popay et al. 1998). These research methods were all developed within the context of extended democracy, and the acknowledgement of people as knowledge resources and experts in their own lives (Andersson *et al.* 2006). Within qualitative research too, methods have been developed to

facilitate people to speak freely and inhibited about their experiences, for example as patients, women or children (Alderson 2000; Prout 2003; Roberts 1981).

The establishment of a widespread initiative for involvement in research across funding organisations and research institutions is relatively new. Involvement mainly became a priority in the UK after the launch of the NHS R&D Programme in 1991 and with the establishment of Consumers in NHS Research, now INVOLVE (Oliver et al. 2001). A paper from 2004 describes how a large number of research funding organisations had developed requirements in their application procedures that researchers explain how their studies would involve members of the public (O'Donnell & Entwistle 2004a). This formalised version of participation in research differs from the participative research methods referred to above. Involvement in this formalised version spans research methods and study designs, and is an add-on to research activities rather than a research method in itself. Furthermore, this expansion of involvement in research has been largely value-based, rather than built on evidence about the effects and impact of such involvement.

It is therefore not surprising that the research evidence on involvement is largely made up of anecdotes and reflections of experiences of involvement (Staley 2009). Producing research in collaboration with, informed by or led by users is a first step. Researching the involvement takes time and is often not resourced within the wider study. Systematic studies on user involvement in research, looking at theoretical, historical and practical aspects, are lacking (Oliver et al. 2004; Staley 2009).

What we do know from available research is that involvement activities have been initiated from across research areas and methods, but that involvement is often associated with qualitative research. Mental health and disability research are areas where service users have established traditions of user-led research. Within specific patient groups there have been collaborations between patients, carers, researchers and medics, for example in cancer, stroke and Alzheimer research (Alzheimer's Australia 2010; Andejski et al. 2002; Fudge et al. 2008). Less is known about the impact of involvement, and there are few ethnographic accounts of the nature of involvement (Harvey 2009). There is limited research on involvement in quantitative research designs and systematic reviewing.

The involvement of younger service users represents different kinds of questions compared with adult participation. In spite of years of initiatives, for example in the sociology of childhood, it is still relatively rare to involve young people fully as partners in academic research. The most common ways of involving children and young people in research appears to be service consultations or evaluations, where their role as peer-interviewers have been developed (Broad & Saunders 1998; Fleming 2010).

This chapter has suggested that it may be useful to consider involvement alongside expertise and two key processes: information-sharing and decision-making. Proposing two alternative ways for considering involvement analytically (Figures 2-2 and 2-3), this chapter therefore concurs with Collin and Evans' (2002) assertion that experience-based expertise must lie at the heart of involvement. It also asserts that the relatively simplistic model of a hierarchy does not fit with the realities of involvement, where multiple ways of making decisions happen at different stages of the research. Figures 2-2 and 2-3 will inform the later data analysis in this thesis.

Chapter 3 THE UK CARE SYSTEM AND LOOKED AFTER CHILDREN

This study involved young people with experience of being in care. The group 'looked after children' has been and is one of the most socially excluded in society, owing to the label of family failure and being 'in care', and the strong association with poverty. Overwhelmingly, children in care come from families with multiple disadvantages (Bebbington & Miles 1989; Fleming et al. 2005; Hayden et al. 1999; Viner & Taylor 2005). This chapter aims to situate this research study in terms of the wider population, practice, policy and research context of looked after children and young people. As far as possible I want the reader to be aware of the lens I am using, and that this lens is coloured by how looked after children are categorised and viewed now.

The work for this thesis started in January 2007 and coincided with the Care Matters White Paper (2007). The young people involved had therefore been receiving a very different package of services compared to a generation before. In fact, the Participation Advocacy Service (PAS) I collaborated with in this study was one initiative set up in the wake of progressive policies from the late 1990s onwards, and subsequently formalised in Care Matters.

The approach to involvement in this study did not aim to be representative for the looked after children population. The young people were volunteers and they were not selected through a process of representation or election. They were involved first and foremost because they had experienced a particular set of services. Because of this, I want to provide a description of the looked after population in the UK, including looked after young people's own views. I hope that this will help the reader to situate the group involved in this review, within the larger population of looked after children.

CURRENT POLICY FRAMEWORK OF SERVICES

The legal category 'Children looked after' refers to all children who are subject to a care order. Most of these will be placed in foster care (65%), some in residential care and some will remain at home with their parents, but under social work supervision (Cocker & Scott 2006). Around 90,000 children pass through the care system in the UK every year, with around 60,000 being in care at any time. 'Children in care' is an administrative category, rather than a description of need. They are defined by law and state responsibility, in the same ways as many other service users, such as prisoners and refugees. Some children will be in care because of their behaviour, some because of a disability, others because of a care order due to parental abuse or neglect. The group differs enormously in terms of age, need, previous experiences and care history. Analyses of outcomes for this group have therefore been critiqued on the basis of clumping together a very diverse group. For example, many children come into care as teenagers and therefore do not 'grow up' in care (Berridge 2007).

UK child protection work has been characterised by the strong role of voluntary agencies and therefore the notion of charity. Initially, at least, work to rescue children from poor parenting and hard labour was coloured by middle-class views on childhood, and this was particularly evident after the introduction of compulsory education in 1870 (Hendrick 1997). Compared with the northern European systems, the UK approach has also been found to be focused on crisis intervention rather than prevention (Hetherington 2003). The current policy framework for looked after children stems from a 2006 government consultation resulting in the Green Paper 'Care Matters: Transforming the lives of children and young people in care' (Department for Education and Skills 2006). The subsequent 2007 White Paper 'Care Matters: Time for change' preceded the 2008 Children and Young Persons Act which provides the legal framework for Care Matters. In these acts, protection and prevention continue to be of highest priority, but a new dimension has entered which is concerned with the outcomes for looked after children, and how they compare with those of the general population. These topics may be considered in the light of the Acheson report (1998), which led an increasing public awareness of social and health inequalities, and social inclusion policies in the 1990s. As corporate parents, local authorities are charged with

having the same expectations for their looked after children as parents of children who live at home. The 2002 Choice Protects initiative was launched specifically to improve outcomes for looked after children, an initiative which was extended to all children under the 2003 Every Child Matters Green Paper (Every Child Matters 2004).

Care Matters focuses on the corporate parenting role of local authorities, family support, placement stability, education, health and well-being, leaving care and improved practice. It instigated the establishment of Children in Care Councils in all local authorities, with direct links to the Director of Children's services, in order to ensure influence by children and young people themselves, on the services they receive. The White Paper also introduced the annual stock take of looked after children, again highlighting outcomes. Local authorities are asked to analyse their looked after children profiles, and to match services according to identified needs. Looked after children are now to be given highest priority in school admissions, and councils have the authority to ask fully subscribed schools to admit looked after children, so that this group can access the most popular schools. Education should play an important part in placement planning, and the white paper initiated pilots of a virtual school which was later rolled out nationally. A virtual school follows up all children in care within the local authority, keeps track of their educational progress, registers absenteeism and provides support accordingly. Finally, the paper introduced further support for care leavers, in particular those going on to higher education.

The operational system of child protection and looked after children is led by the Working Together to Safeguard Children guidance from 1999, which was updated in 2010 (Department for Children 2010). The duties of organising services to safeguard and protect children fall within the Director of Children's Services, but NHS bodies, the police, probation and prison services, youth offending teams, secure training services and education services all have the same duty: to safeguard and promote the welfare of children. Organisations are also asked to encourage a culture of listening and engaging in dialogue with children. The guidance outlines how agencies need to work together, and share information. Local Safeguarding Children Boards function as the local body that co-ordinates the multiagency work to safeguard children. Their activities aim to: a) identify and prevent maltreatment or

impairment of health and development, b) work to target specific groups including children identified as 'in need', c) protect children who are suffering or are likely to suffer significant harm. Four key principles underpin the work with children and families: assessment, planning, intervention and review (Department for Children 2010).

When concern is raised about a child and reported to a statutory agency, following a discussion with senior management and if there is concern about safety, a referral will be made to the local authority children's social care services. Social care services should make a decision on the next step of action within one working day. If an assessment suggests that urgent action is necessary, there will be an immediate strategy discussion between social services, the police and other relevant agencies. Following legal advice there will be a strategy for immediate safeguarding action and how to inform the parents. In all cases, if after initial assessment there is concern that there is actual or likely significant harm being done to a child, there will be a strategy discussion involving children's social care, police, health and relevant agencies, to decide whether to initiate a Section 47 enquiry.

A Section 47 enquiry involves a police investigation of possible crimes committed towards the child, and a core assessment led by a social worker with help from other agencies. If, from the Section 47 enquiry, there is concern that the child is likely to suffer significant harm, the social work manager should convene a child protection conference within 15 working days.

A child becomes looked after either because the parents voluntarily agree to the child being accommodated, or because they are subject to a care order following legal procedures initiated by the social services department, as a result of the Section 47 enquiry. Every looked after child should have a care plan in place within 10 days of being accommodated. These should include plans for the placement, health, education, hobbies and how the child can stay in touch with family, friends, their culture and religion. Care plans are subject to regular review meetings, headed by an independent reviewing officer, and should take a child's wishes and feelings into account, as well as their overall welfare.

Leaving care support has been considerably improved in the last decade, as children have a right to stay in care until they are 18, and to special leaving care support until they are 21. Further support is provided for those who stay on in education, with the specific aim of improving looked after children's educational outcomes.

In spite of the increased resources and support provided following the Care Matters White Paper (2007), the paper has been criticised for aiming to reduce the number of children in care. A review of studies looking at impact of care on children's wellbeing concluded that children in care tend to do better than those who remain with or are returned to their birth parents (Forrester et al. 2009). This has also been found by some local authorities who have tracked the educational outcomes of children, with those remaining at home (under supervision orders) having poorer outcomes (Connelly et al. 2008).

RESEARCH ON THE LOOKED AFTER CHILDREN POPULATION

The reasons why children come into care have varied over the years. Comparing entry into care in 1987 with 1962, Bebbington and Miles (1989) concluded that it had shifted towards being associated with 'deprived' families, and that in 1962 more children entered due to parents' ill health. Another shift has been in the focus of policies. In the nineteenth century interventions were aimed at rescuing children from cruelty and providing them with a safe place and job opportunities, but expectations for this group were low. In addition to safety, policies now focus on reducing inequalities between looked after children and the general population.

Health status

Rates of emotional and behaviour problems are considered to be particularly high for this group, but rates have also increased in the general population (Hayden et al. 1999). Many young people's challenging behaviour impacts on the care they receive and the health of

foster carers, foster siblings, social workers and residential workers. Factors in the family circumstances of looked after children mean that many missed routine health surveillance such as immunisation and dental care (Acheson 1998; Fleming et al. 2005; Hill & Watkins 2003).

A case-control study by Williams et al (2001) found that looked after children were more likely than children living with birth families to experience changes in general practitioner, have incomplete immunisations, inadequate dental care, wet the bed, smoke, use illegal drugs and be involved in offending behaviour. The groups were matched on gender and age, but not on socio-demographic characteristics, which weakens the findings since this is a strong determinant of looked after status (Williams et al. 2001). However, the findings chime with those by Hill and Watkins (2003) whose retrospective longitudinal cohort study tracked looked after children in Southampton through their health assessment and review process. They found that at review stage "Health care plan recommendations from the initial assessment had only been carried out for 23 out of 45 (51%) children" (Hill & Watkins 2003, p. 9). The co-occurrence of mental and physical health problems is also a concern in this population (Hill & Thompson 2003).

A big problem for looked after children is that their health records and decisions involve so many different people: their parents, their carers and their councils. Studies indicate that expectations for looked after children are low, and so efforts to enable them to access appropriate services are also low. Whilst there has been a professionalization of mental health care in society at large, one study reported that severe behaviour problems among looked after children were recommended to be treated with tender loving care, rather than by referral to mental health services (Ward 1995, cited in (Ward et al. 2002).

A study comparing incidences of psychiatric disorder in 1,453 looked after children and 10,428 children from the general population found strongest association between looked after status and disorders where the environment is believed to have a leading role: conduct disorders and post-traumatic stress disorder. All psychiatric disorders, apart from autistic spectrum disorder and generalised anxiety disorder, correlated with being looked after (Ford et al. 2007). This has been replicated in other studies with smaller samples (Dimigen et

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al. 1999; McCann et al. 1996; Millward et al. 2006). The gap between the (adult-identified) mental health needs of looked after children and their peers appears to be wider in the younger age-groups, which suggests that these needs are evident in early childhood (McAuley & Davis 2009).

Educational status

One of the direst outcomes for looked after children is in education. On March 31st 2010, 58% of children who had been looked after continuously for at least 12 months achieved at least level 2 in reading at Key Stage 1, compared with 85% of all children in England. The equivalent figures for writing and mathematics are 51% and 62% respectively for looked after children, compared with 81% and 89% respectively for all children. The gap continues into Key Stage 2, where 36% of looked after children achieved at least level 4 in English and mathematics, compared with 74% of all children. Only 12% of looked after children gained at least 5 GCSEs at grade A* to C, compared with 53% (Department for Education 2010a). Ford et al (2007) found that poor literacy and numeracy levels in looked after children correlated with psychiatric disorders.

Recent years have seen a substantial increase in policy attention and investment into the education for looked after children, although reports on how they were losing out first appeared in the 1960s and 70s (Harker et al. 2004). For a long time looked after children's poor educational outcomes were linked to their pre-care experiences, but a report in 1987 suggested that this was more likely to be linked to the system's failure to adequately support their educational needs (Jackson 1987). This has been contradicted in a more recent analysis, which again suggests that pre-care experiences are likely to be the main cause of later outcomes, depending on when the child was taken into care (Berridge 2007).

Long-term outcomes

Looked after children's overrepresentation within excluded groups continues into adulthood. Compared with the general population, people with a background in the care system are more likely to be unemployed, to have a conviction, to have a psychological morbidity, and to be in poor general health (Viner and Taylor 2005; Cocker & Scott 2006). Again, the question is whether the poor health outcomes for looked after children are due to their pre-care experiences, or whether negative impact on health from neglect or abuse experienced in the home is exacerbated by their care experience (Stanley 2007). A review of studies investigating outcomes of being in care found that in general, looked after children's welfare improved over time, and sometimes compared favourably to children remaining or returned to their birth parents. While acknowledging that the system can do better, the review findings indicate that more rather than fewer children should be taken into care (Forrester et al. 2009). Pre-care experiences, genetic predisposition, the stress of being taken into care and care experiences are all likely to interact and impact on children's social and psychiatric development (Hill and Thomson 2003).

Children and young people's views

Lessons drawn from high profile child abuse scandals in the late 1980s and early 90s included the need to listen to children and young people themselves (Hayden et al. 1999). The most striking finding from studies on children's own views is perhaps the importance many children place on their birth parents, even when exposed to abuse and neglect. A small qualitative study of children's experiences explored children's views on their "significant others". Comparing looked after children with those living with one or both of their birth parents, the researchers found that foster children saw their birth parents as being important because they were biologically related to them, while their foster carers were important because they looked after them (Heptinstall et al. 2001). When asked in one study, a majority of care leavers said that coming into care was the best solution for them, and some said that they should have come into care earlier (Kufeldt and Stein 2005).

A review of six studies from the UK and abroad on children's views on their care, found considerable satisfaction amongst looked after children on the care they had received. The authors note that this contrasts with earlier studies showing evidence of the care system's insensitivity to children's needs. They conclude that this on the one hand indicates the diversity of the population and how certain views can sometimes overshadow a considerable minority, or even majority view. They also suggest that it could reflect the low expectations of the population and skewed samples, as it tends to be easier to collect the views of those in more stable placements (Ward et al. 2005).

In a consultation carried out by the National Children's Bureau (NCB), young people emphasised the importance of information and how this should be repeated again and again to make sure that those coming into care fully understands the process. They also spoke about the need to be heard and consulted in all proceedings concerning their lives and future, and for them to influence the decisions made. Because of their care status, looked after children's activities such as school trips or sleepovers at friends' houses, are guided by multiple procedures. Looked after children themselves have indicated that these security measures, such as police checks of friends' parents before a sleepover and police being rung when they arrive after agreed times, are embarrassing and not what they want. The system has to balance security concerns, concern for birth parents, and children's needs for a 'normal' life. Another wish in this consultation was for more time and stability with social workers, also supported by Munro (2001). All looked after children should now have regular review meetings, and the young people in this consultation were keen to have more say in how these meetings are run and who should attend. The young people also said that when adults discuss their situation, they focus on the here and now, whereas young people would welcome more attention to their hopes and dreams for the future. Finally, young people were concerned about the stigma of being in care (Blueprint 2004).

Davies and Wright (2008) conducted a review of consultations with looked after children and young people and their views on mental health services. They found that children rated relationships with staff as highly important. The quality of the physical environment in which the therapy is situated, and the practical arrangements for it were also highlighted as

important. These findings are mirrored in a service consultation with samples from the general population (Curtis et al. 2004a). Stanley (2007) found in his focus groups with looked after young people that they wanted to have a choice of mental health services in terms of how they are delivered and what kinds of services they receive, with a preference for non-directive approaches .

Studies have found that effective participation by children in their review meetings and other decision-making forums can be limited by the procedures of the system, which means that meetings are often organised without the input of children, which in turn means they do not know in advance who will attend or what will take place in the meeting (Danso et al. 2003; Munro 2001).

Studies collecting looked after children's views have been criticised for viewing children as consumers of services, using questionnaires and structured or semi-structured interviews to gather children's views, rather than asking them to set their own agendas, through participative methods. The views of smaller children have generally not been collected, and we therefore know little about their preferences (Winter 2006b).

CHAPTER CONCLUSION

Research in this field to date has focused mainly on looked after children's needs as identified by adults, the nature of their problems and policy development, particularly focusing on multi-agency communication and collaboration. This means that we now have a better overview of the demographics of this population, and services are better placed to provide targeted support, also owing to initiatives in the Care Matters White Paper (2007). At the same time it has been argued that research and policy initiatives have tended to focus on children's rights to protection and provision, at the expense of their rights to participation (Winter 2006b).

Initially, children were taken into care for their protection, economic measures, or to prevent antisocial behaviour, and there was no concept of children's rights (Munro 2001).

Children's rights were strengthened in the 1970s and 80s, and 1979 was the UN international children's year. The UK ratified the UN Convention on the Rights of the Child in 1991, but the right of children to be listened to had already been incorporated and emphasised in the 1989 Children Act. The emphasis on rights and participation was largely pushed forward by childhood research, which developed participatory methods to enable children to take part in research not just as objects of interest, but social actors (Prout & James 1997).

Winter (2006b) argues that the participative approach has been lacking in research on looked after children. Others have argued that the 'liberalist' model of children's rights, dominant in sociology, which sees age as a randomly drawn criterion by which children are denied their rights, has also been absent in this field. Care professionals and policies tend to see rights in a 'protectionist' model, where adults are responsible for making decisions to protect children, who in turn are too vulnerable to external pressures to make their own decisions (Barnes 2007). This critique is particularly relevant for younger children, although recent legislation has strengthened looked after children's opportunities to influence the care system, such as In Care Councils and participation groups introduced by the Care Matters White Paper (2007).

My study was underpinned by the view that young people have important expertise relevant to any study that focuses on young people, and that learning is gained through experience. This meant that the work with young people was planned as a collaborative project, where they would provide their expertise on being young and being in care, and I would provide my expertise as a researcher and a systematic reviewer. I believed that as the collaborative group would meet regularly, we would introduce each other to important aspects of our knowledge, which would in turn benefit the final review, making it more attuned to the priorities of looked after children.

Chapter 4 THE RESEARCH QUESTIONS AND THEORETICAL FRAMEWORK

Chapter 2 highlighted how the practice of involving service users in research has evolved from multiple fields and areas, and their relevance to researching involvement. Rather than thinking of involvement in terms of a hierarchy, I presented a model which focuses on the process of exchanging ideas and making joint decisions. The third chapter outlined the past and current frameworks in which children are taken into care in the UK, and the demographics of this population. Drawing on these chapters, I now present the research questions for this study. I then give a brief overview of the research design chosen to address these questions, and discuss why I decided on this particular design. The study's epistemological underpinnings are then presented and debated, examining how systematic review and involvement of service users in research grew from different understandings of knowledge.

THE RESEARCH QUESTIONS

This thesis is based on my view that social science can contribute to the development of effective services. From the outset, my research career was strongly influenced by the argument that policy, research and practice should be linked in order to improve outcomes for children and families. This was investigated by the study 'What Works for Children?' funded by the UK Economic and Social Research Council (ESRC), on which I worked as a research officer. The study worked with service planners who were in charge of distributing money to initiatives for children aged 5-13, providing a research support officer to work directly with them, and a research team which summarised relevant research to assist them in their planning (Liabo et al. 2006). One of the findings from that study was the lack of relevance of much research to practice, and the need for research to address the questions that are important to policy makers, practitioners and service users, as well as what

researchers perceive to be important for these groups (Liabo 2005; Stevens *et al.* 2005; Stevens *et al.* 2009).

This thesis also responds to the question of “whether we do research for ourselves, for our professional colleagues or for and with the subjects of our research” (Roberts 1981).

Debates about the role of research in society are central to this. From early on, social science was concerned not only with understanding the social world, but also with drawing conclusions on how the social may be managed. If the findings from primary social research are to have such a practical purpose, we need to be aware that the knowledge produced by social science is intrinsically linked to the relationship between those researched, the framework of the research and those researching. A study may have strong internal validity without any face-value for policy, because it does not focus on what matters to service users or practitioners. This in turn prompts the questions who sets the agenda for social research, who frames and conducts the research and which findings are considered important. Service user involvement in research therefore addresses the question how we produce knowledge in social research, what we research and what concepts we use to analyse our findings.

This study set out to investigate how lay involvement in research can be facilitated, which is a methodological question anchored in the sociological tradition. The study aimed to add to the evidence-base on ways in which users of health and social services in general, and looked after young people in particular, may be actively involved in the research process. At its core, the study was about methods for involving people in research, and about the value of such involvement.

The study was also interested in service user involvement from a particular standpoint: how can researchers initiate and support the involvement of service users in their research? This is different from research where the impetus for the involvement comes from service users themselves, through activism. For researchers, who are experts in research methodology, the question is how to combine research rigour with involving and handing over some decision-making power to people who are not professional researchers. Because of this, I chose to conduct the study around the production of a particular research output decided in advance: a systematic review.

Systematic reviewing is a method at the heart of evidence-based policy and practice. Systematic reviews are used as a tool in both research and policy planning, and are well placed to identify areas in need of further research. Service user involvement in systematic reviews is therefore particularly pertinent, as they generate new knowledge, are useful tools for setting the research agenda, and feature at the top of evidence hierarchies (Boote *et al.* 2011).

The study also aimed to address some of the gaps in the literature, in particular the issue of involvement across different research contexts. There have been many initiatives that have involved patients in systematic reviews, most notably within the Cochrane Collaboration (Kelson 1999; Sakala *et al.* 2001). However, the nature of this involvement itself has not been researched to any large extent. Similarly, there have been initiatives providing participation opportunities for looked after children in research (Monaghan & Broad 2003), but studies have reported obstacles to involving this particular group, which in turn has influenced the research output (Gilbertson & Barber 2002; Heptinstall 2000; Winter 2006a). The research questions addressed by my study were:

- How can young people be involved in planning and conducting a systematic review?
- Can a systematic review be conducted in collaboration with young people and at the same time maintain (or usefully develop) quality standards in systematic reviewing?
- What are the obstacles and facilitators to involvement in each stage of the research process?
- What are the negative and positive aspects of involvement, as experienced by both the young people and the researcher?

Two distinct sets of findings were expected to derive from this research; first a systematic review, and second reflections on the service user involvement in this review. Involvement in this study refers to the process of recruiting and accessing young people, engaging them in doing research, listening to their views, incorporating their views into the research and aiming for this process to be meaningful to both the researcher and the young people. Of particular importance is the extent to which ideas were invited, expressed and understood in meetings between researchers and service users, and whether these ideas were

integrated and retained into the research. In this process there is mutual learning, where the young people were invited to participate in an academic study, as young researchers. By taking an active part in the production of the systematic review, I theorised that they would adapt key terms used in this endeavour, while also bringing relevant concepts, knowledge and experience from their lives, as users of social care services and young people.

RESEARCHING USER INVOLVEMENT IN RESEARCH

Researching user involvement in research is essentially a study of teamwork and decision-making in science. The involvement is an intervention, and the study investigates aspects of this intervention, such as its effect on the research, those involved, or the kinds of processes triggered by its implementation. From this perspective, any research design can be used, as long as the methods are suitable to address the questions. For example, questions about the effectiveness of peer interviewing have been researched by randomised controlled trials (Nilsen et al. 2010), a study design well placed to address questions of impact in relation to specific outcomes of a intervention, including involvement in research.

The research questions driving this study were primarily, but not only, about the nature of involvement. This study set out to research the processes of involving service users in conducting a systematic review, and to capture the experiences of those involved. The questions were deliberately explorative, to reflect the lack of evidence in this field, focusing on how involvement can best be initiated and implemented, and how it is experienced by those involved. The main focus of this study was therefore on the processes of involving non-researchers in a systematic review, and how the involvement was experienced by those taking part. In addition, the study also looked at the impact this involvement had on the systematic review, on the young people, and on me as the researcher.

To address these questions I needed one or more systematic reviews and a population (looked after young people). I also needed to design a study for collecting evaluation data, from the field and the population, on involvement processes, experiences and outcomes.

The chosen study design needed to incorporate suitable methods for capturing all this. Research questions about experiences and processes have traditionally been the domain of qualitative research methods, which are designed to capture the nuances of individual cases, rather than establish averages across a population. The aim is not to seek generalisability drawn from a statistically representative sample, but to consider the particularity of a limited number of cases, or to explore phenomena in their natural environments, in order to understand the meanings people place on the events, processes and structures of their lives (Miles & Huberman 1994). Qualitative research is not suitable for generalisation to populations, but can inform theory, explain individual cases and describe processes in a more detailed way than quantitative methods. Qualitative research can be conducted within many different research designs and methods, including literature reviews, and complemented by use of quantitative methods (Marshall & Rossman 1999).

Considering the aims and objectives for this study, the chosen methods should ideally allow for issues to emerge during the course of the study, in addition to the pre-set questions. Suitable data collection methods for this include observation of research meetings, literature review, in-depth individual interviews or focus groups, analysis of people's written accounts of being involved, and questionnaires. There were several ways of going about designing a suitable study. However, considering my field and population, there were certain constraints that needed to be taken into account.

My aim of assessing the impacts from the involvement would ideally be addressed by including a comparative element so that involvement (intervention) could be compared with non-involvement, or a different kind of involvement than the one I initiated. However, a trial design is suitable for addressing specific and very bounded questions and not for addressing wider and open-ended questions as those addressed in this study. Also, a trial "serves one purpose admirably: the final evaluation of therapies or tests, especially when their clinical value is not immediately clear-cut" (Vandenbroucke 2001, p. 330). This study aimed to investigate aspects of an intervention (involvement) in systematic reviews, and this is an intervention which we know little about in terms of its effects, and in many ways we are still at the development stage of the intervention itself. Focusing on the

particularities of involvement in a review and a range of variables, would therefore be more appropriate than focusing on a single aspect, potentially missing out on key variables.

I wanted specifically to research involvement in systematic reviews, and so I needed to research involvement in other reviews, or produce a review myself, in collaboration with service users. Ethnographies of research have been conducted on randomised controlled trials (Cox 1999; Rapley et al. 2006) and science and technology studies (Beaulieu 2010; Voskuhl 2004). Such ethnographies provide insight into how knowledge is produced within these study designs and methods, and can illustrate the role of the 'social' in scientific production (Latour & Woolgar 1986). Literature reviewing is another way of approaching other people's research. For example, a systematic review assessed the quality of individual intervention studies that were conducted as community-based participatory health research, and drew conclusions about community-based participatory research on the basis of these studies (Viswanathan et al. 2004). This is not ideal, however, for researching gaps in the literature, as attempted by this study.

Researching involvement in other people's studies would enable me to observe service user involvement in practice, without taking part in it myself. Considering that most reports of involvement are currently researchers' and service users' own reflections, this would have been a valid contribution to the field. However, it would have required access to systematic reviews which were going to involve service users on an ongoing basis. It would also have meant that the involvement under investigation would be in a form set up by the researchers or service users of those studies, and I would not be able to try out different ways of involvement myself. Finally, I would have had to negotiate access to research meetings and activities, which would have required a second ethics procedure for the included studies.

I therefore chose to establish a collaboration to produce a systematic review with a group of young people. This would give me the opportunity to experience user involvement myself, and develop methods useful for involvement in systematic reviews. I wanted the study about the involvement to be an analytical account of the process, including my own experiences and the young people's, thus addressing a particular gap in the evaluative

literature of public participation identified by Harvey (2009). He argues that there is a dearth of evidence on the experience of those who participate, and on what actually happens during the involvement processes (Harvey 2009). To capture the in-depth experiences and nuances of the involvement I chose to evaluate qualitatively a collaboration with service users, set up by me, to produce a systematic review relevant to the health of looked after young people.

The benefits of a qualitative evaluation of my own research were that I had control over the level of involvement, who became involved and the kind of research study we conducted. This also gave me the opportunity to try out methods for involving people in reviews. Another benefit of conducting a case study of my own collaboration with service users was that I gained first-hand experience of involving lay people in the research. I was part of the involvement process and therefore able to reflect on it as a participant rather than an observer of other people's work. Practically, it was simpler because there was no need to negotiate access to data or research meetings. The ownership of data lay with me and the young people involved, rather than a third party, and ethical aspects were negotiated within one project, rather than being a second project on top of already existing projects, and therefore with a second level of ethical requirements.

A disadvantage with this approach was that I became personally very involved in the study, and the account of it will therefore be highly subjective. In essence, I was researching my own study and I was therefore also a research subject. I both participated in my own research and researched my own role. This gives direct, lived experience of service user involvement in research, but it prevented me from analysing the process independently of my own involvement. Some attempts were made to address this in the study design, as described in Chapter 5, but findings from this aspect of the study are particular to this group of young people, working on this review, in these circumstances, and from the perspective of the researcher. Thus, this study aimed to contribute to theory-building and conceptualisation of service user involvement, rather than make generalisable statements on the basis of the findings. Considering the lack of in-depth qualitative studies of user

involvement in systematic reviews, this study filled a small part of a large gap in our research knowledge and theory of service user involvement.

EPISTEMOLOGICAL FRAMEWORKS

This study had three main components. First, it employed methods for the involvement of young people in a systematic review. Second, it contained a systematic review, which investigated the question set by the young people involved. Third, the evaluative case study, which looked at how service users participated in the review, employed methods and data collection tools to consider the process of the young people's involvement. The complex nature of this research manifests itself not only in these three levels of methods, but in the diverse research traditions underpinning these. While systematic reviewing has been accused of being positivist (Hammersley 2001), service user involvement has been criticized for threatening a study's internal validity, or reliability, because it involves people with a vested interest in the findings (David 2002). Therefore, systematic reviewing derives from a different epistemological paradigm compared to service user involvement.

Below, I first consider the epistemological theories which underpin service user involvement in research. I then discuss the concept of knowledge on which systematic reviewing is based. This is mainly an exploration of the tensions between these approaches rather than an attempt to consolidate the two. However, work by Popay and Williams (1996), Oakley (2000), Collins and Evans (2002), and Ramey and Grubb (2009) have suggested that research knowledge is optimised by combining principles from both qualitative and quantitative research, and by enhanced participation in research by people with personal experience of the topic under investigation (Ramey & Grubb 2009).

Service user involvement in research

Service user involvement in research is in itself not a research method, but a name for research which provide opportunities for people with experience of the topic under investigation to influence the research framework, or take part in stages in the research lifecycle. The methods for involving service users in a study are not in themselves research methods, but ways of facilitating participation in research. Service users' input into a study can be channelled through questionnaires, people may gain representation on research reference groups, or service users may receive research training to take part in data collection and analysis. Participation may be facilitated through traditional research meetings where users attend alongside other experts, or researchers may use specific tools or activities to facilitate input from service users, such as focus groups, creative workshops or collaborative group-work.

Any study design can therefore in principle involve service users. As the concept of service user involvement in research has taken hold in policy and practice developments as well as academia, it is not seen as confined to a particular research design and there are now examples of involvement in both systematic reviews and medical trials (Braye & Preston-Shoot 2005; Hanley et al. 2001; Lucas et al. 2007; Rees & Oliver 2007).

Although user involvement is not confined to a specific research method, its focus on perspectives in knowledge production resembles arguments within and for qualitative approaches in social research (Trinder 1996). Qualitative research tends to be about people's lived experiences, and about tapping into people's views of society (McNeish 1999; Popay et al. 1998). Arguably, qualitative methods allow for interpretations of data which lie outside of the researcher's original frame of reference (Frankham 2009). Qualitative research methods have a strong tradition of involving research participants at a higher level than mere informants, for example by using member checks, or respondent verification, in its data analysis (Morse et al. 2002; Oakley 2000), or by making community participation part of the research methods, as in participatory action research . Qualitative research also has a track record in developing methods for capturing the voices of socially excluded groups. At times, members of these groups have been trained to assist researchers in their

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work, as in Foote Whyte's 'Street Corner Society', where one of the boys from the Italian youth groups he was researching became his research assistant (Foote Whyte 1981; Orlandella 1981).

Qualitative research's openness to influences from the field under investigation stems from long-held epistemological arguments in sociology and anthropology (Becker 1967; Gouldner 1968; Hammersley 2000). These hold that you cannot observe without also evaluating what you see. Several schools of thought, including postmodernism, social constructivism and critical realism all question whether research findings can ever provide objective knowledge and argue that all research is biased by the paradigm and world view held by those doing the research. Critical theory, developed by Habermas and Adorno among others, maintains that observations of facts cannot be separated from the value standards of the observer (Giddens 1974; Hammersley 1992). Science is framed by its cultural, social and historical context, and researchers must take these into account when conducting their work (Wright Mills 1959). In this vein, feminist researchers argued that a male dominated science was ignoring or subverting the perspectives of women, and therefore produced biased research (Oakley 2000; Roberts 1981).

This prompts the question of whether personal insight into the group under investigation is a pre-requisite for producing valid research. This argument has been put forward by proponents of service user involvement in research (Beresford 2005), but has also been discussed by researchers themselves (Merton 1973; Trinder 1996). On the one hand it is argued that insider knowledge will bias the research because of political affiliations within the field, on the other socially excluded groups have argued that traditional research paradigms are biased because these reflect the ruling paradigms of society and fail to recognise varying perspectives of what it means to be a member of such groups. For example, disabled researchers have argued that the 'social relations of research production' alienate research from its research subjects, in that they replicate the oppressive ideologies operating in society, rather than enable disabled people to fight the oppressions they struggle in their day-to-day life. To break this coercion, disabled people must be involved in commissioning, defining, conducting and disseminating research (Oliver 1992). Similarly, in

mental health, service user involvement in research has been seen as a process which can empower, where patients have won through with arguments that findings have ignored their experiences of services and illness (Trivedi & Wykes 2002).

The problem of insider versus outsider knowledge has been central to the study of knowledge production in social science. Weber and Simmel adopted the aphorism that “one need not be Caesar in order to understand Caesar” (quoted in Merton 1973, p. 123). This suggests that insider knowledge is not necessary in order to conduct valuable research on a specific group, but neither is there a requirement that one is not an insider. In sociology seminal works have been conducted by insiders who are social researchers, as in the case of Becker’s study of dance musicians¹ and feminist researchers (Becker 1963; Oakley 1974).

The role of personal perspectives, or bias, is central to all knowledge production, but more salient in social science because the subjects are also human beings who can articulate their views in contrast to or alongside the findings of research. Any utilisation of research findings will highlight whether the research was attuned to the priorities of the groups which were researched. Some understanding of their lives is therefore necessary in order to focus the research on what matters to them, as well as what matters to researchers and policy makers. The question is how much insider influence is necessary in order to gain such understanding and to make the study relevant.

An important problem with the notion of insider research is that when people with a vested interest in the findings of a study have decision-making power, it bears the risk of their views influencing the analysis of the findings, to bias these towards their desired outcomes for the research. Marginalised groups and patient interest organisations rarely represent one unified opinion. There is a risk that service user involvement will further bias the research towards the interests of the most resourceful service users, or that it becomes a target for particular politicised issues, reiterating inequalities within a group. This is not unique to user involvement in research. Government funding of evaluations of policy

¹ Becker was a professional pianist, as well as a sociologist.

interventions also has a vested interest in 'proving' that the government-funded interventions work. A researcher testing out an intervention which she herself has designed will have the same ethical dilemma, of potential commercial value if the research proves the programme to be effective. However, the fact that the problem exists across the board does not eliminate or reduce it when service users are involved in research.

In comparison to the sociological works mentioned here, where the researchers as scholars remained in charge of the study, service user involvement suggests that people without research training may have decision-making powers on a study. Service users' influence will vary across studies, but the stronger their influence the more they are likely to challenge the researcher as a professional expert who facilitates the production of knowledge, regardless of whether this knowledge aims to be 'subjective' or 'objective'. This can be problematic because while insight can no doubt be gained from experience, academic research knowledge, as opposed to knowledge gained from written or oral testimony, also derives its validity and quality from the application of scientific tools throughout the research cycle. The quality of the research rests on both the technical aspects of study design, and the framework in which the study is situated. The question is whether service users with insider knowledge will challenge traditional methods for inquiry and if so what impact this may have on the validity of the research. For example, HIV activists involved in biomedical research in the US tapped into existing academic divisions of pragmatists versus traditionalists, pushing for more inclusive trials because they were of higher validity (Epstein 1995).

Concerns about research competence and threats of bias come to the forefront when involving users in research methods which aim to accumulate knowledge and provide generalisable findings. Randomised controlled trials and statistical surveys rely on technical knowledge and principles which are constructed to increase a study's internal validity. These study designs are arguably less flexible and accessible to personal input than qualitative research, for reasons described above. The underpinning paradigm of service user involvement in research corresponds largely with that which informed and developed much of qualitative inquiry. Popay and Williams (1996) argues that: "To take lay knowledge

seriously within public health research would ... shift the ownership and control of the research process as a whole away from professional experts" (Popay & Williams 1996, p. 762). I would argue that this challenge increases for research designs which rely on closely monitored and *a priori* protocols.

Systematic reviewing

Systematic reviewing was developed as a method for organising knowledge in relation to specific questions. It has a long history and developed across several fields of research (Petticrew & Roberts 2006). What distinguishes a systematic review from a traditional literature review is its focus on reducing bias by employing transparent methods for identifying, including, analysing and synthesising relevant research. The aim of this method is to facilitate the accumulation of knowledge in relation to specific questions, rather than discussing aspects of ideas within a wider field. Systematic reviewing has frequently been used to enhance knowledge about the effect of interventions, although through extensive methodological and theoretical debate in the past 20 years this focus has broadened and systematic reviewing can be used to address almost any research question (Gough *et al.* 2012).

Early systematic reviews were often produced to serve research itself, by establishing the extent to which a research question had been previously researched, before embarking on a primary study. Systematic reviewing has also been seen as a way of using research to improve policy and practice in a field (Chalmers 2003), particularly in terms of its comprehensiveness and critical appraisal of individual studies. Both these aspects introduce the notion of reducing bias when using research to support service development and practice. By being comprehensive, systematic reviews reduce the risk of missing important studies which may contradict findings from other studies. In the process of critical appraisal the reviewers assess all included studies according to the same pre-set quality criteria. Systematic reviewing is anchored in a research tradition which focuses on internal validity, pre-set criteria for the investigation and an explicit aim to reduce bias. A systematic review

synthesises findings across studies and aims to be replicable and transparent, using requirements similar to those of primary research (Chalmers et al. 2002). Research methods were developed to that end, so that by adhering to pre-set criteria and protocols, systematic reviews would be more reliable and trustworthy than literature reviews conducted by snowballing references or roaming the library.

The results of a well-conducted systematic review will not only list previously conducted studies, or summaries of their results, but synthesise these results into a higher order set of findings. Systematic reviews of quantitative studies are sometimes able to provide pooled effect sizes for specific outcomes, which are weighted averages indicating the impact an intervention is likely to have. A systematic review of qualitative studies will provide a narrative of higher order constructs, similar to a qualitative primary study using grounded theory to derive themes from individual interviews. Systematic reviews have merit for science itself, but can also be used to make informed decisions about practice interventions and policies (Chalmers 2003; Oakley 2012).

Critics of systematic reviews have argued that they tend to analyse research findings separately from their cultural and historical contexts (Clegg 2005; Hammersley 2001). The claim that a pre-set protocol and systematic procedures can produce objective research findings has been challenged, as all reviewing will invariably involve judgement, hence impacting on the validity of findings to a larger degree than often claimed by supporters of such reviews (Boaz & Pawson 2005). The *a priori* design will sometimes veil the later decisions which were made during the course of the reviewing, which blurs the proclaimed transparency (Boaz et al. 2006). It has been argued that the tacit knowledge used by researchers means that they employ skills, think about what they read and work in a way which can not simply be reduced to replicable procedures (Hammersley 2001).

Of systematic reviewing and its closeness to policy and practice, it has been suggested that the presuppositions made for an evidence-based methodology are problematic, and that the underlying epistemological basis of evidence-based practice is flawed (Clegg 2005; Webb 2001). These arguments question the role of the randomised control trial in systematic reviews, and query what they see as positivist epistemology, which they claim

ignores the cultural context in which decisions are made. Evidence-based practice “entraps professional practice within an instrumental framework which regiment, systematises and manages social work within a technocratic framework of routinised operations” (Webb 2001, p. 71). By separating questions of fact from questions of value, evidence-based practice ultimately closes off the possibility of true rational decision-making (Webb 2001).

These criticisms are based on assumptions about randomised controlled trials (RCTs), and that systematic reviews value RCTs above other kinds of research methods. While it is true that RCTs have featured in hierarchies of evidence for studies on effectiveness, proponents have argued for a “horses for courses” approach, where the research question determines the methods used (Harden 2006; Petticrew & Roberts 2003; Sheldon & MacDonald 1999). The assumption that evidence-based policy and practice ignores professional expertise and knowledge does not consider work (Rees & Oliver 2007) which has addressed the context of interventions as well as the importance of including other kinds of knowledge alongside research evidence (Arai *et al.* 2005; Garcia *et al.* 2006; Harden *et al.* 2007; Kitson *et al.* 1998; Liabo 2005; SCIE 2007; Stevens *et al.* 2005; Walter *et al.* 2004).

Systematic reviewing has developed substantially in the years since the establishment of the Cochrane and later Campbell Collaborations, and there are multiple kinds of reviews based on different epistemological traditions (Barnett-Page & Thomas 2009; Boaz *et al.* 2006). While some reviews set out to aggregate knowledge by considering primary studies that indicate direction or size of effects of social interventions, others are configuring in that they predominately arrange the findings alongside their theoretical basis, data sources and emerging concepts (Oliver *et al.* 2012). Aggregating reviews are narrower, and concerned with controlling for bias in the included studies. Configuring reviews are less concerned with bias, and more focused on the richness of data, and the context in which social interventions occur or are implemented. Many reviews will span these two archetypes, particularly those that have included studies on stakeholders’ views and perspectives (Rees & Oliver 2012).

Because most early systematic reviews were based on the assumption that you can accumulate evidence and that steps can and should be taken towards reducing bias within a

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study, they derived from an epistemological basis which traditionally has been seen in contrast, rather than complementary, to the underpinnings of service user involvement in research, which emphasised the importance of lived experience and perspectives. Systematic reviewers themselves have acknowledged that there is bias inherent in the process of reviewing, related to the interplay between the skills and perspectives of the reviewers involved, but there is still a lack of acknowledgement in reviews of the judgements made during the reviewing, as opposed those evident in the *a priori* protocol (Boaz *et al.* 2006).

More than anything, systematic reviews can represent challenges to established 'truths' in professional practice and common opinion, which is also true for service user involvement, which similarly can challenge research frameworks and perspectives. It has further been suggested that evidence-based policy and practice represents a threat to democratic processes, because it assumes "that research can specify not only what has been done but also whether it was good or bad and what should be done; yet it is clear that this necessarily involves value judgements which research cannot validate on its own" (Hammersley 2001, p. 550). This may apply to some systematic reviewers, but increasingly systematic reviews have included research on process and perspectives in their work, comparing it with findings from effectiveness studies (Harden *et al.* 2007; Thomas *et al.* 2004). Rather than a hierarchy of research evidence, these researchers base their work on a view that various research methods complement each other, including research which involves people with experiential expertise of the topic. This is where I positioned this study, and I turn to these arguments now, to consider how they link the positivist background of systematic reviews which focus on objectivity and bias reduction, with the background of research that has involved service users and has focused on perspectives and subjectivity.

The methodological framework for this study

Considering these different anchor-points of user involvement in research and systematic review, one research question driving this thesis is the extent to which a systematic review

can be conducted in collaboration with young people and at the same time maintain or usefully develop quality standards in systematic reviewing. More specifically; how does the involvement impact on the review's quality, perspectives, relevance and results?

This research was conducted within an understanding of knowledge where facts and behaviour cannot be interpreted independently of people's culture and history, and the society in which we live (Berger & Luckmann 1966; Wright Mills 1959). From the start, I acknowledged the political aspect of research and the subjective role of me, the researcher. I worked from a belief that I am unable to analyse my data independently of my own cultural, social and historical contexts. When we talk about service user involvement, we need to ask what we mean by 'service users' and the answer must be contextualized. It is not simply enough to aggregate data about how 'the service user' is defined or summarise definitions in the literature. In terms of researching involvement itself, it means considering it in the history of research as well as society and culture, and current debate. This is similar to Foucault's argument about discourse; "a statement is always an event that neither language .. nor the meaning can quite exhaust" (Foucault 1969, p. 31).

This does not mean succumbing to a postmodernist view of knowledge where everything is relative and in the eye of the beholder. Berger and Luckman's seminal work (1966) describes the process by which subjective meaning becomes real. Because humans cannot be humans unless they socially interact, society becomes a human product, which is experienced as an objective reality; man, therefore, is a social product. The institutional world is objectivised human activity, and there is a dialectic process between man in his 'collectivities' and his social world. There is a world that is real, and we produce knowledge within the parameters of this world. There are objective 'truths', in as much as we have a shared understanding of the world and its institutions (Berger & Luckmann 1966). A practical view is provided by Oakley (2000); "It is one of my premises that most people operate as though reality does exist. It is only academics who make a living arguing the opposite" (p. 20).

This is not to say that we live in an objective world where the ruling thoughts and ideas about truth are indeed 'The Truth'. We live with shared understandings about reality, but we do have different perspectives about this reality, and research that incorporates these

different perspectives is likely to be more useful than research which does not. This view consolidates the 'positivist' thesis that we can accumulate knowledge, with the social constructionist view that this knowledge is socially constructed.

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. Critical theorists' critique of positivism is mainly a critique of ideology. "It is critical of the 'scientism' of science which attempts to give the impression that science is the only form of activity through which objective knowledge of the world can be developed" (Popay & Williams 1996, p. 765). Arguing for lay involvement in research, Popay and Williams suggest that through pluralism of methods we may search for truths while not being anarchistic in our epistemology. It is in this line of thought that I have anchored my own doctoral work.

Within an objective reality, as we collectively experience it, the project of social research is to derive knowledge in a systematic and replicable fashion. This thesis therefore, in a minor way, addresses the production of knowledge. Drawing on Collins and Evans (2002), it argues that service user involvement in research, or the inclusion of experience-based experts in knowledge production, is key to developing useful, relevant and valid research. Arguably, qualitative research has followed this line of argument for some time. So-called positivist study designs such as randomised controlled trials and systematic reviews may have even more to gain from it because interpreters of quantitative data are often further removed from the research subjects simply by virtue of the methods used.

Methods favoured by many researchers within the positivist paradigm have been accused of ignoring the subjective realities of their research subjects, and failing to account for why they reach the findings they do. On the other hand, advocates of the use of trials have argued that it is exactly the innumerable variables in social situations which makes controlled experiments so important for social interventions (Sheldon & Oakley 2001). Involvement of research subjects in framing and planning a study may improve the study's focus, in terms of what outcomes it includes and what questions it asks, and thereby become more relevant to those being researched and therefore to policy and practice. It is

by involving lay people, service users, patients or members of the public that we may further exploit the potential of these methods (Chalmers 1998), and more successfully combine them with qualitative research in a joint attempt at finding policy and practice solutions that work.

CHAPTER CONCLUSION

The research questions addressed by this study first and foremost address gaps in the knowledge of service user involvement in research, and in particular research designs belonging to an epistemological framework which has traditionally aimed to distance respondents from investigators, although this is changing (Staley 2009). The target group for the involvement in this study has historically and currently experienced social stigmatisation, and been at the receiving end of services veering between the protection of the child and the protection of the family. In terms of their own rights, looked after children constitute one group whose rights to protection have overruled their right to participation (Winter 2006a). As stated at the beginning of this chapter, the research questions were:

- How can young people be involved in planning and conducting a systematic review?
- Can a systematic review be conducted in collaboration with young people and at the same time maintain (or usefully develop) quality standards in systematic reviewing?
- What are the obstacles and facilitators to involvement in each stage of the research process?
- What are the negative and positive aspects of involvement, as experienced by both the young people and the researcher?

A key study output would therefore be the production of a systematic review, or the lack of it. A second finding would be my own and young people's reflections on the process of producing that review. This chapter has discussed the extent to which this study therefore encompasses two contradictory traditions within research epistemology: positivism and social constructivism. It has argued that all knowledge is socially constructed, but that

knowledge can nevertheless be accumulative and objectified as useful in terms of the development of services and policies. We live both in a world that is subjective to each one of us, and a collective world which we experience as universally objective and in which knowledge is produced. In line with Collins and Evans (2002) I argue that for knowledge to be generalisable and replicable, it needs to be informed by experts, drawing outside and within the research world. These experts also need to have experiential knowledge of the field, and this is where service user involvement falls into place.

Chapter 5 STUDY DESIGN

This chapter outlines the design of the study. First, under 'recruitment' I describe the study setting, how the young people were recruited as service user researchers, and consider the ethical implications of this research. The level of detail on the context of this research is provided to enable myself and the readers of this work to make judgements on its validity. The role of contextual data has been highlighted as important in order for research findings to be utilised by other researchers and practitioners (Arai *et al.* 2005). Having described the study context, I outline the methods for involving the young people in systematic reviewing, and how their participation was facilitated. This is done under two headings. First, under 'framework for involvement' I describe the extent of the involvement and how it was facilitated. Then, under 'Involvement in the systematic review', I outline the methods used for the systematic review, and more specifically how the young people were involved in each stage of the review life cycle. The last section of this chapter describes the qualitative evaluation of the involvement.

RECRUITMENT

Target group for involvement

The young people targeted for involvement in this study were selected on the basis of their personal experiences. The aim of involving them was to bring to the systematic review the perspectives of children and young people with experience of being in care, since the review would address an issue relevant to this service user group. The target group was young people up to the age of 25, although if someone was older than 25 and already part of a larger group of mainly younger people, they were not excluded from this study. A target number of seven to ten young people was set because it is seen as small enough to facilitate

a discussion, but large enough to sustain some drop-out (Stein 2004). It has been suggested that to encourage equal participation a group should not exceed a dozen (Vernelle 1994). The young people themselves had a say in whether the group stayed that size or whether they wanted to invite more people to join at different stages. I aimed to recruit people from an existing participation group, where they would have experience in acting as representatives as well as individual service users.

The care system in the UK has undergone many amendments in the last few years, and is still changing, mainly due to policy developments in the children services following the Leaving Care Act 2000, the Every Child Matters agenda in 2003 and the Children Act 2004. Part of the policy changes has been an extension of the time at which young people leave care. Previously, people left care at the age of 16, whereas under the Children Leaving Care Act 2000 the local authority now has a responsibility for ensuring accommodation up until the age of 18, to provide educational support until the age of 21, and beyond this if the education continues. For this reason, this study aimed to recruit young people with a recent experience of being in care, but to avoid rigid age restrictions given the new policies in this area.

Although a community, or group of service users, has something in common, this does not mean that it is homogeneous. Groups tend to have power structures and there tends to be inequality between members in terms of wealth, gender and social status (Cornwall & Jewkes 1995). I aimed to set up a group including both young men and women and was aware that there were likely to be gender differences in these experiences, but I did not want to exclude either young men, or young women. It has been suggested that in such groups, young men tend to dominate (Curtis *et al.* 2004b; Graddol & Swann 1989; Spender 1980). As convenor of the meetings I was aware of this and aimed to play my own role in a way that was supportive of equal participation across the group.

When involving service users in a research project there is a question whether they will be representative of this particular user group. For this study, the young people were recruited in order to reflect the views of a wider group, although they were not representatives, as they were not elected or chosen by peers to represent their views. Statistical representation

was not desirable, because the purpose was not to generalise people's views on behalf of the whole population of looked after young people. Rather, their participation was initiated because of their perspectives of having received and used services.

There was a practical element to recruiting young people from an existing participation initiative, but it also meant that the young people were already trained to contribute their views in a formal setting. By recruiting people already active in other areas of participation, I theorised that they would be more aware of the implications of being involved, and that such a group would be more likely to remain stable during the course of the research. Their previous experience of participation was likely to be conducive to participation in research.

I was aware that this strategy would exclude looked after young people who do not take part in such groups, and that the project would therefore be more likely to exclude the most vulnerable of service users. Oliver *et al* (2004) identified in their systematic review that working with service users with special interests encouraged informed debate and active involvement. Conversely, increased involvement with larger numbers was at the expense of the depth of the involvement. Studies which have looked at differing ways of recruitment to user involvement have not indicated that there is a large difference between self-selected membership and other kinds of representation (Oliver *et al.* 2004). Involving people who do not actively participate in groups is likely to require a different set of methods, such as one-to-one meetings (Brafield & Eckersley 2008). This does not solve the issue of representation, however, but the aim of this study was ultimately to investigate the involvement of young service users in systematic reviews, rather than specifically at how to encourage the involvement of hard-to-reach individuals.

Study setting

Young people were recruited from the Participation Advocacy Service (PAS), run by the Children's Services in an inner city borough. PAS is open to all children and young people looked after by the borough, including those placed outside its borders. Young people's

activities include sitting on staff recruitment panels, being involved in the training of social workers, producing training videos for council workers, doing phone consultations with other looked after children, and doing 'mystery shopping' exercises² as part of service audits. Representatives from PAS also regularly attend meetings of the Corporate Parenting Board³. In addition to the participatory work, PAS arranges social events such as football, summer parties and drama workshops. These social events aim to enable looked after children in the borough to meet and exchange experiences, and it is also a way of introducing PAS's work directly to young people. PAS has a monthly panel meeting where the young people decide what activities they want to be involved with.

PAS is run by a participation social worker who has set up a particular style of involving young people in these activities. Her main role in this study was to facilitate the recruitment of young people by presenting this project at one of their monthly panel meetings. During the review process we would talk informally on an ongoing basis, and these discussions informed my own planning of meetings. While she did not have a direct input into my involvement plans, her role at PAS meant that she had a strong influence on the study. The participation social worker, or an assistant social worker, would always be on the premises when meetings were held at PAS.

The borough in which PAS is situated is a densely populated inner-city area with wide income inequalities. The latest report (on March 31st 2010) counted 245 children looked after by this borough for more than 12 months continuously. Of the 25 young people eligible for GCSEs, 6 gained at least 5 A*-C GCSEs (Department for Education 2010a). At 25% this is better than the national average of 11.6%. The Borough scores statistically

² 'Mystery shopping' is the term used when someone, in a planned exercise, approaches a service as a user and then reports back to a management or audit team about their experiences with the service.

³ The term 'corporate parent' was first introduced in the 1998 'Quality Protects' programme. The Borough's 'Corporate Parenting Group' consists of elected councillors and people from across the council's departments. The group meets regularly to discuss issues related to the Borough's role as a corporate parent.

significantly worse on a range of health indicators compared with the England average, including deprivation, children in poverty, teenage pregnancy and drug use (The Association of Public Health Observatories 2009).

Recruitment

I designed an information sheet and a consent form to explain the purpose of the research and what the involvement would entail (Appendix 1). The information was developed to be comprehensible and clear, following frameworks for enabling young people to provide informed consent (Alderson & Morrow 2004; Liabo *et al.* 2002). A seventeen year old friend read through the information to assess its age appropriateness.

I chose to approach PAS about the involvement in this study because I had been in contact with them previously, in relation to another research endeavour. PAS's remit corresponded with the aims and objectives of this study, and the young people at PAS had experience of being involved in other initiatives previously, which I hoped would aid their involvement in the research. The actual recruitment was facilitated by the PAS participation social worker who invited people to an introduction meeting.

At the information meeting the young people were introduced to me, and told about the research. A formal presentation was not given, as the social worker had suggested this would not be appropriate. Going through the information sheet, I explained that they would work with me to produce a review of the literature on a topic chosen by them, but relevant to the health of looked after children and young people. I emphasised that the first part of the project would focus on deciding the topic and research questions. I did not at this stage explain the intricacies of a systematic review, but did say that the aim of the project was to produce a summary of research already done. The young people were asked whether they would like to participate, and asked to provide input into the practicalities of the project in terms of where to meet, membership of the group and the extent of their involvement. They were assured that they could leave the project at any time.

Ethical considerations

The study was granted ethical approval by the Institute of Education ethics committee (Application number FCH 62) in November 2007.

A major concern in this study was the ongoing data collection for the qualitative evaluations of the collaborative work. While this focused on the collaborative work rather than young people's personal histories, it could potentially lead to covert research if young people forgot the dual nature of the study. The young people involved were asked if they would give written consent for meetings to be recorded digitally. The information sheet and consent form explained that notes and recordings from the meetings would be kept confidential. I also stated that if consent was not given, meetings would not be digitally recorded, and I would instead aim to produce detailed minutes.

There are specific challenges to involving people explicitly because of their knowledge of care services. Their use of these services may have led to experiences of being stigmatised, or they may not want to be recognised as users of these services for other reasons. This will have specific relevance to involving them in dissemination activities. Efforts were made to involve the young people in dissemination, including as co-authors of presentations and publications. It has been suggested elsewhere, and was the practice of this project, that author pseudonyms could be used if they wished (McLaughlin 2007).

Because I was asking young people to contribute on the basis of their experiences in the care system, this could trigger emotional responses. One benefit of recruiting a group through Children's Services was that most meetings were held at their offices with the participation worker present. This provided useful back-up if young people wanted personal support, but it was also problematic because she sat in on the first two meetings, which meant that she too was involved in the first stage of the project.

There are ethical implications of paying people for providing data, as it can be seen as coercion, especially for vulnerable groups (Boyden & Ennew 1997). As citizens we have both

a right and a responsibility to participate in publicly funded activities. On the other hand payment for time indicates that their contribution is particularly valued, and it may be a way of ensuring participation of all young people, including those who are dependent on a working income. This study adapted the payment regulations operated by PAS, which was a fixed amount per hour, specified for meetings, training (half of meetings) and presentations (higher than meetings). Because the young people were involved over a very long time and contributed to all stages of the review, the lack of payment in this instance would arguably be exploitative.

FRAMEWORK FOR INVOLVEMENT

This section describes the framework for involvement in the systematic review. By a framework, I refer to the way the involvement was facilitated and implemented. An involvement framework aims to enable service users to have an influence on how the research is taken forward. At each stage of the review, and regularly during the collaboration, the framework was reconsidered with the young people, so that it could be adapted to their views, with the ultimate purpose of optimising active involvement.

A framework for involvement may be usefully considered across four dimensions; the degree of involvement it will facilitate, the forum set up for exchanging ideas, implementation of the framework and methods for decision-making (Oliver *et al.* 2004). Below, I present my framework across the first three of these dimensions. The methods for decision-making are presented in the context of the systematic reviewing process, further down.

Extent of the involvement

A systematic review has identified collaboration as being more effective than consultation in enhancing service users' influence on the research (Oliver *et al.* 2004), and this study

adapted a model where the researcher invited a group of young people to collaborate, using a teamwork model. I sought to work with the young people at all stages of the project, but they had the opportunity to choose to be involved in all, some, or no aspects of the research. Table 5-1 below shows the level of involvement at each stage of the study:

Area of involvement	Level of involvement
Nature of meetings	Collaboration
Research topic and question	Young people-led
Research methods	Consultation
Research analysis	Collaboration
Research dissemination	Collaboration
Evaluation of the involvement	Collaboration

Table 5-1: Level of involvement through the lifecycle of the systematic review

Oliver et al (2004) describe collaboration as “active, on-going partnership with consumers” (p. 5). Building on this definition I planned to encourage young people’s participation in discussions about the research, in making decisions on the research, and in doing the research. This informed the methods I used for involvement, which I developed to capture young people’s views, and to reach joint decisions on key aspects of the review. At the same time, I argue that there are aspects of research on which service users have expertise and aspects where the researcher is the expert. Although one aim for this research was to explore the extent to which collaboration with the young people was feasible across all aspects of the study, I recognised that young people’s influence would vary across the research cycle.

Although my aim was to explore involvement in an overall collaborative model, I retained, as the academic researcher, control over several aspects of the study. First, the initiative for the research came from me, and I decided which group of service users would be targeted to become involved. The young people participated in decision-making at the meetings, as well as on how to conduct the research. But my budgetary control, vested interest in producing a thesis for a PhD, and being the initiator of the project, meant that I was in charge of planning the meetings and driving the work forward. Second, the study framework was set by me in terms of a general topic, the health of looked after young

people, and research methods, in terms of a systematic review. Third, this project aimed to adhere to research quality standards and requirements of a particular kind of systematic review, which would reflect my own skills and perspectives as a social researcher. In terms of research methodology the young people were therefore consulted, but the systematic reviewing followed widely accepted guidelines for clarity, rigour and replicability (Shea *et al.* 2007).

Forum for involvement

To work constructively and productively with any group, it is necessary to build up trusting relationships. This was a key aim for this partnership too, which involved the use of my interpersonal skills, as well as planned actions as a social researcher. Relationship-building derives largely from tacit knowledge, but to facilitate the building of relationships within the group I planned each session with consideration to the physical environment, my own conduct and style of the sessions (Vernelle 1994). In particular, I thought about the timeframe of meetings, location, setting ground rules and establishing a mutual contract with the young people, which included a shared understanding of the tasks in hand.

The central place for involvement was the research meeting. The literature on involvement of children and young people emphasises the importance of creating an informal and friendly atmosphere where they feel comfortable and secure enough to participate fully and to the extent they want (Boyden & Ennew 1997; Cavet & Sloper 2004; Kirby 2004; McNeish 1999). I aimed to present myself in an informal way in terms of clothing, language and presentation of the project. However, because the young people were recruited from PAS they had experience and training in participating in planning meetings, and although they may not have had research knowledge, they were used to presenting their views and being consulted about their experiences as service users. I therefore wanted to balance accessibility and informality with a standard of working together that matched their abilities.

The main participatory methods used for the involvement were activity-based sessions and discussion groups, including focus group meetings, structured debates, voting and training workshops. The group was also given the opportunity to conduct surveys or qualitative interviews with other looked after children in their local authority, to further gain the views of a wider group, although this proved difficult to carry out, owing to time pressure from this and other projects. Systematic reviewing involves technical skills in database searching, reference screening, critical appraisal and research analysis, and research training was an essential part of this project. Again, the young people had a say in the amount of training they received, within budgetary constraints.

Setting up and running the collaborative research group

The collaborative nature of the involvement meant that some practical decisions were made along the way in conjunction with the young people and the participation social worker. I set the framework for the meetings, in terms of a way of working together. I initially worked from a loose and largely flexible agenda but later moved onto a more structured format where I suggested discussion points and presented the young people with options to choose from. Decisions were made jointly about the frequency of meetings and where to meet.

All contact with the young people initially went via the participation social worker and refreshments were available from the PAS kitchen (crisps, biscuits, juice and hot drinks). I provided special treats on certain occasions, such as mince pies for meetings in December. Once a relationship was established between the young people and me, we exchanged phone numbers so that direct contact could be made. During school term times, meetings were held in early evenings, or at weekends. When involving people who were unemployed or at university we would sometimes meet during the day, as some young people preferred that. The study followed the payment policies already operating at PAS, which meant that the young people got a choice between vouchers or transfers to their bank accounts.

INVOLVEMENT IN THE SYSTEMATIC REVIEW

This section describes the methods I used to enable the young people to take an active part in the systematic review, in terms of setting a topic, deciding on a research question, developing a research protocol, participating in the actual systematic reviewing (searching for, appraising and synthesising research findings), and disseminating findings from both the review and the evaluation of our collaboration.

The aims and objectives of this review were not set in advance, and it was one of the tasks of the group to agree these, before developing a review protocol and doing the research. Only one criterion was set for this; that the review would be on a topic relevant to looked after children's health. An underlying objective of the review was that it would be produced with a service user perspective, and so it was particularly important to create opportunities for the young people to express their views in terms of the review topic and questions.

Introduction to systematic reviewing

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

“This study is about how researchers and users of services can work together on a research project. To do so, we will work together on a research summary ... 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”(Appendix 1).

I then provided training on systematic reviewing at each stage of the review. When the review question was set, they were introduced to the specific methods of the kinds of studies which could be used to answer the question. Once the review was under way they were at each stage introduced to the main aspects of that research stage, what it involved

and why. Training was provided at each meeting, sometimes alongside the information-sharing and decision-making.

Systematic reviewing methods

The EPPI software for the management of systematic reviews was used for data management and analysis, and the responsibility for this lay entirely with the researcher. The study aimed to use systematic reviewing methods which met established quality criteria (Egger *et al.* 2000; Petticrew & Roberts 2006; Sackett *et al.* 1998), and to incorporate alternative ways of looking at research as informed by the young people involved. I anticipated that the young people would have views on the extent to which the findings of the review resonated with their own experiences, and how the results could be used to improve the health of looked after young people. We jointly wrote the review protocol which guided the searching for, screening, appraisal and analysis of the relevant studies.

Involvement in the life cycle of a review

To facilitate young people's involvement in systematic reviewing, this study drew on methods from qualitative social science research, in particular methods for doing research with children and young people. I made detailed plans for every meeting, describing each agenda item, involvement method for the item, how this related to the evaluation, how much time we would spend on it, and what I would say. I would start meetings with introductions, reiterate the ground rules, recap on the previous session and present a meeting plan. I would also think of examples in advance to illustrate key points and research concepts. These approaches had three aims: a) to translate and explain research, b) to facilitate the sharing of information relevant to the review, and c) to make decisions on how to proceed with the research. As well as general discussions (like any research planning meeting), meetings used specific approaches to facilitating sharing of information and decision-making (Boyden & Ennew 1997; Liabo *et al.* 2002):

Word association: Participants are shown cards with pictures or words and then take turns in saying what they associate with these. In an alternative version participants look for pictures in magazines and talk about why they have chosen certain images, and what they symbolise for them.

Structured debate: The meeting divides in two or more groups. Each group prepares the case for one option, often using a prepared sheet asking for key aspects of their arguments. The groups then convene to debate their position, and the debate may be concluded by open or closed voting.

Worksheets: These are sheets providing options or pointers for discussion. A specific worksheet was developed for the review protocol, using a Cochrane systematic review protocol template. The young people would discuss each section for the protocol, and I would then write their views down. At the next meeting the young people would then verify or reject any changes, and continue the discussion to complete the different sections (Appendix 2). Some sections were completely empty, others provided the young people with options to choose from, or pointers to what kind of information was relevant.

Creative methods: Using scissors, paint and hobby materials, the young people would create images to illustrate an ideal intervention or how they felt about a particular service. Drawing or toys were used to illustrate different kinds of study designs, by randomising toys (or not) to different interventions.

Word association, facilitated debate, worksheets and creative methods as described above were initiated to elicit young people's views in various ways, and thereby to trigger debate and try out ways of making the meetings engaging, meaningful and enjoyable for those taking part.

There are a range of methods to develop consensus in health priority setting, and the three main methods have been the Delphi method, the nominal group technique and the consensus development conference (Murphy *et al.* 1998). These were not deemed

appropriate for this study, as they are suited mainly for larger consultations to gain consensus among people with different backgrounds. Also, in this study several decisions were made at each meeting, owing to the depth of young people’s involvement. We therefore used open and closed voting, and ranking of priorities, and also reached agreement through open discussion, as in any research meeting. Open voting was a show of hands. In closed voting the participants wrote down their choice on a piece of paper, or ticked their choice, hidden from other participants. Table 5-2 below shows the methods for involvement and decision-making along the life cycle of the review.

Involvement stage	Method for information-sharing	Method for decision-making
Identifying topics for research	Discussions on important areas for research on looked after children	NA
Prioritising topics for research	Further discussions building on list of topics drawn up in the first meeting	Structured debate Ranking of topics Open voting
Protocol development	Discussions on the chosen review topic Worksheet protocol Research training	Structured debate Closed and open voting, including prioritisation of options
Managing the review	Consultation in research meetings: researcher presented alternatives, young people discussed and chose in conjunction with the researcher	Structured debate Decisions made through discussions at research meetings

<p>Undertaking the review:</p> <p>Searching Screening Critical appraisal</p>	<p>Relevant research training</p> <p>Searching and screening workshops</p> <p>Discussions about study design and quality in relation to the review question, using toy figures to illustrate different study designs</p>	<p>Discussions and according to protocol</p>
<p>Analysing and interpreting the results of research</p> <p>Review synthesis</p>	<p>Discussions about personal experiences of interventions described in included studies, using drawing and hobby materials to connect personal experiences to the kinds of interventions identified in the review</p> <p>Discussions about study quality and findings</p>	<p>Discussions and according to protocol</p>
<p>Disseminating the results of the review</p>	<p>Young people participated in the planning of the presentation, choosing which achievements to focus on, using images in magazines to illustrate their priorities. Young people choose the presentation style. I designed the presentation or poster layouts.</p>	<p>Structured discussions and debates with open decisions reached through consensus.</p>

Table 5-2: Methods for involvement in systematic reviewing

EVALUATING THE INVOLVEMENT PROCESS

The evaluation of the involvement process focused both on the quality of the final review, and on the quality of the involvement process itself. To assess the systematic review quality it was submitted to a peer-reviewed journal, and appraised by an experienced systematic reviewer using the AMSTAR approach (Shea *et al.* 2007). I also compared it to two other systematic reviews.

The young people were told that, as well as producing a systematic review, I wanted to study how young people can be involved in a research project. This evaluative aspect focused on four main areas of the involvement process, with direct reference to the research questions: the process of involvement, its impact on me, its impact on the young people, and its impact on the research validity and outputs. This ultimately functioned as a highly subjective qualitative enquiry. Data were collected in order to consider group dynamics, the role of the researcher, how the involvement process was facilitated, how decisions were made and what helped and hindered active involvement. The bulk of data stemmed from audio recordings of the research meetings, or minutes of these meetings when consent to audio recording was denied. Throughout the project I kept a research diary, similar to a fieldwork journal (Hammersley & Atkinson 2007). I used this actively throughout the study, to record expectations, experiences, thoughts, ideas, concerns and practical issues which came up in relation to the involvement process, and in relation to doing the research. Three months into the project, when the review topic had been decided, four young people conducted one-to-one interviews with each other. These interviews were audio recorded, and the young people gave consent for me to use these. At the end of the project I ran two focus groups where we discussed the project overall, what it had been like to be involved, what went well, and what could have been done better.

I planned to interview people who left the project prematurely, but increasingly felt uneasy about chasing people about this, as I worried that they would find my questions prying and somehow threatening. There was also an ethical dimension because the information leaflet stated that they could leave the project at any time. Some data on people's reasons for leaving the project trickled in via those who stayed on, as PAS had an ongoing stream of

people leaving and joining. When the review was finished I invited, via PAS, all people they still had contact details for to come to an evaluation focus group.

Consent was sought to audio record as many of the research meetings as possible, including the training sessions. I had originally also wanted to film some meetings, but given that some young people refused audio recordings, I rejected this idea early on. Meetings which were not audio recorded owing to lack of consent, were minuted. For the early meetings I also drew a map, detailing the room layout, who sat where, any movement or action within the room, and the extent to which people participated in the discussions and activities. After the first meetings I filled in a self-evaluation tool (Boyden & Ennew 1997), which asked:

1. What were the focus and aim of the meeting?
2. Were your instructions clear?
3. Do you have an adequate record of the context in which data collection took place?
(date, time, place, people, context, process, feelings/reactions etc)
4. Was there enough time to engage with all the issues planned?
5. What methods were used to engage in discussion?
6. What methods were used for decision-making?
7. How much did the young people decide, how much did they engage with the decision-making?
8. Who participated more in the discussions/decision-making and who participated less?
9. How did you end the session?
10. What other activities took place in the session – were these related to the objectives of your meeting?

Young people were given options for how to provide feedback: openly as a group discussion, individually to me or another member of the team, or by a questionnaire. This was to record their views on the specific stages of the work, to capture views of people who dropped out at a later stage, and to compare people's expectations and understandings of what we had done, with my own views.

QUALITATIVE DATA ANALYSIS OF THE INVOLVEMENT PROCESS

This study required two sets of data analysis. The first was the systematic review presented in Chapter 7. As described earlier in this chapter, the review followed established methods for systematic reviewing, aiming for academic rigour and quality using the PRISMA Statement (Preferred Reporting Items for Systematic Reviews and Meta Analyses⁴) to enhance transparency and replicability (Shea *et al.* 2007), and aiming for publication in a peer-reviewed journal. The second was the qualitative analysis of data collected during the research meetings, from my research diary, in peer interviews and two focus groups with the young people at the end of the project.

The approach to data analysis was framework analysis, which involves reading and re-reading data to identify themes raised not only by the research questions but also by the data itself (Ritchie & Spencer 1994). The framework of codes was directly informed by the research questions, as detailed in Table 5-3 below.

⁴ <http://www.prisma-statement.org/>

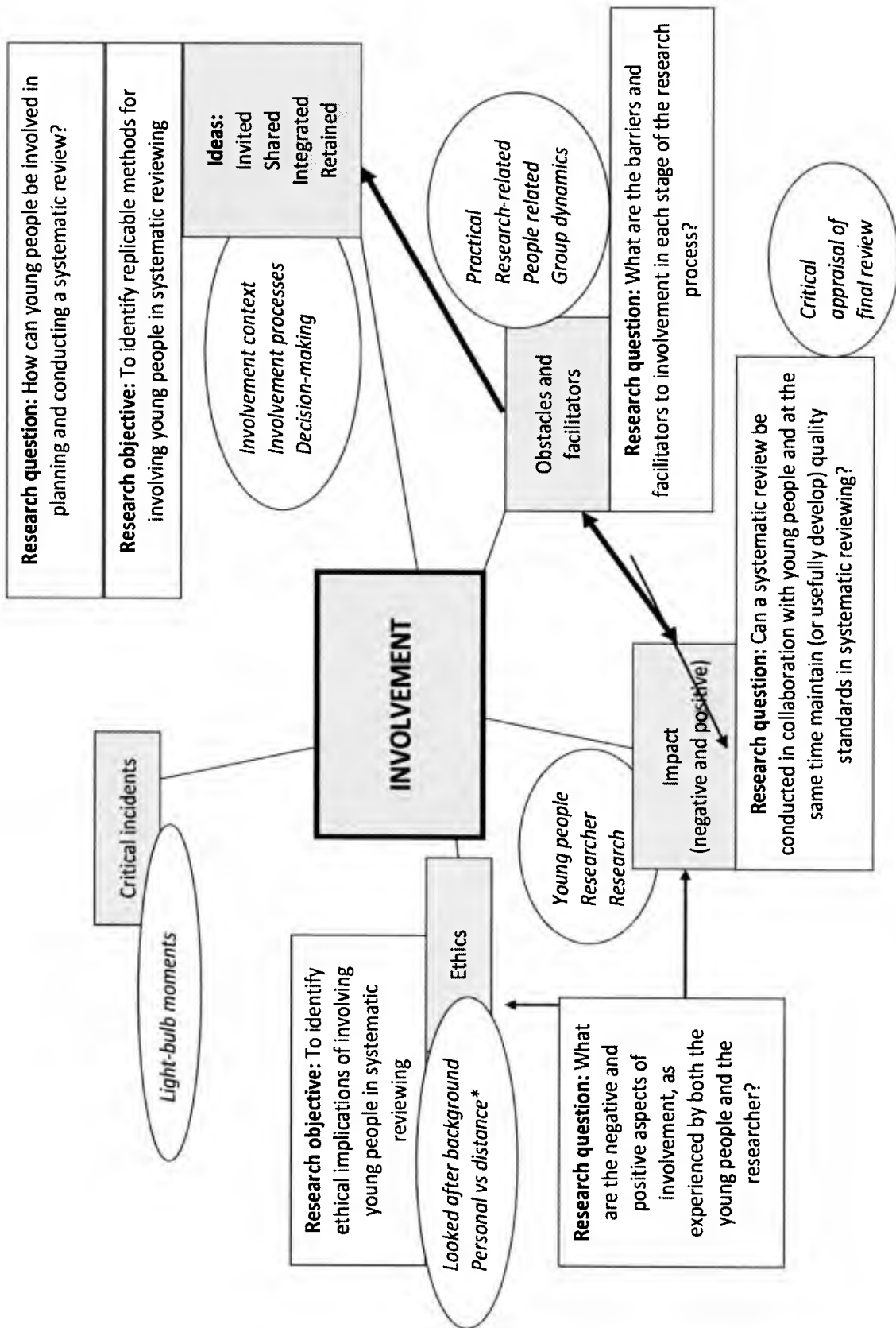
Question	Information	Key data source	Analytical approach
How can young people be involved in planning and conducting a systematic review?	Description of the review process: what happened in the meetings, what was decided and how, what tools did the researcher use to facilitate young people's input? Description of methods and how they were tested and in what part of the research lifecycle. Meeting attendance pattern.	Research meeting minutes/transcripts.	Largely descriptive about methods, looking at which approaches appeared to gain a useful output and which didn't.
Can a systematic review be conducted in collaboration with young people while maintaining quality standards for a systematic review?	Critical appraisal of the systematic review by an academic peer. Submission to peer-reviewed journal. Comparison with reviews on a similar topic.	The systematic review.	Critical appraisal, peer-review.
What are the obstacles and facilitators to involvement across the review lifecycle?	Critical incidents chart. Identified levers and obstacles. Researcher and young people's views.	Research meeting minutes and transcripts. Focus groups at the end of the project.	Framework analysis starting with a loose framework which expanded as themes emerge from the data.
What are the negative and positive aspects of involvement?	Researcher and young people's views.	Focus groups at the end of the project	Framework analysis.

Table 5-3: Focus of the data analysis

As indicated by the table, some of the analysis aimed to identify key aspects of the process of involvement, whereas some was mainly tracking the development of the review. I envisaged that the former would be interpretative whereas the latter would be largely descriptive, as it would provide a description of what happened when the young people and I worked together.

The qualitative data analysis was conducted in Atlas.ti, which is a specialist software developed for this purpose (www.atlasti.com). To assist the data indexing, I first developed a coding, or index, chart displaying the main coding areas corresponding to the research objectives and research questions and informed by Table 5-4 above. I organised these as a thinking chart, considering their relationships to each other. This is shown in Figure 5-1 below, where 'Involvement' is placed centrally, with key aspects of involvement in the grey boxes, which contained the main coding areas. I envisioned the obstacles and facilitators to be closely related to both the consideration of impact, as these would be factors interfering or enhancing impact, and the sharing of ideas.

The coding area 'critical incidents' did not correspond to one particular research question or objective, but was something I recorded throughout the study, in my research diary, to identify important shifts in the relationships within the group, surprising developments, or shifts in my own thinking (Miles & Huberman 1994). The box saying 'Ideas: invited, shared, integrated, retained' shows the initial codes related to evidence of collaboration, or lack thereof.



*Young people's reluctance or willingness to expose personal history in care

Figure 5-1: Main coding areas and corresponding research questions and objectives

This framework developed gradually as I read through the manuscript, refining the codes as new themes were emerging. Within each coding area, my approach was similar to thematic analysis, as I wanted to approach the data as openly as possible. Some of the initial analysis was brought back to the young people for their views. We did this in a dissemination meeting where we planned a research paper describing our joint experiences of working together. A critical incident chart, in the form of a table, was collated.

When the initial coding was completed I had expanded the number of codes considerably, although they still fell into the overarching coding areas as described in Figure 5. I then ran several network analyses, exploring the relationship between the sub-codes and the main coding areas. I also re-coded data which had fallen within each of the main coding areas, but without being attached to a sub-code of this area, developing further sub-codes. Finally, I grouped the data within each coding area, identifying the main themes emerging under 'obstacles and facilitators', 'Ideas invited, expressed, understood, integrated, retained', 'impact' and 'ethics'. Additional codes had emerged which spanned these. For example, some codes relating to young people's status as care leavers or looked after children were relevant to 'obstacles and facilitators', but also to 'ethics'. Finally, sub-codes were re-considered and collapsed into new themes within each main coding area. These are the themes presented in the findings chapters on the involvement process (Chapters 8 and 9).

CHAPTER CONCLUSION

This chapter has outlined the design of this study, detailing the recruitment process, the involvement work and the qualitative data analysis. I was clear from the outset that the qualitative approach chosen to study the involvement process was highly subjective, but I considered the benefits of this approach to outweigh the drawbacks. In particular, this approach gave me hands-on experience of in-depth involvement, it enabled me to aim for a collaborative approach across the systematic review, and it gave me unlimited access to the involvement data. I aimed to use this rich data to inform models for considering

involvement, in terms of both the process of doing it and in relation to its impact, on the research, the young people and myself.

This chapter has also briefly described the systematic review methods. The systematic review is a central finding of the overall study, and much of the process of doing the review was developed in conjunction with the young people. I now turn to the story of how this involvement process panned out.

Chapter 6 YOUNG PEOPLE'S INVOLVEMENT IN THE SYSTEMATIC REVIEW

Having described the background to this study in chapters 2 and 3, which drew on the literature about public involvement and looked after children, and having presented the study context and design in chapters 4 and 5 which detailed the research questions and study design, I now turn to the findings from the systematic review and the analysis of the involvement process. This study addressed four research questions: 1) How can young people be involved in planning and conducting a systematic review? 2) Can a systematic review be conducted in collaboration with young people and at the same time maintain quality standards in systematic reviewing? 3) What are the barriers and facilitators to involvement in each stage of the research process? 4) What are the negative and positive aspects of involvement, as experienced by both young people and the researcher?

This chapter addresses the first of these questions 'How can young people be involved in planning and conducting a systematic review?' The collaboration described here was set up by the researcher, who initiated the work with a group of young people, to produce a systematic review relevant to the health of looked after children. The aim for the collaboration was to facilitate their active involvement across the review, and thereby making the review as relevant to their views and experiences as possible. This chapter first provides a short overview of the involvement process, aligning it to each stage in the reviewing process. It then reports on how the young people were involved in the systematic review.

The overall level of involvement aimed for was collaboration; however, I anticipated that this would vary across the review life-cycle. I hoped that the young people would decide the topic and review question, and then collaborate with me on the protocol, the searching, and the screening. I hoped to consult them on the critical appraisal and analysis. The young people were from the start invited to collaborate on practical decisions about working together as well as in the review itself, although I recognised that this would be limited

because the budgetary power remained with me. This chapter considers the extent to which these aims were met.

The data underpinning this chapter is primarily from the research meetings.

OVERVIEW OF THE INVOLVEMENT IN THE SYSTEMATIC REVIEW

People involved

The young people were recruited from the Participation and Advocacy Service (PAS) described in Chapter 5. In the beginning meetings were held at PAS offices and the participation social worker organised most of the invitations and the catering. Some of the later meetings were held and organised by the researcher at the university. All meeting dates were arranged with the social worker so as not to compete with other PAS activities. This meant that the project added to the PAS portfolio of activities, and was part of their diary. Although the initial group said they wanted to keep the group closed, this did not happen in practice. New people would come to the meetings on an ongoing basis, either because they happened to be there at the time, because other people brought them along, or because the social worker asked them.

The membership of the group was therefore fluid. Throughout the course of the study 20 young people came to at least one meeting, and there were 20 review meetings in total. Five young people only came to one meeting, three young people came to two meetings, seven young people came to three meetings and three young people came to four meetings or more. Two young people, Denzel and Beth, were involved all the way through, attending 15 and 16 meetings in all. Of all the 20 young people, three were from the UK and the rest were unaccompanied asylum seekers from Africa (13), Eastern Europe (3), and Central Asia (1). Young people in the group were mostly in education and some had already left care, or left care during the course of the project. They were aged 16-24. Of the five young people who came to four meetings or more, three were unaccompanied asylum seekers from Africa and they were mainly involved in developing the protocol and searching for studies.

The two young people who were involved in the project all the way through were both from the UK. Because they had been involved for so long, I asked if they wanted to describe themselves for this thesis. Names of all young people have been changed:

Denzel: My name is Denzel and I'm 25 years old white male from London, I was looked after by [name] council from the age of 11 due to problem in my family home and had extensive list of placement moves, which made getting a full structured education very difficult and as a result I left school with no GCSE'S. I did later return to education and did a full GCSE course at Southwark College where I had predicted grades of A*, A, B, B and C, but had to withdraw due to a knee injury. When I was 16 years old I returned home to my mother and I then moved into independent living a year later (at the age of 17), where I have lived independently ever since. Whilst coming through the care system I sought to actively participate where possible and stand up for my rights and the rights of other children and young people. Also during my time in the [council] leaving care service I have been a member of PAS, one of Shaftesbury young people's first young person trustee's and chairperson of the Rights Advisory Group Experts (RAGE).

Beth: I was 19 when I joined the project and was working as a care assistant in a day centre for the elderly, I was living in semi independent accommodation. I wanted to take part in the project as I have experience of being looked after. I came into care when I was 8 and remained until I was 18 when I became a care leaver. I thought it was important to take part as I could give a real account of what it is like to be looked after and give an honest view of the difficulties looked after children can face in comparison with those who are not looked after. I have come on a long way since starting the project, I am now 23 and have just finished my degree, soon start my masters in social work and I am now living independently.

In addition to the young people, the participation social worker attended the first two meetings where we discussed the review topic. She did not participate in the voting, but it is clear that her presence had some influence on the discussions, as indicated later in this chapter. A research student who wanted to learn about systematic reviews contributed to

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the double screening of studies. She attended one of the meetings where we tested out the screening tool, but did not take part in the discussions.

Overview of meetings and their focus

Information about statistics and research on looked after children were shared with the group at five meetings. First, in response to the discussion at the first meeting when some people felt that mental health was an important issue whereas others disagreed, the researcher presented some relevant research findings at the second prioritisation meeting. Later, after the topic 'school drop-out' had been chosen and work on the protocol had started, the researcher presented the group with national statistics of looked after children's education. When providing the search training, one of the examples used was a study on the importance of education to people's health. Finally, two analysis meetings discussed the individual studies included in our review. The young people did not read these studies themselves, but were presented with figures illustrating their evaluation designs, and bullet points of the findings and key characteristics.

An overview of the involvement process is presented in Table 6-1 below.

Review stage	People involved	Involvement methods used
Setting the topic	Beth, Denzel, Ermias, Alex, Imran, Rahel, Tereza, Sophia, Kedija (N=9)	<p>Group discussion listing priority topics</p> <p>Group discussion prioritising the previous list, priorities made by open voting</p> <p>Top two topics debated by two groups, each arguing for one of the topics. Final decision made by text survey to people not at the last meeting</p>
Deciding the review question	Beth, Denzel, Ermias, Birikti, Danait, Mariam, Yonas (N= 7)	<p>Meeting with break-out groups discussing possible populations and interventions</p> <p>Meeting with break-out groups discussing populations and interventions, and concealed voting to make decisions how to focus the question</p>
Writing the protocol	Beth, Denzel, Birikti, Danait, Mariam, Ruta (N=6)	<p>Meeting with open discussion and filling in review protocol with tick-box options for population, intervention and outcomes</p> <p>Meeting with open discussion and filling in review protocol with tick-box options for study types, population and outcomes</p>
Searching	Beth, Denzel, Danait, Mariam, Ruta, Yonas (N=6)	<p>Planning the searches, meeting held in computer lab and including basic search training</p> <p>Searching Google and ERIC in computer lab, some more basic search training</p> <p>Researcher consulted young people on search strategy, open debates and closed voting</p> <p>One young person searched for grey literature on specialist websites</p>
Screening	Beth, Denzel, Ruta, Zahra, Fiyori, Sophia (N=6)	<p>One young person piloted the screening tool developed by the researcher</p> <p>Meeting discussing a selected sample of abstracts, open discussion about inclusion and exclusion criteria, decisions made by open voting</p>

Review stage	People involved	Involvement methods used
		<p>Meeting in computer lab, screening abstracts</p> <p>Meeting in computer lab, discussing double screening from previous meeting, decisions made by open voting, then screening another batch of abstracts</p> <p>Meeting to reconcile screening differences, open voting</p> <p>Meeting to reconcile final screening differences, draw-write technique to discuss relevance of different interventions, open voting to make final screening decisions</p>
Critical appraisal	Beth, Denzel – three other young people attended for the first time but did not actively contribute to the discussions	Discussion about quality in research, prompted by discussing a newspaper articles on research findings.
Analysis	Beth, Denzel, Hakim (N=3)	<p>Discussion about the findings, researcher presented the studies found and the group discussed their relevance</p> <p>Creative methods comparing findings with personal experiences</p>
Writing the review	0	
Dissemination	Beth, Denzel, Tereza, Ermias (N=4)	Presentation at INVOLVE conference 2008, poster at INVOLVE conference 2010, presentation at Folk Us conference 2010, presentation at NCB conference 2011 and presentation at SSRU research seminar 2011. Co-authorship of the review for Child & Family Social Work, and co-planning second peer-reviewed paper.

Table 6-1: Overview of the involvement process in the systematic review

In addition to the review meeting, two rounds of interview training were provided in response to young people's wishes, and six young people attended these. Four young

people were also involved in dissemination activities, including three conference presentations and one poster, and two young people attended a one-day writing workshop to prepare them for involvement in writing a paper about their experiences of being involved.

INVOLVEMENT IN EACH STAGE OF THE SYSTEMATIC REVIEW

Involvement in setting the review topic

The starting point for this review was that the focus and review question should be decided by people who had themselves been looked after, with the hope that they would draw on their experiences when choosing a topic relevant to looked after children's health. The initial meetings were therefore planned to support the young people to lead on the review topic and question, with minimal input from myself in terms of what was decided. The review topic was developed over four monthly meetings from November 2007 – February 2008, and the level of involvement aimed for in these meetings was user-led research.

The young people first suggested six issues that they thought were important to looked after children's health, and voted for their three top preferences. At the next meeting, two groups debated the top two topics, and a final decision was made via text message voting where they were asked to text their preferred option of two alternatives. In many ways, they were leading the debate about what the review should focus on, and I simply acted as a facilitator to the discussion. This is an extract from the second prioritisation meeting at which we discussed the list of issues already compiled:

E: ... Moves are very interesting 'cause I read in Science, hm, someone who's had problems till they're about seven years old, really bad problems, behaviour problems. But when they're actually placed in a stable foster pla foster carers, that problem, hm, over time disappeared and they were normal people. So, hm, play, that problem might occur 'cause of placements movements. You know what I mean? So, it's better to focus on placements.

KL: yeah

[pause]

KL: right, no, no other views on these things? I'm just

D: I think it's all, I think it's all corrupt myself

KL: yeah?

D: In the fact that I think, if we just let young people in care get on with their lives, I don't think we'd have any problems in the fact that, straight away when you come into care, as soon as you're in care, everyone seem to, ah, poor child, what a bad life have spent, and it's like anything in life, if you expect problems you are gonna find problems. You can have a dog, if you expect the dog to go and bite, bite someone, soon as it starts barking, you'll think it's bite, bit someone so, that's why we have so many problems it's because everyone expects people in care to be messed up, that's why people come out of care messed up, it's because nobody that actually bothered to try and do anything before it actually gets to that stage, they just think oh, they gonna come out messed up anyway so it's no point trying. That's why, that's why it's happens, it's because no one wants to bother putting the effort in 'cause they think it's a lost cause before they even start.

KL: so it's about stigmatis

I: [interrupts] I think that's quite right actually ...

(Prioritising research topics, 13th December 2007)

In this exchange we have just discussed mental health, and what research says about this issue, in response to a discussion at the first meeting when they disagreed on whether mental health was an important issue for looked after children. Having presented the findings of two studies on this I encouraged people to come forward with their views. One young person started to initiate the issue of placement moves, another vented his

frustration about stigmatisation, and this in turn was picked up by another. The meeting very much followed this conversational structure. I would provide suggestions or support people's views, but they would ignore or take things forward as they wished.

This open structure was meant to facilitate the discussion so that the young people could suggest topics they wanted, without a framework setting the agenda. The idea was that we would gradually narrow the discussions down from a general topic to a specific question. The problem with this approach was that people easily got side-tracked. For example, a fair amount of time in the second meeting was spent on discussing access to own files:

D: ... too many people have talks behind your backs and have talks down corridors about you, and you're not privileged to, your privilege, the only time you get the information is when you're in a review and even then you get what they wanna give you. You don't get, like I can't just go down to the family court offices and I wanna see my file, I gotta go and ask some woman, down at the town hall, for permission to see my own files. So if information about me, I gotta write off to someone, wait months and months, just to see information about me that I should already have...

....

E: what are you saying, what are you saying we should have our files?

D: yeah.

E: what about if the person loses it, something that's important

A: they can have copy

S: yeah, they, they

A: copies

D: they can have a copy of the file.

E: yeeah

D: 'cause in the end of the day, the end of the day, once, once

E: yeeah

D: once you're in a children's home, when I was in a children's home, they used to have all the files in the filing cabinet, but couldn't go to a worker and say 'I wanna see my file' they'd say there's too much stuff in there'

E: but I know, but

S: ok, wait

A: if you're in a normal family you don't have a file do you? Your parents aren't gonna start writing things

(Prioritising research topics, 13th December 2007)

I found that repeatedly through the process of conducting the review it was difficult to strike the balance between structured sessions which might be leading them down a particular path, and looser discussions which might then not be focused. It is also clear from the early meetings that although I attempted to make them lead the discussions, I did have a significant influence on the outcome, precisely because I was the facilitator. For example, the topic 'positive things about being looked after' was my interpretation of something which was said and not meant in the way I suggested:

D: [exasperated] I'm just saying I don't want the topic to be alcohol and illegal drugs but that's my personal view 'cause I don't want to, don't want to tarnish young people with a brush with alcohol and illegal drugs

....

D: that out of that list there's, out that list there's four things that's already got a lot of attention [unclear word] for children and young people looked after in the fact that, we're always hearing from the council in one of their looked after children with

regards to mental health, bullying is, bullying is always, written about young people, in schools, alcohol and illegal drug use is always on, on the agenda, and so is teenage pregnancies with the [unclear word] offending and lack of motivation are the only two things that you don't hear much about.

.....

[many people try to speak at once, KL's voice comes through]

KL: let me just say one thing, I do hear what you're saying 'cause you feel that looked after children, always very negative, right? We could think of a positive thing, right?

D: can I just

KL: You don't have to think of a negative thing

D: [interrupting] can I just say why I

S: that would be a new thing then on that list

E: yeah

(Prioritising research topics, 13th December 2007)

In this extract, Denzel defended his own preference for offending, by suggesting that alcohol and illegal drugs was too negative and stigmatising. I misunderstood his intentions and thought he wanted a more positively framed issue. This suggestion was then picked up by Sally (social worker) and Ermias, who brought it forward.

The chosen topic was 'lack of motivation to go to school/employment/further education'. In discussions this was changed to only focus on mainstream education. Young people who wanted this focus argued that without education you will struggle in life, particularly in terms of income, which in turn relates to health. They said that education is the basis for

everything else, because if you stay in education you are less likely to get into drug and alcohol misuse, crime and unemployment. Some of them found education so important that they struggled to articulate the rationale, they said it was self-explanatory.

From this, two preliminary research questions were developed. These were a) Why do looked after children not want to go to school or further education? and b) What can be done to prevent looked after children from dropping out of school?

Deciding on a review question

There was a gap of seventeen months between deciding on the review topic and meeting again, because I went on maternity leave for 12 months and came back in the early summer when activity at PAS was reduced owing to the school holidays. The two meetings to fine-tune the review question were held in September 2009. The topic-setting meetings had seen membership dwindle, and on advice from the social worker I had decided to organise batches of sessions closer in time, and to make each session more structured. This was because she thought the falling interest seen after the first three meetings was due to monthly meetings being too far from each other in time, and that a structured approach would move the review forward more swiftly, making their input more evident. This fitted well with the need to write the protocol, and illustrates how the social worker influenced my planning and running of the research collaboration.

The meetings now started with some brief research training where we would define research overall, and then move on to specialise terms for systematic reviews focusing on the particular stage we were at. This would be followed by discussions on particular aspects of the topic, for example at which point in their education people most need support. Rather than initiating an open discussion around the review topic, I presented people with statements or questions and asked them to discuss these, such as "do we think that something can be done to prevent looked after children from dropping out of school?" We also looked at particular aspects of the preliminary questions, by defining 'dropping out' and

'prevention'. One young person did not want these meetings to be audio recorded, so this is from my description of the first meeting:

Talking about the different reasons for dropping out it seemed that they were most interested in the placement issue and household problems ... so I said, ok, could one question be "How can we prevent looked after children from dropping out of school when they move placements?". Yonas said he thought that was a very good question, so I wrote it on the flipchart, but he still struggled to see how this was relevant to health.

....

To make them relate more to the research question I asked them what kind of support looked after children currently get for their schooling. They got quite engaged in this. They said they already have a social worker come into school, and that children don't like this because it makes them stand out, makes them different from other kids.

(Defining the research question, 30th September 2009)

After the first meeting I considered all their views and developed some new and alternative research questions based on these. At the next meeting the group considered the questions and then voted for their favourite, using prioritisation slips. Again from the meeting minutes:

So I handed out the prioritisation sheets and said to put their favourite down as one, second favourite as two etc. People did this and folded them over, I had to remind them to fold it over so that nobody would see their answers. I then said ok how are we going to count the votes, the one with the most 1s or the one with the lowest overall score. They grasped this straight away and chose the one with lowest score because that would be fairest. Then Mariam helped me by reading aloud people's priorities per question and I wrote down the numbers on the big A3 sheet. She quickly found one sheet with only one number on it, it turned out to be Denzel's so

he prioritised while we waited. We mixed his sheet with the remaining ones to keep it anonymous.

(Defining the research question, 7th October 2009)

The final review question chosen by the group, on the basis of discussions, prioritisation, votes and background information was: What is the effectiveness of interventions that aim to help looked after children stay in school?

Setting the parameters for the review protocol

Having decided on a review question, I used the protocol worksheet, described in Chapter 5, to define criteria for the review. Because people disagreed whether we should specify the intervention in advance, the review question was initially broad. The first protocol worksheet gave people options for how to define the intervention(s), which we then discussed. This version of the worksheet is included as Appendix 2.

The options listed in the worksheet were those suggested by young people in previous meetings when discussing the review question. Putting the options into the protocol concretised what we needed to decide in terms of interventions. This is an extract from the meeting where we discussed the intervention options suggested against keeping the review broad and including any intervention that aimed to support looked after children to stay in school:

KL: shall we, what do you guys think, shall we pick some [interventions], or shall we do that [all interventions]?

M: lets try to do that, what did you think

B: I think 'cause there's disagreement I think

M: eh?

B: I'm gonna vote, just to keep [unclear] [laughs] [unclear] be happy

KL: yeah, what do you think Denzel?

D: yeah I think

KL: would you feel more happy about that [any intervention], 'cause that includes these things

M: mm

B: includes everything

KL: it's more holistic

D: yeah I think, I think that's, is, I don't wanna seem like I'm trying to get my own way but I'm

B: no no no no

KL: no no

B: [unclear] agree, you're not happy with that so

D: that is what I think, to make it so, to make it broad like we're still, we're keeping all our options open, I think if we, made a decision right now to go for CBT we'd be, there's a chance we could be saying to the other five, to the other four right, goodbye, and we're wasting an opportunity.

(Protocol writing, 12th November 2009)

In this meeting the young people decided that they would include any intervention that aimed to support looked after children to stay in school, which meant that the review question was not changed. In the next meeting, to facilitate a discussion on how we would define this, the protocol worksheet gave people a choice of three types of interventions.

Discussing these three options, the final text in the protocol reflected what the young people had said:

“This review will include any intervention that has the specific aim of supporting looked after children in their schooling. The intervention may be provided to social workers, foster carers, teachers or children themselves, at home or at school. We have discussed the following interventions: cognitive-behaviour therapy, social work support, carer support, placement stability and virtual schooling. We know that there may be other kinds of relevant interventions which we are unaware of” (p. 3, final protocol).

Searching for studies

I did not expect the young people to be actively involved in the searching, but I did want to provide opportunities for them to influence the search strategy, and to receive search training. I thought this would improve their understanding of systematic reviewing and research in general, and that they might find it useful for their studies or career development. We spent two evenings in the computer labs at the university. I started each session teaching basic searching methods and we would through this training work out a search strategy. As in the extract below from the first searching session:

KL: ... so what words did you think Danait?

DA: I'm not really sure but looked after children, young people who are in secondary school, age 10 to 15, children who are in permanent placement, non-disabled children, care leavers and accommodated children.

KL: Care leavers?

DA: Yeah.

KL: And?

DA: Accommodated children.

KL: Accommodated children, okay, has anybody else thought about the population, anything to add?

R: Children, asylum team.

...

D: Children looked after by foster carers ... Well I suppose the actual term would be children in foster care.

KL: Yeah, we can go back to that.

B: Children with full care order.

(Searching, 2nd December 2009)

In my efforts to engage young people in the review I found that using examples from popular media was a good facilitator. The more I could link in with their personal experiences or interests the more enjoyable they found the meetings. Below is an example from the second search training session:

KL: ... So you're interested in reality TV and you want to do a search on that, okay? But you're interested in a certain type of programme too, so this is, this is the search term, yeah, but you're interested in a type of programme too, sing song programmes or whatever.

D: Reality TV with a musical.

B: Music, dance, social, Big Brother.

KL: Maybe you don't want the social ones, maybe you just, what we're getting at is X Factor right?

B: Oh yeah yeah yeah.

DA: Yeah, right.

KL: So

D: Singing

KL: Singing, yeah

B: Performing

DA: Talent

(Searching, 9th December 2009)

In these sessions we also started to talk about how we would interpret the information we found, considering the information source, its trustworthiness, and relevance to our own research question. The two search training meetings provided limited input into the search strategy, although we did discuss and try out possible search terms. The young people's influence on the search strategy was seen mainly in the inclusion of 'unaccompanied asylum seeker\$' as a search term. A one-to-one meeting with one of them worked better in terms of searching collaboratively for studies, as indicated in the below abstract. At this point the electronic searches had been carried out, and we were searching the websites of relevant organisations:

KL: No, it's kind of... no, I was more thinking of that one.

D: 'Publications'?

KL: Mmm, I think that's it, yeah.

D: That will just take us back to the page we just had.

KL: Will it?

D: It was all under the blue print the stuff I just showed you.

KL: I think there was more of a mix...

D: See, because they go more on the basis of advocacy.

KL: Yeah, I think you're right. Okay, so we can leave them out then.

D: But they did have a bit here that I was very interested in, the 'Links' page.

KL: Oh yeah.

(Searching, 12th April 2010)

Ultimately, almost all searching was done by me, and the main input from the young people was in terms of consultation on the search terms, apart from the session of searching websites illustrated above. Although a collaborative approach was achieved in the latter, the search training meetings functioned mainly as consultation exercises.

Screening search hits

The young people were actively involved in developing the tool for screening study abstracts for exclusion or inclusion in the review. It was important that this tool used language that made sense to those who would be screening. This was done over three meetings, where the young people would log onto EPPI-reviewer, a web-based software for managing systematic reviews, and test out the tool. Four young people were involved in this process. Two young people subsequently double-screened 817 studies, which is 12.5% of the total number of hits. As the screening commenced we also spent many meetings discussing second opinions. In these meetings the voting was a show of hands, mainly because the discussions were not heated, and the young people involved had worked together on the review for a long time and through this period had developed an open and supportive working style. As illustrated in this extract from the last screening meeting:

D: I must admit I'm, this is one that, for once, I'm going to say, I'm not actually too fussed. I would actually be quite, I'm in between so I'm quite happy to, like, I'm swayable

KL: Leave it to me

B: Yeah

D: The fact that, the fact that Beth's already said no [trails off]

B: But, I mean, again, I'm, if it was in, it's in, but I personally don't want it

D: No, what I'm saying is, the fact that you said it's already, for you it's a no, I wouldn't, I wouldn't have an argument to fight on that...

(Screening, 23rd September 2010)

The level of collaboration achieved across the screening process was encouraging and surprising because I had not expected any of the young people to be involved so heavily in reading secondary data (abstracts). Possibly because of this the screening needed more meetings than originally anticipated.

Critical appraisal

The screening process had shown that the young people's views differed considerably from mine on what kinds of study designs they considered suitable for evaluating interventions. On the surface, this meant that they were interested in including cohort studies, surveys and qualitative process evaluations. The screening process had also showed that none of the young people were interested in being involved in activities that required them to read the full studies, as illustrated in this exchange at the second screening meeting:

F: They're really hard to understand. They're not hard to read but they're difficult to understand, it takes quite like, you literally have to sit down and you have to read it more than twice...

SA: Over and over again.

F: ...to understand it.

SA: And only one word can make like, can make a big difference...

(Screening, 30th June 2010)

When it came to the critical appraisal, I therefore decided to engage them in a general discussion about research quality rather than aiming for them to take an active part in reading the studies and assessing them for quality. First, I explained it by using people at the meeting, asking them to imagine we were all recruited to a study in various ways. According to the young people this worked better than using toy figures. I also illustrated study designs by drawing the interventions, population samples and outcomes, and using arrows to illustrate the relationship between these. I felt the most successful way of explaining study design was to ask them how they would evaluate a chosen intervention:

KL: ... if we set up this sports programme for looked after children in [Borough], 50 said they were interested, how would we find out whether the programme made a difference or not?

D: I suppose you could kind of see where they were before they came, so it might be that, I hate to say it like this, but it might be that young people who were always missing school and always bunking off and, like, that you show them people, you pick them for the course

B: You target them

D: Yeah, you target them and that, as a result, their attendance at school got better, and in the process, their work levels and their grades got better...

KL: But how do you know it's the programme?

B: Yeah, they could, they could, something could have changed at home. That's one thing

KL: Stable placement, you know, got back with the family, working out. A real big bully was moved out of the area and suddenly going to school was a joy

B: Yeah

KL: How would you do that, because there is a way

D: Evaluation

KL: Yeah, but how?

B: Talking to them

D: Talking to them, getting their own, getting service users...

KL: Talking to them, yeah, that would be a good idea

D: Service user involvement

KL: Yay

D: I remembered it

KL: So shall I tell you what I think would be best?

B: Yeah

KL: I think the best thing would be if you said, well, there's many ways of doing it, but I think you need a group that doesn't get the programme...

B: Yeah

KL: ...and then you need a group that gets it

B: Oh, comparison

KL: Because then you do something that we call 'control for'. So both groups have all this other stuff going on in their lives, but only one of them has the programme

(Preparing critical appraisal, 23rd September 2010)

I decided to take pointers from this discussion when I did the critical appraisal myself. When developing the protocol the young people had said that they wanted to include any study design that evaluated an intervention. This was widened further during the screening when they also wanted to include studies of people's views. At this stage, however, they said that they wanted studies to have measured outcomes, but that they did not consider a comparison group necessary. In this an extract Denzel explains the point of a comparison group:

D: Because we've got nothing to compare it to, we're not able to compare someone else who *hasn't* had the intervention, like because you, if you've got just one person and you just give it to one person, or you just do it to one group and you give them it all and just look at after, it could be something that has got no bearing to the intervention, it could be that their placement has changed or their schooling's changed or, their emotional wellbeing has changed, or their mental health has changed, so it could just be something else Obviously if you've got 20 people that all have the same intervention *all* change in the same way, that's positive you would find, I think it's a *massive* coincidence if *every* single one of them had something else *other* than the intervention that changed in their life that made them better, or that made them...

(Critical appraisal, 14th October 2010)

Because the systematic review would follow standard procedures for assessing study quality, I decided to follow their advice on study design and include non-controlled studies. I

knew that I would treat these studies with more caution than controlled studies, and I was aware that the evidence box would otherwise be disappointingly empty, and these studies might be instructive in terms of what has been done and what can be learnt from that. I also knew that I would not have acted on their advice if I had thought it would jeopardise the quality of the review. By now, we all had considerable ownership in the review and a stake in the final outcome. We had spent a lot of time and effort to move the review forward, and I decided to take a stronger lead to ensure that there would be a review in the end.

Analysis of the included studies

In terms of the analysis, a similar approach was adapted as for the critical appraisal. In addition, I encouraged them to consider what kinds of interventions they themselves might have found helpful, or talk about services they thought had helped them personally in terms of their education. The aim of this was to situate the findings in relation to their own experiences. In this respect, they were mainly consulted during the analysis. However, they also had a direct input into how I grouped the interventions into categories. The final six groups were informed by the young people's suggestions, which they discuss below. Each intervention was summarised on a small piece of paper and spread across the table:

KL: ... here they all are and I'd like us to go through them and I'd like you to take the lead here, start reading what the different ones are and familiarise yourself ... if you want to sort of play a little bit or sort of fish, somebody fish out an intervention and tell the others what it's about

...

H: This one's also about training foster carers

B: Up in Norfolk

D: Is that not very similar to the 'Catch Up Midlands'?

H: Yeah

KL: So that's similar [trails off]

D: I'm not sure if it is, I'm just asking

H: It is

KL: Okay

B: I've got Educating Liaison Invention, "an education specialist working with Social Workers, Social Workers refer cases where they're unable to resolve an educational issue. The specialist provides advice for the Social Worker or has a direct effect, direct input sorry, into meeting the educational needs of the child. The education specialist had training from an advocacy law firm which also provided weekly technical assistance with individual case". So that's a behind the scenes kind of intervention

D: Are you not sure that would go with this? Because these are both very much like somebody that's employed with the aspect of the looked after children side of things

KL: So you feel it goes with that one?

D: Yeah, I feel, because both of these are kind of although they're like [head of virtual school] isn't actually, well I think [head of virtual school] is actually employed by children's services isn't she?

(Analysing studies, 15th December 2010)

In addition to the intervention categories, the young people also informed my view of the studies. From my perspective as a trained systematic reviewer, none of the included studies were of sufficient quality to provide any information on how to effectively support looked after children's schooling. One young person agreed with me, because she would have wanted to see comparison groups before she trusted the findings. The young person who

had previously said that a comparison group was not necessary, stuck to this view and said the following about one of the studies which found a small reduction in exclusions and improved attendance at post-measures:

D: ... they've made an achievement in the fact that like you can't argue, the attendance has gone down by 3%, the level of, like the attendance, sorry, the attendance has increased by 3% and the average days of people being excluded has gone down. It might not have gone down sizeably, but it's gone down and I think it's about you've got to look at, I think [trails off]

(Analysing studies, 17th February 2011)

Their views on the outcome measures used in the studies also informed the review discussion, because they felt that the most important outcomes were the extent to which young people remained at school, and that motivation and experiences at school were more important than attainment. This influenced how I viewed the included studies, their value, the implications of the review findings and implications for future research.

Involvement in practical decisions about working together

Initially, the young people did not show much interest in questions about how we would work together. This is not surprising given that they had only just met me, and we had not worked together before. As time went by, the stable members of the group started to take initiative in terms of re-arranging meetings for more suitable days, or reminding other members about meetings. This started during the time when we were developing the review question and the protocol. This is a reflection on the second meeting on the research question:

“[Beth] asked if we were going to use this room or the one downstairs. I said I didn't know, and asked which room they usually use. Beth said they're usually downstairs. I

asked whether that room has a table, and Beth said yes it's got a big table. I thought: that's probably better then."

(Defining the research question, 7th October 2009) This was the first I ever heard of there being an alternative room, as we had always had our meetings in the PAS flat. Although Beth did not directly initiate the decision of where to hold the meeting, this is an example of where a young person initiated a change in previous proceedings. In the event, the other young person present did not want to have the meeting there, because it would require them to walk up the stairs after the meeting to collect their vouchers from the social worker. Beth preferred the downstairs room, and we did go for that room because it had a table and a flipchart.

As time went on, they increasingly made suggestions in meetings on how to move discussions forward. By February 2010 we had met almost every month, and sometimes several times a month, for five months. The group had started to understand some of the core elements of a systematic review and the fact that we were doing secondary research based on previously conducted studies. We had also, during this time, experimented with various ways of making decisions: open and closed voting, and general discussions. What Denzel suggests here is similar to approaches tried previously, but this is the first time one of the young people actually makes a suggestion for how to move a discussion forward:

D: Can I make a suggestion?

KL: Yeah.

D: Why don't we all just have, like us five, separately, to have like five minutes to look at this and then we say like... because, for instance, at the moment, we've got nine around the star.

B: So we do like a top three.

KL: Yeah.

D: Or a top three or four to say to people like... and then we come back and then we look at... so, if a person puts in their form what their first, second and third is, then we have a quick look to see...

KL: Good idea.

(Finalising protocol, 9th February 2010)

Sometimes they made practical suggestions with the intention of making things easier for me. What Denzel is referring to below is that it was quite difficult for me to buy vouchers in advance because I never knew who would actually turn up on the day:

D: ... what you can do is rather than buying the vouchers in advance, you could just wait until like afterwards sort of thing.

(Searching, 12th April 2010)

Because the young people were involved in the practical decisions, they also started to show an understanding of how it was necessary to prioritise at times. This was their response when I told them that our paper was not accepted at the 2010 INVOLVE conference:

B: It means we can still go, are we still going? Because people, do you remember the ... woman at Exeter, they did posters and they were still there (laughs).

.....

D: Yeah but would it really justify, if we're only doing a poster, would it really justify taking two or three people. So three or four people going up to Nottingham...

(Planning meeting, 24th May 2010)

In the last six months of the project, the two permanent members of the review group started to make even more proactive suggestions for how meetings should be run, when, or where. For the first analysis meeting Beth told the monthly PAS panel meeting about it to

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encourage more numbers, and two people expressed interest. She then wanted to move the meeting from Monday to Wednesday because it would mean another regular member was free to come. She had already asked the PAS social worker, Sally, if the meeting could be moved, and asked the other people if they could do Wednesday, before contacting me to suggest the change. I actively encouraged these kinds of initiatives, as I saw this as important in terms of ownership of the review and for establishing a true collaborative team.

Active contribution from the young people depended on them feeling confident and able to express their views, and trusting that they would be listened to. As the project developed, so did the relationship between the young people and me, and we became increasingly honest and able to express our opinions freely.

However, this kind of relations and therefore young people showing initiative was only achieved with two of the young people. Most of the others involved mainly treated the project in the same way as they would any other PAS project. Even the two people who did screening over several weeks, one of whom participated regularly over nine months, showed no initiative in terms of driving the review forward or having an input into practical decisions, notifying if they weren't able to come to a meeting, or responding to invitations to take part in dissemination. Conversations with the social worker showed that this was something also experienced by PAS. Some young people developed strong relationships with PAS whereas others treated it more like a job. The people who stayed with the systematic review were also those with particularly strong links with PAS.

CHAPTER CONCLUSION

This chapter has described how the young people were involved in the review at each stage of the review process, and their involvement in the practical decisions. I have tried to illustrate that I was constantly balancing between providing an open invitation for the young people to influence the review, and making sure there was enough structure to the activities

so that they understood the meaning of their input. The longer people were involved in the review, the more involved they became in the practical arrangements. This came from their initiative and because I became attuned to their needs in terms of how I chose to facilitate the meetings, as well as the development of trusting relationships between those who had been involved over time and me. The latter stages of the review were more difficult for involvement because it required in-depth engagement with large textual data in the form of full study reports written for an academic audience.

Rowe and Frewer (2000) have suggested that public involvement exercises are evaluated according to principles and standards for involvement rather than outcomes as these are very difficult to ascertain due to the nature of the processes of involvement. They suggest that projects first be assessed according to a set of acceptance criteria (a), which relate to the effective construction and implementation of procedures, and then according to a set of process criteria (b) which relates to the public's acceptance of the procedures. Tables 6-2 and 6-3 below consider the process of involvement described in this chapter, and the framework for it, presented in Chapter 5, against these criteria (Rowe & Frewer 2000).

a) Acceptance criteria

Criterion	The extent to which it was met in this study	Level
Representativeness: the public participants should comprise a broadly representative sample of the population of the affected public.	Representativeness requires a certain number of participants to ensure a reflection of key characteristics of the population as was therefore not appropriate in this project. Unaccompanied asylum seekers were over-represented in the collaborative group, although those most involved were white British and had different experiences in care, and different life experiences after care.	Low
Independence: the participation process should be conducted in an independent, unbiased way.	I had a vested interest in the process as I wanted it to inform my PhD. This was most notably in the interest of producing a completed review in time for this to be included in the thesis. However, the lack of a review would have been a considerable finding, and I attempted to remain open to different kinds of outcomes from the collaboration, including a break	Medium

Criterion	The extent to which it was met in this study	Level
	down in the process.	
Early involvement: the public should be involved as early as possible in the process as soon as value judgments become salient.	The young people were involved in setting the research topic and review question, but did not have a say in the research methodology.	High
Influence: the output of the procedure should have a genuine impact on the research.	The decisions made in the meetings were directly related to and influenced the production of the review. It is clear from the meetings that I played a directing role in keeping the review in line with established quality criteria for systematic reviews.	High
Transparency: the process should be transparent so that the public can see what is going on and how decisions are being made.	The young people were presented with timelines and evidence of how their influence was making a difference on the review, but this was not optimised at the start of the project. Clearer timelines should have been presented, and reiterated, as the project proceeded.	Medium

Table 6-2: The study's scores on acceptance criteria

Table 6-2 above indicates that the process allowed scope for considerable involvement from the young people, but that it should have been more transparent in terms of the timeline of activities. A plan for the review was presented at each stage, but not discussed in-depth. This meant that young people, when discussing the first set of topic-setting meetings, were still confused about the purpose of the exercises, bar the fact that they were informing a piece of research. They were not clear about what their views would inform, the research methodology or the final output.

This study did not attempt to recruit a representative sample of the population. This might be a more pressing issue for policy exercises when part of the task is to prioritise resources or delivery of services. Similarly in terms of 'independence', this might be more important in exercises where different representatives have a vested interest in the outcome, as for example in the building of new railway lines or roads. In this study too, the young people

felt very passionate and at times competitive about how the review was shaped, and which perspectives were incorporated. Because of the narrow nature of most systematic reviews, and because this review had to be limited owing to time restraints, the prioritisation of issues comes to the forefront. Making decisions on the research topic, review question and the inclusion criteria was a more contentious process than I had anticipated in advance.

b) Process criteria

Criterion	The extent to which it was met in this study	Level
Resource availability: public participants should have access to the appropriate resources to enable them to successfully fulfil their brief.	All travel was covered and they were given vouchers for taking part following the policies used at PAS, or at a higher rate. In addition attempts were made at providing adequate subsistence and special meals during longer meetings.	High
Task definition: the nature and scope of the participation task should be clearly defined.	Some tasks were clearly defined while others were not. This was partly due to the complexity of the systematic review.	Medium
Structured decision-making: the participation exercise should use/provide appropriate mechanisms for structuring and displaying the decision-making process.	At an early meeting we voted openly which made me distrust the result due to dynamics in the group. We later concealed all voting but discussions would arise even when the procedures were agreed in advance. This was mainly related to one person who would always challenge results when they went against his preferences. Providing written information and agreements for voting procedures might have reduced such conflict.	Low
Cost effectiveness: the procedure should in some sense be cost-effective.	The budget to support the participation was under spent, mainly because of the reduced numbers in the last year of the collaboration. I have not considered the young people's impact on the review against the cost of involving them.	Medium

Table 6-3: The study's scores on process criteria

While the study was strongly supported by the funding agency, it suffered initially from a lack of structure in the decision-making. One person's engagement highlighted this, as he was particularly concerned with fairness and would always contest decisions that went against his view. While the collaboration got better at managing the decision-making, he also softened his approach and acknowledged the need to reach compromises. The nature of the research (systematic review) complicated some of the tasks, and it was sometimes difficult to convey both the focus of the meeting and the implications of decisions for later work. While I considered offering young people advance training in systematic reviewing, I did not do so because I was concerned that people might not stay on the project after the training. Ongoing training was beneficial because it supported short-term engagement in the review, but it also complicated some decisions because young people lacked understanding of the later implications of decisions made.

Chapter 7 A SYSTEMATIC REVIEW OF INTERVENTIONS TO SUPPORT LOOKED AFTER CHILDREN IN SCHOOL

Having described how the young people were involved in each stage of the review process, I now turn to the second question addressed by this study, 'Can a systematic review be conducted in collaboration with young people and at the same time maintain quality standards in systematic reviewing?' This question is here addressed by presenting the systematic review conducted by the young people and me. This chapter only focuses on findings from the review, whereas subsequent chapters present findings on the process of working together on the review.

The review question chosen by the young people was: What is the effectiveness of interventions that aim to support looked after children in school?

INTRODUCTION TO THE REVIEW TOPIC

The young people chose to focus the review on education because they thought education is the underpinning factor that determines everything else: if you have an education you get a job, having a job gives you money, having money helps you take care of your health. Not everyone in the group agreed on the extent to which education is important to health, and one person who initially voted for education changed his mind about its importance. But most people agreed that dropping out of school can impact on children's mental health, as they lose out on enjoyable activities and engagement with peers. One young person argued that staying in school is the most important outcome in this respect, because of the social skills you learn there.

The young people's views were supported by research, which has found the educational outcomes for looked after children to be poor compared to the general population (Weyts 2004). In the UK, 12% of looked after children gained 5 or more A-C GCSEs compared with 31% of those with free school meals (Department for Education 2010a; Department for Education 2010b). Research has indicated that education is important to later health (Kenkel 1991; Lleras-Muney 2005), and that dropping out of school is linked to substance abuse and

involvement in crime (Prevatt & Kelly 2003; Thornberry *et al.* 1985). Substance abuse and criminal activity are in turn seen as risk factors for dropping out from school, as is being in care (Goddard 2000; Mensch & Kandel 1988). Looked after children's attendance at school is now similar to that of the rest of the population, which could be due to closer monitoring of attendance and stronger policies to support education for this group (Department for Children Schools and Families 2010). However, looked after children are still more likely to be temporarily or permanently excluded than their peers (Department for Education 2010a).

In the UK the poor educational attainment of looked after children was not highlighted until research in the 1980s (Goddard 2000; Jackson 1987; Stein & Carey 1986), and it was not until the Care Matters White Paper (2007) that local authorities were charged with undertaking major improvements in how looked after children's education is supported and prioritised. Under this legislation local authorities set up Virtual Schools responsible for tracking looked after children's attendance and attainment and facilitate targeted support accordingly. The White Paper improved access to computers, highlighted the role of designated teachers and introduced incentives for positive behaviour and achievement. These initiatives were not based on evaluations of the effectiveness of interventions, however, but on perceived needs and gaps in the system.

The effectiveness of social care interventions is largely under-researched in general (Stevens *et al.* 2009), and research on looked after children presents particular problems in terms of access and the number of gatekeepers involved (Heptinstall 2000). The objective of this review was to identify effectiveness evaluations of interventions aimed at supporting looked after children to stay in school, or improve their attainment, to assess the quality of these evaluations, and to consider the strength of their findings in relation to the review question.

METHODS

The group developed a review protocol (Appendix 3).

Inclusion and exclusion criteria

The young people wanted the review to include interventions targeted at children aged 10-15 in mainstream schools who had been placed by the authorities to live outside of their family setting. The age limit was set because it encompassed the transition from primary to secondary school.

The intervention had to support the attainment or improve the attendance of looked after children, and be delivered to carers, children, or professionals, or implemented at a strategic level, such as reorganization of services or introduction of new procedures. Initially, the review was mainly focused on interventions to support children to stay in school, rather than attainment, but this shifted during the screening process when the inclusion criteria were amended to include studies on attainment as well as dropping out. Originally the young people wanted the main outcomes to be attendance, exclusion and final year exams. This facilitated a manageable search strategy, but limited the scope of the review, as it excluded important outcomes such as mental health and satisfaction. On the other hand this put our focus on outcomes currently set as UK government targets, enabling us to identify studies of particular relevance to these.

At first, the young people did not want to exclude studies on the basis of their study design. During the screening they changed their mind to only include studies that had made attempts at measuring outcomes at baseline and follow-up.

Search strategy

I conducted the electronic searches in March-June 2010 in: Educational Resource Information Centre (ERIC) 1966-, Dissertation Abstracts 1980-, International Bibliography of Social Sciences (IBSS) 1951-, Social Sciences Citation Index (SSCI) 1991-, Conference Proceedings Citation Index (CPCI) 1990-, the Australian Education Index (AEI) 1979-, the

British Education Index (BEI) 1975-, Social Policy and Practice 1981-, Social Services Abstracts 1979-, Sociological Abstracts 1952-, Applied Social Sciences Index and Abstracts (ASSIA) 1987-, Embase 1980-, Medline 1950-, PsychInfo 1890-, the Cochrane Central Register of Controlled Trials (CENTRAL) , and Cumulative Index to Nursing and Allied Health Literature (CINAHL) 1981-.

The following string of search terms served as the basis for all searches: (looked after child\$ or adopt\$ or residential care or in care or foster\$ or accommodated child\$ or group home\$1 or care order\$1 or special guardian\$ or placement\$1 or orphan\$ or children\$ home or public care or custod\$ or child\$ welfare or unaccompanied asylum seeker\$1 or welfare care) AND child\$ or young person\$1 or young people or boy\$1 or girl\$ or teenage\$ or schoolchild\$ or youth\$1 or adolescent\$ or juvenile\$ AND (education or school) adj4/near4 (attendance\$1 or nonattendance\$1 or absenteeism\$1 or exclusion\$ or expel\$ or suspension\$1 or dropout\$1 or drop out\$1 or truan\$ or refus\$ or phobia or disengag\$ or attainment or result\$1 or exam\$1 or complet\$ or support\$ or stay in school or stay in education or achieve\$ or success)

I conducted free-text searches in English only, in title and abstract, and matched to subject headings or mesh terms. No date or language limits were set. The group searched Google, and one young person scanned the websites of the following organisations: Who Cares Trust, Fostering Network, Princes Trust, A National Voice, Brooks, NCH Action for Children, Barnardo's, Voice of the Child in Care, Shaftesbury young people, and the NSPCC. I searched the website 'Social Programs that Work', and the bibliographies of relevant reviews and studies. I contacted UK researchers with expertise in looked after children's education. Authors of a Campbell review of drop-out interventions scanned their bibliography for studies that focused on looked after children.

Screening

I imported all search hits into EPPI-Reviewer 4, a web-based electronic software for managing systematic reviews, informed by experiences from more than 200 reviews supported by or carried out at the EPPI-Centre (Thomas *et al.* 2010). EPPI-Reviewer facilitates electronic import of all search hits and supports screening, critical appraisal and synthesis of results. I devised a screening tool and tested this on studies from the search hits, using text mining. Text mining is an electronic way of deriving high quality data from text, in that it categorises terms according to their frequency. Using this, certain items were identified that were particularly relevant, because they contained a high frequency of relevant words, such as 'looked after children' and 'secondary school'. The screening tool was then refined by the young people in a series of five meetings:

1. One young person tested the screening tool, and the tool was revised accordingly.
2. A group of four young people then used the tool on a set of study abstracts.
3. A group of three young people used the tool to screen 53 studies in EPPI-Reviewer 4. A comparison was run to assess inter-rater reliability. We tested the reliability on whether people independently included or excluded the studies, as the tool did not have mutually exclusive codes. For example, a study excluded on population (not looked after children) might also have been out on intervention (not school support). There were 25 disagreements, of which 19 were done by one person who was new to the study. When excluding her choices there were still a disagreement rate of 11% (6 disagreements across 53 studies).
4. A meeting of three young people discussed the screening tool further, resolving differences and clarifying each category. Two young people screened studies at home, using EPPI-Reviewer 4. Young people's screening was compared to the researcher's, and this time the inter-rater reliability was 94% for one young person (14 disagreements across 244 studies) and 91% for the other young person (22 disagreements across 247 studies).
5. Three young people and the researcher discussed and resolved the 36 disagreements.

The protocol had initially stated that interventions had to be targeted at supporting children to stay in school. During the screening process the young people decided to change the protocol to include also studies that had measured attainment. We therefore changed the review title and question to reflect this, but the search had focused on drop-out interventions, and some interventions to improve attainment may therefore have been missed. The young people also wanted the screening to pick up studies which had collected children's views on effective educational support. A separate coding category was created for these studies.

In total the young people and the researcher double screened 817 study abstracts (12.5% of all hits). In addition, a researcher in training and the researcher double-screened another 734 abstracts. A total of 24% of the electronic hits were double screened and all included studies were coded in EPPI-Reviewer 4.

Data extraction and critical appraisal

As described in Chapter 5 the review followed established guidelines for data identification, storing and analysis (Shea *et al.* 2007).

I extracted data for each study into EPPI-Reviewer 4 on population, setting, intervention focus, outcomes, publication year, and study quality criteria (comparison group, sample size, how outcomes were measured). I devised two different tools for data extraction and critical appraisal; one for research studies and one for policy pilots (Appendices 4 and 5). Policy pilots, although research studies, have different starting points and aims than trials of interventions. Policy pilots often aim to change the local service uptake, shift attitudes or improve strategic approaches to a problem, rather than testing out a particular intervention. Some policy pilots will develop as they are implemented, and their outcome measures are often official statistics rather than data collected on individuals.

The data extraction tool for research studies was based on the EPPI-Centre 1997 Health promotion data-extraction guidelines and the EPPI-Centre tool for assessing the quality of

outcome evaluations (August 2002). Elements from these tools were then used to devise one for policy pilot studies, which was also informed by a review of government pilots (Jowell 2003). The tools were set up in EPPI-Reviewer 4 and all included studies were coded in this database by the researcher. The young people were not involved in this stage of the review, but I met with them and discussed quality criteria in research.

Some studies that had been included on the basis of the abstract were excluded at this stage because of information in the full study report. Reasons for exclusion at this stage were either that they did not measure any outcomes and were process evaluations only, or because their intervention targeted children with behaviour problems, which the group had decided to exclude.

Interventions varied considerably in nature and focus. Some interventions included changes to the administration of educational services for looked after children, some changed the environment of children's homes, and some targeted individual children. I deemed meta-analysis inappropriate because of the wide variety within programmes and study design. I conducted a descriptive review of each study and the young people grouped the studies into categories based on the content and nature of the interventions, collating similar approaches together. The findings were considered under each of these.

FINDINGS

The electronic search strategy identified 6514 study abstracts (Figure 7-2). We found no additional studies when searching Google or specialist websites, or when contacting experts in the field. I found three relevant studies when screening references of literature reviews, but was unable to locate the full report for two although I contacted authors and publishers (Staub & Lenz 2000; Wolfendale & Bryans 2004).

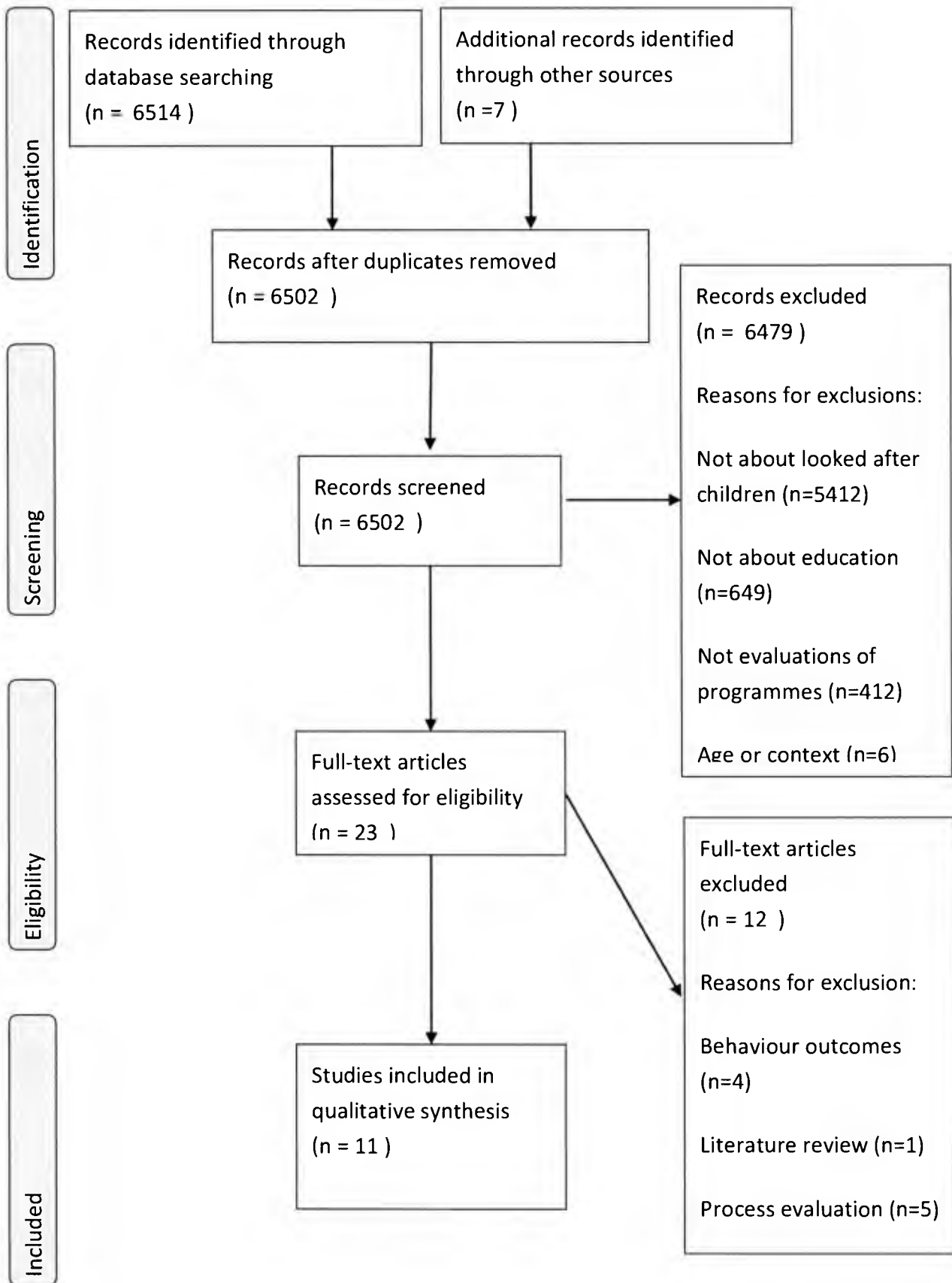


Figure 7-1: Overview of flow of studies through the review

Study characteristics

Of the 11 studies that fulfilled the criteria of this review, six were before-after evaluations without a comparison group, four were policy evaluations of implementation processes and outcomes, and one was a before-after study with a non-equivalent comparison group. The young people devised six intervention categories, based on the characteristics of the interventions evaluated: 1) strategic interventions, 2) pilot interventions of spending targeted money, 3) residential school, 4) community project, 5) reading encouragement, and 6) tutoring.

Strategic interventions

Strategic interventions were those applied at an organisational level, to change policy and practice to support an improvement in looked after children's educational outcomes. Strategic interventions aimed to strengthen the relationship and communication between education and social care services, and focused on changing practice rather than providing direct support, although some included initiatives that worked directly with children and young people.

There were three studies of such interventions. Two were English policy pilots: one pilot implemented in three local authorities (Harker *et al.* 2004) and one evaluation of the Virtual School Heads pilot implemented across eleven authorities (Berridge *et al.* 2009). Both these studies compared educational statistics for looked after children across all participating authorities. The third evaluation was a US study of the impact of having an educational specialist to advise social workers on educational problems (Zetlin *et al.* 2004). This study compared outcomes for the intervention sample with a non-equivalent sample from the year preceding the study.

Pilot of spending targeted money

One study evaluated a Scottish pilot of 18 authorities who were given money to improve the educational attainment of their looked after children (Connelly *et al.* 2008). While the report presents process findings from individual projects, the outcome findings relate to children from across the authorities. The researchers collected data before and after the interventions.

The projects provided five main categories of support: direct support (e.g. tutoring, mentoring, nurture groups, book parcels), personal education planning, transition support (between primary and secondary school), staff development, and provision of technological support (e.g. computers, internet access).

Residential school

One US study evaluated outcomes for a residential education programme for young people in care (Jones & Lansdverk 2006). The aim was to provide young people with a stable placement that would support them through high school and prepare them for further education or work, and facilitate permanent relationships that would last beyond their time in the school. The study considered outcomes for the study sample in relation to findings from other studies of looked after children's educational attainment.

Community project

One US-based study evaluated a community initiative which combined mentoring, carer involvement and vocational support for young people in foster care (Lee *et al.* 1989). The intervention was based on the ecological systems theory which argues that the environment and the youth can both be changed. The project directed its efforts at "improving the transactions between youth and their environment, enhancing the adaptive and coping capabilities of the youth, and improving their environment"(p. 6). The study measured young people's outcomes at years 1, 2 and 3 of the project.

Reading encouragement

Two UK studies evaluated interventions aimed at encouraging looked after children to read, with the hope that this would improve their literacy. The Letterbox Club sent monthly parcels in the post to looked after children, containing books, maths games and stationery (Griffiths *et al.* 2009). This study tested children's numeracy and literacy at the start and end of the project. The Reading Rich intervention included book gifts, worked directly with residential care homes to improve their reading environment, and initiated activities to encourage reading and writing (Finn 2008). This study interviewed children about their literacy at the start and end of the project.

Tutoring

Tutoring is often initiated by birth parents to boost their children's exam results and thereby their chances of getting into particular schools or universities. Interventions in this category aimed to provide looked after children with the same opportunity, to catch up with their class mates or prepare for final year exams. Three studies evaluated tutoring. Two UK pilots evaluated Catch Up, a structured tutoring programme delivered by foster carers and teaching assistants (Fraser *et al.* 2008; Worsley & Beverley 2008). The pilots tested children's literacy at the start and end of the project. One US study compared three different tutoring approaches delivered by volunteers (Lustig 2008).

All included studies and their key characteristics are show in Table 7-1 below.

Study	Sample size/follow up	Population, intervention, comparison and outcomes (PICO)	Length to follow-up
STRATEGIC INTERVENTIONS:			
<p>Berridge D. et al (2009) Looked after and learning: evaluation of the Virtual School Head pilot. London: Department of Children, Schools and Families.</p>	<p>Official statistics on all children in each of the 11 participating authorities 2005-08. Results on Key Stages: N per year ranged from 100 to 140 children. Results on GCSE results: N per year ranged from 315 to 405. Survey of 31 children, 25 carers, 21 designated teachers and 10 social workers.</p>	<p>Population: school-aged looked after children. Intervention: the Virtual School Head is a person responsible for monitoring and tracking the education of looked after children, and working across agencies to achieve this, within a local authority. No comparison group. Outcomes: achievement at Key Stages, achievement in final year exams, exclusions, days missed at school, self-perceived success at school.</p>	<p>The official statistics included relate to the period of the pilot, as does the survey.</p>

<p>Harker R. et al (2004) Taking care of education: an evaluation of the education of looked after children. London: The National Children's Bureau.</p>	<p>Official statistics on all children in each of the 3 participating authorities 2000-2002. The overall number per year ranged from 20 – 56 children. 56 children participated in baseline and follow-up interviews (including standardised scales).</p>	<p>Population: school-aged looked after children. Intervention: person responsible for working within the local authority to improve looked after children's education, and coordinate local efforts to do so. No comparison group. Outcomes: achievement at Key Stages, achievement in final year exams, exclusions, days missed at school, attitudes to education and sense of belonging at school, strengths and difficulties questionnaire, self-esteem questionnaire (standardised).</p>	<p>The official statistics included relate to the period of the pilot. Baseline data by the standardised questionnaires was collected in the first year of the pilot, and 18 months later (pilot still ongoing).</p>
<p>Zetlin, A. et al (2004) Improving education outcomes for children in foster care: intervention by an education liaison. Journal of Education for</p>	<p>60 treatment and 60 control cases (non-equivalent at baseline).</p>	<p>Population: children in foster care, aged 5-17 years. Intervention: specialist education officer to support social workers on education cases. Comparison: group randomly drawn from a different social services office. This office did not have an education liaison</p>	<p>One academic year after the education liaison officer was introduced.</p>

<p>Students Placed at Risk, 9(4), 421-9.</p>		<p>officer.</p> <p>Outcomes: maths and reading test results, Grade Point Average, attendance, number of schools, special educational need status.</p>	
<p>PILOT OF SPENDING TARGETED MONEY:</p>			
<p>Connelly, G. et al (2008) The educational attainment of looked after children – local authority pilot projects: final research report. Edinburgh: Scottish Government Social Research.</p>	<p>Baseline collected for 722 children and follow-up measures available for 636 of them, but not on all measures. Follow-up sample size for attendance and exclusion rates was 551. Baseline and follow-up sample sizes for attainment were 232</p>	<p>Population: school-aged looked after children. Some interventions targeted pre-school children, but outcomes for these were not measured. Intervention: providing authorities with money earmarked 'looked after children's education', spent in different ways across authorities. No comparison group. Outcomes: attendance and exclusion rates, national assessment results, national qualification results.</p>	<p>One academic year into the pilot project period.</p>

	<p>for reading, 229 for writing and 235 for maths.</p> <p>Interviews with 51 young people, 14 foster carers and 111 professionals.</p>		
RESIDENTIAL SCHOOL:			
<p>Jones, L. and Lansdverk, J. (2006) Residential education: examining a new approach for improving outcomes for foster youth. Children and Youth Services Review, 28, 1152-68.</p>	<p>School completion rates provided for 206 students.</p> <p>At 6-month follow-up N=42, at 12 month follow-up N=24.</p>	<p>Population: looked after young people with no prospect of returning to their birth families and lacking a stable placement option, but without serious behaviour problems.</p> <p>Intervention: residential school.</p> <p>No comparison group.</p> <p>Outcomes: school completion status, further education, housing, employment, social support and substance use.</p>	<p>School completion rates were recorded for the first three cohorts that entered the residential school.</p> <p>Longer-term outcomes were measured 6 and 12 months after the</p>

			young people left the school.
COMMUNITY PROJECT:			
Lee, S. et al (1989) Keep youth in school: a community based practice model to keep at risk youth in school. Washington DC: National Catholic School of Social Service and The Catholic University of America	97 young people participated across three years, 87 of these were active participants and the data relates to these. The sample varied from quarter to quarter.	Population: looked after young people aged 12-15 years and deemed at risk of dropping out of school. Intervention: community-based project including mentoring, career development activities and meetings for carers and professionals. No comparison group. Outcomes: grade changes, attendance, staying in school, self-esteem, attitude to school.	The evaluation followed the project over 3 years and data was collected during these years.
READING ENCOURAGEMENT:			
Griffiths, R. et al (2009) The Letterbox Club 2007 to 2009: final evaluation report. London: Booktrust and the	Original sample size not stated, follow-up test results available for 765 children.	Population: looked after children in years 3/4 and 5/6. Intervention: Monthly parcels of books, maths games and stationery, over a six month period.	Children were tested at the start and end of the intervention which lasted 6 months.

<p>Department for Children, Schools and Families.</p>		<p>No comparison group.</p> <p>Outcomes: maths and reading test results.</p>	
<p>Finn, M. (2008) Evaluation of Reading Rich. Edinburgh: Scottish Government Social Research.</p>	<p>74 young people participated, follow-up data collected for 41 of them.</p>	<p>Population: looked after children aged 7-16, primarily in residential homes.</p> <p>Intervention: Support to improve the reading environment in children's homes and workshops to encourage reading.</p> <p>No comparison group.</p> <p>Outcomes: reading activity, attitudes and ability.</p>	<p>Children were interviewed at the start and end of the intervention which lasted approximately one year.</p>
<p>TUTORING:</p>			
<p>Fraser, A. et al (2008) Compass/Catch Up literacy intervention pilot for LAC. Thetford: Catch Up.</p>	<p>10 children, follow-up measures available for 5 of them, plus three additional children who were not included in the original sample.</p>	<p>Population: looked after children aged 11-14 years and in foster care.</p> <p>Intervention: A tutoring programme called Catch Up, delivered by foster carers (primarily).</p> <p>No comparison group.</p>	<p>The intervention ran for one calendar year and tests were administered during this period (at the start, mid-point and end).</p>

<p>Worsley, J. and Beverley, J. (2008) Catch Up pilot for looked after children 2007-8. Norfolk Virtual School.</p>	<p>26 children entered the study and follow-up results were available for 20 of them.</p>	<p>Outcomes: reading comprehension.</p> <p>Population: looked after children spanning national curriculum year groups 2-10.</p> <p>Intervention: A tutoring programme called Catch Up, delivered by teaching assistants (primarily).</p> <p>No comparison group.</p> <p>Outcomes: gains in reading age, using test results.</p>	<p>Children received two terms of Catch Up and were tested before and after the intervention.</p>
<p>Lustig, M.L. (2008) A silent and significant subgroup: closing the achievement gap for students in foster care (Doctoral Dissertation). University of California San Diego, California State University San Marcos, San Diego State</p>	<p>Follow-up measures available for 88 young people. The size of the original sample is not stated.</p>	<p>Population: looked after children aged 5-18 years.</p> <p>Intervention: one of three tutoring interventions, all one-to-one but with slightly different approaches.</p> <p>No comparison group.</p> <p>Outcomes: reading, spelling and arithmetic, measured by the Wide Range Achievement Test.</p>	<p>The children had to receive 12 weeks of tutoring between baseline and post-tests.</p>

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Table 7-1: Study characteristics

Methodological quality of the included studies

There was a wide range of methods represented in these studies, although all of them but one used a non-controlled before-after design to assess impact from the intervention. Some of the studies included a process evaluation and provided comprehensive information about the intervention, population, implementation and methods, whereas other studies provided sparse information on any of the same elements. The methods used for measuring outcomes varied considerably, from using official statistics to standardised tests, to self-reported questionnaires. The main quality concerns were the lack of a control group, lack of accurate reporting of numbers, very small samples sizes and large loss to follow-up.

Reasons given for loss to follow-up indicate the difficulties associated with researching this population: looked after children are a highly mobile population and tracing individuals is difficult with placement moves, changes in legal status, inadequate or incomplete local authority data management systems, problems with access to data, and one study was affected by a natural catastrophe (Lustig 2008). We do not know the baseline number (N) for the study that did not report loss to follow-up, but the follow-up sample was large in comparison to the other studies, at 765 in total (Griffiths *et al.* 2009).

Many of the studies compensated for the lack of a control group by comparing results with official statistics or findings from other studies. While this is of benefit in interpreting the findings, its reliability depends on the quality of the comparison data. Four UK evaluations reported discrepancy in the local authority data collected for looked after children's educational outcomes (Berridge *et al.* 2009; Connelly *et al.* 2008; Finn 2008; Harker *et al.* 2004). Because data monitoring is a specific function of the Virtual School, data quality is likely to have been improved considerably since the time of the evaluations.

INDIVIDUAL STUDY RESULTS

Study results are presented for each intervention category.

Strategic interventions

Study	Staying in school effects	Attainment effects
Virtual School Heads Pilot (Berridge <i>et al.</i> 2009)	No clear change found, based on small numbers. The authors said that improved data collection procedures during the course of the pilot could have influenced the findings.	Figures for attainment were generally better in the pilot areas than overall nationally. Due to small figures in each authority the authors stated that observed changes may be attributed to individual differences within the population rather than the introduction of a virtual school head.
Taking Care of Education (Harker <i>et al.</i> 2004)	Authorities in the pilot reduced their permanent exclusions to zero, similar to a downward trend nationally. School absences fell to below the national average in one authority, remained stable in another, and increased to three-fold the national average in the third.	No clear indication of changes in key stage results and GCSE examinations. The authors stated percentage changes were not meaningful due to small numbers in some cohorts. They also stated that it is difficult to ascertain impact of services because the population was so diverse.
Education liaison (Zetlin <i>et al.</i> 2004)	Treatment group reduced their absences from 15.56 to 13.74, and the control group also reduced from 12.39 to 7.59. The reduction was larger in the control group than in the treatment group ($t=2.31$, $p<.03$)	The intervention group improved their maths and reading test scores at post test whereas the control group deteriorated. The differences from pre to post test were not statistically significant, but the differences between the groups at pre-test were, indicating that the intervention group was catching up with the control group. There were no statistically significant differences between the groups in terms of Grade Point Average.

Table 7-2: Strategic intervention results

Overall, the strategic interventions did not identify any clear trends in school attendance and attainment resulting from the programmes, but collaboration between different

departments improved. It is important to emphasise that two of these studies did not primarily evaluate the impact of the intervention, and that this was one element of an evaluation framework mainly focused on implementation issues and stakeholders' views (Berridge *et al.* 2009; Harker *et al.* 2004).

The Virtual School Head pilot survey found that one in three children were more concerned with their placement or school move than with educational progress and the authors expressed concern that this anxiety was not reflected in the adults' responses. Also of concern was the number of 'not sure' responses among adults, which might indicate that they were unaware of the children's needs, views and behaviours.

In the Taking Care of Education evaluation emotional well-being and self-esteem scores improved at 18-months follow-up. No other changes in scores reached statistical significance. Young people placed importance on encouragement from carers and teachers as a trigger to their achievement in school. Children valued interventions that made them feel special, but did not want their looked after status to be highlighted in front of school peers. Being singled out for a session was reported by children to be a negative aspect of some initiatives. Some young people said that they did not value support when they had no problems in the first place. The evaluation questioned why the authorities did not support looked after children to attend mainstream activities and concluded that integrating educational support in placements and placement moves is central to helping looked after children succeed in school.

Pilot of spending targeted money

Study	Staying in school effects	Attainment effects
The educational attainment of looked after children (Connelly <i>et al.</i> 2008)	Attendance increased from 78% to 81%. Average number of days excluded fell from .85 days to .65 days.	Baseline not collected. When comparing National Assessment Levels from one year to another, 40% of the children in the pilots advanced by one level (mean improvement 0.4-0.5 level), which is much better than the average progress for this population, and similar to the advances nationally made by young people not in care. The improvement reached statistical significance.

Table 7-3: Results from the pilot of spending targeted money

The researchers struggled to complete follow-up, because of a mobile population and the number of projects involved. The study found that the attainment in the children improved, although we are not told the characteristics of those for whom assessment tests were available, and whether they differed significantly from the other children. Attendance increased by 3%, and interviews with young people, carers and professionals also indicated that attendance improved.

The authors concluded that individualised and flexible approaches were most successful, and that the projects were valued by carers and families, as well as young people. One of the main problems reported was finding qualified staff. A lot of work went into establishing relationships between projects, social work and education departments and with schools, and projects were concerned about what would happen to these relationships after the end of the pilot period.

Residential school

Study	Staying in school effects	Attainment effects
Residential school (Jones & Lansdverk 2006)	156 out of 206 (76%) completed high school and 7 out of the 206 (3%) left to a lower level of care.	Not measured.

Table 7-4: Residential school results

As a placement the school achieved some permanence, because the pupils' average length of stay was 448 days, compared with their previous history of 338 days per placement. The authors conclude that a high school completion rate of 76% is promising, considering that an additional 3% left to a lower level of care and other studies have found high school completion rates between 55% and 77% in this population.

Interviews at 6 and 12 months follow-up were carried out with 42 and 24 young people respectively. At 6 months 28% of young people were attending college, which was comparable to other studies. The flux in housing and employment was also less or the same compared with other studies of care leavers. The main cause of concern in this evaluation was the rate of substance abuse after discharge, which was higher than would have been expected. Overall, the authors conclude that the school achieved outcomes comparable to foster care, which was not an option for these youths.

Community project

Study	Staying in school effects	Attainment effects
Vocational support and	Around 10% of the young people in each year were school dropouts and the project was not able to re-engage any of them.	Grades improved initially after 3 and 6 months, but not after one year. All measures were taken during the intervention.

mentoring (Lee <i>et al.</i> 1989)	Attendance improved significantly in the first year of the intervention but not after that. They do not say anything about the strength of this effect or give any numbers to back up the statement.	
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Table 7-5: Community project intervention results

Overall the evaluation found no significant impact from the intervention on attendance and school attainment, bar the first project year. The most popular and well-run element of the project was the mentoring component. The vocational component was not so popular, mainly because the young people felt that the jobs offered were too menial. The Saturday tutoring was poorly attended, but tutoring was overall a popular initiative amongst the young people who stayed with the project. The project struggled to engage carers.

Reading encouragement

Study	Staying in school effects	Attainment effects
Letterbox Club (Griffiths <i>et al.</i> 2009)	Not measured	<p>Reading was recorded as standardised scores. If all children made an average gain score of 0 from pre to post test (8 months' progress in 8 months), this would have been an average progress. Year 3/4 children made a mean gain score in reading of 4.4 in both years. Year 5/6 children made a mean gain score of 2.5 in 2007 and 3.5 in 2008.</p> <p>For maths, 40% of the children increased by at least one National Curriculum level in 2007, and 32% did so in 2008. For children progressing at an average rate, the usual expectation would be that 33% would make such an improvement.</p>

Reading Rich (Finn 2008)	Evaluation framework included attendance records, but this data was not collected.	No difference on reading ability found at post-test (N=16). Of 22 children, 17 increased their reading frequency at post interviews. The authors conclude that the one-to-one sessions that Reading Rich nurtured between carers and young people appeared to have impact on perceived reading ability, while the writers' interventions had an additional impact on writing ability.
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Table 7-6: Reading encouragement interventions results

The Reading Rich evaluation set out to evaluate the impact of the intervention on reading, but changed its focus and so only a very small component of this evaluation collected baseline and follow-up reading scores. Interviews with participating children’s homes staff and young people found that the writers’ residencies were very popular and the interventions appeared to improve carers’ awareness of literacy as an out-of school activity.

The Letterbox Club evaluation had a large sample and found statistically significant effects. Children who scored high on attainment improved the most. The lowest achievers deteriorated between pre and post test. The report does not provide other information on the characteristics of the children.

Tutoring

Study	Staying in school effects	Attainment effects
Catch Up (Fraser <i>et al.</i> 2008)	Not measured	All children gained in reading age (between 0.3 to 4.0 years). At a normal rate a child is expected to improve his reading age by one month per month of observation (Clisby <i>et al.</i> 2000), so for this one-year intervention the expected gain would be one year in reading age. This expectation was exceeded by three children, met by three children and two children fell below this rate of improvement.
Catch Up (Worsley & Beverley 2008)	Not measured	The average gain in reading age was 17.15 months over 7 months of intervention. The gains ranged from 1-30 months. This average gain is similar to when Catch Up is delivered to mainstream pupils: http://www.catchup.org.uk/CatchUpLiteracy/CatchUpLiteracySuccess.aspx
Three tutoring models (Lustig 2008)	Not measured	Statistical significance from base-line was achieved in reading and sentence completion for two of the tutoring models, and in spelling for one tutoring model. There were no statistically significant differences between the three tutoring models.

Table 7-7: Tutoring interventions results

Many children dropped out of the studies because they moved school and/or placements. Those who did stay until follow-up appeared to improve their skills. The sample sizes for two studies were very small, but the US study comparing three different forms of tutoring included follow-up measures for 88 young people. One of the UK pilots of strategic interventions found that tutoring was very popular (Berridge *et al.* 2009), and it has been

found to be an effective intervention for improving reading and maths skills in children aged 5-14 (Ritter *et al.* 2006).

DISCUSSION OF THE FINDINGS

This review found 11 studies that had measured outcomes from interventions for looked after children, relevant to school attendance and attainment. Across all, there were quality problems related to the lack of a comparison group or large loss to follow-up. Two studies used official statistics from a period when these were reported to be unreliable. Three studies had very small samples of 20 and less young people. Based on common elements across the interventions, we identified six categories of interventions, but even within each category it was difficult to synthesise the findings due to different outcome measures, study design and interventions.

While the wide variety of interventions prevents a clear answer to the review question, it may be instructive to consider what can be learnt in terms of developing future programmes and evaluations in this field. In spite of their methodological weaknesses, some of the studies are examples of multi-component interventions, namely interventions which target more than one aspect of a service, as in the strategic interventions. Some of these put considerable effort onto measuring standardised outcomes. Some of the obstacles experienced with both implementation and evaluation are common across the studies and echo reports of difficulties in researching the care system in general (Gilbertson & Barber 2002; Heptinstall 2000).

Nine of the studies were reported as being pilots, or early evaluations of a newly developed programme. This indicates 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 (Berridge 2007; Jackson 1987; Research in Practice 2000). The leap from correlation studies to outcome evaluations of interventions has yet to be made.

Wholey (1987) suggests programme theory and clarification of intended uses of evaluation findings is important in evaluation development. He argues that involving key policy makers, managers and staff in this task is essential, and lines up four problems that inhibit useful evaluation (Wholey 1987). First, there tends to be a lack of a definition of the problem, the intervention, the outcomes or the impact. Second, there is often a lack of a clear logic of testable assumptions linking resources required, implementation, outcomes and impact. Third, there is also often a lack of an agreement on evaluation priorities and uses of evaluation. Finally, if any of these first three problems are present, this is almost always followed by an inability or unwillingness to act on the basis of evaluation information. To move forward rather than simply state that 'more research is needed', it may be prudent to consider the studies included here across Wholey's first three dimensions:

Was there a clear definition of the problem, the intervention, the outcomes and the intended impact?

All of the studies had as an explicit or implicit starting point looked after children's low achievement in school, based on official statistics showing this, or research reports highlighting this issue (Department of Health 2002; Jackson 1987). UK research has been criticised for lacking a broader sociological perspective when attempting to explain the achievement gap between looked after children. Berridge (2007) argues that this has resulted in insufficient explanations which do not take into account the effect of social class and early, pre-care experiences in the family home. He argues that looked after children's educational failures have been wrongly attributed to the care system, when social risk factors associated with family breakdown in themselves are linked to educational failure (Berridge 2007). This is supported by a study looking at the reunification of maltreated children with their families, which found that those who returned home had poorer outcomes than those who remained looked after. The overall outcome was well-being, which included a measure of school adjustment and well-being (Wade *et al.* 2010). Statistics indicate that children who have spent longer in care do better at school than those with a shorter time in care (Department for Education 2010a).

The nature of the interventions in this review and the background information provided indicates that they were developed in response to the system's failure to provide adequate education to this group of children. Some studies mentioned the impact of abuse and neglect on children's wellbeing and for this reason the residential school provided integrated mental health services, but overall there were few in-depth descriptions of the problem bar references to the inequality in school results and attendance.

The studies' focus on improving the system is likely to be a result of research findings which have highlighted both the achievement gap and lack of an education focus in the care system (Winter 2006b). One aim for the system is to ensure that it at least provides appropriate educational support to looked after children. As 'corporate parents' local authorities should provide the same level of care as biological parents.

Findings from this review support further exploration of the problem which goes beyond the focus on system response. With the 'Care Matters' white paper in 2007, and the introduction of the Virtual School, the care system is geared up to making sure looked after children are monitored in school, and that those at risk of dropping out are identified and targeted. Future interventions need to consider other aspects of the problem for why looked after children do not perform well in school, such as the effect of emotional trauma resulting from pre-care experiences (Berridge 2007).

Most of the studies provided adequate detail about the intervention components, but the study about spending targeted money found that "The research had limitations in terms of providing detailed accounts of the pilot activity" (Connelly *et al.* 2008, p. 5). This was also reflected in the evaluations of strategic interventions, which contained detailed descriptions of the process of interpreting the strategic roles and activities resulting from them, rather than what was intended from the start. Interviews with Virtual School Heads, for example, identified how this role varied across authorities, although some elements were similar. What needs to be further discussed in relation to such pilot studies, is which components of an intervention need to be present across all sites, and which elements can be adapted to fit local needs and views.

Figure 7-2 below shows the wide range of outcomes included in the studies. It is worth noticing that some evaluations did not report clearly on the tools used to measuring outcomes. For example, reading age is widely used as an indication, but it was not always clear on what tests this was based. Reading age has also been criticised as a measure, and one evaluation stated that standardised scores are the most reliable (Griffiths *et al.* 2009; Vincent 1974).

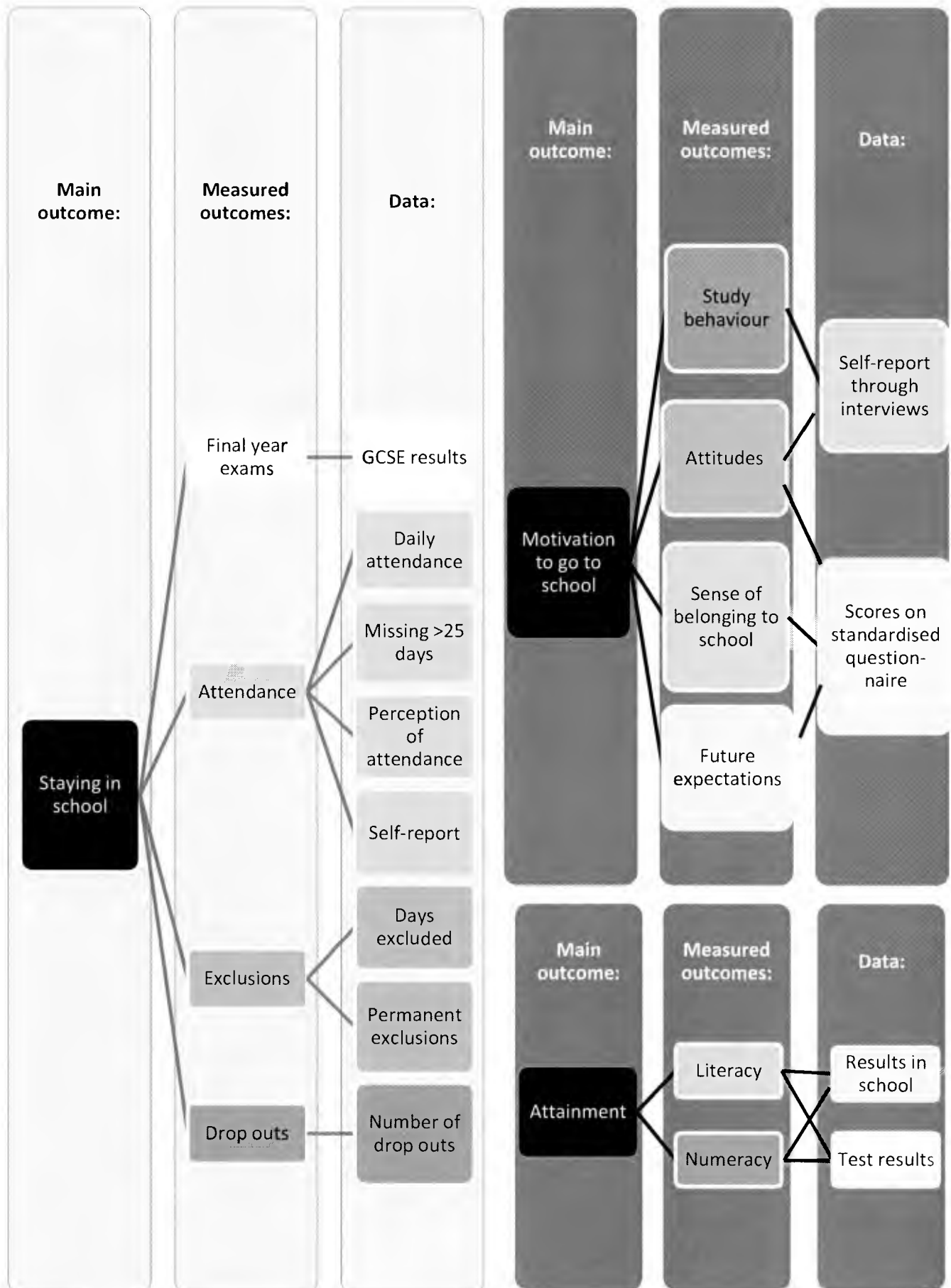


Figure 7-2: Outcome measures used in the included studies
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None of the studies had asked children and young people, carers, or professionals working with them what their desired outcomes would be. The issue of outcomes is potentially contentious, and perhaps especially so in education. Higher education may be seen as primarily a middle class value, and some professionals may see attitude and motivation as more achievable than changes in attainment. A young person who gets expelled frequently may change his behaviour in ways that are not caught by the measuring tools used. Also needed is a discussion about realistic expectations for children who have experienced long-term abuse or neglect.

Was there a clear logic of testable assumptions linking resources required, implementation, outcomes and impact?

Only two of the studies provided in-depth description of the rationale for how the intervention would produce change. The residential school intervention aimed to meet young people's needs to support a healthy transition from adolescence to adulthood, focusing on placement stability, ongoing care, education and the provision of mental health services to address trauma from abuse and loss (Jones & Lansdverk 2006). The community intervention study was based on ecological systems theory which argues that the environment impacts negatively on the young person, who in turn feels powerless to improve his situation. The theory suggests that the environment and the youth can both be changed and the project directed its efforts to "improving the transactions between youth and their environment, enhancing the adaptive and coping capabilities of the youth, and improving their environment" (Lee *et al.* 1989).

The other study reports did not provide a description of a theory of change beyond brief explanations. For example, the Letterbox intervention stated: "Getting a parcel through the post is exciting for anyone, and the Letterbox Club uses this excitement to encourage looked after children to enjoy playing games and reading at home" (Griffiths *et al.* 2009). The nature and focus of the interventions indicate that they were based on three explanations:

- Looked after children's education is not co-ordinated well, and their educational progress is not monitored. This means that support can not be timely, nor targeted to individual needs. The strategic interventions fit here.
- Looked after children often fall behind at school owing to placement moves and family problems, which means that they require help to catch up with their peers. Direct support interventions, such as tutoring fit here, as does the residential school but with a more holistic approach.
- Looked after children's home environment does not support their learning, so the home environment needs to be changed to facilitate leisure reading and home work. The reading encouragement interventions and the community support project fit here.

For some of the studies, in particular the policy interventions, there appears to have been a gap between the expectations at the start and what was achievable in the funded time period, both in terms of the delivery of the intervention, and its impact. One of the reading encouragement interventions (Finn 2008), had intended to collect outcomes of wider academic activity and educational attainment, but the researchers became concerned with both the reliability of available data and that the participants "were not involved in the programme for a sufficiently long period to assess its educational impact" (p. 22). This indicates that the intensity and dose of the intervention were not sufficient to suggest there might be an impact on academic achievement, something echoed in the interviews in the evaluation of the pilots of providing targeted money (Connelly *et al.* 2008). Practitioners overall were cautious about the measurable impact of interventions.

Was there an agreement on evaluation priorities and uses of evaluation?

The UK policy evaluations indicate that there may have been a gap between different stakeholders' understandings of the programme. This relates to what Howe has pointed out, that words mean different things to different groups, and that the notions of population, intervention or outcome can differ significantly between those delivering the programme,

those commissioning it, and those in charge of the evaluation (Hawe 1994). This particularly plays out in policy evaluations of initiatives commissioned by central government departments, where the intervention is designed centrally, but with scope for local interpretation. The gap between intended outcomes and service delivery and what actually happens becomes evident in the evaluation, which may also contain elements that are at odds with the priorities of the practitioners.

The lack of good quality outcome evaluations of interventions to improve looked after children's educational outcomes reflects a wider lack of evidence for this population, for which there are several possible explanations. First, there is a long-standing scepticism in UK social work towards effectiveness research as practitioners think this goes against the core values in social work, which are about individual approaches, support and relationships, and not something that can be standardised within a single approach (Webb 2001). Partly for these reasons, paradigm wars have been rife in social care research, resulting in a lack of consensus on what should count as evidence (MacDonald 1999). There are some good reasons as to why controlled evaluations are harder to conduct in social care than in health. In particular, the organisational context is not set up to support research and, as Macdonald has pointed out: "Social services departments ... rarely stand still long enough to achieve the stable environment required to conduct an experiment from which we can draw conclusions with confidence" (MacDonald 1999, p. 30). But rather than revert to study designs which are inadequate to address impact questions, she argues that these methodological challenges need to be further explored and not simply dismissed as reasons for not researching effectiveness in social care.

Second, as argued by Berridge (2007), there is a lack of theoretical grounding in UK social work research, partly as a result of its close collaboration with government departments. Sound intervention research, as highlighted by Wholey, depends on soundly developed theories of how change can be achieved. In addition, research on looked after children is difficult as previously described (Gilbertson & Barber 2002; Heptinstall 2000).

Finally, only one of the studies included in this review had involved looked after children and young people in the service planning, and none had done so in the programme evaluation.

One school in Reading Rich invited two students to choose the selection of books provided to other children, and this was a very positive experience for the young people (Finn 2008). The Taking Care of Education evaluation considered the extent to which the pilots consulted with looked after children. Two of the authorities felt that the pilot project had improved this aspect of their work, but looked after children were not involved in the development of the interventions or the evaluation.

REVIEW CONCLUSION

The overall conclusion from this review is that we do not know the effectiveness of programmes that aim to support looked after children to stay in school, or programmes that aim to improve their achievement. Some of the studies showed considerable effort by policy makers, practitioners and researchers to develop, deliver and evaluate interventions. However, looked after children themselves were not involved, and there appeared to be a gap in expectations between different stakeholders. There is clearly room for collaboration in this field, in terms of developing clear definitions of the problem and potential solutions, detailed interventions and incorporated programme evaluations from the intervention design stage onwards.

This review only included interventions that had attempted to address the impact of an intervention on attendance, literacy and numeracy. There are several other evaluations of which have focused on process and participant satisfaction (Bryderup 2004; Fletcher-Campbell 2001; Jackson 1989; Pritchard *et al.* 1998). Such evaluations, and those included in this review, contain valuable information in the future development of support for this group. In light of considerable efforts to provide a coherent service, it is perhaps time to identify the most effective ways of providing equal opportunities to one of the most disadvantaged groups of children and young people.

CHAPTER CONCLUSION

This chapter has presented the systematic review conducted in collaboration with the young people. A shorter version of this review has been published in *Child & Family Social Work* (Liabo *et al.* 2012). The review is the most important output from the collaboration as well as a finding in relation to the involvement, because it shows that a systematic review involving young people in key decisions can follow established systematic reviewing procedures and at the same time incorporate their views. The review is also a reference point for the next two chapters which first consider obstacles and facilitators to the involvement process and second how the collaborative work influenced the research, the young people, and myself.

The impact of the collaboration on the systematic review will be considered in Chapter 9. This chapter fits neatly with the review itself, but I first turn to the obstacles and facilitators to involvement identified in this study. I do this because the impact, or lack thereof, is defined by the obstacles and facilitators inherent in the environment, the research design, the people, and the involvement models. Presenting these first therefore contextualises the analysis and presentation of the impact. To assess the impact of user involvement in research it is necessary to consider both how ideas were integrated into the research and how the involvement process shaped the expressed ideas. This is why I now turn to considering the obstacles and facilitators to involvement.

Chapter 8 WHAT WERE THE OBSTACLES AND FACILITATORS TO INVOLVEMENT?

This chapter addresses the study question ‘What are the obstacles and facilitators to involvement in each stage of the research process?’ Here, obstacles refer both to factors that prevented young people from taking part or making a contribution, and factors that reduced their contribution or held it back. Facilitators are factors that enabled young people to express their views and engage with the review.

Obstacles and facilitators often go hand in hand. Well organised plans before meetings facilitate involvement, whereas a lack of plans is likely to be an obstacle or even a barrier. What is an obstacle for some can be a facilitator for others and vice versa. Some young people preferred to meet at the university, whereas others preferred to meet at the offices of the Participation and Advocacy Service (PAS) where they were recruited from. Some people saw the opportunity to present at conferences as an incentive to stay involved, whereas others did not want to go. Some facilitators have side effects. For example, payment for people’s time is likely to be an encouragement to take part, but can also create tension if someone is seen to be a free-rider by not contributing to the work.

Although the overall aim of the involvement was collaboration, the extent to which people are able to collaborate will depend on what I have called ‘the framework for involvement’. This refers to how the collaboration was set up, where, with whom and with which involvement tools. In essence, it relates to involvement as a social intervention. The framework is largely changeable from study to study, as it is ultimately developed by the researcher when deciding to recruit people from one particular organisation, and using a particular set of methods to engage them in a particular research design. Ultimately, the obstacles and facilitators are of interest in terms of their effect on people’s ability to contribute to the review, as illustrated in Figure 8-1 below:

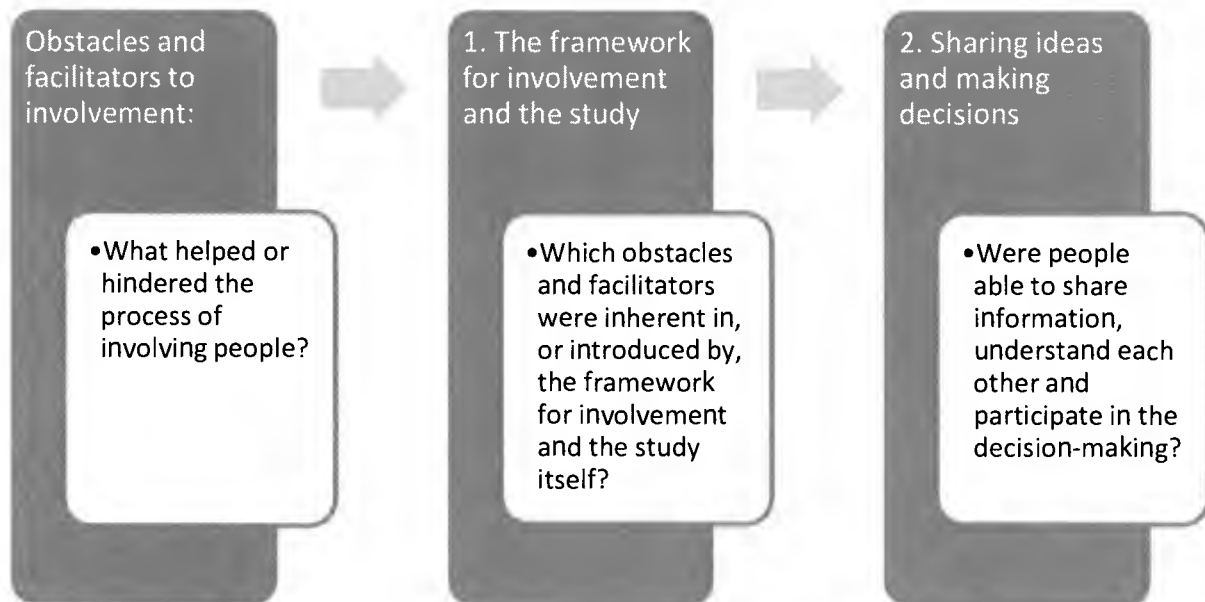


Figure 8-1: Considering obstacles and facilitators to involvement in research

Any approach to involvement is intended as a facilitator, as it is consciously implemented with the aim of encouraging the sharing of information and the decision-making. In spite of this aim, any involvement approach may introduce some unintended obstacles, and certain approaches will be pertinent to some settings and not others, depending on the aim of the collaboration, the target group, and the research project itself. The analytical challenge is to identify unintended obstacles, as well as unintended facilitators, and matching these to the study design and key characteristics of the people involved, including the researcher.

Some obstacles and facilitators to involvement are unavoidable because they are part of wider organisational structures such as the university or service user organisation. A well-known challenge to service user involvement in the UK is that some people can not be paid for their participation, because it can affect their benefits. Academic conferences tend to be organised during the working week, which may prevent people in education and work from attending. This is something that is inherent in the system, and not introduced by any particular research project.

The coding area 'obstacles and facilitators' was a very large one in the framework analysis, and emerging codes clustered around four areas: 1) the systematic review, 2) the people involved, 3) the environment in which we worked, and 4) the methods employed to facilitate the collaboration. Some obstacles and facilitators were relevant across these. For example, providing a succinct and understandable description of systematic reviewing methods hinges on involvement in a systematic review as opposed to another, perhaps simpler, research design, as well as on my abilities as the researcher to provide adequate explanations. The data underpinning this analysis was from the meeting transcripts or minutes, the two focus groups at the end of the project, and my research diary.

Figure 8-2 below shows the four main areas of facilitators and obstacles identified in this collaboration. These are presented as part of a whole coding area 'obstacles and facilitators' (the circle), where each part influences the other. The letters (a) – (d) indicate the order in which they appear in the text. The squares detail the components of each area, which in turn contained particular obstacles and facilitators to the overall involvement.

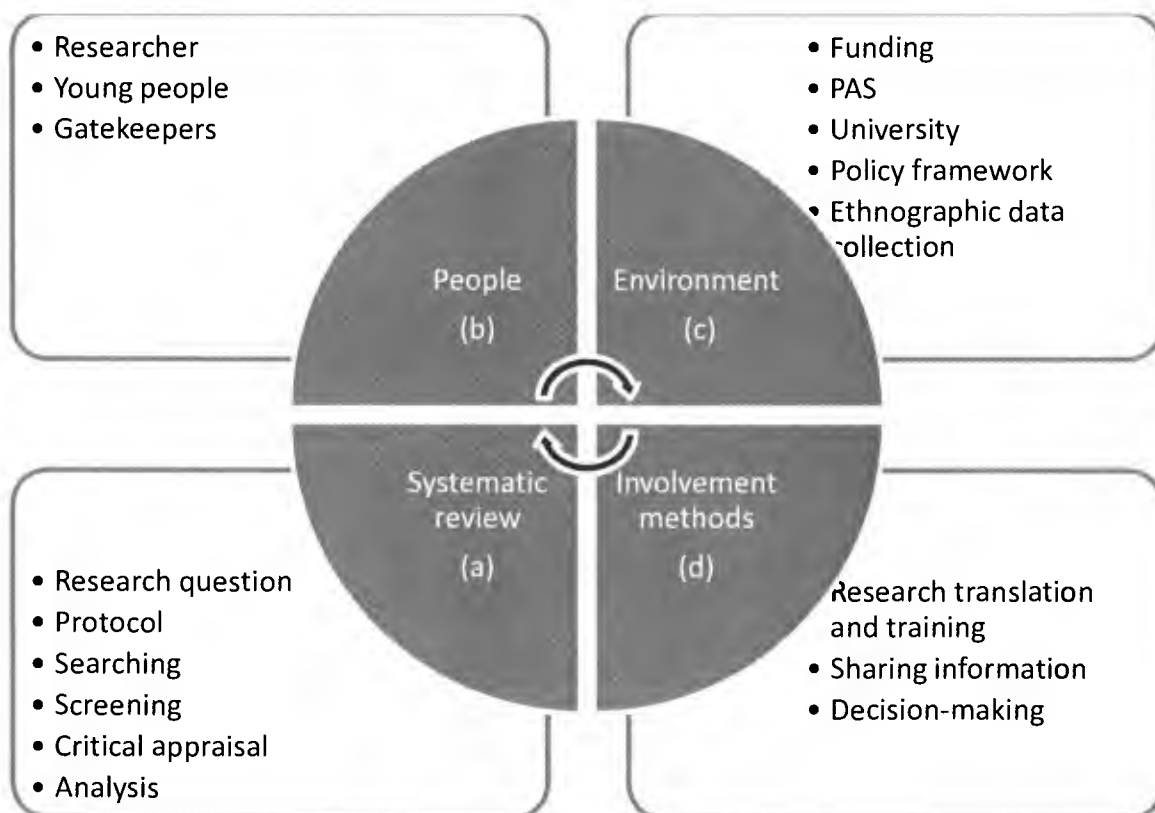


Figure 8-2: Sources of obstacles and facilitators to involvement

This figure shows how each of the stages in a systematic review (a) contains elements that facilitate collaboration and elements that hinder it. The same goes for people (b), including the researcher, the young people, and the gatekeepers who were mainly the professionals working at PAS. Each of us had skills and personalities that influenced the joint work.

Several aspects made up the environment (c). The funding enabled incentives to be put in place for the young people's participation, and the university and PAS formed the structural organisations in which we worked, as did the wider policy framework albeit more indirectly. The fact that I was researching the collaboration as well as doing the review also formed part of the environment, because this meant that meetings were audio recorded and that I was trying to facilitate the meetings and young people's involvement in the review, as well as collect qualitative data to inform my reflection on the meetings. Finally, the involvement methods used to facilitate the sharing of information and making of decisions contained both obstacles and facilitators to the overall collaboration. I next consider these four main areas, and explore further the obstacles and facilitators introduced by each.

OBSTACLES AND FACILITATORS INTRODUCED BY THE SYSTEMATIC REVIEW

The only non-negotiable aspect of the research was that the group would produce a systematic review. This therefore formed the background to the whole enterprise. Systematic review as a research method is not new, but it is not well known in comparison to primary research methods such as surveys, interviews and observation, although systematic reviews are increasingly being reported in the mainstream media, for example as basis for NICE recommendations. The fact that systematic reviews are not well-known study designs meant that more explanation and introduction was required than for observations or interviews, which resemble journalism and also form part of engaging with society. This is not the case for systematic reviews, which require training in specialist skills such as searching, screening and critical appraisal. The data are already formatted into academic text, and the synthesis of studies requires extensive reading and re-reading of this. Because

the data is already formatted, the language can be inappropriate for the service users involved.

I was conscious that changing the data to make them more understandable or less stigmatising would mean that the young people would be assessing my interpretation of the studies. The screening therefore only used original abstracts. During the analysis I translated the study findings and used figures to illustrate the study designs. The young people had indicated that the abstracts were difficult to read, and I therefore felt that the full studies needed simplifying in order for us to discuss them in-depth. Reading in itself is a particular skill that requires a certain level of concentration and familiarity with academic language. Desktop work is likely to suit some people and not others.

The secondary nature of reviews also means that they require knowledge of research designs and a common framework for assessing research. The latter became particularly evident during the screening, when people had different views on what constitutes evidence. In the following extract Sophia and Beth discuss a study abstract. Sophia was new to the study, although she had done a course on research at college. Beth had been involved from the start. I spent the first half hour of the meeting explaining our study, before they paired up to screen abstracts. Here Beth and Sophia discuss one abstract:

B: ... basically its guidelines for parents and workers on how to support the education of young people. Sophia thinks

SA: Yes, I do, cause like, I mean, basically it says support, like the carers should give to their [unclear]

B: yeah

SA: Yeah. So basically like give a checklist of essential information required by carers to support the child and like advice to do if like things go wrong and everything. So I say that actually it is a good research to see like what kind of options or what guidelines are out there that actually can improve the relationship between them,

and like how these two groups can work better together so they can have a good outcome in education and

KL: Okay, but Beth, you're not sure? Why are you not sure?

B: I don't know (laughs). It says 'guidelines', and its like, well, you can have so many guidelines, it doesn't mean they're going to be implemented.

KL: Okay, that's what you were thinking?

B: So that's what I'm saying. So they could have these guidelines but it might not make any difference to people staying in school or not staying in school. So I think it focuses on interventions, but it doesn't focus on outcomes

(Screening, 30th June 2010)

This illustrates both different views on research and how Beth knew the protocol and the focus of our review, whereas Sophia did not. Related to this is that systematic reviews require reviewers to be familiar with research methods to the extent that they feel confident in making quality judgements on them.

Each stage of a systematic review requires painstaking attention to detail. I found that I sometimes struggled to trust young people to do the research themselves, because I was unsure whether they understood or agreed with the importance of being rigorous and attending to details. This is from my research diary after a session of searching:

I found that I didn't trust him to fully search a website, to look at all reports carefully. ... because I don't know whether they fully understand how meticulous they have to be. Furthermore, I do not trust that I am able to convey this to them, nor that I am able to provide adequate training to equip them with the necessary skills. Finally, even if they did get a lot of training, and good training, you still need practice and on-the-job training to learn the craft.

(Searching, 12th April 2010)

From this I realised that there is a substantial difference between involving people in setting the research question and developing the protocol, and people doing research tasks. In peer research, service user involvement is considered to influence the data collection in a positive way, because it is done by someone closer to the research subject in social status, and therefore better placed at making them feel comfortable and able to speak freely (Greene *et al.* 2009; Kilpatrick *et al.* 2007). This becomes redundant in systematic reviews. Considering the technical expertise needed for high quality systematic reviews, I felt that young people's most important and relevant input was in setting the parameters for the review, and in analysing the findings.

In spite of this prejudice on my part, the young people were actively involved in both the searching and the screening, and had insightful comments to make in terms of the study quality. Some people said that the searching was one of the most enjoyable aspects of taking part, and one young person was only involved in the screening but contributed substantially at this stage. Several young people commented that the literature searching was useful to their skills development and relevant to college work. One young person said that she became involved because she saw it as good preparation for starting university. While I had felt that young people's input in the protocol was important and fruitful, they referred to the more technical aspects of the review as interesting:

D: ... I've got to test myself throughout this project and put myself into new areas that, and do things that I maybe might not have felt that comfortable with doing previously

(Focus group, 26th May 2011)

Any researcher who involves service users in their research will introduce them to their own epistemological framework. Some service users will resist this, but others and in particular those who are unfamiliar with the academic world, are likely to adopt the researchers' views on this. Systematic reviews are anchored in an epistemological tradition that believes in the accumulative nature of knowledge. The young people were therefore socialised into

that particular stance, and I acted as a gatekeeper to the review, which could be seen as going against the ethos of collaboration.

OBSTACLES AND FACILITATORS INTRODUCED BY THOSE INVOLVED

The main purpose of involvement in research is to enable people with different backgrounds, experiences, and expertise, to meet and share ideas. This will often require people to step outside their comfort zone and get familiar with a completely new code of practice. Some will aptly move between different worlds and adapt to a new environment, while others find it difficult. Some people are good at identifying rules and expectations inherent in their own world and are therefore skilled at introducing it to new members. Service user involvement requires academic researchers to adapt their language and descriptions of their work while service users are invited to be involved due to their familiarity of a field or services. Their specialised language and understandings are what the researchers want to learn and tap into.

People's experience and knowledge relevant to the collaboration

This was the first time I had involved service users in research. My relevant experience was from using creative research methods with children, and working with planners of children's services to encourage them to use research. I therefore had some experience in communicating research, but none in involving people actively in doing it. To address this lack of knowledge, I tried find relevant in-depth training courses and manuals for how to practically set up a research collaboration with young people, but was unable to identify relevant courses. There were at the time guidelines for what to consider when involving people in research (INVOLVE 2003; Kirby 2004), but few in-depth descriptions of methods for involvement and tools for sharing information. Once the collaboration was established, I struggled to find people who could provide research training to the whole group.

Much of the approach to involvement was therefore shaped by qualitative methods for childhood research (Curtis *et al.* 2004b; Curtis *et al.* 2004a), and by in-depth reflection on the methods and discussions after each meeting. Listening to audio recordings made me aware of how my own personality influenced the involvement initiative. I realised early on that in spite of conscious attempts at simplifying my language, I had a tendency to confuse meanings, provide too much information at once, use complex words and shift from one issue to another. This extract from one of the early meetings illustrates how I crammed too much information into one section, thereby confusing my own meaning and the process for prioritising the topics:

KL: I think that we choose, we prioritise them, that's my suggestion. We say, 'this one is definitely not, this one is the next at the bottom', and we work our way up, and the last three or four will probably be the hardest to agree on. And we may need to do a vote and just go for the one, you know, and then, ehm, and then, we go for the top one, and see what, and the thing about research is we need to make it very specific so if we choose to go for alcohol and illegal drugs, there are so many questions we can ask about that. We can ask about, you know, the stats, we can ask about how to stop people taking, we can ask about how to prevent people from starting in the first place, do you see what I mean?

(Prioritising research topics, 13th December 2007)

Similarly, I was too eager at times, thereby disrupting their activities or preventing them from expressing their views:

KL: Well, I think it's tricky. What do you think, Denzel? I'll give you time to read it, sorry

(Preparing critical appraisal, 23rd September 2010)

After the first two meetings I realised that I needed to improve and simplify the way I talked. I started to prepare detailed notes of what I was going to say, so that I could consider my language and explanations in advance and think through the most important areas where

confusion might arise. This helped, but after some time I found the opposite problem, that my explanations could be too simple and brief. Even with a manuscript for what I was going to say I got stressed when things did not go to plan, would forget the original manuscript and get confused.

There was a lot to focus on in the meetings; reflecting on the collaborative processes while discussing aspects of the systematic review, communicating clearly and succinctly, and making the meetings engaging for the young people. This might have been easier for someone with a calmer personality, and I felt that my facilitator skills improved as I gained more experience. Overall, this is where the individual personalities of the researchers will play out. In this study I was the only researcher and the involvement efforts were naturally more vulnerable to my personal weaknesses. Others have recommended that within research teams one person takes lead responsibility for public involvement (Boote *et al.* 2011).

This was also the first time some of the young people had been invited to take part in a research project. Some had advised on the design and content of a questionnaire for University College London. One young person had just dropped out from university where she had studied social science, and she returned to university during the course of the project. One young person was particularly interested in research and was due to go to university. Others had limited or no experience of doing research. The fact that some young people had relevant experience was a strong facilitator to the collaboration, but also meant that there was a wide range of knowledge and experience within the group. This could make it difficult to facilitate some meetings, as in my description of a screening meeting below. Two of the young people had been involved in writing the protocol and the searching workshops, and two (Sophia and Fiyory) were completely new:

Sophia asked questions about the validity of the included research ... She had done a course on research methodology when doing psychology. I don't think Fiyory understood that the review was about studies rather than primary data, even though in my mind this was the best discussion we have had about the review, mainly because of Sophia's questions, which were very informed. But perhaps it was

confusing because three of us know what a systematic review is, and Sophia is familiar with research, so we might have used words that were difficult to understand for Fiyory.

(Screening, 30th June 2010)

The knowledge differences in the group were also commented on by Denzel, who was completely new to research:

D: ... most of the work I've done has been around participation groups and charities and that and it hasn't really been on the whole research, so I'm still trying to come to terms with that, whereas I think someone like Beth will find it a lot easier because she's used to researching for her university course ...

(Searching, 12th April 2010)

At times the knowledge differences acted as a facilitator to people's participation because those with topical knowledge would contribute to explanations. The following is an extract from a lengthy discussion where Yonas questioned the validity of the expression '1 in 10 people':

DA: Let's say that there are 100 people in school, in one class, and 50 of them pass.

Y: Pass for what?

DA: Like the exams or whatever, alright, whatever exam it is, yeah? 50% pass, that means 50 of 100 passed, right?

Y: That's it.

DA: Yeah? But they can say 5 in 10... like 50% of any ratio is like...

Y: Right, but when you say something like a statement, when you read a statement 'out of ten people, three people have AIDS'...

DA: Yeah, that's basically it.

Y: ...that means you can pick any ten people out.

KL: No, no, it doesn't, no, no, you're making a conclusion out of something that isn't, okay, let Denzel say it.

D: Right, look, Yonas as I said, that cancer bit, one in twenty people are affected by it, so that's like if I get on a bendy bus in the peak hour, that's got 130 people on it, that's like me saying "Oh, so there should be 10 or 20 people on this bus that are affected by cancer." It doesn't mean that, no one on that bus might have cancer.

(Finalising protocol, 9th February 2010)

As young people gained experience, both in terms of research knowledge and familiarity with the collaborative nature of this project, they increasingly showed initiative themselves to engage people in discussion and explain the project to newcomers. People's engagement in the meetings was a strong facilitator to moving forward with the project and in terms of helping me develop my approach. The decision to focus on an effectiveness question sprang from Ermias' observation that the different questions under debate seemed very similar.

Audio recording consent was not granted at that meeting so this is from my minutes:

Ermias ... said, but that question is almost the same as 'how can looked after children's behaviour be improved etc' so I stuck that question up with the other one and asked if they could tell the difference. They started focusing on the topic, I said "but isn't there another difference?", and Ermias chipped in "the way it's asked". I said enthusiastically "yes!". He said one is about the problem and one is about how to improve it.

(Defining the research question, 7th October 2009)

Because of Ermias' observation about the nature of the different questions, the original question 'Why do looked after children drop out of school?' was outvoted in favour of 'What can be done to prevent looked after children from dropping out of school?'. It was

Ermias who explained the difference between these two questions in a way that made sense to the group, and made sense to the extent that they changed their views.

People's commitment to the research

An unexpected challenge was the cultural differences between the young people and me on the practical running of meetings. I had to ask at the start of every meeting that mobile phones were turned off because people would not do so automatically, and even when we had agreed to turning off phones young people kept checking theirs throughout the meeting. I found this disrupting, but young people appeared to keep their phones on most of the time. For example, I once rang a young person when she was at the cinema, and she picked up the phone and left the film to finish the conversation.

At most meetings someone would arrive 15-20 minutes late, or people would say they had to leave early even when the finishing time had been advertised in advance. This would cut down our effective meeting time because I had to repeat information to latecomers, and it was also boring for those who had come on time. After a while I started to say that the meeting was closed to new people after 15 minutes, but it was difficult to turn people away. Meetings at the university were more prone to being delayed, as they required a longer journey for people.

It was also difficult to get confirmation in advance of who would come. According to the participation social worker this was also experienced by PAS. Some people would confirm that they were coming but be absent, while others would not reply and then attend. It was difficult to plan meetings when I did not know how many and who would come, and I often had to adjust my plan because fewer people than expected had showed up, or because someone completely new arrived unexpectedly.

Young people's commitment outside of the project, especially exams or moving when starting university, affected their attendance. We lost two particularly interested people this way. My own personal life also interrupted the project when I became pregnant and went

on maternity leave 6 months into the collaboration. This meant that many of the people who had been involved in setting the topic for the review had left PAS when I returned. Some of the young people had to cancel or change meetings due to health problems. One person gave a combination of reasons why he chose to leave:

I: eh, I can't, I prob, I prob, maybe out of boredom, probably didn't get into it as much I thought it was gonna be, a bit too much thinking for me

KL: [laughing] a bit too much thinking

I: probably yeah. I think there was also that, it was 2007 wasn't it? yeah I think I was doing my Fifteen⁵ course in that year I think ... I was group seven yeah, so there was that, and also I think I just, wasn't for me

KL: so it was a mix

I: it was a mix of things, I think it probably was 30% it wasn't for me, and then obviously the other 70%, Fifteen I got, when the apprenticeship kicks in

(Focus group, 26th May 2011)

The fewer people involved, both on the research and service user side, the more vulnerable a project is to these kinds of continuity issues, which have also been identified in other similar initiatives (Boote *et al.* 2011).

I had planned to work with a stable group of 10 young people. I had been aware that this might be ambitious, because continuous involvement over time requires commitment, and young people often lead busy and mobile lives. I found that meetings of around seven people or more were difficult to facilitate, and that 4-5 was an optimal number. Larger

⁵ Fifteen is the apprenticeship restaurant in London set up by celebrity chef Jamie Oliver to train disadvantaged young people who would like to become chefs.

groups made it difficult to have satisfying discussions and for everyone to express their views.

Shifting membership

We had originally said that we would have a closed group, but that changed as people dropped out and others joined through friends. In autumn 2009 the young people initiated a discussion about membership:

D: can I just ask what we're gonna do about the numbers, because they seem to, people seem to keep coming and going, it's like, I'm just

KL: yeah, I feel that is working out quite well because of what I've said to Sharon now is not to invite any new people, so my biggest problem is, if they come new people in all the time, who hasn't, you know, you guys are starting to get your head around what a systematic review is now, but, and what research is, and do you know what I mean?

D: [on top] what I mean is like the ones that were here last time

KL: yeah

D: they've missed a big piece of

KL: yeah

D: so that's like, I'm just

KL: I know. What do you think we should do about it? Exclude them? [laughs]

D: I think we should [unclear]

M: limit the number, of people

B: ... we have the six people and then we do have one who's really interested and I've spoken to her, she's really really interested.

(Protocol writing, 12th November 2009)

Shifting membership and attendance was a major obstacle to the involvement process. Some new people would provide fresh perspectives but it was time-consuming to explain basic information at each meeting. When I knew new people were coming I would plan activities accordingly. For example, for the critical appraisal meeting I planned a general discussion about research quality, rather than anchoring it in our own review, using newspaper articles on research, rather than study abstracts. Even so, I still had to gain people's consent, which meant some introduction to the systematic review. This got tiresome both for the experienced young people and me. On the other hand, there were times when the shifting membership worked to the project's benefit, as described by Denzel:

D: ... me and Beth didn't have much to do in the searching that because we were so busy with other things, if it weren't for Ruta and ehm Zahra we wouldn't have a systematic review because there would've been no searching done because. So I think that there's different parts of it that we have to say as much as people re-joining and joining and, like, is a case of, it happens and I think, PAS learnt when we had our own research money that, how hard it is to do...

(Focus group, 26th May 2011)

This review was planned with a linear involvement pattern: people were involved in all stages from start to finish, and participated in research tasks and planning. This made it more vulnerable to shifting membership, because it required lots of input, frequent meetings and an understanding of systematic reviews. A non-linear approach, where people provide information about their relevant experiences, and the researchers interpret this and then verify their interpretation with those involved, is less vulnerable to membership, because research knowledge is then secondary to their experience.

Involving looked after young people and care leavers

The young people were used to presenting as service users through their work with PAS. Some of them had done some high profile work, including presentations at Parliament and meeting with the Minister for Health. The participation social worker was heavily involved in preparations for these events. Working with me without her was a leap of faith for them. They did not know me from before, they did not know what kind of prejudices I would hold, and yet I asked them to contribute to something based on their experiences in care, something which is both extremely personal and stigma-laden. When discussing research with them, this was brought into sharp focus, because the outcomes identified in research have tended to be very negative: poor mental health, poor educational outcomes, poor physical health, obesity, teenage pregnancy and offending. The young people themselves were aware of stigmatisation of looked after children, and raised this early on when we were prioritising the topics:

I: ... I think when a young person goes into care and he goes to school or college or when you talk to your mates and they say 'now where's your mum and dad' and you say 'well I'm in care', instead of people actually sitting back and actually asking you why is that, you might say 'well my mum passed away or, you know, she had drug problems', I think they always look on the fact that maybe you have done something wrong, and that you know it's your fault you're in care.

(Prioritising research topics, 13th December 2007)

Statistically and culturally the process of being taken into care is associated with poverty, mental illness, inadequate parenting and the loss of kinship (Bebbington & Miles 1989; Viner & Taylor 2005). The structural conditions which produce stigma in our society have been linked to the importance of reciprocity: "... if reciprocal exchange is an important value, then the capacity to engage in acts of reciprocal exchange may be important in the determination of any one group's 'social value' (Reidpath *et al.* 2005). Initially, many in the group spoke of

'looked after children' in the third person, as illustrated in this exchange between Alex and Imran about why so many looked after children drop out of education:

A: ... sometimes of the [unclear] looked after child as well, they find it hard to [unclear] people find it hard to progress, onto a further stage, you know for example you know if you wanted to, you want to achieve big

I: [unclear] specially for young people who are looked after, maybe they come from [unclear] damaged background, so it could affect their education. So they probably come from a background where there hasn't, there's been no structure to it. So it comes to school, there's no discipline. They've never had that discipline you know.

(Prioritising research topics, 16th January 2008)

Awareness of their social status also influenced my own engagement with them, and on my presentation of research. For example, I discarded a finding in relation to obesity both because it seemed tenuous and because I felt uncomfortable raising it with the group. I was aware that some young people might not want to be identified as users of social services, and that participation in this project might in itself be conceived as labelling. To counter this I kept emphasised their expertise and knowledge, and showed evidence of how their influence on the research was integrated and retained in the research products. This is from my research diary on 11th November 2009, having worked with them for about one year in total. The text has been slightly altered to anonymise one of the participants:

I find that the longer I work with the group the more sensitive I get to the fact that being involved in this is actually quite stigmatising in itself. I find that I am thinking more carefully about the kinds of examples I give, and that it's quite important to do so because people do take things personally, it's the way we are. For example I'd like to provide an example of a systematic review, and I wanted to pick one that is about [type of] interventions, because that's relevant to our review. I found the one on programmes to prevent [negative outcome] and then worry because I know one of them has a history of [that problem].

(Research diary, 11th November 2009)

As the group became more established the young people started to draw more extensively on their personal experiences. When someone suggested that we look at the effectiveness of Cognitive Behaviour Therapy, this intervention was further explained by another person who had experience of receiving it. Another person spoke about his disrupted education in relation to the review topic. Working with people over time facilitated their active involvement and enabled them to contribute more fully. The longitudinal aspect of the study also gave me the time to develop my skills, as described earlier.

Pre-existing relationships between the young people involved

Although all of the young people had been in care, they had been so for different reasons and had a variety of experiences ranging from multiple placements, a high degree of permanency, residential care and foster care. This was another challenge to the involvement process, because they had strongly held views on the basis of their personal histories in care. Group dynamics were shaped by the perceived success of people's placements, as in the following extract from a prioritisation meeting:

I: ... I think a lot of it also depends where you're brought up, and I always said, everyone knows now, I had a fantastic, I went to private school, Gresham's at first school, best school in London, I grew up in Norfolk, I was in a stable family, I got spoiled, I got to do my cricket professionally, I got to play my rugby, I got to do my cricket and sport, I got a fantastic

D: [interrupting] congratulations

I: but what I'm saying is how people use that. 'Cause you get some people yeah, who get all the stuff there, and then they decide not to

D: but some people haven't got that luxury

[Many people at once]

D: when I was in care I was moved around nineteen, I was moved around nineteen times. I didn't have the luxury to go to school. At thirteen I was in Somerset, they wanted to put me through to my GCSEs, you know what happened? [Council] said 'we don't have the funding to keep you down there, the place is too expensive'

(Prioritising research topics, 13th December 2007)

Harvey (2009) has argued that participants' experiences of public engagement exercises are often dramatic and emotional, but that this is rarely captured in evaluations. Some people may be better skilled or trained at acting out their formal or stylised 'roles' (Goffman 1961). Being involved is likely to be emotive for those contributing on the basis of personal experiences. For people with experience in the care system this may be particularly strong owing to the problem of stigma discussed above, and the link to childhood memories. Presentations of research could at times trigger emotional responses, as in the second meeting, where I presented the results of a study which had compared outcomes for those who had been in care with those who had not:

D: [interrupts] you can't compare young people, you can't compare young people in care to young people out, who are out of care, there's just no comparison. You're always gonna find that there's a difference, there is just no, there is no comparison that can be made, because when you're not in care you've got a lot, you're at home, I'm not saying it's always lovely, but you've got a home, you've got a family environment, you've got the stability. You're not thinking 'why, where's my next move, how, when I'm I gonna be moving school'. You can make friends, you can live a proper life...

(Prioritising research topics, 13th December 2007)

The quote above is from the second meeting where we discussed what topic the review should focus on. I had naively come to the group without considering how existing group dynamics could influence the discussions. Some people took on leading roles, reminding us

when we were veering off topic or supporting other people's viewpoints. Some people were more rebellious and would tend to always challenge the majority's views. Some young people got on very well with each other while others were frequently in conflict. The most important lines of conflict and alliances only became apparent to me after about one year of collaborative work, through comments by and conversations with long-standing members.

There were also conflicts related to the running of the project, as some people disagreed with practical decisions, for example on meeting times or travel arrangements. Over time I got more attuned to potential areas of conflict, and better skilled at preventing disruptions of the meetings. I would sometimes ignore comments and reiterate the focus of the meeting, but other times take complete charge because personalities and comments were starting to dominate, as in the exchange below when matching peer interviewers with interviewees. (These planned peer-interviews were not carried out and differ from those carried out three months into the research):

D: ... the only way this could turn into a big row is if you had had, it's if you've got in your head a list of people that you want to interview and you

K: I'll be honest, I

D: And you don't get any of them and it's like oh and you get, and you end up getting

KL: Okay, okay OKAY, let me just then put my foot down and say what, it's not going to be like that okay. It's not going to be like that. But it is important that everybody's clear that it's going to be fair

....

[Mention of names]

KL: NO, I don't, no seriously, no SERIOUSLY, you've done it several times now and I don't want to have any comments or [unclear]. You, yourself said that we shouldn't have the gossip stuff going on

(Planning meeting, 24th May 2010)

I initially found it difficult to intervene as above, but gradually realised that it was necessary, and that doing so acted as a facilitator to maintaining the working relationships in the group. It is likely that these occasions made some people feel sidelined, although I aimed very hard to avoid that. Ultimately, the collaborative work was emotionally charged for all of us. I was aware of my researcher role as opposed to a social worker or a friend, engaging with people over a long period of time includes informal conversations and personal investment. Conflicts would also cement relationships through resolving arguments, as indicated by one young person's reflection at the end of the project. This is him commenting on photographs he has selected to illustrate his feelings about the research involvement:

D: ... I could probably say that, that is me in Exeter [laughs about a picture of a fire ball] but again it's just, it's like you look back at things like that and you laugh and then, I've gone for [a photograph of] a glass of whiskey because it's a good whiskey and it's excellent so I think that kind of shows what our, what our systematic review is, excellent.

(Focus group, 21st June 2011)

Combination of personalities and experiences

As a group of individuals we brought personal skills and experiences to the collaboration which acted as both obstacles and facilitators to the joint work. Vernelle (1994) has argued that the group relationship develops in stages, starting with anxiety and moving on to disputes for status and control. This was something identified by the two most long-standing members themselves, who said that they had at times struggled for prime position. A third stage is characterised by intimacy, as the power struggles settle and a working relationship is established, leading on to a fourth stage of differentiation when members start to feel attached to the group and see it as valuable (Vernelle 1994), as indicated in the

quote above. The latter stages of the review certainly saw a calming of relationships as well as the young people themselves taking on stronger roles as mediators of conflict.

Being involved over time in heated discussions, late evening meetings and nerve-wrecking conference presentations requires emotional investment as well as time. I shared those stresses and achievements with the young people and learned substantially from them about the care system and being looked after, which in turn triggered further reflection on research and its inherent values. But it was ultimately the young people who entered into a completely new social setting and undertook, in Denzel's words "a journey into the unknown".

Cartwright and Crowe (2011) have suggested that desirable skills for service users involved in decision-making on health service development or research are that they are able to self-manage, organised with the ability to keep to timetables and commitments, have basic literacy and an ability to reflect, are open minded and like working in a group or team, are able to work within a structure and have a desire to learn, that they are able to challenge other people's views and those of researchers, and that they are personable (Cartwright & Crowe 2011). One young person involved in this review met all these criteria, and some met most of them. One young person who was involved over a long period of time struggled on most of these accounts but still made important input on the review, and contributed to the mutual learning. Involving people who do not meet such pre-set criteria is important because they may have different perspectives on services and their behaviour may derive from experiences within the system. On the other hand it is important to be aware of how their behaviour can influence the group dynamics and the success of the collaborative work.

OBSTACLES AND FACILITATORS INTRODUCED BY THE ENVIRONMENT IN WHICH WE WORKED

This section describes obstacles and facilitators identified in the environment in which the study was placed. The environment refers both to the physical environment, as in meeting rooms, and the structures of the organisations in which it was set up. This study was

designed in a particular way, it received funding from the National Institute for Health Research (NIHR), the researcher was based at a university, and the young people were recruited from PAS. All these factors contributed to and challenged the smooth running of the collaboration.

This involvement initiative was supported by generous funds for young people's training, incentives and subsistence at meetings. I was able to provide young people with shopping vouchers as payment for their time. The young people did so partly in order to enhance their CVs and the study was therefore competing both with other initiatives at PAS and paid work. The vouchers also acknowledged that the young people were meeting regularly, sometimes weekly, and included research work.

The importance of the vouchers was confirmed by the young people. They would discuss different kinds of vouchers, ask in advance for vouchers from particular stores, and tell me what they were using them for. It was clear that the vouchers were welcome contributions to their household budgets. Once the vouchers acted as an instigator to conflict. Two young people were going to a conference, and they were going to attend a day each. When it turned out that one day included an evening meal, the other young person questioned whether the payment for the second day would reflect that a meal was not included. More than indicating that payment for time can be contentious this shows how some people will be very concerned with equal opportunities within the group.

I also had a generous budget for subsistence at meetings. The food was repeatedly commented on, and one young person had remembered the catering for the Christmas meeting in 2007, when we met after my maternity leave in 2009. The young people's strong commitment to the project indicated that the food was a positive addition rather than serving a key function, but the symbolic and social role of food is worthy of a study on its own, documented in literature and film as well as social studies (Germov 2008). The provision of food at meetings both facilitated small talk and provided fuel, especially in meetings arranged during lunch or supper hours. One young person would often say that she had not eaten before the meeting. The importance of food has been noted in involvement guidance as well as by qualitative researchers (Curtis *et al.* 2004b; Kirby 2004).

The recruitment of young people from PAS was made possible by the participation social worker, who introduced the study to a panel meeting and arranged the recruitment meeting. She was concerned that the young people themselves should make the choice of taking part or not, and acted as a strong facilitator for access to potential collaborators. The project soon became part of the PAS portfolio of work. To make sure we did not compete with other PAS activities, I would always agree meeting dates with the participation social worker before setting them up with the young people.

Recruiting through PAS meant that the young people were already familiar with representing the interests of looked after children, presenting their views, drawing on their experiences from the care system, and attending formal meetings. In the beginning all meetings were held at PAS offices, which meant that the social worker got to know me, I became familiar with their offices and staff, and the young people could meet in a familiar environment. Having a social worker on site was particularly useful in the early stages of the project. When the discussion got heated in the second meeting, one young person got upset and left. The social worker then spoke with him and he decided to rejoin the meeting. Initially, PAS also took care of the reimbursement of travel and vouchers, and provided most of the snacks, and invoiced me later for this. This was convenient because it was one less thing to prepare before the meetings.

PAS was also in charge of inviting people to the earlier meetings. Because the young people were looked after, the participation social worker had to be protective in terms of their personal data and identifying information. Later on in the project I asked the social worker if I could ask the young people for their contact details, so that invitations could come directly from me. I suggested this after PAS had forgotten to send out an invitation to a meeting, which resulted in only one person attending. She had contacted PAS when she did not hear anything more about the meeting which I had mentioned previously.

I became aware from young people's comments that there was competition at PAS for sitting on recruitment panels and training days, because of the payment rate for these. Some people felt left out of these jobs. The participation social worker said that certain qualities were needed for these tasks, such as listening to others, following an agenda, being

well presented and able to speak clearly and succinctly. Because of this, some people felt sidelined in favour of those with a more natural aptitude for these jobs. One young person felt that this had been a challenge to the collaboration on the review:

B: ... I also wouldn't do it with anyone I know, young people I know

KL: oh ok. mm

B: because I think that's caused, that's caused, I think we can honestly say, 'cause we know each other outside of the project that it's caused [arguments]

(Focus group, 26th May 2011)

PAS was based in the borough where I live and this was an unexpected facilitator to my relationship with the young people. It meant that we had a common frame of reference, and I knew what they were talking about when referring to local councillors, shops, or areas. I would sometimes see people in the street and stop for a quick chat and catch up.

Some of the young people were completely new to the academic environment and saw this as a positive aspect because they liked getting to know new places. Others would not attend meetings held outside PAS, which prevented them from attending the searching session at the university computer lab. Most of them lived nearer PAS than the university, and on one occasion someone gave up on coming to the university because of heavy traffic.

The academic setting included the opportunity to attend research conferences. Two people were particularly keen on this, and one of them initiated our submission to the INVOLVE conference in 2010 on the back of her experience at the 2008 conference. Going on trips was not always straightforward, and twice did a young person miss their train. One overnight conference resulted in a major conflict between two young people, which was subsequently solved with the help of the participation social worker. Even so, the opportunity to present at conferences remained a big incentive.

The start of this study coincided with the introduction of the Care Matters White Paper in 2007. This formalised a whole range of initiatives to support looked after children and many

of those I worked with had benefited from these, such as free laptops, education grants and social events. The group was not organised politically to promote particular aims for looked after children, although they all saw participation as important to improve the quality of the system. They all said they had joined the study in order to make things better for looked after children, and provide a looked after child's perspective on the research. Some had received good care and those who had not agreed that the system had changed for the better. There was no lack of passion in the group, but there were positive as well as negative views on the care system. The initiative for the review had come from me, and so the onus was on me to engage them and introduce them to how research is part of the overall policy exercise of improving matters for looked after children.

This involvement was therefore researcher initiated. The young people did not approach with a burning issue or epistemological stance, and I needed to think carefully about how to introduce them in an engaging way. Research as activism has a strong tradition in mental health, disability and HIV movements, but critiquing research paradigms and policies requires a level of analytical capacity which in turn result from ongoing participation in spheres where these issues are discussed. Following on from this study, some young people applied successfully for funds from the National Youth Agency Young Researcher Network, to conduct a study on children's views on participation (Mulcahy *et al.* 2011).

Finally, the study design of my PhD investigation was part of the environment of the collaborative work. The double nature of the study (doing a systematic review with young people, and using that as the focus of a qualitative evaluation) also acted as a barrier to involving the young people effectively, because it required me to be both researcher and part of that researcher's field (as a systematic reviewer involving young people). It also required me to keep several aims in mind at once: gathering data on the process of involvement, proceeding with the systematic review, and engaging with the young people.

This was an unexpected challenge to the collaboration and one that I was not fully aware of until the last year of the fieldwork. It was particularly brought into focus when some of the young people did not want the meetings to be audio recorded. Had the recordings only served as help for developing the involvement methods, it would have been less important.

When they were part of data collection in a highly subjective research study, their omission became more problematic, because I was left to rely on my own notes and recall from the meetings, both of which are more biased than an audio recording. It was also difficult, as the only facilitator and chair, to take detailed notes of what people said.

The double nature of the study also had ethical implications. My role as a researcher of the group was overshadowed by my role as group facilitator and research initiator. There were probably times when young people forgot about the recorder and spoke more freely than they would have done in an interview with an external researcher, but the most intimate discussions were always conducted off record. On the occasions when I left the room during a meeting the young people would almost always turn the recorder off, or not say anything, and they would remind each other of the recording if discussions got sensitive.

OBSTACLES AND FACILITATORS INTRODUCED BY THE INVOLVEMENT METHODS

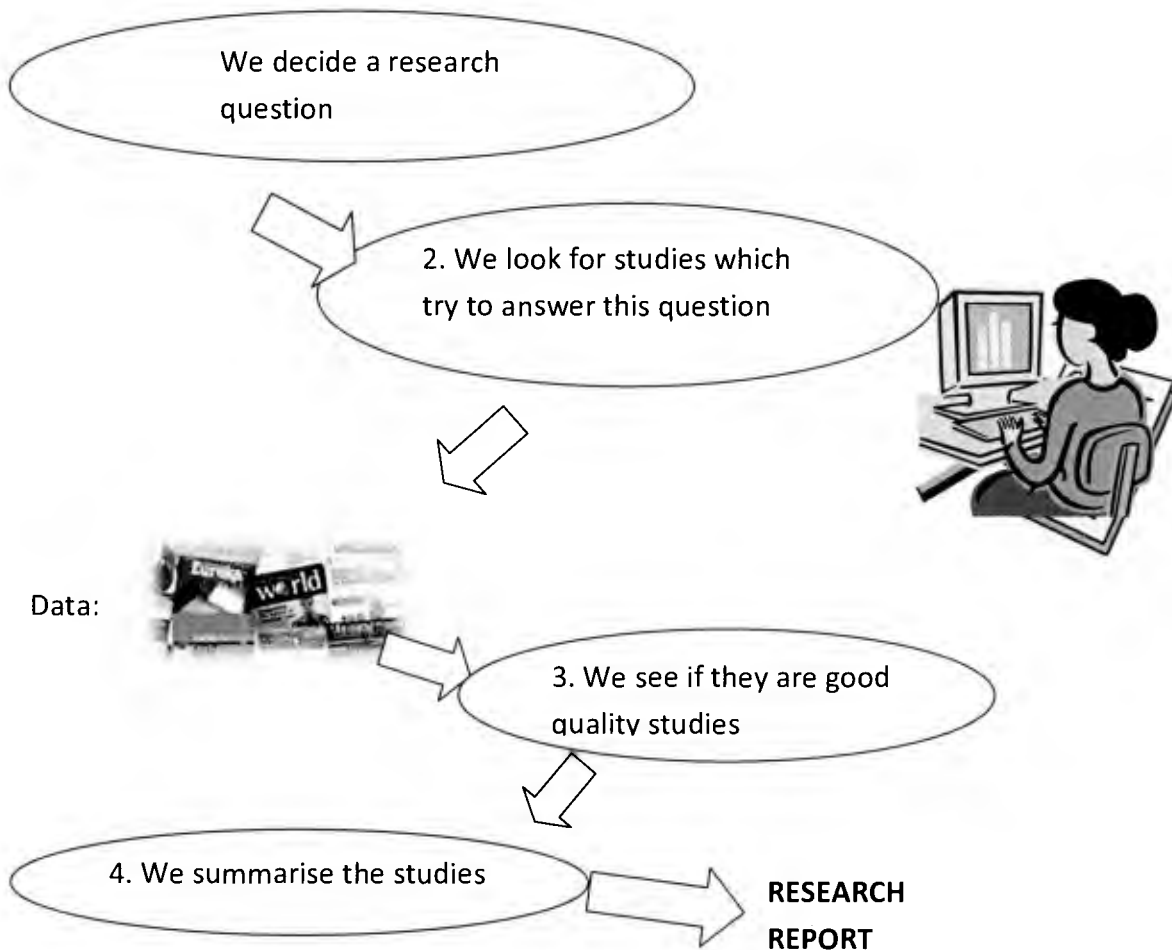
As described in Chapter 5 (study design), the involvement methods aimed to a) translate and explain research, b) facilitate the sharing of information, and c) making decisions, and the findings are presented under these three headings.

Translating and explaining research

Many of the young people had no knowledge of research, and those who did were not familiar with systematic reviews. Most meetings therefore started with basic research training. This facilitated the subsequent discussions and decision-making, but it sometimes made me more like a teacher than a collaborator. Because there was so much they needed to learn in order to contribute knowingly and meaningfully, explanations focused on research designs and data collection methods. This meant that large parts of the meetings resembled a workshop rather than collaborative input into the review.

Although I was conscious of my use of words from the start, I soon realised that my language was too complicated. As researchers we are trained to pay attention to details and accuracy, but when working with people new to research, it may be more important to provide an accessible explanation. For example, I used an A3 sheet with illustrations which described the systematic reviewing process as consisting of four simple steps (Figure 8-3):

A systematic review is a summary of research:



This means that our findings are backed up by more data than if we just looked at one study, or did our own little study.

Figure 8-3: Explanation for 'systematic review'

This attempt at simplifying the description of a systematic review still included words likely to be unfamiliar, certainly in terms of what researchers mean by them: 'research question', 'data', 'findings', and 'good quality studies' are all key terms which needed explaining.

Involving people in research is a challenging task for someone who is primarily a researcher and not a youth worker or a teacher. Preparing was time-consuming, and even when I had planned thoroughly, unexpected events would divert me from the planned schedule. I got more flexible as time went on, and as trust developed between the young people and me, I was less stressed about the running of the meetings.

The more I was able to visualise or materialise concepts, the more they engaged and understood. Showing them a systematic review, a review protocol, statistics for looked after children's education, and drawing processes, outcomes, and interventions all helped. The problem with images is that they leave more open to interpretation, but this was weighed against the potentially confusing or boring explanations using words only. The problem with using examples was that they would lead people to get side-tracked. The below extract is from when I used the 'Scared Straight' review to illustrate how social interventions can have harmful effects (Petrosino *et al.* 2002):

KL: ... they found that those that had been given a prison tour and been talked to were more likely to offend

R: Oh

D: I'm not surprised. It's like a holiday camp. It's like, and the thing is... What gets me is when we put this, as a society we put this view that, we see these, like, we see these programmes and you get the, oh, yeah, my kids, my kids are at home, I wish I could spend Christmas with them. I'm never going to offend. And the thing is, that's what the government want you to see...

[Long discussion about what prison does to you]

KL: Can we not talk about whether prisons are good or bad? My point is just, my point was nothing to do with prisons, but the fact that you can do stuff to people and think it can't possibly be bad

(Preparing critical appraisal, 23rd September 2010)

As people gradually understood the basic concepts of a systematic review it became easier to involve them, both in the review itself and in other related tasks such as dissemination. I found that it took consistent participation across several meetings before most people fully integrated the knowledge.

Sharing information

The information-sharing was facilitated by the involvement methods described in Chapter 5, mainly general discussions, structured debates, worksheets and creative methods, supported by examples. Occasionally I would run out of time to cover everything in my original plan, and this invariably influenced my ability to run the meeting, and the success of the methods employed.

The working model for this review was collaboration, and I hoped that at least some of the young people would take part in the research tasks as well as the overall steering of the review. I aimed for active participation based on their initiative as well as mine. This meant that I would not prepare everything for them, but would ask them to present ideas and make active decisions based on these, rather than comment on something prepared by me in advance. For example, 'education' was not a topic I expected to be working on with the group, and during the data analysis they organised the categories differently to me. It is likely that the review would have looked very different if I had provided them with particular options rather than inviting them to come up with ideas themselves.

My demand for active involvement was a likely barrier for getting more people involved in the review, something also suggested by the young people themselves. The fact that the

project was challenging and required hard concentration at the end of a long day most likely meant that some people did not return after one or two meetings. One young person felt that this was a positive aspect, however, because it meant that those engaged were truly committed and would not drop out.

In my eagerness to involve them as fully as possible in all processes and decisions, I sometimes planned too many activities and provided too much information. I wanted them to have a complete overview of the review, when it might have sufficed to focus on a single part. The problem with breaking down the process into segments, is that people may then not be aware of the implications of the decisions they make. Decisions made on the protocol will impact on all subsequent stages of the review, and decisions made during the searching and screening will impact on the critical appraisal and analysis.

Throughout I was concerned with the trade-off between providing a structured and consultative meeting presenting options, which might be easier to understand, and a looser approach inviting their views based on information (but not options) which might be too challenging. This is from my research diary after the review topic had been decided:

“I tried first to be very open, to leave a lot of the decisions for the young people to decide. This did not work particularly well, because they did not have a framework for making those decisions. ... It worked much better when we put the [conference] presentation together, although I then had a clear idea of what we were going to say, and their input was mainly on the presentation format, which in many ways they designed (although I put together the slides). Which is the most participatory, and when do they have most say? In the former they had a lot of say but didn't contribute much because the remit was a bit unclear. But also, when they did make a decision they didn't follow it through [reference to them wanting to do peer interviews], again, I believe, because the remit was unclear. In the latter they contributed more, but within stricter limitations.”

(Research diary, 11th August 2009)

Each meeting started with a re-cap of what we had done in the previous meeting, and how that would feed into the review. Providing evidence of this integration was important, so that people could see how our discussions and decision-making fed into the protocol, and later, the review. I would also cross reference previous meetings in relevant discussions, as a way of linking the meetings to each other. Some of the discussions and people's views were incorporated into the review protocol and presentations, thereby being reinforced as particularly important elements, or turning points. These kept being mentioned by young people as evidence of their involvement, and for why the review had turned out as it did.

The data analysis revealed how this had contributed to a narrative of the collaboration, a narrative that was owned by everyone involved over a period of time, and by PAS. For example, Denzel would mention that he had been against the topic of the review but wanted to be a part of it even so, and Beth would reiterate how they had shaped the inclusion criteria for the population and also phrased the review title. All these influences were evident in the review protocol. When going back through the data I realised that some of the narrative was not supported by what had actually happened. What we had come to agree on as 'truths' in our joint story of doing the review, turned out to be a mix of what had actually happened, with what had been remembered. Going back to the group with this finding was interesting, but it did not seem to influence their view on what had happened and what the experience had been like.

Making decisions

Most of the decisions on the review were made through discussions reaching general consensus. I found that formal prioritising and decision-making created tension in the group. I had not considered in advance how much a systematic review requires you to prioritise, especially when writing the protocol and doing the screening. Being specific about the inclusion and exclusion criteria is essential to a well-run review process and a good quality review. It can, however, be hard to prioritise when you're drawing on your own lived

experience, and you can clearly see how different topic areas interlink. In Denzel's own words:

D: ... it was like we were slicing and dicing it was like, hang on a minute ... what makes that bit of me more important than that bit of me, it's like...

(Focus group, 26th May 2011)

It was particularly difficult to focus the review on interventions and outcomes. The young people were used to drawing on their experiences to inform policy and practice, but the review required them to consider which interventions were of most interest, or relevance, which outcomes were most important, and what overall focus would they like for their review.

The prioritisation caused several arguments. People had passionate views and the topic was close to their heart. In the end the review was a result of compromises, and many good ideas and proposals had to be rejected, both because systematic reviews are easier to conduct with a narrow question, and because of time pressure. This did not get easier as time went by, although I became more skilled at facilitating the discussions, and the young people themselves got better at reining themselves in when tempers ran high.

Voting was a source of conflict, but it did move the discussions forward. The first time we voted by asking people individually and openly to nominate their top priority topic area. That did not work well:

S: Shall we just go around? Since we've started. Beth?

A: Which one? Illegal drugs?

KL: No no, she can choose from any of these or yet another one. There is not two
[laughs]

A: Illegal drugs yeah?

B: Or illegal drugs, yeah, I go for illegal drugs.

KL: are you sure, I feel a certain

[many at once]

A: Imran illegal drugs yeah?

I: Alcohol and illegal drugs

KL: Sorry is this [all at once]

A: ??? illegal drugs?

[laughing]

A: I'm not telling them what to do I'm just

(Prioritising research topics, 13th December 2007)

We voted again after more discussion and Alex and Ermias, who had originally been leading the vote for 'illegal drugs', changed their minds and voted for 'positive things about being looked after' and 'lack of motivation to go to school' respectively. After this first experience of open voting we made all big decisions by voting anonymously. This made people's choices less open to influence from others, but it did not make it any less contentious. Below, one young person vents his frustration after the vote has gone against his preferred choice:

D: But I'm just saying, every big decision, it hasn't not gone my way, so I'm just...

KL: Now that's not true because like you said, the exclusion number and attendance, those were the two most important ones.

R: Yeah, but it can't be everything go my way as well, because...

B: And there might be things that haven't gone Ruta's way, my way, Denzel's way, Yonas' way.

(Finalising protocol, 9th February 2010)

I found that it was important that all decisions were taken at meetings and that other mediums of decision-making, such as phoning people up individually or texting, were not ideal even though this widened participation to more people. We did do one vote by text and some people later claimed they had not been included. When asking people for their views over the phone after one meeting I realised the importance of a discussion immediately before a vote. When people have a chance to explain their views to others, people change their minds, and through deliberation stronger consensus is reached. Decision-making is a collective and creative process. In a meeting there is also room for clarifying expectations and reassuring people in terms of the voting process. Texting, email and phone conversations are useful for informing people, and may work when set up in a formal way and linked to a particular discussion.

CHAPTER CONCLUSION

This chapter has examined the obstacles and facilitators inherent in the involvement framework. These emerged along four elements of the framework: a) the systematic review, b) those involved, c) the environment, and d) the involvement methods.

This involvement was in a systematic review as opposed to a study design of people's choice, or a more traditional method used for peer research, such as in-depth interviews or observation. Systematic review methods are highly technical and the secondary nature of this research makes it less conducive to involvement because the methods are not as intuitive. The data for systematic reviews are less accessible and understandable to people who are not socialised into the academic world, and the planning of a review requires knowledge of a variety of research designs and concepts, in addition to systematic reviewing itself. On the other hand this also clarifies and highlights the interface between research and

'the general', and it is therefore easier to distinguish relevant discussions from general life conversations which are part of most meaningful relations.

When analysing my own role and impact I was confronted with both positive and negative aspects of my personality. I managed to keep the meetings informal and relaxed, and achieved a friendly rapport with the young people, which has been highlighted as important in qualitative research (O'Kane 2000). But I also had a tendency to get stressed and therefore unclear during meetings. There was a lot to pay attention to, and I sometimes felt overwhelmed. For these reasons, having only one researcher was a challenge to the involvement process.

Young people came to the project with a wide range of research experience. There was a lot of enthusiasm, interest and ambition in the group, which helped the review move forward. Looked after children are a stigmatised group, and this represented a particular set of challenges, mainly because I did not want them to feel stigmatised by taking part in the review. At the same time, involving people in research can make the research less stigmatising itself, as indicated by the young people framing the review question more positively than I might have done without their input. Different backgrounds, experiences and viewpoints, in addition to working relationships established within PAS, meant that there were internal group conflicts.

The funding of the project, the connection with PAS and the policy context facilitated the work because it enabled me to meet with a group of young people, to support their participation with vouchers, food and travel expenses, and drawing on the support of an experienced participation social worker. My relationship with the social worker and the learning I gained from her were invaluable. For some young people the university connection made the project more interesting whereas others did not want to attend meetings outside PAS. Ultimately, the design of the study itself at times interrupted the collaboration, because I was simultaneously focusing on engaging with the young people to produce a systematic review and gathering qualitative data on the involvement process.

Finally, the methods employed to support the involvement introduced some obstacles. My efforts to translate and explain research were not always successful, and the prioritisation and voting tended to create tension in the group. The most successful approaches contained clear and concrete examples and outputs, such as the review worksheet which grew from meeting to meeting. I realised during the screening process that I should have introduced study abstracts during the protocol stage because engaging with these drew out what kind of information young people found important and relevant.

Figure 8-4 below is a summative overview of the main obstacles to involvement identified in this study and according to the four main areas outlined at the start of this chapter.

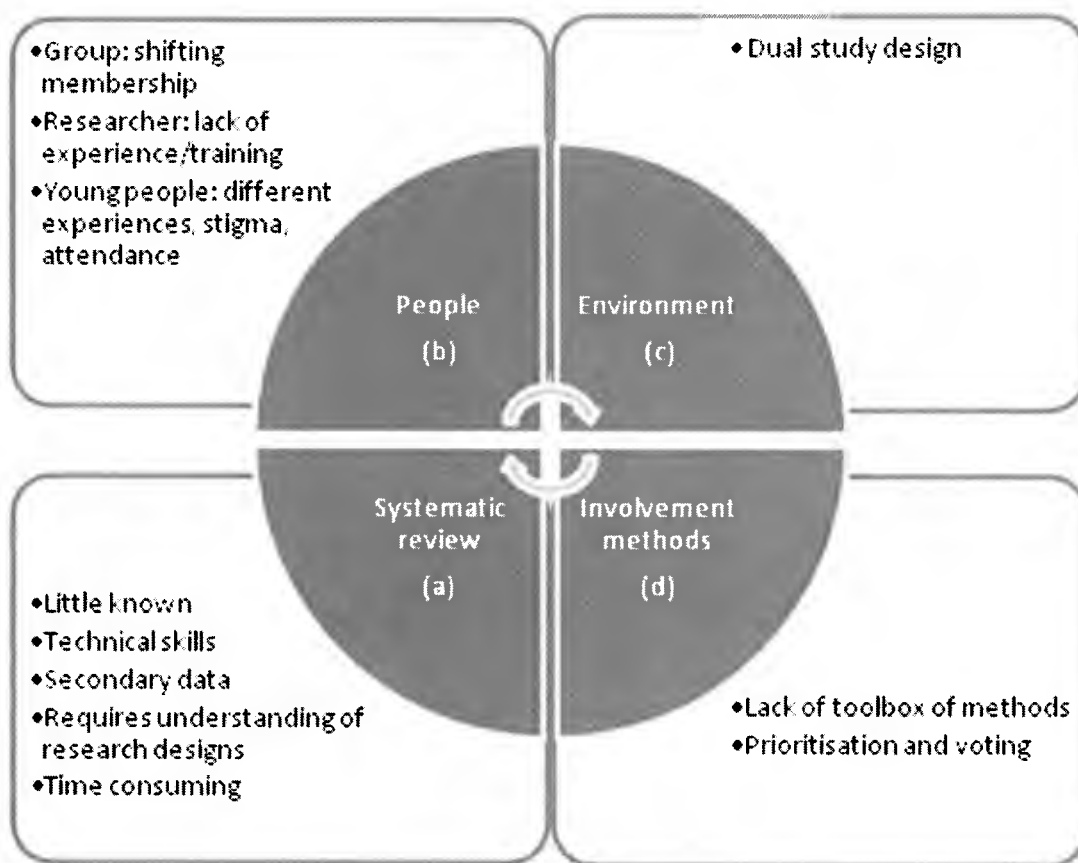


Figure 8-4: Main obstacles identified

As indicated in Figure 8-4, the most inhibiting element of the environment was the dual nature of the study. I had particular reasons for choosing this design and I was aware of the implications for the qualitative evaluation. I was less aware of how this would impact on the

involvement process. Other main obstacles clustered around the systematic review, however, as this shaped almost all efforts of engagement, information-sharing and decision-making. In particular, the secondary nature of systematic reviews makes them less conducive to involvement than research designs collecting primary data.

My preparation for this study identified a lack of detailed descriptions and tested approaches to involvement, such as those in for example childhood research which provide careful descriptions of methods (Christensen 2004; Curtis *et al.* 2004a; O'Kane 2000). This is linked to Harvey's (2009) observation that ethnographic research on public participation is lacking. I also found that formal prioritisation and voting created tension, and that methods that facilitated structured debate and deliberation were more successful.

Figure 8-5 below complements Figure 8-4 by providing an overview of the main facilitators identified within each area.

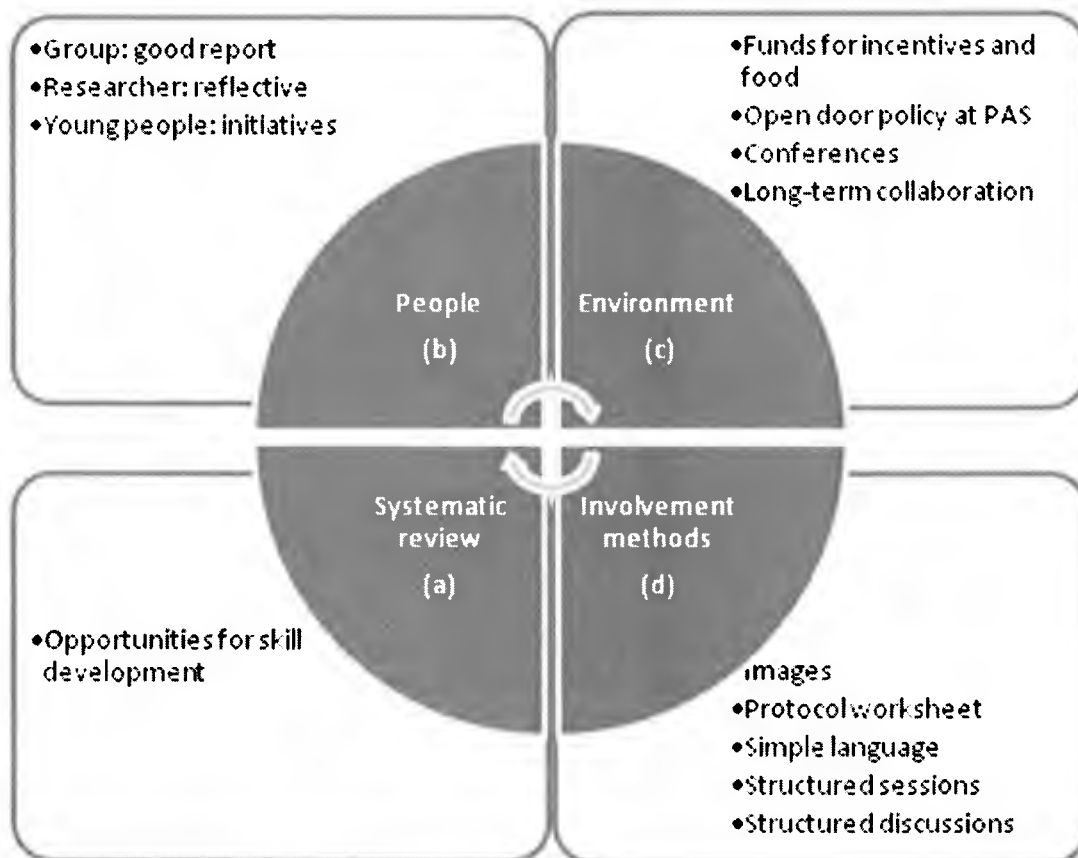


Figure 8-5: Main facilitators identified

The funding environment enabled me to adequately thank the young people for their contributions and hard work, and the open door policy at PAS enabled me to work with the young people and learn from them and the social worker. The conferences operated as strong incentives for two of the young people. An unexpected facilitator of the study design was the length of time set aside for the collaboration. Although also a barrier to some people, this provided those who stayed with the study and the researcher with time to develop skills and establish relationships.

The list of emerging involvement methods is a contribution to the tool box of methods argued for here. These methods were developed within this project and would benefit from wider use and testing. Finally, the systematic review also contained an important facilitator, as many young people appreciated how it provided them with training on new and important skills, in particular the searching.

Ultimately, I acted as the main facilitator to the project, in that the review would not have been initiated without me applying for money and setting up the collaboration. I also introduced some obstacles, as described, through my personality and skills. None of this would have happened without the young people, however, and the willing collaboration of the social worker.

Chapter 9 HOW DID THE INVOLVEMENT OF YOUNG PEOPLE IMPACT ON THE SYSTEMATIC REVIEW?

This chapter addresses the research question 'Can a systematic review be conducted in collaboration with young people and at the same time maintain quality standards in systematic reviewing?' This was also addressed in Chapter 7 which presented the final review. This chapter further investigates how the systematic review was shaped, or not, by the involvement of the young people. The process of integrating people's ideas into research is the essence of involvement, and consists of inviting people to share their views, making decisions together, and then incorporating these decisions into the research (Oliver *et al.* 2011). There may be good reasons for why ideas are not integrated and retained, but if the final product does not reflect people's views there is reason to question the involvement process and why it was instigated in the first place.

An argument for service user involvement in research is that it will make the research more relevant because it will encompass an experience-based perspective as well as researchers' formal knowledge (Entwistle *et al.* 1998; Smith *et al.* 2002). Assessing this in a formal evaluation has been acknowledged as difficult, because because the question of 'more relevance' hinges on a comparison element related to 'more relevant than what?' (Staley 2009). It is also hard to capture the role played by personal connections and relationships established during the involvement process, which has been identified as particularly important in terms of subsequent impact (Lindenmeyer *et al.* 2007).

This chapter addresses the question of impact by considering whether there appeared to be a connection between the involvement of the young people and the quality of the research. To address this the framework analysis looked for evidence of impact on the research in terms of decisions made in the meetings, and in terms of evidence of impact in the final review. I also looked for other reviews with a similar focus, and compared these to ours in terms of scope, focus, and quality.

YOUNG PEOPLE'S IMPACT AT EACH STAGE OF THE REVIEW

This review was initiated both to produce a review informed by looked after children's priorities, and in order to facilitate reflection, personal experience and in-depth analysis of involvement. Its underlying rationale therefore sprung from a researcher's inquiry into involvement rather than service users' request for information. In spite of this strong anchoring in involvement and collaboration, the main influence on the review came from myself. As the main gatekeeper I initiated it, decided it was going to be a systematic review rather than another research design, and I came to the project with preconceived views on what makes a good quality systematic review and what kinds of research designs best answer certain kinds of review questions. Similarly, although I aimed for a true collaborative relationship with the young people, I was in charge of planning the research meetings and ultimately set the parameters for their involvement. All involvement that is initiated by researchers in a pre-conceived research project will primarily be shaped and restricted by the researchers in charge.

Even so, the young people's influence on the review was considerable, particularly because they were in charge of setting the review topic, and they actively contributed to and vetoed protocol decisions. That the group included outgoing personalities with strong views further enhanced their influence. Their participation was essential for this study, and they therefore had more impact and control over the review than if the prime purpose of the research had been to produce the review. I first consider their impact at each stage of the review, before considering the quality of the systematic review itself.

The obstacles and facilitators to the collaboration form the backdrop to the consideration of young people's impact. If the process is unclear or unfair, the final integration of ideas could be more influenced by obstacles and facilitators than by service users' views and opinions. For example, if the service users do not feel safe to voice their views because a service provider is present, the end result from the involvement may not derive from service users' priorities but what service users deem acceptable to say in certain forums. When considering young people's influence on each stage of the review I have tried to contextualise this with the obstacles and facilitators identified in Chapter 8.

Young people’s influence on choosing the review topic

Figure 9-1 below shows the most important factors that influenced the review topic. Discussions and decisions on the review topic ran over three meetings and this figure shows how the young people appeared to have had considerable influence on the direction of the review, but this was partly obscured by the involvement process.

Obstacles and facilitators to the decision-making	Review stage	Young people’s INFLUENCE ON THE REVIEW
<p>Voted on favourite topic by show of hands, which meant one person influenced other people’s choices.</p> <p>Group split into two to construct arguments for one of two topics. Researcher helped one of the groups write, which was seen as favouring their topic (education).</p> <p>Only one young person responded to the text message voting. Some young people later questioned whether the text message went to all young people.</p> <p>Only one young person came to fourth and final topic meeting, which meant that we did not have a final discussion about the chosen topic.</p>	<p>DECIDING ON THE REVIEW TOPIC</p>	<p>The topic was chosen by the young people through discussion and voting, but their impact was limited by the involvement process.</p> <p>The chosen topic was ‘lack of motivation to go to school/further education/unemployment. This was changed to being just ‘education’, and then into two preliminary questions:</p> <ol style="list-style-type: none"> 1) ‘Why do some looked after young people not want to go to school or continue to further education?’ 2) ‘What can be done to prevent them from dropping out?’

FINAL REVIEW:

Young people led the discussion about the topic, but process was led by the researcher.

The final review was about education and related to motivation and dropping out of school.

Figure 9-1: Impact on the review topic

At this stage I was an involvement pioneer in that I had not previously involved young people in research, and I had limited training. Some meetings were not structured enough, and the timing of most meetings (spring) coincided with the young people's exam periods, resulting in one meeting being cancelled because few came.

The voting 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 also influenced the votes because I helped one group write down their arguments when they expressed reluctance to do so. Because this group had argued for education, some young people thought felt with my help this group won the argument. This also highlights how writing might be an obstacle to the involvement of some young people who might prefer oral discussions.

The young people themselves pointed out problems with the process, mainly relating to lack of clarity about how the topic was chosen. In spite of this, they felt that the final topic had been their own choice, and that this contributed to their ownership in the final review.

Young people's influence on the review question

The review question was decided more than a year after the review topic because of my maternity leave. At this stage, new people joined the group and for this reason I considered whether an additional topic discussion was needed. I decided against this because of the prolonged process of arriving at a topic with the previous group, and because it was likely to take up a lot of time. The participation social worker also advised against revising the topic. The new group therefore started by defining the review question.

Figure 9-2 below shows the obstacles and facilitators impacting on the decisions when refining the review question.

Obstacles and facilitators to the decision-making	Review stage	Young people's INFLUENCE ON THE REVIEW
<p>Mostly new people attended the meetings, who had not been involved in setting the topic.</p> <p>More structured sessions providing options and suggestions rather than open discussions.</p> <p>Choice of 6 questions developed by the researcher based on group discussions on education's implication for looked after children's health.</p> <p>Secret voting in light of experiences with show of hand when setting the topic.</p>	REFINING THE REVIEW QUESTION	<p>One young person led the discussion by pointing out differences between different <i>types</i> of questions. His preference won the vote, which was that the review would look at how to improve the problem rather than describing it. He also argued that we should look at the effect of cognitive behaviour therapy.</p> <p>Two young people wanted the review question to be more positive and say 'supporting people to stay in' rather than 'preventing people from dropping out'.</p> <p>The chosen review question was: 'Does cognitive-behaviour therapy help looked after children to stay in school?' This was subsequently changed during the protocol development.</p>

FINAL REVIEW:

The final review question focused on improving the problem, by looking at the effectiveness of interventions.

The final review question used the wording 'stay in school' rather than 'dropping out'.

Figure 9-2: Impact on the review question

The discussions ran over two meetings. By this stage I had reflected on the topic-setting process and the meetings were therefore more structured and focused, and the voting on the question was concealed. However, because of the aim to collaborate with rather than consult the young people, I found that many smaller decisions leading up to bigger decisions were made through deliberative discussions. For example, discussions about the population at this stage did not involve voting, but people's views on this were written down to support

the final question. This is from my own evaluation sheet which I filled out immediately after the meeting:

We used disclosed voting twice. However, we also made decisions openly, like a normal meeting, where the decisions were driven by the most confident people. I am aware of this, but not quite sure how to deal with it. On the one hand this is the way it is in all meetings so why should it have to be more democratic in this meeting, it is impossible to vote on every single issue, because there are so many small decisions to make. On the other hand it is not ideal that a few people take charge, because apparently small decisions can have very decisive influence on the direction of the study.

(Defining the research question, 7th October 2009)

The group dynamics meant that one person, who commanded respect amongst other young people at PAS, dominated the discussion and the vote for 'type of question' favoured his preference. Quieter young people only spoke when reporting back on the break-out groups, which indicates that this can be a good way of encouraging more people to share their views, although they may have spoken only during the feedback.

One problem during this process was inherited from the topic-setting: because some young people disagreed with the chosen topic's relevance to health, they struggled to engage with setting the question. This was exacerbated by the fact that many people from the previous group had dropped out, so the new group had effectively inherited a review topic they had not chosen. The shifting membership of the group influenced the involvement process, which in turn influenced the progress and engagement in the review.

Young people's influence on the review protocol

The process of setting the review question led into the process of developing the protocol shown in Figure 9-3 below.

Obstacles and facilitators to the decision-making	Review stage	Young people's INFLUENCE ON THE REVIEW
The protocol worksheet clarified the process and the aims of the discussions and decisions.	DEVELOPING THE REVIEW PROTOCOL (PICO)	<p>Young people's particular impact on PICO were:</p> <p>Population: looked after children aged 10-15 in mainstream schools, not disabled and not in kinship care.</p> <p>Intervention: changed from cognitive-behaviour therapy, to any intervention aimed at supporting looked after children to stay in school, which changed the review question to:</p> <p>'What is the effect of interventions to support looked after children to stay in school?'</p> <p>Comparison: Studies did not need to have a comparison group to be included in the review. Case studies and process studies would be included.</p> <p>Outcomes: attendance, exclusions and final year exams.</p>

FINAL REVIEW:

The protocol shaped the review and guided the searching, screening and synthesis. It helped the young people to see how their views were integrated into the research.

The wide inclusion criteria for study types meant that the search strategy could not use study design filters.

One study on kinship care excluded from the final review.

Figure 9-3: Impact on the review protocol

At this stage the involvement process was highly structured, which sprung directly out of this particular feature of a systematic review. The discussions were structured by the protocol and PICO, and this made it easier for the young people to see what kinds of ideas

they were asked to share, and how that fitted with the final product. This is an extract from when the young people were defining the population:

D: ... I know speaking from experience that the fact that I had so many placement moves, and I was having to continuously move school, impacted on my education.

KL: yeah, yeah

D: there'd be some young people that to, to them that would be brilliant and, like

KL: I don't think many placements is ever going to be conducive, like a good thing for school

D: no it's not, so

KL: no

D: I think young people that have had lots of placement, and I think the only way you're gonna find that is young people who have been accommodated because, young people

B: does that mean young people who have been in foster care?

D: oh yeah

B: but not with grandparents, I think it should just be people who've gone into

KL: not, no we can, we can include that

D: are we, is incl

KL: it's up to you

B: see I don't think we should have that because

KL: ok

B: I think it has to be people that have been taken away from their family

KL: ok

B: I think that's, I think

D: yeah but sometimes you're taken away from your families, and you're later put back into the care of your family

B: no but I don't think that, obviously, I'm, I'm just saying you know people who have been away, whatever, it doesn't matter if they've come back or whatever, that's fine, it's what I think that, people who've gone away from their families and lived with someone they don't know.

(Protocol writing, 12th November 2009)

This discussion related to the decision to focus on looked after children only. I had suggested that we could focus on a wider group, but the young people wanted to include only children who had been accommodated, because they felt that placement issues for looked after children were relevant to their schooling. This then took them onto the issue of kinship care, which they wanted to exclude. This decision went against my preference because kinship care is increasingly used as an option for looked after children, and although many young people will know those they move to, their move might still disrupt their schooling. However, I felt that due to my strong gatekeeper role it was important to let the young people lead on the decisions on which they had a strong view, and which were informed by their own experiences.

Young people's influence on the searching

In contrast to young people's considerable impact on the protocol, they had a limited impact on the searching, as indicated in Figure 9-4 below:

Obstacles and facilitators to the decision-making	Review stage	Young people's INFLUENCE ON THE REVIEW
<p>Young people received training on searching. Some young people could not attend because they did not want to come to meetings outside PAS, and the search training had to be held where there were enough computers for everyone.</p> <p>When searching I found myself worried about whether the young person was thorough enough when looking through relevant websites.</p>	<p>SEARCHING FOR STUDIES</p>	<p>The young people's involvement did not change the search strategy, although they conducted some preliminary searches on Google.</p> <p>The young person who hand searched websites was happy to do this, but did not want to read the in-depth descriptions, which he passed on to me.</p>

Figure 9-4: Impact on the searching

The group met over two workshop evenings at the university where they received basic search training in which they learned about how to plan a search and identify search terms, and how to conduct advanced searches in Google. One young person also did some hand searching with me in a separate session. The young people came up with suggested search terms, but these did not differ from another review's search filters for 'looked after children' (Brodie *et al.* 2009), bar terms for 'unaccompanied asylum seekers'. These added terms did not make a difference to the search results, which is an indicator that the involvement did not affect negatively on the quality of the review.

As described in Chapter 8 I was concerned that the young people might not be thorough enough when scanning search hits, as evident in the following extract:

KL: Oh yeah [laughs]. Do you want to look at 'All Publications'?

D: Could [yawns] do I suppose.

KL: Or just 'Books, Guides and Multi Media'?

D: No, 'All Publications'.

KL: Oh it's ridiculous. Just, see this is why I want to audio record because I've actually taken over, taken the computer away from you now.

(Searching, 12th April 2010)

While this shows my reluctance to give up control over the review process, this meeting felt more collaborative than those with the larger group. With only the two of us Denzel had ample time to voice his views. This created a sense of true collaboration, as in the following extract where he makes me aware of a potentially relevant area:

D: That will just take us back to the page we just had.

KL: Will it?

D: It was all under the blue print the stuff I just showed you.

KL: I think there was more of a mix...

D: See, because they go more on the basis of advocacy.

KL: Yeah, I think you're right. Okay, so we can leave them out then.

D: But they did have a bit here that I was very interested in, the 'Links' page.

(Searching, 12th April 2010)

The electronic searching was conducted by me, but was informed by the work done in the workshops, in the same way as an information officer who plans searches from discussions with reviewers.

Young people's influence on the screening

I had anticipated that the young people's engagement would gradually drop off after the searching, but there was a surge in activity during the screening. As shown in Figure 9-5

below, the young people had a considerable input into the development of the screening tool, which was tested out during three meetings. The screening further resulted in a change of the protocol, mainly widening the inclusion criteria. The young people’s decision to include studies on attainment was integrated and retained into the final review. Their decision to include studies on young people’s views on educational interventions was integrated into the review protocol but not retained in the final review because time was running out for completing the review within the funded time period.

Obstacles and facilitators to the decision-making	Review stage	Young people’s INFLUENCE ON THE REVIEW
<p>Young people tested out the screening tool and each category in the tool was discussed and changed according to young people’s views. Young people screened in pairs and individually. Some people left and new people joined. This delayed decision-making because new people had to be introduced to the study and the review, and the main principles of systematic reviewing.</p>	<p>SCREENING STUDY ABSTRACTS</p>	<p>After the initial screening young people wanted to include attainment studies and those collecting young people’s views. This meant that the search strategy might have missed relevant studies, because it had focused on ‘staying in school’ only.</p> <p>The screening process identified studies with mixed and overlapping populations. Young people did not want to include studies which focused on young offenders or those with behaviour problems. These studies included looked after children but the young people wanted the review to focus on all looked after children, rather than sub-groups of this population.</p>

FINAL REVIEW:

Attainment studies were included in the final review, but **views studies were not due to time issues.**

Figure 9-5: Impact on the screening

Young people's view that the inclusion criteria should be expanded at this stage reflected previously expressed ideas, which had been scrapped to make the searching more manageable. The wish to include studies on looked after children's views also highlighted my influence on the protocol which only considered intervention evaluations as evidence of effect, as this had been my interpretation of their wish to focus the review on 'how to improve the problem'. Ruta, who screened the most studies, felt particularly strongly about this, whereas Denzel was more cautious because he was concerned with keeping the review focused:

R: ... but we found some of them really relevant while we were looking but although they are relevant they've still got some views so you can't like just exclude them because of their views, that's what I was thinking.

D: That's what I said when we were doing this in the first place so I agree, I totally agree but as I said then, we just need to be very careful on how much ... because before we know it we will end up getting to a stage where we are asking kids about sweets ...

(Screening, 21st July 2010)

As a result of Ruta's concern the young people agreed to include studies on young people's views, and these studies were initially included for critical appraisal. Unfortunately this change was not reflected in the final review because there was no time to critically appraise and synthesise these studies. None of these studies had considered young people's views on specific interventions. The inclusion of attainment reflected the views of the two young people who were most heavily involved in the screening. Both were high academic achievers who left the study when they started university.

Young people's influence on the critical appraisal

Figure 9-6 below shows the impact of the young people's involvement in the critical appraisal, which ran over two meetings and mainly consisted of discussing principles of study quality, rather than looking in-depth at included studies. During screening they had expressed reluctance to read more than the abstracts, which were complicated enough in themselves. The study was also running out of time.

Obstacles and facilitators to the decision-making	Review stage	Young people's INFLUENCE ON THE REVIEW	FINAL REVIEW:
Again, new people joined, which delayed the meetings. Researcher's use of toy figures to explain study design did not work very well.	CRITICAL APPRAISAL OF INCLUDED STUDIES	Young people decided to only include studies that had measured impact before and after the introduction of the intervention, thereby narrowing original criteria specified in the protocol.	All studies included in the review had made attempts at measuring the impact of the intervention. All other identified studies were excluded.

Figure 9-6: Impact on the critical appraisal

At these meetings I explained the main principles of evaluation, and types of evaluations. We discussed examples of studies reported in popular media. The two meetings resulted in one important decision: that studies would be included only if they had made some effort at measuring change in young people as a result of the intervention. Although five young people attended the meeting where this decision was made, only Beth and Denzel were actively involved because the other three were completely new to the study.

Young people's influence on the study synthesis, analysis and writing of the review

Three meetings were set aside to discuss synthesis and analysis. Figure 9-7 below shows that discussions about the studies findings and characteristics were informed the analysis, in particular by prompting my own reflections and comparing them with the young people's.

Obstacles and facilitators to the decision-making	Review stage	Young people's INFLUENCE ON THE REVIEW
The researcher simplified the study abstracts by explaining the characteristics of the interventions and outcomes. The young people were encouraged to consider the interventions in light of their own educational experiences. Linking studies with own experiences worked well.	SYNTHESIS OF STUDY FINDINGS AND ANALYSIS	<p>Young people organised interventions into six main categories.</p> <p>Young people's discussion on outcomes informed the review discussion.</p>

FINAL REVIEW:

Review kept the intervention categories and the discussion reflected young people's views on outcomes.

Figure 9-7: Impact on the synthesis and analysis

In particular, their categorisation of interventions resembled but improved the ones I had developed in advance of the meeting, and their views on the outcomes differed considerably from the majority of the studies which had attainment as their primary outcome. Looking at the range of outcomes included across all the studies, they decided that motivation to go to school was the most important, followed by 'staying in school':

B: ... I mean motivation to go to school, that might not necessarily impact or [??] for the test results, the GCSE results, it might not impact that. But it will impact the attendance 'cos they're motivated to be there and it might also influence exclusions and dropouts, so it depends on what outcomes...

KL: So if a study didn't include the motivation, would that be a big problem? Or if it didn't include staying in school.

B: I think you have to include both.

KL: You think all three of them or just those two?

B: I'm not bothered by attainment to be honest, I'm not that bothered 'cos I don't think it should, you see, for me, I think, you know, 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.

KL: It's really interesting that you say that because, like I said, all the studies, bar one, so ten studies [had attainment as an outcome]

D: 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.

(Analysing studies, 17th February 2011)

At the time of the analysis and consideration of the included studies I had worked with the young people for three years. We had met over 23 meetings and discussed ongoing issues related to both looked after children and systematic reviews. My reading of these studies was therefore informed by knowledge I had gathered through these discussions, and through reflection on these discussions.

The young people were not involved in the writing of the review. This was mainly due to the amount of training needed to learn academic writing. They were involved in the writing of an article about the involvement process, however, having attended a writing workshop day at the university. Of course, by the time of the writing my thinking had been greatly informed by the relationships that I had formed with the young people during the course of the study.

In addition to the direct impact from the young people on the review described here, the collaboration also influenced my own reviewing, which in turn influenced the review. The discussions within the group highlighted my own assumptions which I had previously taken for granted. For example, I had wanted to include young offenders and those with

behaviour problems, because of overlapping populations. The young people disagreed because they were concerned about labelling and stigma. For them, the decision to focus on looked after children meant that this was the target group, and most looked after children are not offenders. The research student who contributed to the double screening also met with the group on two occasions and felt that this influenced her consideration of the titles and abstracts, because it made her consider whether the young people themselves would identify with the groups described. Overall, this analysis exposes how much value judgements and interpretation goes into the reviewing process, which is often obscured by the *a priori* style of writing adopted by many systematic reviews.

THE QUALITY OF THE SYSTEMATIC REVIEW

Having considered how the review was shaped by the involvement of the young people, I now turn to the question of whether the review was conducted according to accepted standards for systematic reviews. To address this I draw on a comparison of our review with two reviews of educational support interventions (Brodie *et al.* 2009; Prevatt & Kelly 2003), and an experienced systematic reviewer's critical appraisal of our review, using the AMSTAR checklist (Shea *et al.* 2007). The analysis then considers whether our review has any strengths or weaknesses that can be traced back to the involvement.

Comparison with two reviews: scope and focus

The two comparison reviews both focused on educational support, one on drop-out prevention programmes (Wilson *et al.* 2011) and one on looked after children (Brodie *et al.* 2009). I did not read these before our review had been submitted and accepted in a peer reviewed journal. Table 9-1 below contains the authors' own summaries of each review.

Wilson S, Tanner-Smith EE, Lipsey MW, Steinka-Fry K, Morrison J. Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth. Campbell Systematic Reviews 2011: 8

(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.

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.

Brodie I. Improving the educational outcomes for looked-after children and young people. 2009: London; Centre for Excellence and Outcomes in Children (C4EO)

(Report summary) This review tells us what works in improving educational outcomes for looked-after children and young people (LACYP), on the basis of a systematic review of the research literature and analysis of key data. It aims to provide evidence that will help service providers to improve services and, ultimately, outcomes for children, young people and their families.

The review was carried out by the University of Bedfordshire on behalf of the Centre for Excellence and Outcomes in Children and Young People's Services (C4EO). The National Foundation for Educational Research carried out the data analysis.

Liabo K, Gray K, Mulcahy D. A systematic review of interventions to support looked after children in school. In Child & Family Social Work (2012)

(Journal abstract) A systematic review of interventions to support looked after children to stay in school included interventions that aimed to prevent drop-out or exclusions, and those that aimed to reduce absenteeism in the care population. Studies were critically appraised and their results considered. No study was found robust enough to provide evidence on effectiveness, but promising interventions were identified. The review highlights the lack of evidence in an area which has received a lot of policy attention in the past few years. Future evaluations need to be underpinned by lessons learned from existing evaluations, clearly defined theories and definitions, and by the views of professionals, researchers, policy makers and young people in care.

Table 9-1: Published abstracts or summaries of each review

The summaries above are framed by the expectations of the publisher (Wilson *et al.* 2011), journal (Liabo *et al.* 2012) or with the target audience of the report in mind (Brodie *et al.* 2009). Systematic reviews are, like primary research projects, driven by different aims and epistemological frameworks. The review's size and breath is likely to depend on the question asked and the methods employed (Gough & Thomas 2012). Table 9-2 below presents an overview of the research questions of these reviews.

Review	Review objective or question
Wilson et al (2011)	To examine and summarise the effectiveness of different programmes and identify those with the most reliable effects. A separate analysis was included for programmes targeted at teenage parents.
Brodie (2009)	<p>What do we know about the accessibility, acceptability and effectiveness of policies, services and interventions initiated by central, regional and local government and independent sector?</p> <p>What are looked after children and young people's views on what constitutes positive educational outcomes and how do they compare with those of policy-makers, children's services personnel and independent sector providers?</p> <p>What do we know about the contribution made to positive educational outcomes for LACYP by the attitudes, skills and abilities of foster, residential, kinship carers, teachers and birth families and interventions to support this contribution?</p>
Liabo, Gray and Mulcahy (2012)	What is the effectiveness of interventions to support looked after children in school?

Table 9-2: Research questions of three reviews

The review questions differ both in scope and language used. Wilson et al (2011) used the term 'drop-out prevention', which is the commonly used term in research in this area. Brodie (2009) focused on outcomes, with an emphasis on attainment, again the outcome most commonly measured in evaluations in this area. Our review contrasts therefore with both of these, in that the young people wanted the review to be positively framed and therefore avoided the term 'drop out'. The young people also saw attendance and exclusions as a precursor to achievement, and therefore first chose to focus on these

outcomes, although attainment outcomes were included at a later stage. This is in contrast to Brodie (2009) but not Wilson et al (2011).

The focus of the Wilson et al (2011) review was similar to ours bar the population and our later inclusion of interventions evaluated in terms of attainment. Brodie’s (2009) review was commissioned by C4EO (Centre for Excellence and Outcomes in Children and Young People’s Services), which aims to support local authorities and services to improve outcomes for children. This review’s practical aim of supporting service planning may explain their comprehensive framework and wide questions, as policy implementation needs to consider process, effectiveness of programmes and user views. The young people initially wanted our review to include a wider range of outcomes, whereas I was concerned with the risk of not completing the review within the timeframe. Faced with this risk they decided to narrow the outcomes.

How the three reviews differ can be analysed in terms of distinguishing aggregative reviews and configurative reviews mentioned above. Oliver *et al* (2012, p. 74) illustrated this distinction as shown in Figure 9-8 below:

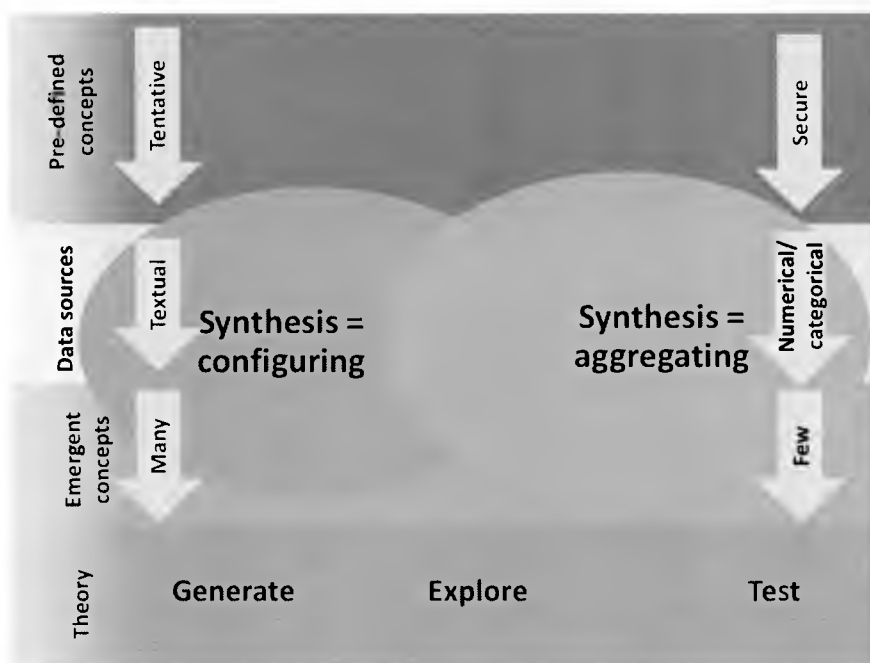


Figure 9-8 : Spectrum of approaches to synthesis in systematic reviews (Oliver *et al.* 2012)
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In the above figure, aggregating reviews focus on testing theories, whereas configuring reviews focus on generating theories. Most reviews will contain aspects of both. Wilson et al (2011) asked theory-testing questions and after finding several hundred relevant studies, were therefore able to focus on the original aim of investigating the effectiveness across programme types. In contrast, Brodie (2009) aimed for both theory-testing and building. Our review began with a theory-testing question, but when facing a dearth of appropriate data to answer a theory-testing question we redirected our efforts to studies in light of a theory of evaluation (Wholey 1987).

Some features of our review which came from the young people’s direct input were absent in the Brodie (2009) review. Most notably these were the exclusion of kinship care, the exclusion of younger children, and the emphasis on ‘motivation to go to school’ as an important outcome. The young people involved in our review did initially want to have a broader scope, in particular in terms of outcomes and the inclusion of studies collecting young people’s views. Table 9-3 below compares the two reviews’ perspectives on looked after children’s education. The review by Wilson *et al* (2011) is not listed in this table because it did not focus on looked after children.

Where reviews differed in perspective on looked after children’s education	Impact on the review’s scope		Supporting arguments for restricting scope (Liabo, Gray and Mulcahy, 2012)
	Brodie (2009)	Liabo, Gray and Mulcahy (2012)	
Scope	Broad and beyond interventions	Focus on interventions only	A wider scope provides more comprehensive evidence for policy and practice, but a narrower scope makes the review easier to manage and focuses the search so that it may identify more studies.
Assumptions about intervention applicability	Broad and no stated limitations	Interventions for looked after	Scope restricted to make the review more

	on intervention characteristics.	children in general rather than sub-groups, and excluding those in kinship care.	positive, to focus on mainstream looked after children rather than those perceived as 'problematic' in the system.
Outcomes for judging 'effectiveness'?	The body of evidence was weak in terms of evaluation, but stronger in terms of description. Included studies on children's views.	Studies identified were not of high enough quality to merit recommendations for policy or practice, mainly due to the lack of a control group, small sample sizes and large loss to follow-up. Views studies identified but not included in the final review due to time limits.	It is important to focus on independently measured outcomes because these could differ considerably from people's own perceptions.

Table 9-3: Comparison of perspectives of two reviews on looked after children's education

Our intention had been to include children and young people's views on whether an intervention was effective or not. Brodie (2009) analysed such studies in terms of the kinds of outcomes children and young people saw as important in relation to their school trajectory, but did not integrate these with those of the evaluation studies.

AMSTAR assessment

Table 9-4 below compares the three reviews using the AMSTAR checklist. The AMSTAR assessment of our review was conducted by an experienced systematic reviewer from the EPPI-Centre (<http://eppi.ioe.ac.uk/cms/>). Our review was published in the peer-reviewed

journal *Child & Family Social Work* (Liabo *et al.* 2012). Because of concern about reviewers being influenced in one direction if they knew that young people had been co-researchers, this aspect was not mentioned at first submission, as we wanted the review to be assessed on its own merit irrespective of authorship. The review was recommended for publication with some changes and peer reviewers' comments are included in Appendix 6.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Was an 'a priori' design provided?	Detailed criteria were set in advance. This is a review of studies which had evaluated the effect of prevention or intervention programmes aimed at primary or secondary students for increasing school completion or reducing school dropout.	A parameters document specified the context for the search including review questions, key definitions, aims and objectives, population, outcomes and search dates. Inclusion criteria for studies not specified.	The research question (p. 1) and inclusion criteria (p. 3) were established before the conduct of the review. Although both the research question and the criteria were changed during the review process, this is made explicit and is justified by the research goal of user involvement.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Was there duplicate study selection and data extraction?	There was a procedure for comparing coding of included studies and programme types were coded by two independent coders. Five coders coded a random sample of each other's studies.	There is no information on how studies were selected and data extracted. There is a description of how the scoping review informed the main review, and how the screening was conducted in two phases.	Title and abstract screening was sufficient: A total of 24% of the electronic hits were double screened (although not clear if this was a random sample) and there was a consensus procedure for disagreements. However, it appears that there was only single screening of the full-text papers for eligibility and only single data extraction.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Was a comprehensive literature search performed?	Yes and databases and search terms are provided.	Yes and databases and search terms are provided.	Yes, 16 databases were searched and date ranges were reported for each. Search terms were reported, although not separately for each source. The search was supplemented by consulting specialized registers, experts, and by reviewing the references of relevant studies and reviews.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Was the status of publication (i.e. grey literature) used as an inclusion criterion?	All studies were included irrespective of language and publication status.	The status of publication was not used as an inclusion criterion. Included English language studies only.	The publication status of each included study was not presented and there was no statement that the authors "searched for reports regardless of their publication type". It was stated clearly that no date or language limits were set, and publication status was not listed as an explicit exclusion criterion.
Was a list of studies (included and excluded) provided?	A list of included studies provided in supplementary materials about to be made available on the Campbell Collaboration's website.	There is no list of included studies.	Included studies are listed. Excluded studies are not listed, but at least the number of studies excluded for each reason are presented and reasons for exclusion given.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Were the characteristics of the included studies provided?	The review lists attributes across the 167 studies in a summary table.	There is no description of included studies. There is a list of how many studies addressed each review question.	Characteristics of included studies are listed: samples size, follow-up, PICO, and length to follow-up.
Was the scientific quality of the included studies assessed and documented? 'A priori' methods of assessment should be provided.	Studies were assessed on study design and a summary table shows the number of studies in each design category.	There is no information on the scientific quality of the included studies, bar a statement that they were assessed on the extent to which the methodology fitted the study question.	Used the EPPI-Centre tool for assessing the quality of outcome evaluations (August 2002) and was informed by Jowell (2003) for policy pilots. Study quality criteria were listed as comparison group, sample size, how outcomes were measured.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
<p>Was the scientific quality of the included studies used appropriately in formulating conclusions?</p> <p>The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.</p>	<p>The review included nine methodological variables in the meta-regression models to consider the impact of methodological rigour on the effect sizes found and reported.</p>	<p>No.</p>	<p>Yes – with caveats. Authors reports on the quality of the included studies generally. However, there is little discussion of study quality for each study (although some studies are noted as having small samples or loss to follow-up). This makes it difficult to gauge the quality of the contribution of each study to the overall conclusions. The quality of the evidence base as a whole is integrated into, so we can see how overall quality was used in formulating conclusions.</p>

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Were the methods used to combine the findings of studies appropriate?	Results were pooled and tested for heterogeneity, which was found. The results reported the random effects weighted odds ratio.	There is no information about the synthesis methods or how the recommendations link to the research evidence.	The reason for synthesis choice is described and appears appropriate given the heterogeneity in intervention types. A particular strength is that the young people were involved in grouping the studies into categories.

AMSTAR checklist	Wilson et al (2011) Dropout prevention and intervention programs: Effects on school completion and dropout among school-aged children and youth	Brodie (2009) Improving educational outcomes for looked-after children and young people	Liabo, Gray and Mulcahy (2012) Interventions to support looked after children in school
Was the likelihood of publication bias assessed?	Yes the authors conducted several tests for publication bias, presenting funnel plots and a table.	No	No. As far as I can tell, publication bias was not assessed in this study. Searching of various websites and google, plus Dissertation Abstracts (for grey lit) and conducting expert contacts (for 'file drawer' and 'in progress' research) will help to protect against publication bias – the authors should emphasise this as a strength of the study.
Was the conflict of interest stated? Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.	No	No	Can't answer.

Table 9-4: AMSTAR comparison of three systematic reviews

The review by Wilson et al (2011) was a high quality systematic review conducted according to the criteria set by the Campbell Collaboration (www.campbellcollaboration.org). Our review did not match up to their transparency and reporting standards stipulated by the AMSTAR assessment. The AMSTAR assessment indicates that our review was more transparent than the review by Brodie (2009). None of the other reviews identified studies relevant to ours, which indicates that our search strategy and inclusion criteria were sound.

Our review originally aimed for an *a priori* design. We set a specific review question and designed a protocol but this was changed during screening and critical appraisal, which in turn changed the review question because the scope was broadened. While this does not meet the AMSTAR quality criteria, the involvement of young people meant that these decisions were transparent and reported in the review itself. We acknowledge that the search strategy did not account for the change in outcomes, which might have influenced the final result. This shows how the involvement actually highlighted something often covert in systematic reviews aiming for an *a priori* design. As the review progresses, new aspects of the review question come to light which are likely to influence the inclusion criteria for studies and change the original protocol. Such changes may or may not be transparent. I would argue and have tried to illustrate here, how the involvement of young people in our review exposed this process to a large extent.

The collaboration on this review indicates that it can be difficult to conduct *a priori* systematic reviews with people who have little or no research experience, simply because they may not appreciate fully the consequences of the decisions made. 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 arguably shows that the involvement of service users can highlight these often hidden judgements and thereby improve review transparency.

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. Deciding to focus on a particular question, developing the question, and writing the protocol are all iterative processes that involve interpreting professional and research knowledge. Further interpretation and deliberation occur at each stage of the review, as illustrated in the first part of this chapter, which pointed to the most important aspects of young people's influence on the review. The involvement process exposed the systematic reviewing as described earlier and above. It also showed systematic reviewing as a process in which knowledge is socially constructed.

Although I acted as a gatekeeper for the review quality, I 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 group made me reflect in-depth about the language I use and in 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 views on themselves. Introducing new perspectives to the study made me focus on how the content was portrayed elsewhere, and how we would portray it, trying to identify hidden agendas and values inherent in language.

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 configurative 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. Considering the three reviews in relation to Figure 9-8 by Oliver *et al* (2012) presented earlier gives the following picture (Figure 9-9):

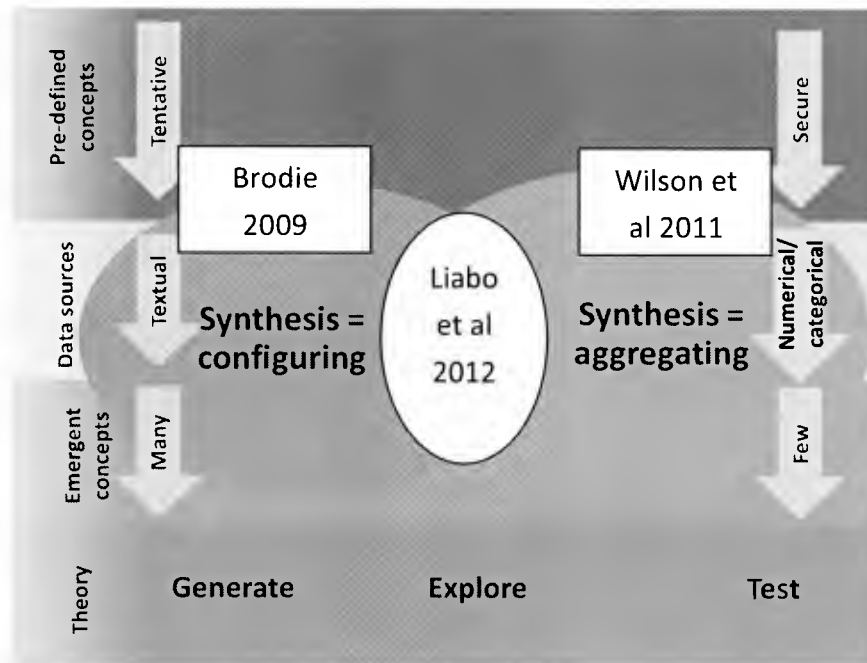


Figure 9-9: The three reviews' synthesis on a spectrum (adapted from Oliver *et al* 2012)

In comparison to Wilson *et al* (2011) and Brodie (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. I argue that this process was directly informed and motivated by the young people's involvement, and this chapter has attempted to illustrate this.

CHAPTER CONCLUSION

This chapter has analysed the young people's impact on the review, first by considering their influence on each stage of the reviewing process, then by comparing the final review with two other reviews and against the AMSTAR checklist (Shea *et al.* 2007).

Although I acted as the main gatekeeper of the review quality, the young people's influence was considerable in terms of focus, although constrained and facilitated by contextual

factors such as shifting group membership, methods for voting, and involvement approaches. Overall, their impact was also constrained by time. Involvement lengthens a research project and in particular when people are as closely involved as in this collaboration. There were times when the young people's views could not be incorporated because we needed to move on with the review to get it done within the funding time-frame. Most notably young people's impact is seen in the review topic and the review protocol, the inclusion and exclusion criteria, and in the reflection on the findings. My collaboration with the young people also influenced my own reviewing, making me more attuned to the language used in the title and abstracts, and more aware of my own assumptions about the review topic, population and outcomes.

Our review was not of poorer quality than another similar systematic review, although it did not meet some AMSTAR criteria, most notably lack of an analysis of publication bias. There was a difference in language between the three reviews, mainly with our review using more positive wordings such as 'staying in school' rather than 'dropping out'. This chimes with findings of another study on involvement (Lindenmeyer *et al.* 2007). The decisions made alongside our review were arguably made more transparent than the other systematic review on looked after children's education, as the the involvement of young people forced decisions not documented in the protocol to be articulated and justified.

In terms of the AMSTAR checklist, our negative points were not due to the involvement apart from the diversion from an 'a priori' review question and protocol. We started off with a peer-reviewed protocol which was subsequently changed during the screening. This stems from hidden assumptions about the progress of the review, and therefore my inability to steer the decision-making process in light of later review stages, the shifting membership which meant that new perspectives influenced discussions, and the young people's lack of experience in research and in particular in reviews. However, I have also suggested that the idea of a fully *a priori* review in itself is flawed, as knowledge is socially constructed through deliberation over the review question, the protocol, and every other stage of the reviewing process. Rather than weakening the review, I have tried to illustrate how the involvement process strengthened it, both in terms of transparency and analysis of the findings.

The impact from the involvement was enhanced because the collaboration ran throughout the review life cycle. While young people's impact was stronger in the early stages of priority setting, they provided invaluable input also when doing research tasks, such as screening. This analysis has shown that in this instance, the involvement resulted in improved science. This came about by placing a strong emphasis on the young people's experiential expertise as being crucial to the topical framing of the review, while I retained control as technical expert on systematic reviewing.

Chapter 10 WHAT WERE PEOPLE'S EXPERIENCES AND LEARNING FROM THE COLLABORATIVE RESEARCH?

This chapter addresses the final research question 'What are the negative and positive aspects of involvement, as experienced by both young people and the researcher?' This relates to young people's views on the collaboration. It also addresses a second aspect of impact from involvement; impact on those who take part. This is an essential aim for some participatory research projects, which explicitly or implicitly aim to empower those who are involved, through knowledge, experiences and by facilitating their voice to be heard in a new forum. For this research study, the impact on those involved was initially seen as secondary to the impact on the review. I was sceptical of the idea that empowerment was something that could be introduced through an academic exercise, and thought of any beneficial effects on the young people and myself as a positive add-on. However, as the project progressed, the impact on all involved gradually emerged as an important outcome of the collaboration, particularly for the researcher.

To consider people's experiences and learning, the framework analysis included young people and the researcher's views on being involved, frustrations expressed and achievements. While this was informed by the meeting transcripts, the dissemination activities and informal discussions after conferences or meetings, the main source of data for this came from the two focus groups ran at the end of the project. Transcripts from meetings, peer interviews and focus groups also informed an analysis of how the young people's understanding of research developed over time.

PEOPLE'S VIEWS ON BEING INVOLVED

The data on people's views were mainly collected by me, apart from the four peer-interviews conducted after the first three meetings. The young people are likely to have amended their answers, knowing that I had a vested interest in positive responses. Even with the peer-interviews they knew that I would be listening to the audio recording. Rather than ask them directly what they thought about the project, I would ask what had been

interesting and what had not worked so well. By the end of the project, the people who had been involved throughout provided bold, in-depth and critical answers to my questions. When they conducted the peer interviews with each other nobody had anything negative to say about the project at all. At the end of the project, Beth and Denzel had quite a few points to make about what had made involvement in the systematic review problematic.

For example, they were both upfront about finding the meetings boring at times:

D: ... 'are you feeling bored', what, well me personally I have low concentration span anyway so there's not many meetings where I can say, have kept me one hundred and ten percent entertained for the whole meeting so

....

B: ... I think some meetings, at times, may have been a little bit, [sharp outtake of breath] dry

....

B: like you really had to concentrate, but then I don't know if they were the days when I was tired and I wasn't focused

(Focus group, 26th May 2011)

It was clear that I had been unable to describe the systematic review and what we needed to do on it in a simple, straightforward and engaging way. Both Denzel and Beth said that they found the participation in the review challenging and more demanding than what they had been used to at PAS, where the participation social worker would usually provide them with a list of options to choose from, rather than ask them to come up with their own formats and ideas.

B: ... it's very different to PAS, 'cause you come into PAS, you mean, obviously you have to be focused, but it's not, you're not, you're thinking obviously, but it's not hard

D: we're very, we're very spoilt by [participation social worker] as well in the fact that

B: all the hard stuff she deals with [laughs]

....

D: ... [preparing for] the Exeter presentation ... I kind of walked in expecting it to be just like [participation social worker] when, literally, everything would be done, and all we've got to kind of do is like, ok yeah, and just move things around

(Focus group, 26th May 2011)

As described in Chapter 8 my concept of involvement differed from the young people's experiences of participation. I wanted them to have the opportunity to shape the review according to their own views, and was reluctant to provide too much structure in this process because I was concerned about being too influential. They expected to come along and make choices on the basis of prepared information and options. This highlights the importance of clarifying expectations at the start of the project, but it also shows how methods for involvement will shape people's contributions. Involvement will often involve a trade-off between clearly structured, but consultative, exercises which may limit contributions but be easier to understand, and open sessions where people can have a stronger input into shaping the final product, but which require more technical knowledge for the participation to be meaningful. The demanding nature of the project also had a positive side, as explained by Denzel:

D: I think that goes back to what we said about ownership of the group [and when I was talking to the previous leader of the council, I said] ... 'this is our systematic review', I said, 'the researcher's there to help us', I said, 'but we've really' and he was kind of shocked that we ... when I was going through everything that we had done, you could see in his facial expressions, he was shocked by the amount that we had actually done, because ... in PAS, we're sort of, everything's done for us, we're mollycoddled to a certain extent ... whereas in your, your project we're just like, you

know what, this is your stuff, if you, if you guys don't wanna do anything that's fine, but we won't have anything to show for it at the end of it.

(Focus group, 26th May 2011)

This was echoed by Beth when describing an incident at a conference:

B: ... we were having lunch and this man was like, so I'm just about to do a systematic review, how have you done it? And Kristin went, oh ask Beth, and then you were talking to other people so I was like oh my God [laughs] what do I say to this man

KL: [laughs] but he wanted to involve people in it

B: he wanted to involve young people and he wanted to know what, what the young people had actually done

KL: ah, ok

B: 'cause I think he was like, well did they, did she just talk to you and then did it all? And I was like no, we, we practically done everything really

(Focus group, 21st June 2011)

As described previously, the shifting membership was a challenge throughout the project. For the two who participated throughout, this was seen as a negative experience as it put pressure on them to continue their involvement and, more importantly, made the meetings very repetitive. When new people joined they needed information about the project, we had to go through the consent form and we had to explain introductory research concepts. Beth and Denzel did enjoy being involved in that process, but also felt frustrated when people then did not return to later meetings:

B: ... I guess the repetition, and the meeting when we had new young people come to when, you had done, some screening had been done and you had brought ... the ones that hadn't been, abstracts that hadn't been consent on ... I think me and Ruta ... were the only two people who had been involved, and it was bit frustrating trying to get other people to understand where we were coming 'cause they kind of, some of them weren't getting it, and it was kind of starting to get a bit frustrating, there wasn't like a confusing, yeah

.....

D: I definitely think if I was gonna do it again, for me, it would have to be, like, I'm not sure I could do it with young people, because, I just think from both this and the PAS research I've realised that ... people that are over the age of six, like, 14 up to the age of 21, are, are very unreliable in the fact that they can work, they can change their mind quite quickly.

(Focus group, 26th May 2011)

The PAS research referred to above was a peer-research project funded by the National Youth Agency. PAS applied successfully for funding to conduct research into which ways children and young people would like to participate in their work. The project was largely led by Denzel and Beth, drawing on their experiences from the systematic review, and they felt that this peer-research been inspired by the work done on the review. Again, this was a project which required more in-depth input from young people and over a longer period of time than what was usual for PAS projects, and Denzel and Beth found themselves left with a lot of the work because people dropped out along the way.

B: ... the PAS research as well, because, again, the, all work fell onto me and Denzel, and at times I thought that was really unf, not like un [unclear] PAS, was really unfair, so that kind put in my head I didn't wanna do something like that again

KL: it's quite involved

B: 'cause I just felt that, so many people are so unreliable, and I thought it was actually quite, you know, people promised they would help and then didn't

KL: mmm

B: and so, but the project had already accepted the money so we had to keep going with it, but then the people [unclear] credits for the project

KL: yeah

B: but not actually do the work. so that annoyed me a little bit

(Focus group, 26th May 2011)

The social worker said that PAS had tried in the past but failed to engage people over a longer period of time, and their projects would therefore be short-term. She therefore considered this project to have been a success on that account.

Getting people through the door also proved difficult for the training events even when the young people had expressed interest and enthusiasm before. Those who did attend enjoyed the training and remembered it as highlights of the project. I also enjoyed getting external people in to provide fresh ideas and perspectives. Imran left the project in spring 2008, but three years later remembered the training he did at the university:

I: I haven't been to enough meetings [unclear] but, the ones that I think I've been to [unclear] haven't really been boring. The one that really sticks to my mind is the Russell Square, 'cause that was really enjoyable actually, I remember that, that was a great day, and that was fun and, yeah, the ones I've been to so far haven't been boring.

(Focus group, 26th May 2011)

Those who attended conferences (3 young people) also cited these as particularly enjoyable aspects of the project. Ultimately, the young people said that the project was characterised

by how challenging it had been, but also by their sense of achievement when the review was completed. Beth said she would not want to be involved in a systematic review again because of the amount of time it took, and the lack of commitment from other young people. However, when a request came from another systematic reviewer, she was interested and initiated a phone conversation to follow up an email correspondence. Denzel said he would consider being involved in other systematic reviews and both wanted to bring their experience to other committees or panels relevant to research. Here Beth sums up the experience:

B: then I've put three words which are commitment, trust and perseverance, which I think I've spelt wrong, ehm, commitment in the sense of you had to be committed, trust that we had to trust you, in the sense of what we say doesn't go anywhere else that comes [unclear], but then trust you as well in the sense of, you know, you don't just listen to us and not do anything about it ... like if we say to you, look, actually, like thinking back, we don't wanna include disabled children in our study because, and that's [unclear] because actually they have lots of other different needs which might be different and that wouldn't be a fair kind of thing, and you were like, ok then ... and you trusted our opinions, and I put perseverance ... we've had to persevere with things, and again we've had disagreements ... but then we've come back and we've persevered with our disagreements ...

(Focus group, 21st June 2011)

EVIDENCE OF YOUNG PEOPLE'S LEARNING

A major outcome identified from the collaboration was joint learning for both the young people and the researcher. Wenger (1998) argues that learning is in its essence a social phenomenon which comes about through participation in the social, and what he calls 'communities of practice'. This is similar to Vygotsky's theory which considers the

sociocultural system of learning as imperative to learning itself, and that this system is created by both instructors and students (Moll & Whitmore 1998).

'Communities of practice' relate to practice as a source of coherence for a community, in that it has mutual engagement, a joint enterprise and a shared repertoire. The collaboration on this review may not be described as a complete community of practice, but did share some common attributes. Our joint enterprise was the systematic review, we had a set of concepts which we used when discussing the review, and we had mutual engagement in the forming of relationships, meetings and maintenance of the group.

Wenger argues that as social beings we see knowledge as 'competence in valued enterprises'. This is relevant for involvement because it aims to recognise experience-based knowledge as valued on par with certified and professionally learned knowledge. Initiating the involvement of service users therefore forms part of a wider movement to increase the parameters of 'valued enterprises', which are made meaningful through the participation in the learning. Informed by this theory of learning, I considered people's learning in this project by tracking our use of language and my own reflections throughout.

Denzel and Beth were the only young people who were involved throughout the project from start to finish. Other people joined for shorter periods of time, many of them contributed actively, and many developed an understanding of research and systematic reviewing during the months they were involved. However, because Beth and Denzel sustained their involvement over such a long period, it is particularly interesting to follow their membership in the research project, and how this influenced their engagement with the systematic review and with research in general. These are therefore qualitative longitudinal data on two young people's development as they gained experience and thereby expertise in research. It is also part of the story of how the collaboration was sustained by their ongoing learning and contribution.

I first present a timeline of their understanding of the project. This was a complex study, and although I provided them with an information sheet in conjunction with the consent form, and reminded them of this information at the start of every meeting, there is a leap from

hearing information to being able to express it in own words. Table 10-1 below shows people’s descriptions of the project in May 2008.

Question: What do you think Kristin is trying to do?		
May '08	B: eh Kristin I think, eh, is trying to find, find out how ehm, young people in care, children and young people in care are like, health, education, if they’re like, just how is it [unclear] education in care	These quotes are from their peer-interviews 4 months into the project and after the review topic had been decided. During this period I had focused on their priorities for a research topic and spent less time discussing systematic reviews and research.
	I: eh, I think she’s, obviously, eh, there’s issues about being in care and stuff, what are the biggest and vital issues, and how to address them, and obviously the best people to listen to are the young people who have grown up in care themselves	
	E: yeah. Kristin’s project initially started with eh, ‘cause it’s a research that she wanted to conduct with looked after young people but eh, she wasn’t sure how she wanted to know what we, how, were most interested in, which aspect of our life, so we had suggestions such as education, drugs, eh, teenage pregnancy, alcohol abuse, and all these ideas, however, we had to come up with one idea which is the, which we’re, we’re gonna be conducting our research on, and finally we settled in with education by a majority vote	

Table 10-1: Young people's descriptions of the project, may 2008

In comparison, Table 10-2 below shows young people’s descriptions of the project during the protocol development and searching sessions in the autumn of 2009 and in February 2010. I would start each of these meetings asking them about the previous meeting and key concepts of the work.

Question: What do you think Kristin is trying to do?	
Oct '09	<p>B: ... obviously we gonna have to actually do some interviews aren't we, we're gonna have to do the actual research</p> <p>KL: yes, which is the systematic review</p> <p>B: [on top of last word] review. And from, we're also looking at secondary data as well aren't we?</p> <p>KL: that's the</p> <p>B: [on top] that's the</p> <p>KL: that's the systematic review</p> <p>B: I get it now, I do get it</p> <p>KL: no no</p> <p>B: [unclear] we're gonna look maybe on other, so other people have done this sort of research and look at their information and pull what they've found</p>
Nov '09	<p>B: ehm, and we decided, previously, ehm, last year that, ehm, education is actually a big impact on looked after children's health, so we've come up with a question, and I can't remember exactly the wording of the question, but eh, from that question we're gonna look at reviews that other researchers have done, to kind of back up, or to find out, you know, what we're saying is right? Is that kind of what we're doing? And then, Kristin's gonna do the big write up.</p>
Feb '10	<p>Y: Research about health, maybe, I don't know.</p> <p>KL: Yeah, that's a start.</p> <p>B: And we came up with education affects... you see, I get confused whether it's health affects education or education affects health, so I think we're trying to find out something about dropping out of school</p> <p>DA: yeah</p> <p>B: I can't, it's so far back now, what um not inputs, but like interventions that keep people in school or stop them from dropping out of school.</p>

	KL: Yeah, yeah, spot on
	R: And it's like as well, which like what question [unclear] or whether it's [unclear]
	KL: Yeah, absolutely
	[followed by discussion of what they did at the last meeting]
	KL: ... but overall, what we're trying to do, what are we trying to produce?
	B: A systematic review.

Table 10-2: Young people's descriptions of the project, 2009/10

Until the development of the review question and protocol, in the autumn of 2009, I had referred to our research product as a 'literature review', because I did not feel that they needed to know the intricacies of the methodology when deciding on the research topic. This changed as we needed to specify the topic and work on the question and the protocol, so I started to introduce the young people to research concepts and use a simple A3 sized sheet of the main stages of a systematic review. After three meetings I would ask them to provide a definition themselves before I showed them the sheet. They found this exercise difficult, because as Beth said "I know it but then when you have to word it it's like what?" Beth's developing understanding of a systematic review is shown in Table 10-3 below.

Question: what is a systematic review?	
Dec '09	B: 'Cos when I think of the word systematic I think of a system, so like what you do, like in stages, and that's kind of what it is isn't it? KL: Yeah, that's good.
Two months later:	
Feb '10	B: Is it looking at other people's research to ask our question, kind of.
One month later:	
Mar '10	B: ... a systematic review which is by looking up on databases other people's research to see if it's relevant to what you're trying to find out, and we are trying to find out interventions to help looked after children stay on at school, that kind of...

Table 10-3: Beth's descriptions of a systematic review

When we presented the review to other members of the Participation Advocacy Service (PAS) at the end of the project, Beth had a clear idea of how to explain the systematic review to research novice young people. Rather than presenting them with a definition, she suggested that we present the step-by-step process of our work, and conclude that this was the systematic review.

Denzel, who also took part in the project from start to finish, quickly provided good explanations for a systematic review and the group would often ask him to explain it for them. This might explain why he became skilled in providing simple but accurate explanations, as shown in Table 10-4 below.

Question: what is a systematic review?	
Dec '09	D: Is it when we search other types of, we review other types of research and we take the bits that are relevant to what we need out and throw the rest away?
One week later:	
Dec '09	D: It's a review of research that has already taken place with same or similar objectives to ours.
Four months later:	
Apr '10	D: So it's a study... KL: Yeah D: ...of results about interventions with regards to people to keeping looked-after children in school.
Nine months later:	
Sept '10	D: That's it. It's just a review. It's a summary of research.
Eleven months later, writing:	
Aug '11	A systematic review is a review of other studies (research) done within a specific subject area. It asks a specific question within a chosen area and looks for relevant studies to answer your chosen question. It looks at both positive and negative aspects of the research already done and also looks at the quality of research done. Some pieces of research may not be of relevance, because it does not match the research protocol.

Table 10-4: Denzel's descriptions of a systematic review

Denzel’s definition increasingly started to include more words such as ‘objectives’ and ‘interventions’. At the end of the project he said that “the systematic review, when we first started it, seemed really complex for me ... brain challenging, but then towards the end it’s like, us, I’m looking at now and think what the hell was I, what was complex about ‘cause it seems really easy”. When we started to collaborate on a joint paper in August 2011 Denzel wrote a comprehensive definition of a systematic review, including the quality assessment and relevance of the protocol.

The more the young people were encouraged to recount the previous meeting, and provide definitions and explanations of concepts central to the review, the more they appeared to engage with the research and also develop an ownership in the final outcome. Table 10-5 below shows a timeline of extracts from meetings which indicates how Beth and Denzel engaged in the research, using skills they had acquired during their involvement.

Using the protocol during screening:		
Jun '10	<p>B: ... ‘cause Sophia’s like we all have our own opinions, but then I was going to say good to have your own opinion, but we have a protocol, and you have to follow the protocol</p> <p>KL: yeah</p> <p>B: so we can’t really base it on opinion, we have to base it on what’s actually included, so to match up to the protocol</p>	<p>In these two extracts Beth and Denzel show awareness of how the review is guided by a protocol. It is particularly interesting in relation to Denzel, as he had been frustrated early on in the process exactly because we needed to be restrictive in scope.</p>
Jul '10	<p>D: ... we need to be a bit strong and say, “this is our protocol, we’re sticking...”, so that we don’t expand it anymore otherwise before you know it we’ll end up with how we were at the beginning</p> <p>KL: exactly</p> <p>D: where we were just about to review the whole world...</p>	
Critical appraisal:		
Sept '10	<p>B: But then, like, I mean, the, the evaluation bit, I guess that she went back to school, really, that’s what happened afterwards, and she established relationships with her peers, so, I mean, I would keep it in, but I’m not, if it’s not in, it’s not</p>	<p>These two extracts illustrate their engagement with</p>

	<p>in</p> <p>D: Are we not in a position where, again, how do we know the art therapy was actually instrumental in getting her into</p> <p>B: But then we could look at that if we looked in the</p> <p>KL: I think that's a very good question, really, really good question, yeah</p> <p>D: Because, as we said earlier, when I said something, I can't remember, I think you said it, where many things could have changed, so she could have moved away from where the abuse happened, many things could have actually changed to actually make her want to get back into school</p>	<p>study quality.</p> <p>First, we discuss a study abstract of a case study (N=1). Denzel is concerned about the study design, and whether it will be able to address our review question.</p> <p>The second extract is a description from a critical appraisal meeting (audio recording not consented by all young people).</p>
Oct '10	<p>Beth made the point that the article itself states that more research is needed ... Kristin then asked her what kind of study she would trust. She said she would want parents' point of view, a proper comparison and explanation about the dummy [intervention] and the real one. She would want to see the protocol and the methods.</p>	
Analysing the findings:		
Feb '11	<p>B: ... I think if you give cash to local authorities and then within those local authorities, they decide what your maths going to be, and then you pick... you don't pick, the random selection of children who will receive that and who won't receive that</p> <p>KL: Which they could have done, yeah, yeah, but they didn't</p> <p>B: That's what I didn't get, no, so they're silly</p> <p>.....</p> <p>B: So I just don't think it's a lot because each authority would be doing different things</p> <p>D: Possibly</p> <p>B: They probably would, none of them would do the same</p>	<p>This is at the very end of the project. Beth and Denzel have seen the review from the start to finished, and by now they are discussing the study results competently and with insight. They are still care leavers, but they have gained new knowledge and experience from the research world.</p>

	<p>things</p> <p>D: Right, but then don't you think that that actually means that there's 18 different interventions that have possibly worked</p> <p>B: But not really, 'cos it's only 3% and it could have just happened anyway</p> <p>D: But just think if it had gone the other way, from 78 down to 75, we'd be doing urrgggh</p> <p>B: No, we wouldn't, I'd be like...</p>	
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Table 10-5: Beth and Denzel's engagement in the research

These extracts indicate that those who stayed with the review developed a sophisticated understanding of research and learnt the basics of all stages of a review. They would not claim to be expert systematic reviewers, but through active involvement in most stages, by doing research or by advising on research tasks, and through discussions about their involvement, they attributed meaning to previously incomprehensible elements of the activities.

These timelines also show that it took time before people formed a clear understanding of the aim of this work. This is something most researchers experience at the start of a project, and these young people were volunteers who only met a few times each month, with some longer breaks in-between. It is therefore to be expected that their learning might be slower than for someone working on a project on a daily or weekly basis.

These extracts are almost entirely from Beth and Denzel. This was not intended at the outset of the analysis, but they were the most active participants in meetings and other people would look to them to lead on the discussions. Some people contributed mainly by nodding or shaking their heads. Beth and Denzel said that this was similar to PAS activities where people would not say much and they therefore felt they obliged to contribute and thereby avoiding silence and no contribution at all. They sometimes felt under pressure because this gave them a particularly strong role which they might not have otherwise

acquired. The timelines also indicate that those who participated over a longer period gained confidence, experience and thereby found the work easier.

IMPACT ON THE RESEARCHER

My own thinking about involvement and research was informed by the collaboration with the young people, and lies at the heart of the data analysis, both for the qualitative evaluation and the systematic review. Chapter 9 spoke about how the collaboration influenced my systematic reviewing, thereby shaping the review indirectly as well as directly, as well as future reviews. My research diary also recounts episodes and interactions which showed me new sides to the young people and myself, and showed how my perspectives were widened as a result. This included simple things like not being aware of how much cheaper tabloid papers were before one young person said that he preferred The Times but would buy The Sun because of the 80p price difference. This and other incidents highlighted the cultural and social differences in the group.

One person said he was impressed by my authoritative attitude when asking students to vacate the computer suite at the university so that we could start our searching workshop. I was initially puzzled by his comment, which he repeated at later workshops in the computer suite, but subsequently saw it as an indication that he felt I had confirmed the group's worth against or within a university environment. More importantly, it made me reflect on my own conduct, how I appeared in front of the young people, whether this was a positive or negative aspect. Another meeting triggered a different set of reflections:

... Beth ... asked me if I had been busy with my research. I thought 'well, no actually, I've just been moving papers around and dealing with logistical issues and trying to write a paper' ... So what did I do between the last two meetings with the group? I went on a long holiday (3 weeks). I went on a 2-day course on creative methods in research. I had my upgrade. I saw my supervisors. I attended a seminar. I worked on an article for a peer-reviewed journal. I worked on one of my thesis chapters. I

transcribed a meeting from last autumn. I thought about what the group should do next and I planned our meeting. All this is obviously part of being a researcher. Even so, when I was asked 'have you been busy with your research' I felt like saying 'no, I haven't done any research', because 'busy with research' to me somehow implies that I should have been either collecting (as in searching) or analysing (as in analysing meetings) data.

(Research diary, 11th February 2010)

The above refers to the time period between a searching workshop in December 2009 and a meeting the following February. A simple question from Beth made me reflect both on my actual tasks as well as my view on research, prompting me to take a step back and try to consider my work from the outside in.

A large part of my ongoing reflections related to my role as the researcher on this collaborative study, in particular the amount of control I took in meetings and of the review. As described previously, I initially tried to take a back seat at meetings, but realised that more structure was necessary in order to produce concrete outcomes and decisions. I was uncomfortable with the role as a research 'teacher', because I felt it could dominate meetings and also present them with my particular view of research which I knew would contradict other academics' views. As gatekeeper of the review's quality I was concerned that this could reduce the young people's impact and make the collaboration closer to a consultation. There were also times of conflict when I effectively censored meetings. Although I saw the necessity of it, and the young people supported it, I felt uncomfortable. Sometimes this highlighted agendas of my own that I had been previously unaware of, as shown in this extract from my research diary:

I think it's often easy to believe we are open to influences but when we scrutinise our rationales and motivations we realise that we are perhaps not. So for example in terms of the INVOLVE abstract: I started out thinking simply that they would write the abstract with me, collaboration. I then looked at the call for presentations and

realised that the young people may want to do something different than me, and immediately my own preferences came to the front “well, it must be a paper... “

(Research diary, 10th March 2010)

Encounters with the young people made me reflect on the group dynamics, my role, and wider social questions, and I ultimately felt that this had a major impact on my personal as well as professional life. These reflections were triggered both by regular interactions with people who were younger than me and with different life experiences, as well as the nature of the qualitative evaluation, which meant that I kept a frequent and detailed research diary. My encounters with the young people also gave me insight into lives removed from my own white middle class rural upbringing in Norway, as well as the life I live in London. I worked with people who at times were living on £35 a week, and therefore struggled to participate fully in the opportunities provided by this city. I learnt how childhood memories and relationships often stay with you, even when you try very hard to distance yourself from them. I heard about the system from both the young people and the social worker’s perspectives. I therefore entered their community of practice, by learning terms and concepts used by them, and gaining insight into their experiences. At the same time, since their expertise mainly lay in their experiences, I could not learn to the same extent as they could. They could become experienced systematic reviewers, and use their experiences to inform this work, whereas my experiences with them would only ever be limited to second-hand knowledge.

CHAPTER CONCLUSION

This chapter has considered the negative and positive aspects of involvement as seen from the view of the young people and the researcher. First, it presented young people’s views on being involved, highlighting the different expectations for their participation, and how the challenging aspects of the review and the group dynamics had positive outcomes. In

particular, the young people and the researcher developed a good working relationship and achievements included well received conference presentations and a published paper.

This chapter also outlined evidence of young people's learning through the project, and described their growing confidence on the review as well as competence in managing the group dynamics. The longitudinal aspect of the collaboration which spanned five years benefited this learning, which in turn benefited the review as well as all involved. This illustrates how long-term participation is likely to be more useful to researchers and service users than one-off meetings or shorter term involvement. As service users gain experience in research and acquire an understanding, they become more apt at making relevant and valuable contributions, based on their experiences. Ongoing relationships unlock potentials in both researchers and service users as they learn to trust each other and appreciate each others' contributions.

The 'lay' experience is not a contradiction to learning about new systems or methods. Service users do not lose their unique experiential knowledge because they acquire membership in a new 'community of practice', such as being members of a research project conducted in the vein of 'service user involvement in research'. Rather, the knowledge acquired through such involvement enables them to build further on their experiences and consider more adequately how they may or may not link in with research. A wider and more coherent involvement of service users in research may gradually streamline these initiatives and unlock its potential further.

I have also presented reflections on my own learning throughout the collaboration, which influenced my systematic reviewing, my overall work as a researcher, and personal reflections on wider political questions. Drawing on Wenger's theory of learning, I believe our collaborative model of working facilitated mutual learning in this project. This was mainly achieved for the two young people involved all the way through, and for myself, as we established a joint ownership and sense of achievement through a set of practices which involved doing the research and attaching meaning to this experience. There was a developing sense of belonging in the group and those involved gradually identified as systematic reviewers, or service user researchers.

Chapter 11 DISCUSSION AND CONCLUSION OF FINDINGS

OVERVIEW OF FINDINGS

This thesis has addressed questions of how to involve young people in a systematic review, the obstacles and facilitators to this, and the impact of such involvement on the review and on those involved. It has described the process of setting up the collaboration, the ethical considerations and plans for how to involve the young people. Following on from that I have described how the young people were involved in the systematic review, presented the final systematic review, and provided findings from my analysis of this process.

This study was two-pronged in its approach. It produced a systematic review in collaboration with young people and the review itself is therefore a major finding. I analysed the involvement processes and worked with the young people to identify positive and negative aspects of these. The analysis of the obstacles, facilitators and impacts is therefore a second set of findings.

Oliver et al's (Oliver *et al.* 2011) framework for considering involvement and its impacts underpins this chapter's overview of the findings of this study. Their analytical approach sees involvement in terms of three main stages: A: drivers for involvement, B: processes of involvement, and C: the impact of involvement. Obstacles and facilitators will be inherent in both the drivers, A, and the processes, B, and will shape the extent to which there is impact or change, C, resulting from these, as evident in the research or the people involved. Figure 11-1 is an adapted version of the framework developed by Oliver et al (Oliver et al. 2011) and provides an overview of these three stages and their key aspects.

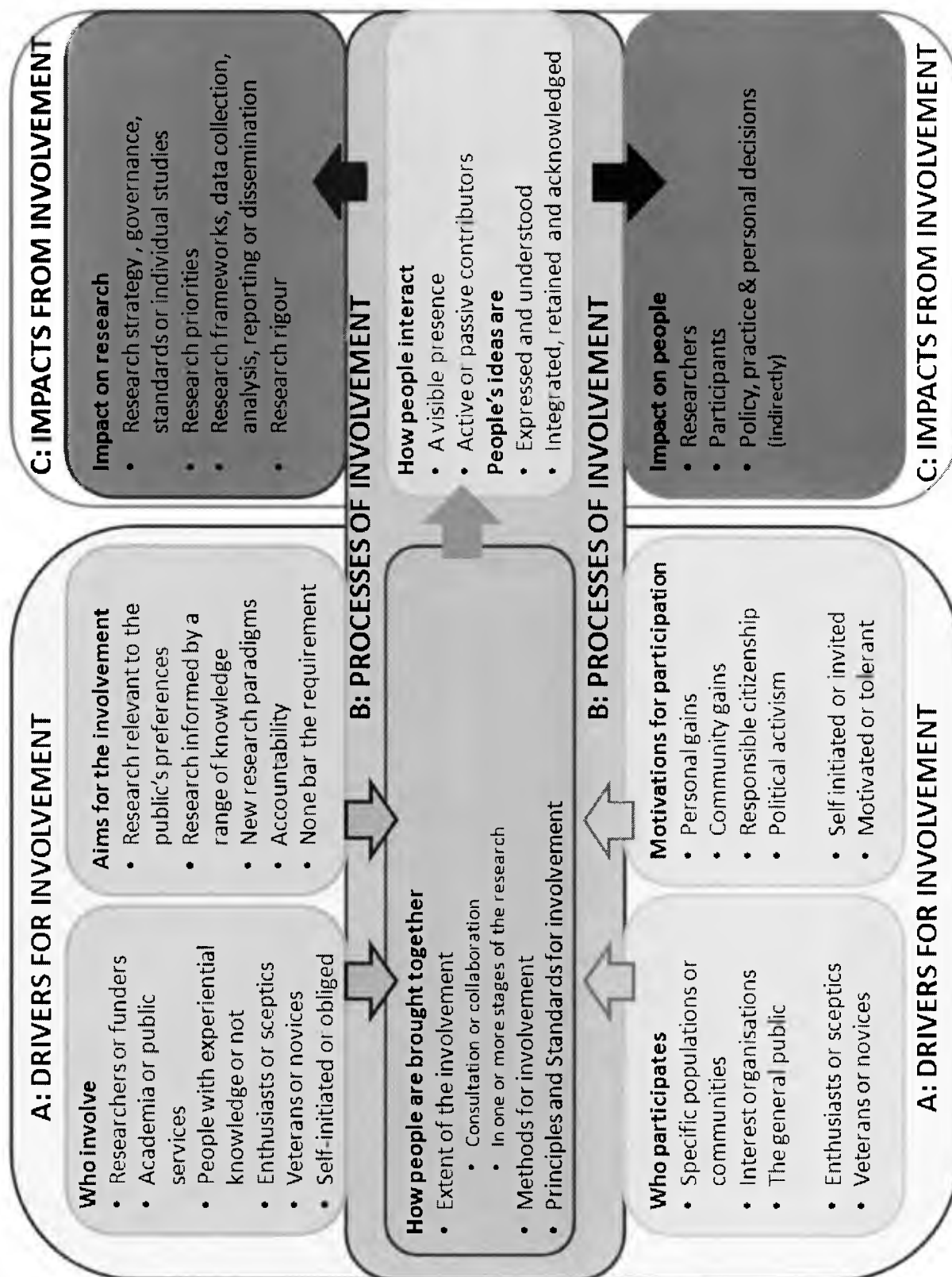


Figure 11-1: A framework for considering impact of involvement (adapted from Oliver *et al* 2011)

Figure 11-1 distinguishes between those who involve others, and those respond by participating, but characteristics of these groups might overlap if the researchers themselves have a personal, as well as professional interest, in the field. Even so it might be argued that researchers who have such knowledge still need to involve people from the wider community due to their own dual membership of both academia and the expert group. If not, they can be considered in terms of those who involve others and those who participate, as they will be wearing two sets of hats, and the framework will illustrate the content of each hat.

The drivers for the involvement, A, relate to the characteristics of those leading the involvement and their reasons for doing so, and the characteristics of those who participates and what their motivations are for getting involved. This is the element of the framework that accommodates, in this study, my motivations as a researcher and the young people's motivations for taking part. These are described in the introduction and the recruitment section in the study design chapter (Chapter 5), as well as in the analysis of what it was like being part of the collaboration.

The involvement processes, B, relate first to how people are brought together. This is about the extent of the involvement, the forum for involvement, and the principles and standards for involvement. Second, these processes relate to how people interact and the extent to which their ideas are expressed, listened to and understood, and how they are integrated into the research frameworks and products. In this study the involvement processes were described in the study design chapter (Chapter 5) and Chapter 6 which described the young people's involvement in each stage of the review. Underlying these processes were a set of obstacles and facilitators, as described in Chapter 8. These also relate to the framework's impacts of involvement, C, which is about whether the involvement made a difference to the research and to the people involved. This was described in Chapters 9 and 10.

The key features of this study have been plotted in the version of the framework presented as Figure 11-2 below.

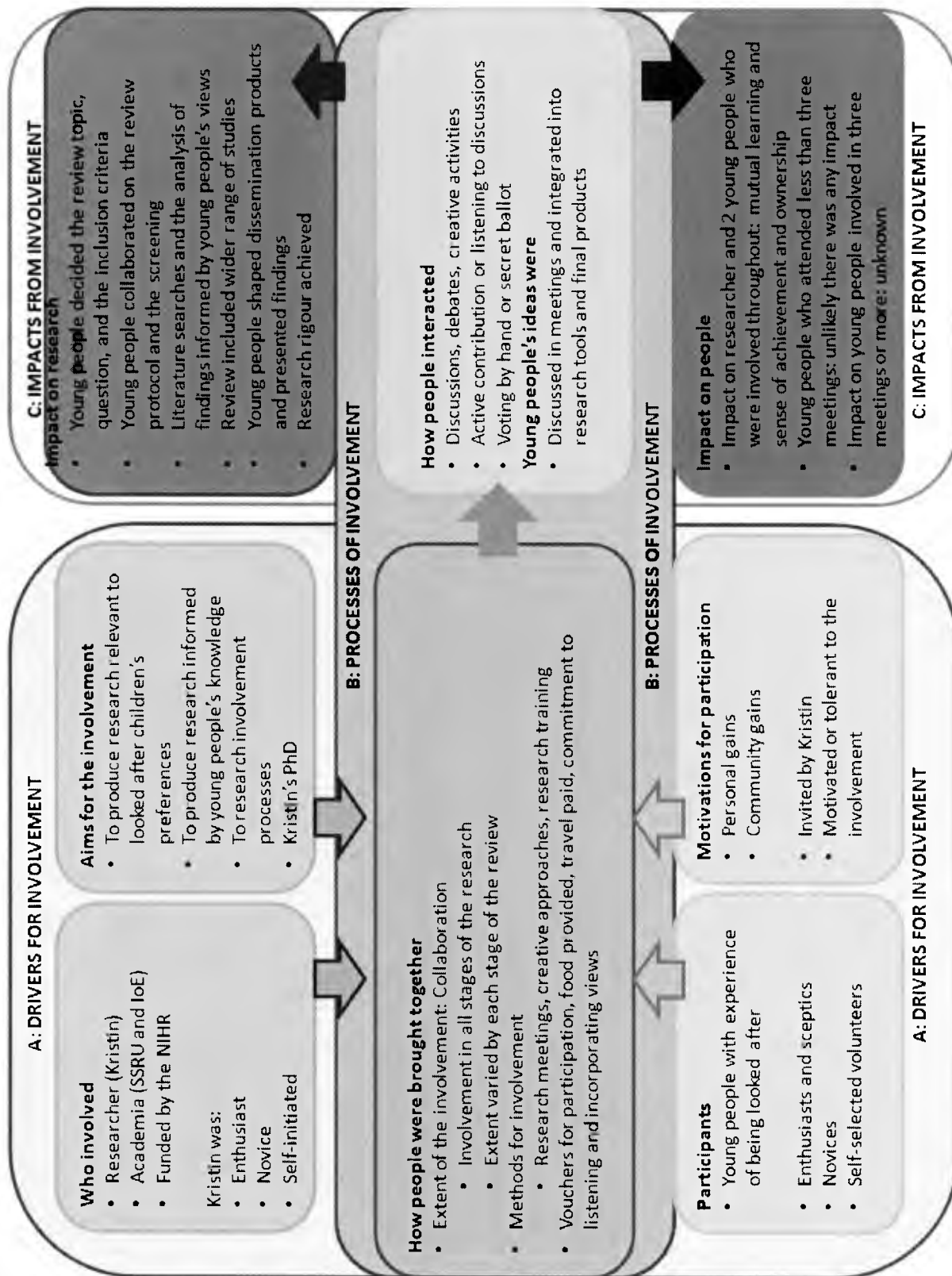


Figure 11-2: Overview of our involvement study

Figure 11-2 presents the framework adapted from Oliver et al (Oliver et al. 2011) with the drivers and aims of this study, the key characteristics of the participants and the processes, and how this influenced those involved and the systematic review. This framework does not incorporate the obstacles and facilitators to the involvement, although as described in Chapter 8 these shaped the extent to which people's views were expressed and heard in research meetings, and integrated and retained in the research reports. Chapter 8 also discussed how facilitators or drivers for the involvement may not have the intended effect on the process.

The key involvement process is the extent to which participants' views are expressed and heard in the group, and subsequently integrated into the research framework or products. In this review young people's views informed every stage, although their impact was stronger at the beginning of the project. If the involvement is approached with an open attitude to change and collaboration, people's views are likely to be included in the research. Successful involvement and impact therefore hinges on the researcher's willingness to consider different approaches to framing the research in light of concepts raised by new perspectives.

Following on from this brief overview of this study, I now turn to summarise my findings in relation to each research question addressed by this thesis. I then consider the ethical implications of involvement before closing with a discussion about implications for further research.

THE RESEARCH QUESTIONS

How can young people be involved in planning and conducting a systematic review?

This question relates to B in Figure 11-2: processes of involvement, in particular how people were brought together, the extent of the involvement and the methods used to facilitate it.

The overall aim was to collaborate with young people for the practical and research decisions required to conduct a systematic review. This was achieved with people who were involved throughout (Denzel, Beth and me), and when setting the review topic and question, writing the protocol, searching and screening studies. This was evident both in the review protocol and the final review, and in the recordings and minutes of the research meetings. Most of the process was driven by me, but young people were actively involved in the discussions and the voting, and engaged with the key decisions. Denzel and Beth also initiated practical decisions.

Findings from this research echo other studies which have found collaboration to be an optimal approach to involvement (Oliver *et al.* 2004). The young people felt listened to and had an ownership in the systematic review. This was partly achieved by showing ongoing evidence of how their views were incorporated into the review process, something which was particularly well facilitated early in the work during the writing of the review protocol. This further relates to the importance of making aims and objectives visible and tangible, which was better achieved when using pictures, items or models rather than words. Overall there was an ongoing problem of language, both because some of the young people spoke English as a second language and because of my difficulties with diverting from specialist research language. There was also a balance to be had between making information simple while respecting and acknowledging the young people's competencies. It proved difficult to support ongoing involvement but when achieved it produced a strong sense of ownership in the review, learning by everyone involved, and the development of new relationships.

The methods used to facilitate the involvement were initially loose in structure with the aim of being sensitive to young people's own input and preferences. For this reason, the first meetings were led by very open questions. The problem with this approach was that the young people had not been involved in research before, and became unsure of what was expected of them. I therefore changed the approach to be more structured, providing them with options to choose from and organising the meetings around some key activities or decisions. I found that there is a tension in involvement between providing a structured approach which might increase people's understanding of the involvement but also limit

their chance to shape the final product, and a looser approach, which might be sensitive to people's own ideas but which they may find confusing. The longer people had been involved and the more familiar they were with research, the less structured it was necessary to be.

I did find it difficult to keep the meetings interesting, in particular introducing and training young people in key concepts of systematic reviewing. Not all young people felt that they needed training and many lacked commitment to attend when it was arranged, although those who did were very enthusiastic about it afterwards. If training is provided up front there is a risk of people dropping out before the research starts, while if it is provided alongside the involvement there is a risk of people being unaware of the later implications of decisions made at an earlier stage of the review. The benefits of ongoing training, as provided in this project, is that people can take part in specific stages, but without having to commit to time-consuming training at the beginning, when they may not be clear about what the involvement will entail.

The principles and standards for involvement in Figure 11-1 (B: processes) refer to criteria for how the involvement exercise is implemented, in terms of ethical issues, reimbursement for time and expenses, subsistence, and codes of conduct. The study established good practices for supporting the young people's participation through the reimbursement of all expenses, and provision of vouchers for their time and subsistence. While each meeting started with a confirmation of certain codes of conduct, this proved more difficult to adhere to as young people had different practices from the researcher in terms of mobile phones and time keeping. I was constantly debating the extent to which I could demand certain standards of behaviour and levels of participation, while not wanting to appear exclusive and also considering the importance of including the views of those struggling to operate within a set framework.

The collaborative project described here met over a combined period of 2.5 years. Some young people were very active in meetings, while others rarely voiced their views. There was a certain amount of conflict in the group, which related both to the sensitivity of the topic and to the personalities involved. Conflicts which had developed between young

people during their work with PAS were continued into this project and at one point the participation social worker had to be involved in resolving them.

A clear finding from this project is that there is value in face-to-face meetings because attempts at making decisions via text or over the phone highlighted the benefits of hearing people's views and debating different aspects of an issue in a wider group. This study also found that a combination of methods will help facilitate the incorporation of the views of people who are uncomfortable with speaking in groups, and those who are concerned about disagreeing in public.

Ultimately, the question is whether the processes described here enabled young people's ideas to be expressed openly, be understood by the researcher and other young people, be integrated in the research and retained there, and finally acknowledged as theirs. This was achieved in this project in spite of the obstacles identified in the processes of involvement, mainly due to the young people's perseverance with the project and my own commitment to being led by young people's views and ensuring the quality of the review. There were times when these aims conflicted, but the process was then transparent so that key decisions were noted in the protocol. This study found that the essence of a successful collaboration is a two-way flow of information. The project was most productive when there was mutual understanding of each others' preferences and needs. Evidence of this is found in the review protocol, which was largely based on the young people's views, and the systematic review itself, which only diverted from the protocol when instructed by the young people.

This illustrates the importance of personal commitment and attitudes in research, also highlighted elsewhere in relation to successful involvement (Lester *et al.* 2006). The findings from this research also show the importance of the participation social worker. She was instrumental in inviting people to collaborate on the study, she was at hand when someone got upset during a meeting, and she helped when conflict occurred within the group. Her model for involvement shaped people's expectations for what the research involvement would be like, which had an impact on how the young people experienced this project. This emphasises the role played by people close to, but outside of the research decision-making.

Involving service users puts demands on researchers which go beyond their science skills. Drawing on the expertise of another profession enhanced my own learning on the project and improved the experience for the young people.

What are the obstacles and facilitators to involvement in each stage of the research process?

Because the obstacles and facilitators underpin the involvement process and the collaborative work, they were evidenced in the description of these. Chapter 8 described how they clustered along four elements of the collaboration: a) the systematic review, b) those involved, c) the environment of the collaboration, and d) the involvement methods.

First, systematic reviewing is not a well known research method and because it is secondary research, the data is already formatted for an academic audience, which makes it less accessible to people new to research. This also means that although the study itself may seek to avoid stigmatising individuals, the data may contain terms or references deemed inappropriate by those involved. This was occasionally the case in this review.

Second, in terms of those involved, certain personalities and skills were more conducive to working in partnership, and these were present to a varying degree in the young people and myself. I felt that I was often too stressed to manage the group effectively, and I struggled to provide clear and concise descriptions of key concepts or tasks. As for the young people, it is important to involve also those who do not meet a set of ability criteria as their perspectives may differ from those who interact more smoothly with the system, but this may create problems for the collaborative work as it did in this study. Tension in the group impacted negatively on the collaboration and progress of the review but ultimately improved and strengthened relationships as they were resolved. I lacked relevant experience and training to deal with these conflicts but learnt and got help from the participation social worker.

Third, the study was generously funded and both PAS and the university had facilities to support the collaboration. The young people indicated that vouchers were important to their involvement, but not essential, and not the only reason they chose to be involved. They also commented on the nice food provided by the project and at conferences, and the opportunities to travel when disseminating our work. These were all facilitators to the collaboration.

Fourth, although the involvement methods were always intended to facilitate young people's involvement, this was not always achieved. I tried creative methods using images and art work which some young people liked while others did not. I found that these methods can be very helpful in diffusing conflict, as people get focused on the task in hand and get some time to themselves while everyone else focuses on their own task. Creative methods required careful planning and very clear information about their aim and relevance to the review, which I achieved to a varying degree. The young people engaged particularly well with the writing of the protocol, the searching and the screening, which were all very practical tasks with tangible results.

It was easiest to involve the young people in writing the protocol as this was a very concrete exercise and it was simple to incorporate their views as the protocol grew, inspiring them to continue their involvement as they could see evidence of their views being taken seriously. It was difficult to involve them in reading the full studies and writing the review, as this required engagement with academic text. While it was very important to involve the young people in the protocol development, their engagement with the screening was also essential, as key decisions were clarified and changed during this stage. Their involvement in the searching felt largely tokenistic although for some this was the most enjoyable aspect. I had anticipated that working with them on developing search terms would introduce us to new search terms not used by other reviews, but this was not the case. Although they worked on the search strategy, the review itself was mainly based on a strategy developed by myself.

The most complex aspect of involvement methods was to facilitate the voting. I had not expected the voting to represent any difficulties and was therefore surprised at the level of

animosity it created, even when voting was concealed and when the counting rules had been agreed in advance. One person frequently questioned the fairness of all decisions and the participation social worker confirmed that he also took on this role in PAS more widely.

Throughout the process I found it difficult to retain focus on both the young people's wishes and the review. Some of the obstacles may therefore have been related to there being only one researcher involved, and all responsibility for both the involvement and the review quality falling on me. The benefits of a larger team of experienced researchers or involvement experts is that people will usually present with different strengths and weaknesses, and can complement each others' skills.

Can a systematic review be conducted in collaboration with young people and at the same time maintain (or usefully develop) quality standards in systematic reviewing?

The question of whether involvement of service users 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 research, this is likely to weigh heavier than the relevance argument which have so far been evidenced in involvement evaluations (Oliver et al 2004). This is particularly important for study designs which at least traditionally have aimed at aggregating knowledge, such as systematic reviews, because such designs have a strong focus on internal validity.

The qualitative evaluation found that the young people's impact on the review was substantial. They chose 'education' as the main topic for a review which was originally set to be about health. Education has been identified as one of the most important determinants of health, and in choosing this topic the young people challenged the review to go beyond obvious health-related topics such as drugs, alcohol, and teenage pregnancy, focusing instead on fundamental opportunities for optimising health in the long term. They also shaped the review framework, and were actively involved in the screening, which resulted in the inclusion of a particular pool of studies.

This process challenged my own research training, unwritten assumptions about research and implicit prejudices about young people. Sitting face to face with service users 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, we were people from different groups who met and discussed the review on an ongoing basis. Because of our differing skills and expertise we were more aware of what each of us brought, or didn't, 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 a lot 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. I have found that involvement improves the internal validity of a study by making research decisions more transparent and accountable. I have also found that involvement improves the external validity because it makes the research more relevant to the field.

The process described in this thesis was initiated by me stepping out of my comfort zone and inviting people outside of academia to take an active part in the study and by committing the study to incorporating their views. I was able to balance this with academic rigour because I recognised their experience-based expertise as having intrinsic value to

shaping the study's question and focus. The evaluation of this process has shown the creative activity of asking review questions, and how this contrasts with the technological aspects of methodology, focusing on answering questions.

In tune with Collins and Evans' (2002) notion of the Third Wave of Science Studies, where they place the importance on topical experts, I considered the young people's expertise as essential in terms of the review's focus, and my own expertise essential in terms of the technicalities of conducting the review tasks. However, when their expertise challenged mine I adopted an open attitude and was willing to change the review for what I initially thought would be the worse. This is particularly evident in the inclusion of low-quality studies. The young people focused on relevance whereas I focused on rigour. They pushed for including literature which would normally have been excluded in an effectiveness review, which in turn challenged me to consider the value of such studies while at the same time emphasising their limitations. Without the young people's involvement from the beginning to end, the review would have been empty. As a result of their involvement, we published a review which focused on what we can learn from evaluations conducted thus far.

In-depth engagement as described here hinges on the willingness of service users to dedicate time and effort to research. While the point of payment and adequate recognition has been made across involvement guidelines (INVOLVE 2005; INVOLVE 2010; Kirby 2004), less has been said about the characteristics required of those who become involved. I set out to involve young care leavers in general, and did not draw up a list of requirements in advance. A range of different personalities therefore attended the meetings, some very quiet young people who barely spoke, others who were highly opinionated and at times dominated the discussions. While I made attempts at ensuring all views were heard, particularly through the use of break-out groups and anonymous voting, there is no doubt that people with strong opinions, loud voices and charisma, are likely to have a stronger impact than their more hesitant peers.

In their toolkit for public involvement Cartwright and Crowe (2011) provide a list of desirable skills of involved members of the public. This includes 'able to self-manage',

'organized', and 'like working in a group/team' (p40). The young people who held such attributes were easier to involve and this enhanced their influence. Young people who did not have these skills also provided invaluable contributions, and invariably their experiences of the care system differed from other people's. It is particularly important to be inclusive when engaging socially disadvantaged groups where some members are likely to have missed out on basic opportunities such as a stable education and nurturing home environment.

What are the negative and positive aspects of involvement as experienced by both young people and the researcher?

The young people conducted peer interviews with each other after the review topic had been chosen. Some filled in anonymous questionnaires after the completion of the review protocol, and three came to a focus group where we discussed the collaborative process. Two young people further elaborated on their experiences at a meeting where we planned a joint paper on working together. The latter discussion also included my own reflections, as did my research diary and meeting notes.

Through these discussions it became clear that the young people and I had different views on what constitutes involvement and participation. In their work at PAS they were used to making choices from a list of options, or commenting on suggested models rather than coming up with completely new ideas themselves. I was wary of providing options or ready-made products as I felt this might exclude certain views from being presented, and might suppress unique suggestions from the young people themselves.

All three who were involved from the start to finish of the review (Beth, Denzel and the researcher) mentioned group conflict as a difficult aspect of the project, but all acknowledged that relationships were strengthened as we worked through the disagreements. Another ongoing obstacle for everyone in the group was the shifting membership and how some young people show interest in participation, but did not come

to agreed meetings. After a while the young people themselves raised this as a problem, but also felt a tension between wanting new members to provide new perspectives and ideas, and the repetitiveness of meetings with new members because they required new introductions to the project. Again, the lack of a formal structure for inclusion meant that new members could simply turn up on the day. A more formal invitation might have worked better, accompanied with a special beginners' session. In spite of the hard work, the young people felt a strong sense of achievement, both from having produced a full systematic review and from seeing their own views reflected in the research products.

Some of the sense of achievement arose from the mutual learning between the young people and the researcher. Young people gained insight into research and learnt about research and systematic reviewing, while the researcher got first-hand accounts of what it is like to be living in care and learnt about the system through interesting discussions rather than only from governmental documents and research reports. I also got the chance to test out different approaches to involvement and the young people willingly gave honest and constructive feedback to these, which in turn improved my skills for communicating research and opening up research tasks to participation. The collaboration triggered my own reflections on my conduct, role in the project and research work, and I got to know people with different backgrounds to myself, which in turn triggered further reflections.

This mutual learning is a result of people with different backgrounds collaborating on projects that span the boundaries that Wenger has called 'communities of practice'. Wenger's sees learning primarily as social participation, in which we engage in the creation meaning, practice, community and identity. Wenger defines meaning as talk about our ability to experience life and world meaningfully, practice as talk about shared historical and social resources and perspectives, community as talk about the social configurations in which our enterprises are defined as worth pursuing and identity as talk about how learning changes who we are and creates personal histories of becoming in the context of our communities (Wenger 1998, p. 5).

We are all at the same time members of multiple communities of practice. Service user involvement when optimised, will span a particular research community and a community

of patients, service users or other stakeholders. This might explain why collaboration appears to emerge as the most successful involvement model, both in terms of impact on research and impact on those involved. When patients learn to understand the principles of science they both become more skilled at informing research projects in terms of field expertise, and at challenging certain approaches. This was the case for HIV activists in the USA who from the 1980s onwards challenged established notions of eligibility for recruitment to drug trials. As activists became knowledgeable in trial methodology, they understood and joined existing scientific debates about 'pragmatic' versus 'fastidious' approaches to drug trials (Epstein 1995).

The young people who sustained their involvement in the review over a period of time gradually started to question certain decisions made early on, without losing sight of the review protocol. But gaining more insight into systematic reviewing and research design did not remove them from their experiences as care leavers. While I could not fully join their community of practice, our collaboration introduced me to their perspectives, terminology and identities. This was in itself a highly valuable outcome of the involvement.

WHAT ARE THE ETHICAL IMPLICATIONS OF SERVICE USER INVOLVEMENT?

This analysis of involvement has focused on the processes of the collaboration and how this influenced the production of the systematic review, the review itself, and those involved. Involvement as practiced here recognises people's unique and valuable expertise gained from experience of a particular set of services. Young people are recognised as equally competent and knowledgeable as other experts and ethical issues mainly arise when young people are not invited to the decision-making table.

However, the study design itself represented an unexpected ethical problem, because the young people were both actively involved in the review, and being researched in the course of that process. It was not practically possible to separate out the two activities, which meant that if you were a member of the collaboration you were also automatically being

researched. This meant that a focus on doing the collaborative work at times concealed the qualitative research study and vice versa. For example, ethical guidelines for the research study required that participation was voluntary and that people might leave the project at any time without repercussions. For the involvement exercise it might have been conducive to draw up contractual agreements on their participation and reimbursements.

The young people took part in something that they were unfamiliar with, and were asked to draw on their personal experiences in doing so. There was a risk that this would bring up child protection questions, or past experiences. Initial meetings were therefore held at the PAS office, with the participation social worker at hand.

Looked after children are a stigmatised group, and some people might not want to be identified as looked after because they worry about judgement from others. This might have implications for recruitment to an involvement initiative, and also for dissemination, when some people might not want their full name disclosed. Different experiences from care brought up tension in the group as some people appeared to feel that they had lost out compared with others who talked about the opportunities they had had.

As relationships developed in the group, more personal information surfaced at meetings. This blurred the boundaries between being a researcher and a colleague to the young people. People who work together over a longer period of time often become friends or confidantes, but in relation to working with young people this is more problematic because of the power relationships inherent in the group, and because of the need to treat everyone equally.

Some ethical problems arose from situating the collaboration in a different organisation from my own, and dealing with gatekeepers there as well as directly with the young people. As the project progressed, the main gatekeeper would sometimes not be present during meetings and her colleagues would be at hand for support. I once overheard the assistant social worker saying to the young people that they had to come to the next meeting in order to get their vouchers. I had to raise with him the different nature of this work, and that

because this was research the young people needed to know that they could leave the project whenever they wanted without repercussions.

Ethical considerations also relate to the balance between resources used for involvement and the benefits to the research. This study indicates that much was learnt from the collaborative work but the review took considerably longer than it might have done and resources for travel, vouchers and meeting subsistence made it more expensive. On the other hand, the involvement of volunteers was much cheaper than involving other kinds of experts who might have charged professional consultancy fees.

STRENGTHS AND WEAKNESSES OF THIS RESEARCH

Throughout this report I have aimed to provide a transparent account of both the successes and failures of the research process as well as the collaboration itself. The exploratory nature of the evaluation of the involvement is only fruitful if hindsight is used to consider negative as well as positive experiences, and what might have prevented certain problems from occurring. Managing the involvement proved a major challenge as I was new to the activity, and struggled to balance the informal style which is advised by some literature, with a well-managed process which might help support the project through particular challenges such as shifting membership and conflict.

While the exploratory nature of the evaluation of the involvement is a strength in this respect, it also means that the findings are largely based on reflections and self-analysis, and therefore highly subjective. This is a study of a researcher's reflections on involving young people in a systematic review, and it therefore focuses on the processes and impact as they emerged in my analysis of data and interaction with the young people. These findings need to be contextualised in light of other studies and in light of the particular setup for this study. I have aimed to be transparent in my account but I will nevertheless have overlooked aspects which might have been obvious to someone else.

This appears to be one of few in-depth studies of involvement in research (Cartwright & Crowe 2011) and while the evaluation is highly subjective it also presents a wide range of detailed data and gives a picture of the messiness of involvement, which is often not evident in guidelines and descriptions of how it ought to be implemented. But the evaluation did not go entirely to plan in terms of data collection. Some young people did not give consent for meetings to be audio-recorded. In these instances I chose to focus my attention on facilitating the meeting, and spent time afterwards recollecting what had been said and done because it was not possible to be both facilitator and take detailed meeting notes. Because a small number of young people were uncomfortable with the idea of audio recording, I abandoned the plan of video recording some meetings. This meant that I did not have images of my own conduct in the meetings, which would have been helpful in the analysis.

I had intended to follow up everyone who dropped out of the study, to ask them what they thought of the collaboration and their reasons for leaving. I made some attempts at doing so, but it proved difficult to gain contact details for people because of their looked after status, and it also felt inappropriate to chase them for something which was a voluntary participation project. Again, this illustrates how the collaborative review collided with the evaluation. At the end of the project everyone who had ever attended a meeting was sent a letter inviting them to a focus group to discuss their experiences, or to contact me or the participation social worker directly to provide feedback, but only four people responded. The lack of independent assessment of the collaboration is clearly a weakness of this study, but unavoidable given the nature of the research project (a part of a PhD).

IMPLICATIONS FOR FURTHER STUDY

This thesis started from the premise that involving people with experiential expertise in research would make this research more relevant to their needs and priorities. The study did not set out to recruit a representative group of looked after young people, but settled for a group of people with a background in participative policy and practice. Through

methods developed in childhood studies, the group collaborated on all stages of the review. When this work started principles, standards and guidelines for involvement were in place, but there was little information in terms of practical approaches to translating scientific concepts and engaging young people in doing research other than peer interviews.

This work has made a step forward towards evaluating involvement's impact on research, and on those involved. This can be seen with the help of an adapted version of a framework developed by (Oliver *et al.* 2011). This framework highlights key stages in the involvement process as well the aims of the impact: whether people's views were expressed, understood, integrated, retained and acknowledged in the process of the research planning and conduct, and in the final research reports. This framework provides an overview of the practical elements of involvement, however, I would argue that more integration of theory is needed when planning and considering involvement. We need more inclusion and integration of group theory, theories of learning, and theories of expertise. While much practical work on involvement has been conducted in health research, theories of public involvement are developed and discussed by sociologists of knowledge production. A stronger link between these two academic disciplines would benefit both.

The question of expertise relates to whether a certain kind of expertise can be lost or gained during and after the involvement, and what kind of expertise we are seeking. Some argue that any extension of science beyond academia is important, because this challenges established notions of research conduct. Others argue for a narrower definition of expertise, referring to only those with unique topical expertise, which also excludes scientists who do not have in-depth expertise in the topic under investigation. The question of expertise is essential to further development of involvement models and practice, and is only touched upon in this study. Bolder work is needed to question the issue of service users' right to involvement versus the need for high quality, rigorous research. I suggest that applying Wenger's social theory of learning is useful for considering how people can both be research experts and experience based experts, and that mutual learning should be a desired outcome in involvement initiatives.

Much drama and emotion were identified in the involvement processes in this study. Harvey (2009) has suggested that this is rarely reported in evaluations of public involvement. More research is needed on how this challenges or not the scientific notion of objectivity (or reduction of bias). Alongside this is a need for further investigation into particular methods for engaging members of the public or service users in research projects. There is ample literature giving general advice, but few specific approaches or tools. This study has described some new approaches and reflected on their usefulness.

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APPENDIX 1: INFORMATION SHEET AND CONSENT FORM



Would you like to do some research?

People involved in research normally fill in questionnaires or take part in interviews organised by researchers. In this study people with experience of being looked after will work together with a researcher, and make decisions on what the study should be about.

What is this research about?

This study is about how researchers and users of services can work together on a research project. To do so, we will work together on a research summary. You will help decide the theme for this summary, which should be about something that really matters to looked after children and young people.

The study is called 'The health of looked after children and young people: collaborating with service users on a systematic review'. We can change the title to something more relevant to our project once we get going.

What will we do?

Lots of research has been done on looked after children. Some of this is used to improve services, but some of it is never read and used. 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. The summary will be presented to people who plan services and people who work with looked after children.

Everyone involved will help shape the project and make decisions, but it needs to include a summary of research. If people want to do more, for example do interviews with young people in care or take photos to illustrate the research, there will be opportunities for this as well. People can also be involved in writing about the research or giving presentations.

We will also talk about what it is like being involved in research, and let other researchers know how they can involve young people in their work.

Who will be involved?

This project is for people under the age of 25, who have experience of being looked after in local authority care. We can be flexible about age. About ten people with experience of

being in care will be involved, in addition to one researcher. The participation social worker can also come along to the meetings, if you would like to.

How much time will it take?

We will meet about once a month. The whole project will take about a year and a half, but nobody needs to commit for the whole period. At the first meeting we will talk about how we would like to work, and then people can decide how much they want to be involved. Travel costs will be paid, and there is some money to pay people for time spent on the project. You can leave the project at any time.

Who funds this research?

This research is funded by the Department of Health.

Will my input be identified?

When we write up the findings from the study, nobody will be able to identify who said what. That is, unless you would like them to. You can contribute to writing about the project, as a named author or by using a different name.

Any questions? Contact:



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Institute of Education, 18 Woburn Square,
London WC1H 0NR. Tel 020 7612 6377,
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SSRU
Social Science
Research Unit
Institute of Education
University of London



Do you want to take part in a research project about young people in care?

This form explains what will happen to the information that comes out of the research meetings. Because this is research information I need to treat it with extra care. Please ask me (Kristin) if you have any questions or concerns about this.

Is it ok to record the meetings? This will help me evaluate how we are doing. We can stop the tape at any time. OK Not OK

After the meetings I will listen to the tape and take notes from it. These notes will not identify your full names or any other personal details. The notes will be in a password protected area of my computer, or in a locked filing cabinet. OK Not OK

At the meetings we will make decisions on what the research should be about and how we should do it. OK Not OK

The findings from this research will be published and presented to people who want to improve the situation for looked after children or care leavers. OK Not OK

People can leave the team at any time, but it would be good to know why you are leaving and what you thought of being involved in this project. OK Not OK

I have read the consent form and filled in the form above. I agree to take part in this project and know that I can leave at any time.

Name.....

Signed Date

Kristin: I confirm I have explained the project and what is involved in taking part.

Signed Date



APPENDIX 2: PROTOCOL WORKSHEET

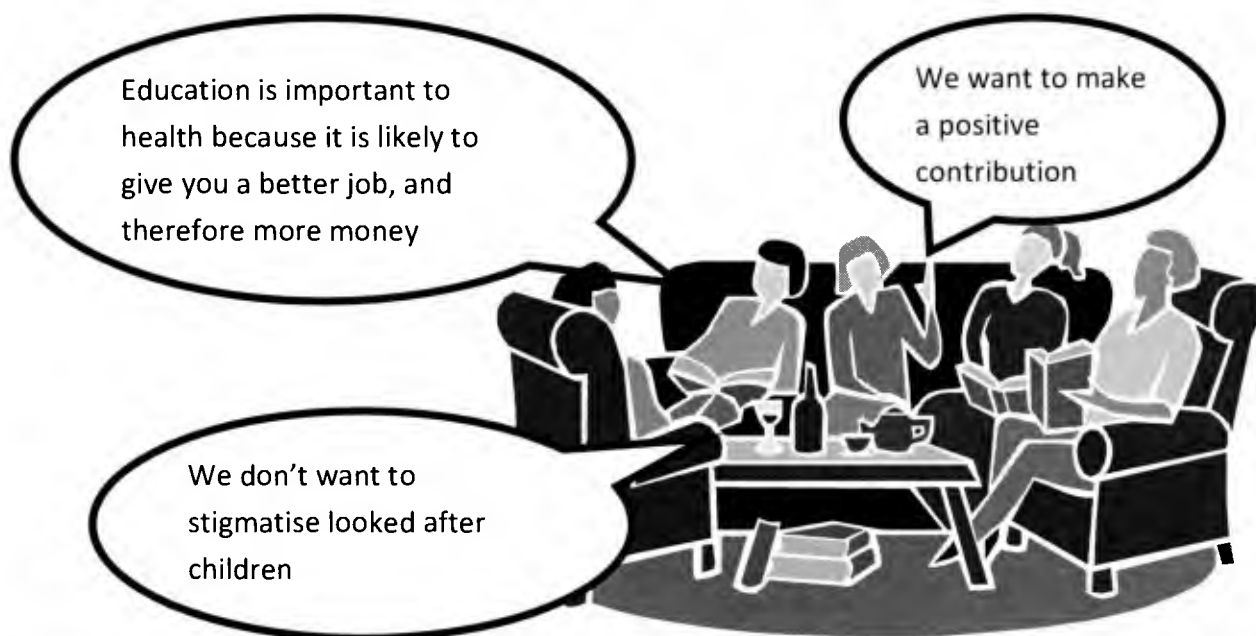
Review question:

Does cognitive behaviour therapy or social work support or carer support help looked after children stay in school?

Background and objectives

This question asks how we can improve something

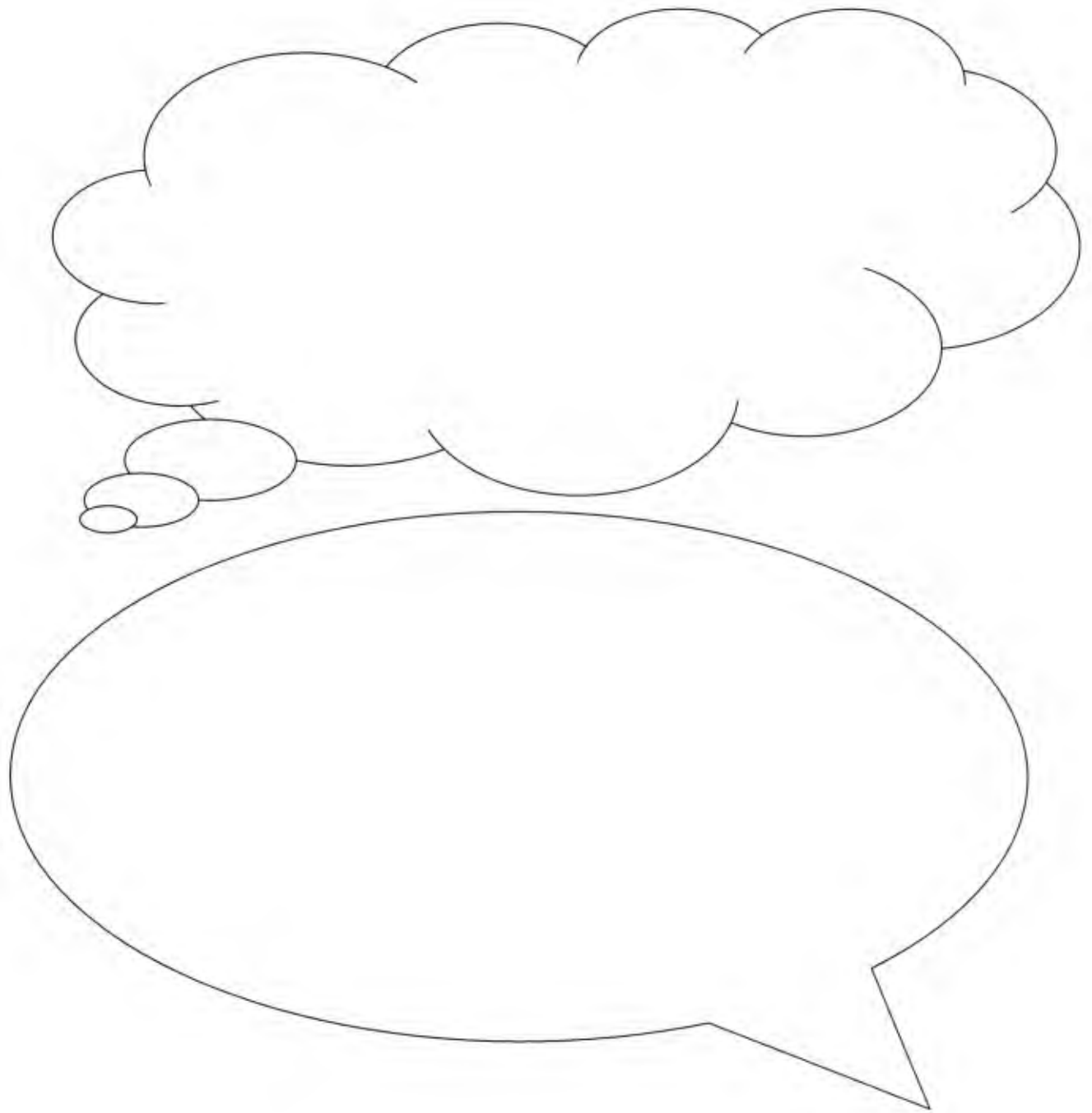
This is a specific question, and a review question needs to be specific



Not everyone agrees that this is an important question for looked after children's health. Some people made the following points:

"There is no relationship between education and health"

"Education is useful but not essential"



Criteria for studies in this review

3.1 Types of interventions

We need to choose one or more of the below services as focus of our review

Cognitive behaviour therapy

Cognitive-behaviour therapy is a collective term for programmes that aim to change children's thinking in order to change their behaviour. The training often comprises three stages: identifying a problem, finding solutions, practicing solutions. Cognitive behaviour therapy can be provided in groups or to individuals.

Social work support

All looked after children have a social worker. In this review we will include social work support which is in addition to this, for example extra hours for the social worker to support people's schooling

Carer support

All looked after children have a carer, either a foster carer or residential carers. In this review we will include training of carers to support people's schooling.

Placement stability

Placements can affect people's schooling. In this review we will include special planning of placements to support people's schooling, for example a rule which says that children are never moved during school term-times.

Virtual schooling

This is a new service which many councils have started up. People with different skills work at the virtual school and they:

Monitor the progress and attendance of looked after children, provide support around exclusions, promote education during change of placements and change in schools, provide access to mentoring and enrichment activities, deliver training and support to all corporate parents.

3.2 Types of participants

Children aged 10-13, or in years 5 and 6 at school.

Children with behaviour problems

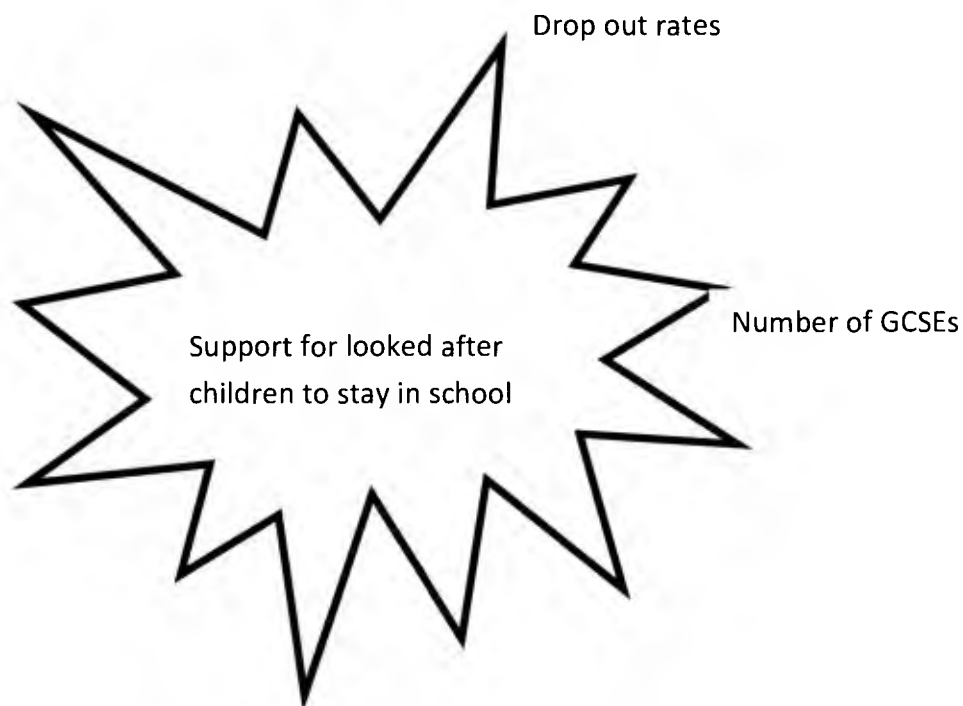


Should we include studies with children who are not in care?

Yes No I don't have a view on that

3.3 Types of outcomes

How do we know whether the intervention is successful in making looked after children stay in school?



Study types

Search methods for identification of studies

Methods of the review

APPENDIX 3: SYSTEMATIC REVIEW PROTOCOL

Review title: Interventions to help looked after children in school

Background and objectives

This systematic review protocol has been developed by young people who have been in care, and Kristin Liabo who is a researcher. The search and methods sections were developed mainly by Kristin.

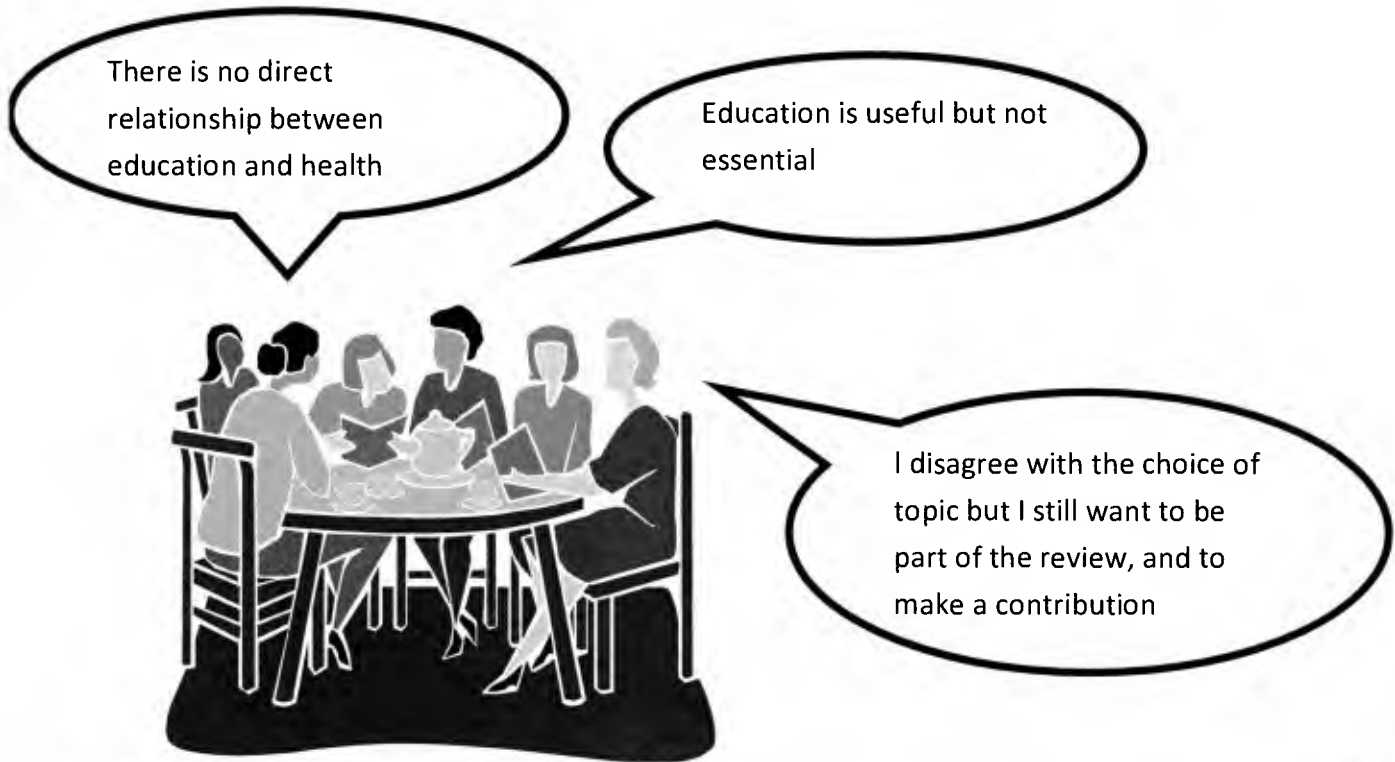
This review asks: Can targeted interventions help looked after children stay in school?

We have chosen this type of question because it asks how we can improve a problem. We want the review to identify studies that look at solutions rather than studies just describing the problem. We also want to include studies which have asked looked after children themselves about school and education.

The starting point for this review was that it should focus on a topic relevant to looked after children's health. It might therefore be surprising that we have chosen to focus on education. However, in comparison with other children, looked after children lose out on their schooling. There are many reasons for this, including type of placement, the number and timing of moves in care, the extent to which their social workers and carers support their education, and their own personal interests. The reasons why we have chosen education are shown below:



Some people in this group have seen by themselves how lack of continuity in school can potentially impact on your mental health, because you get separated from peers. We know that there is research which shows a link between education and health (Kenkel 1991; Lleras-Muney 2005),(Kenkel 1991; Lleras-Muney 2005) but not everyone in the review group agrees that this is an important question for looked after children's health. Other points made in the discussions were:



Background statistics on looked after children in the UK:

44% of children aged 16 or over, who ceased to be looked after in March 2009, gained at least one GCSE or GNVQ. In the general population of pupils aged 16, 99.2% gained at least one GCSE.

7% of children aged 16 or over, who ceased to be looked after in March 2009, gained at least 5 GCSEs at grade A* to C. The national number for all children is 69.7%.

Of the care leavers with whom local authorities were in touch, 63% were in education, employment or training around the time of their 19th birthday.

Source: Department for Children, Schools and Families. Statistical first release: Children looked after in England (including adoption and care leavers) year ending 31 March 2009.

Criteria for studies in this review

Types of studies

We will include studies that have researched the nature or effect of targeted interventions to help looked after children stay in school. We will include the following study designs:

- Studies of how interventions are meant to work, including studies of people's views on an intervention.
- Studies which have looked at how the intervention worked for one group, without any comparison group: before-after studies and process studies.
- Studies which have compared children who got the intervention with children who did not get it: comparison studies.

We have discussed the advantages and disadvantages of the different study designs listed above. We have elected to include studies about how interventions are meant to work and views studies because we feel that this kind of research provide important information which may not be picked up by a comparison study focusing mainly on effects. We may need to revise this decision in light of our search results, in which case we will do a second vote on which study types to include.

We will exclude research on people's views on what can be done to help looked after children stay in school. We want to focus on the nature and effect of targeted interventions. However, *we will include young people's views on education and school, because we feel that these are important to the review question.*

Types of interventions

This review will include any intervention that has the specific aim of supporting looked after children in their schooling. The intervention may be provided to social workers, foster carers, teachers or children themselves, at home or at school. We have discussed the following interventions: cognitive-behaviour therapy, social work support, carer support, placement stability and virtual schooling. We know that there may be other kinds of relevant interventions which we are so far unaware of. These will be searched for and included if the studies meet our criteria.



Types of participants

Because of our review title and the kinds of interventions we will include, the participants of some studies may include social workers and carers. We are interested in interventions which are targeted at:



Boys and girls, aged 10-15, or in years 6 - 11 at UK schools.

Children and young people in mainstream schools.

Children who have been subject to a full care order and placed by the authorities to live outside of their family setting. This means that we are interested in interventions for children who have been placed with someone they did not know from before, excluding kinship care.

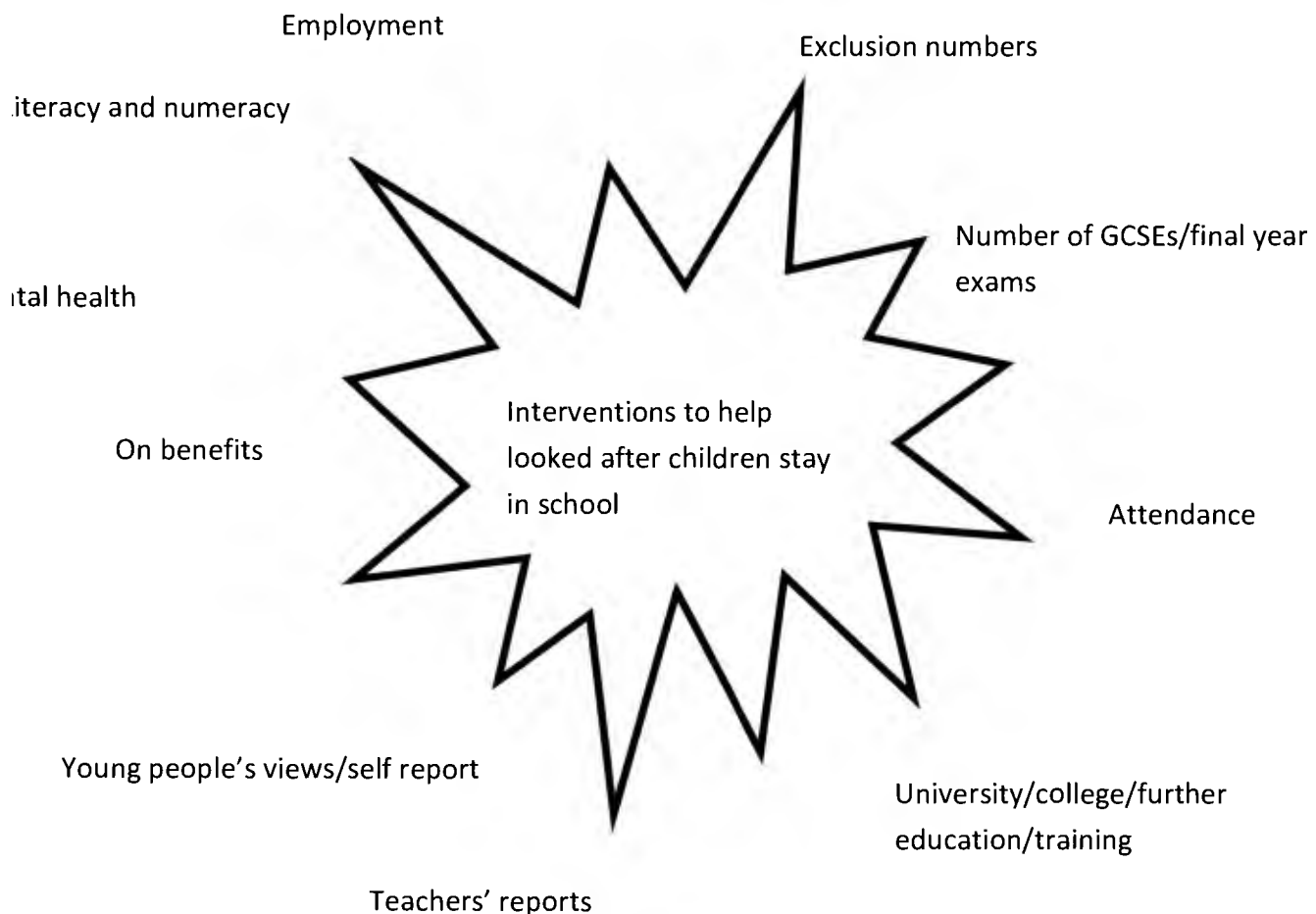
We will exclude studies of interventions aimed at children with a learning disability. This is because we want the focus of the review to be on mainstream children in care, and for whom the main issue in regards to their education is being in care rather than having a learning disability.

We will exclude studies of interventions aimed at young offenders, because a lot of young offenders are living at home, and this is a sub-group of the larger population of looked after children, and one with specific needs.

We will not include interventions for homeless children.

Types of outcome measures

The outcome star below shows the outcomes we have identified as important to the review title.



Search methods for identification of studies

The search strategy will identify interventions to help looked after children stay in school.

We will do free-text and index searches of the following electronic databases: Educational Resource Information Centre (ERIC), Dissertation Abstracts, International Bibliography of Social Sciences (IBSS), the Social, Psychological, Educational and Criminological Trials Register of the Campbell Collaboration (C2-SPECTR), the Educational Evidence Portal (EEP), Australian Education Index (AEI), British Education Index (BEI), ChildData, Social Services

Abstracts, Sociological Abstracts, Applied Social Sciences Index and Abstracts (ASSIA) and Social Care Online.

We will search the Cochrane Controlled Trials Register and the National Research Register (UK).

We will search Google for unpublished and published reports. We will look at the website called Social Programs that Work to see if they have identified any relevant studies.

We will look through bibliographies of relevant reviews and studies to identify further studies.

We will use established search filters (by either the Cochrane or Campbell Collaboration) to identify relevant study types.

Data collection and analysis

Search hits will be stored and screened in EPPI-Reviewer. Kristin will screen all hits, and a random sample of 10% of all hits will be screened by a second person. The 10% will be screened early on, to inform Kristin's screening of the remaining 90%. Screening will be based on title, abstract and key words, and studies will be excluded on the basis of topic, design, population and intervention. The studies remaining after initial screening will be excluded or included based on full-text reports.

Data will be extracted on study participants, intervention, duration of follow-up, participants' views and outcomes as specified above. Where available, data will be extracted on costs, setting, and factors which affected the implementation of the intervention. Data will also be extracted on study design. Effectiveness studies will be coded to whether it is a comparison study, their method of group assignment, method of allocation concealment, blinding of outcomes assessment and loss to follow up.

Studies will be assessed for quality, using pre-set criteria. The analysis of the effect of interventions will be sensitive to the quality of study design.

APPENDIX 4: DATA EXTRACTION TOOL FOR RESEARCH STUDIES

Study question

Study rationale

Describe the theoretical model behind the intervention/study, as well as the arguments stated for why this is an important question to address.

Study participants

Ages

Number

Write down both overall number and, if different, number included in the evaluation.

Boys (please put number into info)

Girls (please put number into info)

Intervention (s)

Length

Comparison

Outcomes

Please describe the outcomes here, then put in the results under each relevant sub-heading.

Attendance

Including truancy

Exclusion

Final year exams

Includes high school graduation rates, completing comprehensive school.

Reading

Numeracy

Writing

Literacy (if other measure used than reading/writing)

Achievement

Multicomponent tests (literacy, numeracy, knowledge)

Multicomponent test

Grades

Attitudes to school

Attitudes to reading or writing

Setting (tick only those that apply directly)

Urban

Rural

School-wide

Community-wide

Targeted at individuals

Home-based

School-based

Community-based

Institutional

The intervention is delivered in a special institution

Country

Method(s)

RCT

Non-randomised comparison study

Before-after study

Qualitative research methods

Results

Outcomes measured

Attendance

Including truancy.

Exclusion

Final year exams

Reading

Numeracy

Writing

Literacy (if not reading/writing)

Multicomponent tests

Testing more than one thing in one test (literacy, reading, numeracy, knowledge)

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Grades

Attitudes to school

Attitudes to reading or writing

Intervention group

Attendance

Exclusions

Final year exams

Reading

Writing

Literacy (if not reading/writing)

Numeracy

Multicomponent test

Comparison group

Attendance

Exclusions

Final year exams

Reading

Writing

Literacy (if not reading/writing)

Numeracy

Multicomponent test

Qualitative findings

Process findings

Authors' conclusions

Critical appraisal

The critical appraisal tool was developed by using the tool used in the conduct disorder review, and the EPPI Centre tool for assessing the quality of outcome evaluations long and short tool.

Source of funding

How were the comparison groups selected?

Randomisation (describe how)

Matched controls (describe how)

Unmatched controls

No comparison group

How did the different groups compare to one another?

Equivalent

Non-equivalent

Other (specify)

No comparison group

Study drop outs

How many dropped out?

Was information given on who dropped out?

Yes (describe)

No

Partly (describe)

Not applicable

How were outcomes measured?

Standardised questionnaire to participants

For example Child Behaviour Checklist, Strengths and Difficulties Questionnaire.

Standardised questionnaires to significant other

For example teacher, parent or social worker.

Test results

For example final year exams.

School records

For example report cards, attendance list.

Interviews with participants

When were outcomes measured?

Before/at start of intervention

During the intervention

Immediately after the intervention

1-6 months after the intervention

7-12 months after the intervention

More than a year after the intervention (specify)

Not clear

How were data analysed?

Intention to treat

Available at follow-up only

Not clear

100% data available for post measures

Are there any obvious shortcomings in the numerical reporting?

Yes (describe)

No

Do the findings flow from the data?

Yes

No (specify)

Unclear (specify)

APPENDIX 5: DATA EXTRACTION FOR POLICY PILOT STUDIES

Pilot aim

Pilot rationale

Does the pilot provide a theory for why this strategy is piloted?

Did the pilot specify intended outcomes?

Yes (specify)

No

Unclear (specify)

Pilot aims to measure:

Impact

Process

Impact and process

Pilot type:

Summative

Does it set out to determine whether and to what extent a policy is having its desired effect or impact on its intended target groups?

Formative

Does it set out to shape a policy and/or determine why, how and under what conditions it may be best directed or implemented?

Summative and formative

Policy intervention or strategy

Policy pilots don't always simply test out a particular intervention, often they look at the impact or process of a wide brief on local authority policies. Was there an overall strategy as well as local interventions/services as a result of the strategy? Provide a full description here.

Intervention/strategy description

Length

Target group

Ages

Number

Comparison

Did the pilot compare one area with another, or pilot areas with the national picture?

Setting

Urban

Rural

School-wide

Community-wide

Targeted at individuals

Home-based

School-based

Community-based

Country

Strategic intervention

Policy and system intervention. A strategic intervention would focus on changing systems and policies. This could also include new direct services, but this option is to capture whether the intervention had a strategic element.

Evaluation methods (impact)

Randomisation

Controlled comparison group

Uncontrolled comparison group

Comparing official statistics

Before-after measures collected

Interviews

Not applicable, impact not evaluated

Evaluation methods (process)

Document analysis

Focus groups

Individual interviews

Survey

Audit

Not applicable, process not evaluated

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Findings

Impact

Outcomes

Intervention group

Only use this if the pilot looked at outcomes specifically related to those recruited to the pilot, as if it was a research study. This category does not apply to official statistics of all target group children in an area.

Comparison group

Process

Implementation

Describe findings related to the implementation of the pilot policies/practices.

Satisfaction

What was reported on the satisfaction levels among service deliverers and service users?

'Fit' to practice

Does the process evaluation consider the extent to which the pilot initiative needed to be changed in light of trying it out?

Other process findings

User involvement

Service users

Had users of services been involved in planning the pilot or informing its framework in any way?

Practitioners

Had practitioners been involved in informing the pilot framework in any way?

Unclear

None stated

Quality of pilot

Quality criteria were developed from 'Trying it Out: The role of 'pilots' in policy-making' and the EPPI-Centre tool for assessing the quality of outcome evaluations, long and short tools.

Funders

Pilot funded by

Pilot evaluation funded by

Organisation/individuals commissioned to evaluate

Who identified the aim(s) of the pilot?

Policy makers (national departments)

Policy makers/planners (local)

Consumer interest group

Sample of the target group

Sample of practitioners

Not clear (describe)

Was the pilot preceded by systematic gathering of evidence?

Yes

No

Not clear/not stated

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Did the pilot stipulate its precise purpose in advance?

Yes (specify)

No (specify)

Not clear

Did the pilot evaluation design fit with addressing the stated aim of the pilot?

Yes (specify)

No (specify)

Unclear (specify)

Was the pilot based on a needs assessment?

Yes, based on expressed need

Expressed need refers to what one can infer about the need of a community by observing their use of services.

Yes based on normative need

Normative needs refers to what expert opinion defines as need.

Yes based on felt need

Felt need is what people say they want or what they think are the problems that need addressing.

Yes based on comparative need

Comparative need is derived from examining, for example, the services provided in one area to one population and using this as the basis to determine the sort of services needed in another area with a similar population.

Yes, other (specify)

Stated but no information given

Not stated

Do the authors indicate any specific barriers to developing/delivering the pilot?

Yes (specify)

No

Do the authors indicate any factors favourable to developing/delivering the pilot?

Yes (specify)

No

Which processes were evaluated?

Perceptions, understanding or acceptability of the services

Accessibility of the services

Consultation/collaboration/partnerships

Content of the service/strategy

Implementation of the strategy

Delivery of services

Costs

Quality of any materials

Skills and training of policy makers or practitioners

Other (specify)

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Not a process evaluation

Who were the data collected from?

A sample of the target group

A sample of practitioners

A sample of policy makers

Other stakeholders

For example parents or community groups.

Unclear/not specified

Are there any inconsistencies in the reporting of the pilot evaluation data?

Yes (describe)

No

How were participants recruited to the evaluation?

Randomised (describe how)

Selected (describe how)

Not clear

Not relevant (not a comparison study)

If comparison evaluation: how did the groups compare?

Equivalent groups

Non-equivalent groups

Not clear

Not relevant (not comparison evaluation)

How were outcomes measured?

Standardised tool

For example the Child Behaviour Check List, or the Strengths and Difficulties Questionnaire

School record

Any record collected for each particular child included in the evaluation, for example test results, days of unexplained absence, exclusion record.

Tests

Questionnaire to target group

Questionnaire to significant other

Questionnaire to policy makers/planners/managers

Interviews/focus groups with target group

Interview/focus groups with significant other

Interview/focus groups with policy makers/planners/managers

Analysis of relevant official stats

How many were lost to follow-up measures?

How does the evaluation deal with loss to follow-up?

Intention to treat analysis

Analysis of available data

Unclear

Any information on those that dropped out?

Yes (describe)

No

Unclear

When were outcomes measured?

Ongoing collection at various points during the pilot period (specify)

Immediately after the target group had received the pilot programme

A while after the target group had received the pilot programme (specify)

Unclear

How were outcome data analysed?

Numerical analysis (describe)

Narrative analysis (describe)

Are the conclusions backed up by the data?

Yes

No (specify)

Unclear

Was there a plan for how the evaluation findings would be used?

Yes (describe)

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Not mentioned (describe)

Unclear (describe)

APPENDIX 6: PEER REVIEWERS' COMMENTS ON THE SYSTEMATIC REVIEW

The review was submitted to Child & Family Social Work 1st of May 2011. We received two sets of reviews. The first response was received on the 5th of July 2011:

Dear Ms. Liabo:

Manuscript ID CFSW-05-11-0061 entitled "A systematic review of interventions to support looked after children to stay in school" which you submitted to Child & Family Social Work, has been reviewed. The comments of the reviewer(s) are included at the bottom of this letter.

The reviewer(s) have recommended some revisions to your manuscript. Therefore, I invite you to respond to the reviewer(s)' comments and revise your manuscript. Please ensure that your revised manuscript is no longer than 7000 words including the abstract and references.

Reviewer: 1

Comments to the Author

I think this is a very interesting and important contribution, as looked-after children and education is high on the social-policy agenda both in the UK and other countries as a means of increasing the possibilities of social inclusion.

As long as the CFSW accepts the format of the article, I think it should be published as it is - with one addition: Please describe the EPPI-reviewer briefly, how it works, what it builds on, whether it is frequently used etc.

Reviewer: 2

Comments to the Author

This is a most important topic and I am suggesting the following changes.

Methods

I like how you write up the search strategy and I think this provides a very good example of how the internet is making it possible to use information in a very different manner. It will be most helpful for students undertaking research at post graduate level.

I suggest that you perhaps point to the limitations of the narrow outcomes that you are examining. Much of your discussion is taken up with a discussion of issues connected to these limitations, so I suggest that this is flagged as a context marker at this stage.

Structure of the paper

It is obvious that you did a great deal of work but I think the presentation is very confusing. Tables need to be named and refs of the material under discussion need to be included in the text. There is need for greater coherence /explanation between the flow diagram, the interventions /categories and the tables that are presented. How did you get to these themes/categories? The text explaining the process is not as clear as it needs to be.

Presentation of Tables

Include the refs in the accompanying text, smaller font. Give table names and explain terms PICO.

Discussion

Overall this is very important work and it will make a contribution. You make come very interesting points in the discussion but I recommend that it could be more critically argued. I think that perhaps more explanation of the reduction from 6502 to 23 is needed. What are the consequences of the omission: I have a number of questions that I would like more answers to:

What was lost by not including some of the material left out?

What are the parameters of the debate re outcome measures being 'potentially contentious' (which you show good insights) for your actual study? I think it is extraordinary to think that not children carers or professionals have been asked about their desired outcomes? Is there information available in the general foster care literature that you could

have drawn on? I would like to see refs to the other evaluations that you mentioned in the conclusion.

I think your conclusion would be enhanced if you reference it back to material that is available re school outcomes for children across the class divide as this would provide an important context marker to go forward.

Amendments in response to the reviewers' comments were submitted on July 13th 2011, and these received the following response on October 24th 2011 and a second set of comments:

Dear Ms. Liabo:

Manuscript ID CFSW-05-11-0061.R1 entitled "A systematic review of interventions to support looked after children to stay in school" which you submitted to Child & Family Social Work, has been reviewed. Unfortunately, the two original referees were unavailable to review the resubmitted manuscript. There are, therefore, further comments for you to consider from the second referees. I realise this is very frustrating for you at this stage, but having looked at the paper again, I think a judicious attempt to address the relatively minor concerns will strengthen the paper further. The comments of the reviewer(s) are included at the bottom of this letter.

Reviewer: 1

Comments to the Author

I think this is a very well written, concise and interesting article about a theme that is highly relevant both in Great Britain and for other European countries. also I think the methodology section is very good, since it problematizes issues that are very important within our field.

When I wrote "publish, subject to amendments", this is connected with one small point: that the tables (1-13) are a bit difficult to follow because the layout is so very similar. On my part I lost track of the contents after a while. Would it be possible to describe all the studies in one table, with the necessary information, and then highlight the categories and present the most pertinent results for each category in the ensuing tables?

Reviewer: 2

Comments to the Author

General

The paper provides a useful overview of interventions to improve the education of looked after children. The paper was limited possibly because of the lack of research in this area or the quality of that which exists. The author(s) acknowledges this and the subsequent need for further developments in this area accompanied by robust evaluation.

The style of the paper is occasionally awkward e.g. avoid the use of 'had to', 'problem for why' . The information contained in the tables is useful.

The paper would benefit from a thorough proof read to identify spelling and grammatical errors.

Abstract/ Introduction:

The abstract and title suggests that the focus of the paper is on school participation (interventions to prevent drop out, absenteeism and exclusions) however, the authors do not include reference to research that has demonstrated high levels of truancy, exclusion and drop out amongst young people in care, instead they focus on research on achievement/attainment. The author should be clear and consistent throughout as to whether they are interested in school attendance or achievement or both. Most of the evaluations in the review seem to focus on improving achievement rather than participation.

Page 1 Line 46. is the objective to identify the effect of the evaluations or the intervention?
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Page 1 Line 50+ This might be better placed within the methodology. Also, it would be useful to hear more about how LAC and care leavers were involved e.g. how did they recruit and access these young people? Did they participate in a focus group or reference group etc, what were the research questions and were they involved in commenting on results?

Methodology

The inclusion criteria for the review could be a little clearer and concise. Page 2 line 14+ - this paragraph seems a little confused. The author might consider separating the issues around pre – post test evaluations and those using control/comparison groups. I'm not sure that the justification for length of follow-up can be located in the reasons stated.

Page 2 line 39+ can this be included in an appendix?

Page 3 line 55 – how do the authors define 'comprehensive evaluation designs' particularly given their comments on study quality, which suggest that the evaluations were of limited quality in terms of sample size, attrition, lack of accuracy around numbers etc (page 5 line 33+)?

Discussion

The discussion could benefit from more interpretation from the author(s). Sub headings/section might help to organise the material.

Page 8 line 12. Robust pre-post test evaluations are equally valid in identifying effect.

Page 8 line 42+ Important to consider distance travelled for this group (see Mike Stein and colleagues work) e.g. pre-post test evaluations of young peoples outcomes (whether attainment or participation) is often more useful than comparison/control group evaluations as it will demonstrate individual progress.

The conclusion could be stronger. Would be useful if authors could draw out some of the findings from the evaluations to suggest areas of further development e.g. what are the recommendations and learning points for development of future interventions and evaluations.

The review was accepted for publication in Child & Family Social Work on January 19th 2012.