Collection of examples of service user and carer participation in systematic reviews

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Introduction

SCIE is committed to the participation of service users and carers in all aspects of work. However, to date the only published report of user involvement in reviews is that by Braye and Preston-Shoot (2005)[1].

This collection of examples of user involvement in systematic reviews has been produced to complement SCIE's updated systematic review guidelines (Coren and Fisher, 2006 [2]). The intention is that this document will be updated as new reports of user involvement in reviews become available.

The three examples included here differ, and each provides an example of user involvement in systematic reviews in different aspects of the review process.

Example 1, (Sarah Carr and Pete Fleischmann) the systematic review of consumers' perspectives on electro-convulsive therapy (ECT), is a unique example in social care research of a service user-led systematic synthesis of research. The review was undertaken in order to include user perspectives on ECT as compared with clinically rated outcomes.

The way the review was conducted had an impact on all stages of the review, including the type of evidence used and the identification and analysis of knowledge that included user testimony. In this review the lead researchers were service user researchers with experience of the treatment being evaluated, and additionally there was a project advisory group that included service user members.

The review addressed a number of issues including those of power and authority within the review team. Conducting study appraisal from a user perspective had a major impact on the process and findings of the review, demonstrating in particular how differently different stakeholders interpret similar data. The findings of the review influenced the subsequent guidelines developed by the National Institute for Health and Clinical Excellence (NICE). The authors of this report make recommendations in relation to conducting a review in this way and discuss the many benefits.

Example 2 (Rebecca Rees and Sandy Oliver) was funded by the Department of Health and conducted at the Evidence in Policy and Practice Information and Coordination (EPPI) Centre and concerned HIV prevention in men who have sex with men. This review involved service user organisations participating in the review on its advisory group.

There was no explicit budget or responsibility within the research team for this work. A primary role of the advisory group was to prioritise topics for the review focus, in a topic where priority outcomes differ for different stakeholders. A key innovation was the method of consensus development used to incorporate diverse outcomes. This process has influenced methodological development within the EPPI Centre and also has been cited in the Cochrane Handbook of reviews of effectiveness[3].

A key recommendation from this report is the need for a dedicated budget and staff to maximise the potential contribution from advisory group members. The report also recommends that more prospective evaluations of the role and influence of service users on systematic reviews are commissioned in order to add to the knowledge base in this important area.

Example 3 (Ruth Stewart and Sandy Oliver) is from a review that was part of a series of pieces of work to develop evidence-based policy in the National Newborn Screening Programme. In this piece of work, the user involvement was mostly concerned with the interpretation and implementation of the findings to form guidance.

This project was funded by the Department of Health with a specific budget for the user involvement element of approximately £20,000. The project was also conducted at the EPPI Centre.

The authors of the report note that user involvement influenced the detail and wording of the leaflets produced and also enabled the users to become involved subsequently in other similar projects giving input into guidelines and research. The researchers put a lot of effort into the involvement of the service users, many of whom were parents of young children with complex and serious health needs. The authors' conclusions and recommendations raise the difficulties experienced in recruiting unaffiliated parents, and those whose experience of screening led to a negative result (a child without the condition). They discuss the challenges of working with parents of children who have serious health problems and issues in relation to payment for the parents' time.

The plan is that these reports will be the first in an ongoing collection that will inform the development of this important area of systematic review work. If anyone reading this report has experience of a systematic review that involved service users and carers, whether as a service user, carer or researcher, please contact Esther Coren (esther.coren@scie.org.uk) or Sarah Carr (sarah.carr@scie.org.uk) at SCIE to discuss the possibility of incorporating a report of the experience in an update to this collection.

Esther Coren
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References

1   Braye, S. and Preston-Shoot, M. (2005) 'Emerging from the shadows' Service user and carer involvement in systematic reviews' *Evidence and Policy*, 1 (2), pp 173-193.

2   Coren, E. and Fisher, M. (in press) *The conduct of systematic research reviews for SCIE knowledge reviews*, London: Social Care Institute for Excellence.

3   'Cochrane Handbook' www.cochrane.org/resources/handbook

EXAMPLE 1

Systematic review of consumers' perspective on electro-convulsive therapy

Sarah Carr
and Pete Fleischmann

A. Background

A1. Background to the systematic review

This systematic review is a rare example of service user-led secondary research work. It was possibly the first user-led systematic review to reach the international peer-reviewed literature.

Electro-convulsive therapy (ECT) is a treatment for mental health problems that attracts controversy. Around 11,000 people receive ECT in England annually. There is a consumer viewpoint that is highly critical of the treatment.

This review aimed systematically to describe and summarise consumers' perspectives on ECT. It also sought to understand the sources and nature of the controversy about ECT between some consumers and professional bodies representing practitioners of ECT. Coming directly from the critical perspective of the service user, the reviewers sought to ascertain patients' attitudes on the perceived benefit of the treatment, as distinct from clinically rated outcomes.

The project was commissioned by the Department of Health and carried out by the Service User Research Enterprise (SURE) at the Institute of Psychiatry in London. The Service User Research Enterprise is an example of service user participation that is embedded within an organisational system rather than a process specifically established for an individual project.

A2. Background to the Service User Research Enterprise

The Service User Research Enterprise was established in 2001 in response to the requirement from major funding bodies, including NHS R&D, for evidence of user involvement in research proposals. The level and degree of user involvement required varies between funding bodies and between specific tenders, from representation on steering committees through to full involvement in the research process. This is a very recent development and the obstacles are not underestimated.

User involvement in research at the Institute of Psychiatry (IoP) and the South London and Maudsley Trust (SL&M Trust) began before the recent funding requirements referred to above. This was largely through the efforts of the Centre for Recovery in Severe Psychosis (CRiSP) which conducted two collaborative trials with service users and involved service users on its steering group. Additionally, the Health Service Research Department and the R&D Office convened a conference of service users local to the South London and Maudsley Mental Health Trust in May 2000. The conference was asked to identify service users' priorities for research and the top priority that emerged was full user involvement in the research process for this service user group. A further conference was held in December 2002.

Example 1 **User involvement in systematic reviews**

The work of the Centre for Recovery in Severe Psychosis and the results of the conference led to the establishment of a group to discuss how service user involvement at the Institute of Psychiatry and the South London and Maudsley Trust could be taken forward. It was decided to set up the Service User Research Enterprise and the first coordinator was appointed at the end of March 2001.

The Service User Research Enterprise is part of the wider user participation structure within the Institute of Psychiatry and the South London and Maudsley Trust. The South London and Maudsley Trust and the Institute of Psychiatry R&D steering group is responsible for managing the South London and Maudsley Trust's research and development activity. As such it is an extremely powerful and influential committee in terms of both defining and implementing the South London and Maudsley Trust's research priorities.

Meaningful user involvement in this kind of committee is very rare and the South London and Maudsley Trust R&D committee has provided a budget to overcome some of the pitfalls. To avoid an unstable arrangement that depends on one or two individual users and which could be open to accusations of tokenism, the Consumers' Research Advisory Group (CRAG) has been established. This group has been meeting for three years and has two interrelated functions: to facilitate and support user involvement in the R&D steering group and to identify local users' views about research. The Consumers' Research Advisory Group consists of up to 20 local users. It currently has members from Southwark, Lewisham, Lambeth and Croydon as well as the Addictions and Older People's Directorates.

Two Consumers' Research Advisory Group members attend meetings of the R&D steering group with two members of Service User Research Enterprise staff. These representatives are selected from the Consumers' Research Advisory Group and rotated bi-annually. The Consumers' Research Advisory Group is intended as both a support and a reference group for the representatives. The whole group meets regularly and discusses the agenda and papers for each meeting of the R&D steering group. Then the representatives attend the meeting. This structure is intended to provide consistent and accountable user representation.

Service User Research Enterprise staffing and funding

The initial brief for the Service User Research Enterprise was largely local to the Institute of Psychiatry and the South London and Maudsley Trust. However, because of the national context and the new interests of funders in service user involvement in research nationally, this brief has widened.

The approach that the Service User Research Enterprise takes on specific projects and the choices made about participating in projects is guided by a number of sources including the Consumers' Research Advisory Group; service user conferences; and the

Service User Research Group for England (SURGE), which is part of the wider national Mental Health Research Network.

The Service User Research Enterprise is co-directed by a service user researcher and a clinical academic, who share management of the organisation. It has a steering group which aims to have 50 per cent user representation, with 25 per cent clinical academics and 25 per cent senior managers. The majority of research workers at the Service User Research Enterprise are service users or survivors. The infrastructure is still underpinned by a grant from the South London and Maudsley Trust with additional support from the Institute of Psychiatry and the Health Service Research Department. Grant income in the form of collaboration with other departments in the Institute of Psychiatry and with outside agencies also contributes to organisational funding. Much of this is connected with projects falling into priorities defined by local service users.

The Service User Research Enterprise's mission statement

The Service User Research Enterprise's core aim is to involve service users at all levels of the research process in a collaborative way (Service User Research Enterprise, 2004[1]). It pursues this aim as follows:

- It identifies local service users who are interested in research, finding out how and at what level they would like to be involved, and facilitating this in accordance with the aim of collaboration. The Service User Research Enterprise aims for this involvement to be meaningful and skill enhancing and to impact upon research in the Institute of Psychiatry and the South London and Maudsley Trust.
- It tenders for national projects relevant to established users' priorities and with a substantial consumer involvement component. Where tenders are successful and posts are funded the Service User Research Enterprise aims for them to be filled by people with experience of using mental health services, to build up the capacity of the unit and the presence of service user researchers at the Institute of Psychiatry. Researchers who fill these posts are encouraged to register for higher degrees to build their research capacity further.
- It disseminates the way it works and the outcomes of the work to the widest possible audience. So, when the Service User Research Enterprise publishes results of its research in academic journals it also publishes them in formats and journals accessible to service users.

Example 1 **User involvement in systematic reviews**

B. What happened?

B1. User participation in the review

Review team and authorship

This review was commissioned by the Department of Health and was conducted and co-authored by two service user researchers with direct experience of ECT (one of whom was the lead investigator) and two clinical academics at the Service User Research Enterprise. It ran in parallel with a meta-analysis of the effectiveness and safety of ECT conducted by clinicians at the Centre for Evidence Based Mental Health at Oxford University.

Both reviews were overseen by a Department of Health ECT advisory group, with the final reports being co-presented to the commissioners and later at the Royal College of Psychiatrists annual conference. In practice, the focus of the clinical review was moderated by the user perspective review through the inclusion in the report of the issues of ECT and memory that arose among the findings of the consumers' perspectives review.

Twenty-six papers seeking users' views about ECT authored by clinical academics and nine authored by user organisations either alone or in collaboration with clinical academics or voluntary organisations were reviewed. The review team also collected 139 first-hand accounts of experience of ECT, or 'testimonies', making innovative use of the internet and other electronic material. This material was logged using a specially designed grid and subjected to a 'narrative synthesis', applying 'equally rigorous methods to the synthesis of non-quantitative data as are applied to quantitative data' (Marsh and Fisher, 2005[2]). The review showed that users' views, even when collected by authors explicitly endorsing the treatment, were often at variance with the published statements of professional bodies. It also revealed the complexity of users' views of the treatment.

Project reference group

The review took advice from an internal project reference group, composed of 12 people, which met twice during the lifetime of the project, with several points of communication in between. The group comprised representatives of user and voluntary groups with a stake in ECT research and researchers with an interest in user perspectives on the treatment. The reference group had a majority of people with direct experience of ECT and was effectively user-controlled.

The self-defined local and national user-led groups represented on the project reference group were:

• Share in Maudsley Black Action (SIMBA)
• Communicate (at the Maudsley)

- Manic Depression Fellowship
- AWAAZ Mental Health Project
- United Kingdom Advocacy Network (UKAN).

These user groups were identified and recruited through the networks the user researchers at the Service User Research Enterprise were already part of. The project team ensured that the reference group had black and minority ethnic representation from both a local Asian, African and African-Caribbean user group and an Asian user organisation.

Role of the project reference group

The group advised on the location of the literature and the focus of thematic analysis, and reviewed drafts of the report. It recommended that the reviewers should consider the emotional impact of ECT among the review outcomes, an issue of central importance to service users but previously not addressed in research reviews. The user group Communicate located an important unpublished study of ECT. The group looked at draft reports and contributed to drafting the final study report.

Department of Health ECT advisory group

A draft report was discussed by a 16-member Department of Health advisory group (comprising clinicians, academics, service users and policy makers) to both projects in November 2001 and reviewed by two Department of Health nominated academics. The Department of Health advisory group included representatives from two user-focused mental health organisations with an interest in ECT. Three of the members of the Department of Health advisory group were also part of the project reference group. The final report was submitted to the Department of Health in January 2002 and accepted for peer-reviewed and other dissemination in March 2002.

B2. User participation impact on the review

The impact of user participation in this systematic review was significant at several levels.

Review methodology and findings

Firstly, the fact that this review was user-led influenced the type of evidence included. The review considered three types of evidence. Academic research studies were located using Psychinfo, Medline, Web of Science and HMIC. User/voluntary group studies were identified by the user researchers who had prior knowledge and contacts. The project reference group also contributed to identifying such studies. Testimonies or first-hand accounts of the experience of receiving ECT were sourced from websites, various print media and video archive.

Example 1 **User involvement in systematic reviews**

Secondly, study research methods and consequent findings were interrogated from a user perspective. All the studies were reviewed in terms of their methodology and found to be very diverse and of variable quality. All the studies started with certain assumptions and values concerning the intervention that led to differences both in participant selection and in interpretation of data. A template for analysing the substantive themes was developed which ensured that no single approach to ascertaining consumers' views on ECT was privileged. The different strategies used by clinical and consumer research to summarise data were also examined to see how diverse conclusions may be reached on the basis of very similar data.

The consumer reports estimated lower satisfaction with ECT than did the clinical reports. Rather than put this down to biased sampling the user researchers showed that the methods used to elicit satisfaction ratings influenced reported satisfaction. The two user researchers who did the empirical work for the study had received ECT themselves. This was a strength in that it anchored the review in the standpoint of recipients of the intervention itself and gave a user-oriented perspective to the appraisal and interpretation of the included studies. This resulted in a service user perspective on the appraisal of the included studies concluding that the study designs may have overestimated the extent to which users were satisfied with the intervention, taking account of doctor–patient power relations.

The critical perspective of the service user researchers revealed some important methodological inadequacies in the studies of ECT. The variation in the complexity of the questions, the timing of the assessments and the professional status of the interviewer were highlighted.

Review dissemination

Guided by the user-directed ethos of the project, the review team wanted to make the study findings accessible to as wide an audience as possible. The dissemination strategy was also designed to raise awareness of consumer perspectives and to encourage both public and professional discussion of ECT.

As well as publishing papers in international peer-reviewed journals (Rose, Wykes, Leese, Bindman and Fleischmann, 2003[3]; Rose, Fleischmann and Wykes, 2004[4]; Rose, Wykes, Bindman and Fleischmann, 2005[5]), the team also wrote articles for user-focused publications (Fleischmann, Rose and Wykes, 2003[6]) and sought public media coverage. Media coverage included national radio and local television. A video of the service user and survivor testimony was also produced.

The full report is available for free download online:
http://www.ect.org/resources/consumerperspectives.pdf

Review findings impact

This review considered the following themes, which were identified by service users as being important:

- persistent memory impairment following ECT
- consent for and information about ECT
- perceived benefits of ECT
- emotional responses to ECT.

The review found that patients were reporting persistent memory loss. The reviewers estimated this to be a side effect for at least 30 per cent of people who had undergone ECT. This was in contradistinction to professional clinical opinion that long-term memory loss is not a problem with ECT. It appears that this argument is made because tests of new learning do not show deterioration in people who have ECT. However, the participants in the studies included in this review complained of gaps in past memories rather than difficulties with recent memories.

The review also looked at consent and information and found that nearly half the consumers felt they were given insufficient information about ECT before the treatment. Almost a third of those who signed a consent form did not feel they freely chose to have the treatment. These findings were consistent across all data sources.

These findings impacted on the National Institute for Health and Clinical Excellence guidelines on the use of ECT. They particularly influenced the guidance on obtaining valid consent for treatment in all cases and the recognition of the possible risks involved with the treatment, particularly concerning both short-term and long-term memory loss.

The National Institute for Health and Clinical Excellence guidelines acknowledge that 'a number of individuals find their memory loss extremely damaging and for them this negates any benefit of ECT' (National Institute for Health and Clinical Excellence, 2003[7]). They therefore recommend that 'a risk–benefit assessment for the individual should be made and documented. It should include the risks associated with the anaesthetic, whether the person has other illnesses, the possible adverse effects of ECT (particularly problems with memory), and the risks of not having treatment. There should be ongoing checks for any signs of memory loss, and as a minimum, a check at the end of each course of treatment' (National Institute for Health and Clinical Excellence, 2003[7]).

As regards consent, the National Institute for Health and Clinical Excellence guidelines state that 'the doctor should keep strictly to recognised guidelines about consent, should not put any pressure on the person to give their consent and should remind the person that they have the right to change their mind either for or against the treatment at any time' (National Institute for Health and Clinical Excellence, 2003[7]).

Example 1 **User involvement in systematic reviews**

The report published in the *British Medical Journal* opened up a user-led critical dialogue with the Royal College of Psychiatrists about patient satisfaction and memory loss. This led to a review of standards for ECT training and the re-evaluation of the information on ECT provided on the Royal College of Psychiatrists website.

C. Conclusion, discussion and recommendations

The type of service user participation seen in the systematic review of consumers' perspectives on ECT is currently rare. The review took place in an organisation that already had an established service user research group with various networks. Because the Service User Research Enterprise is structurally integral to the Institute of Psychiatry and the South London and Maudsley Trust research programme, this assured service user participation in the review. Therefore the work did not follow the usual model of non-user researchers creating a participation strategy and recruiting service users to take part in review work.

Because the core review team consisted of user researchers and non-user researchers working in collaboration, there were some concerns about power and authority. This is inevitable in a situation where new methods of partnership are being developed (Carr, 2004[8]). Time and commitment was needed to build up trust between the user and clinical researchers and for equitable working patterns to be established. In the case of this review it was important in terms of power sharing for the lead investigator to be a service user. It was also important that the second user researcher had good training and support. This took the form of on-the-job training and research supervision sessions with the lead investigator.

The lead investigator and second author were both service users with experience of the treatment under scrutiny. This gave them a significantly greater degree of credibility and trust with the other service users and survivors who took part in the work.

The review team had direct access to service user and survivor groups through the pre-existing networks of the two user researchers. This made the process of identifying and recruiting members for the project reference group far quicker and easier.

The research question and the nature of the review were shaped by service users and their interests about a controversial psychiatric treatment. Service users and survivors were therefore motivated to influence a study to which their experiences and opinions were central. The review methodology then took this user perspective into account, both in terms of the type of research identified and included and how it was analysed.

Example 1 **User involvement in systematic reviews**

References

1   Service User Research Enterprise (2004) *Service User Research Enterprise annual report 2003–2004*, London: Institute of Psychiatry.

2   Marsh, P. and Fisher, M. (2005) *Developing the evidence base for social work and social care practice,* London: Social Care Institute for Excellence, p 45.

3   Rose, D., Wykes, T., Leese, M., Bindman, J. and Fleischmann, P. (2003) 'Patients' perspectives on electroconvulsive therapy: systematic review', *British Medical Journal*, vol 326, pp 1363–1366.

4   Rose, D., Fleischmann, P. and Wykes, T. (2004) 'Consumers' perspectives on ECT: A qualitative analysis', *Journal of Mental Health*, vol 13, no 3, pp 285–294.

5   Rose, D., Wykes, T., Bindman, J. and Fleischmann, P. (2005) 'Information, consent and perceived coercion: Consumers' views on ECT', *British Journal of Psychiatry*, vol 186, pp 54–59.

6   Fleischmann, P., Rose, D. and Wykes, T. (2003) 'Life saver or memory eraser?' *Openmind,* vol 122, pp 12–13.

7   National Institute for Health and Clinical Excellence (2003) *Technology appraisal guidance 59: Guidance on the use of electroconvulsive therapy,* London: National Institute for Health and Clinical Excellence, p 10.

8   Carr, S. (2004) *Position paper 03: Has service user participation made a difference to social care services?* London: Social Care Institute for Excellence.

9   Royal College of Psychiatrists website: http://www.rcpsych.ac.uk/crtu/centreforqualityimprovement/electroconvulsivetherapy.aspx

EXAMPLE 2

An example from sexual health promotion

Rebecca Rees
and Sandy Oliver

The authors would like to acknowledge the work of this review's advisory group and the other members of the review team for their involvement in this work. Further details of this work can be found in Rees, Kavanagh, Burchett, Shepherd, Brunton, Harden, Thomas, Oliver and Oakley (2004), which is downloadable in full free of charge at: http://eppi.ioe.ac.uk/

Example 2 **User involvement in systematic reviews**

A. Background

A1. Background to the systematic review

HIV health promotion and men who have sex with men (MSM): A systematic review of research

This report describes user involvement in a systematic review of research into sexual health promotion among homosexually active men. The review included input from an advisory group made up of a range of potential review users. These included people from organisations campaigning on behalf of, and providing services for, men who have sex with men. It is this latter group of people that we are referring to when we use the term 'user' in this report.

The work to involve users described here is innovative in two ways. Firstly, the review of literature had two phases, an initial systematic map to describe the range of existing research, and then a synthesis of the findings of a selection of these studies. This map informed the advisory group's discussion and their recommendations about priority areas for study. The second way in which this review is innovative is its use of formal consensus development methods. The advisory group, independently of the research team, decided which sexual health outcomes were to be prioritised in the review. This was done through a structured process of listing and discussing potential outcomes and then voting to identify the outcomes favoured by most group members.

The focus of this work

Men who have sex with men are the group at greatest risk of acquiring HIV infection in the UK. After remaining stable for over a decade at approximately 1,500 a year, new HIV diagnoses in gay men reached a record 2,214 in 2004 (HPA, 2006[1]).

Highly collaborative work on HIV health promotion for gay and bisexual men has been ongoing in the UK since 1996, when a number of health promoting and campaigning agencies came together to form the Community HIV and AIDS Prevention Strategy (CHAPS) partnership.

In May 2002, the EPPI Centre was commissioned to conduct a systematic review of sexual health promotion for men who have sex with men. This review was to update and extend the scope of a previous systematic review completed in 1996 (Oakley, Oliver and Peersman,1996[2]).

The evidence included in this work

The review was to pull together the following kinds of evidence:

- research knowledge
  - > through the description, analysis and synthesis of published and unpublished research studies
- experiential knowledge of practitioners, policy developers, researchers and service users
  - > via the advice and decision making of members of a review advisory group.
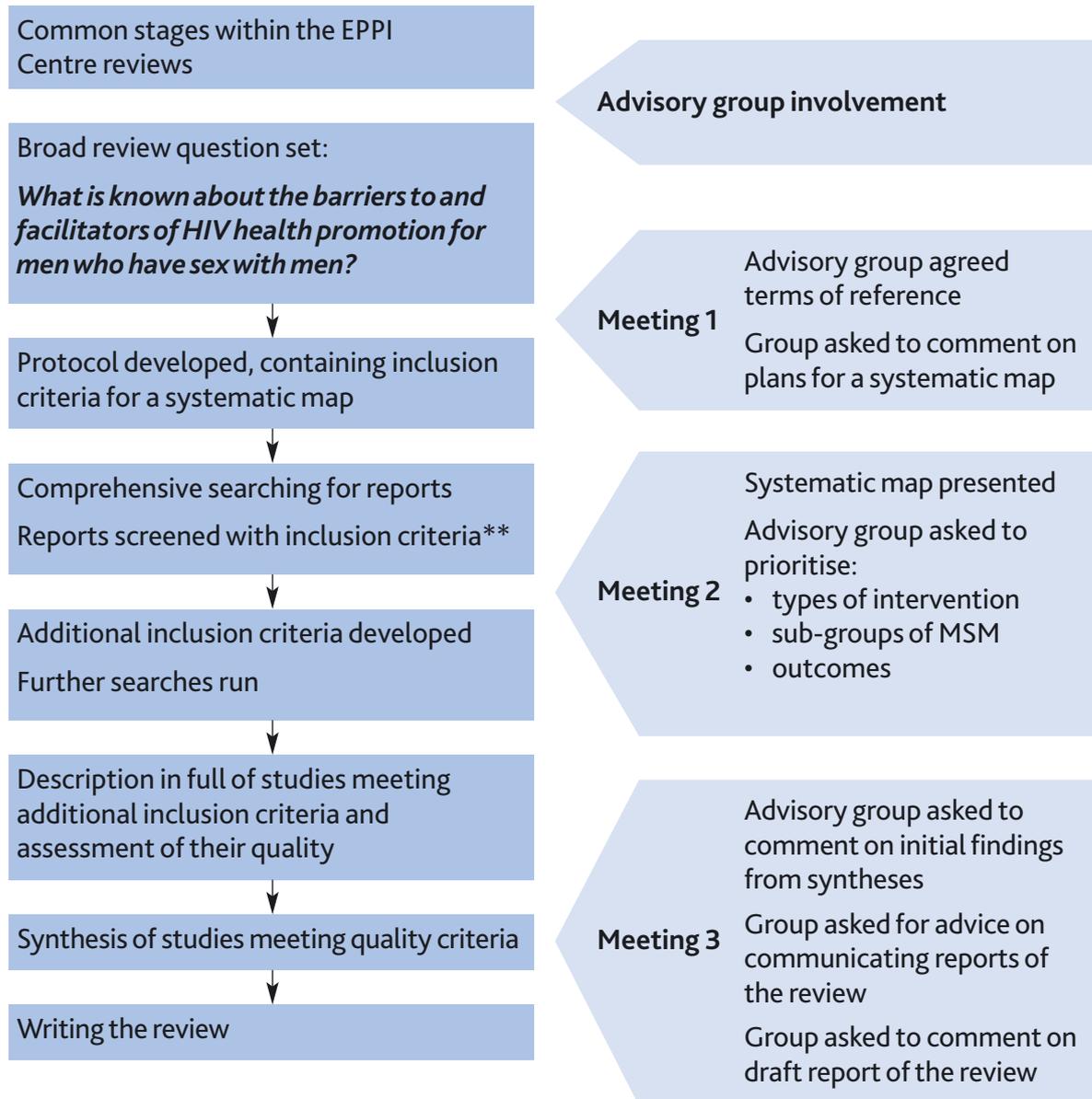
The programme of work

The review was commissioned as part of a series of reviews conducted by the EPPI Centre by the Department of Health (DH) for England and Wales. The DH specified that the review should:

- build upon the Department of Health's National Strategy for Sexual Health and HIV, published in 2001
- be about the barriers to and facilitators of HIV health promotion for men who have sex with men
- focus on disadvantaged groups of men who have sex with men
- use methods similar to those used in previous EPPI Centre reviews (see Figure 2.1)
- include UK and relevant international research
- include research capturing the views of service users
- take into account the views of the research partner for the Community HIV and AIDS Prevention Strategy initiative (Sigma Research).

The left-hand side of Figure 2.1 outlines the plan for the review presented to the DH in the summer of 2002. Two stages were planned. In an initial stage, the researchers would search for, screen and describe systematically a broad range of existing research.

The second phase would then involve three different syntheses, each addressing a more specific question about HIV health promotion for men who have sex with men. Further detail of this approach to synthesis can be found in several reports (for example Rees, Kavanagh, Burchett, Shepherd, Brunton, Harden, Thomas, Oliver and Oakley, 2004[3]; Thomas, Harden, Oakley, Oliver, Sutcliffe, Rees, Brunton and Kavanagh, 2004[4]).

Example 2 **User involvement in systematic reviews**

Figure 2.1. Stages in the review of HIV health promotion for men who have sex with men (MSM) showing points at which the review's advisory group was involved

Common stages within the EPPI Centre reviews	Advisory group involvement
Broad review question set: *What is known about the barriers to and facilitators of HIV health promotion for men who have sex with men?*	
Protocol developed, containing inclusion criteria for a systematic map	**Meeting 1** — Advisory group agreed terms of reference Group asked to comment on plans for a systematic map
Comprehensive searching for reports Reports screened with inclusion criteria**	**Meeting 2** — Systematic map presented Advisory group asked to prioritise: • types of intervention • sub-groups of MSM • outcomes
Additional inclusion criteria developed Further searches run	
Description in full of studies meeting additional inclusion criteria and assessment of their quality	**Meeting 3** — Advisory group asked to comment on initial findings from syntheses Group asked for advice on communicating reports of the review Group asked to comment on draft report of the review
Synthesis of studies meeting quality criteria	
Writing the review	

*** As is reported elsewhere (Rees, Kavanagh, Burchett, Shepherd, Brunton, Harden, Thomas, Oliver and Oakley, 2004[3]), three separate syntheses were conducted at this point: i) one of trials to address the question 'Which interventions are effective for sexual health outcomes?'; ii) one of studies of the views of men who have sex with men to address the question 'What are the perspectives of sub-groups of men who have sex with men on HIV-related sexual health?'; and iii) one that juxtaposed the findings of synthesis (i) with the findings of synthesis (ii) to ask 'Which interventions evaluated for effectiveness build on the views of these sub-groups of MSM and which do not?'*

The idea for a review advisory group came from the steering group for the EPPI Centre as a whole.

The design of the user involvement in this work

The remainder of this report refers to involvement of members of organisations campaigning on behalf of, and providing services for, service users. It also refers to involvement of other members of the review's advisory group. Where it is possible and useful to distinguish between different kinds of advisory group member we have attempted to do so.

We used elements of explicit consensus development methods (Murphy, Black, Lamping, McKee, Sanderson and Askham, 1998[5]). This involved:

- inviting participants to reflect the full range of potential users the work is intended to influence, in order to explore areas of uncertainty to be addressed by the research
- providing all participants with background information in advance
- structuring part of the interaction with two rounds for rating decisions, and sharing reasons and arguments for different points of view.

The aims

Advisory group input into the review was sought in order to access a variety of perspectives on the issue of sexual health for MSM in the context of HIV. It was hoped that this would make the review more relevant for a range of groups and would help increase awareness of the review's findings. These groups included, but were not restricted to, actual and potential service users. These include HIV positive men who have sex with men, and men who have sex with men seeking information, advice and support regarding HIV and sexual health more generally.

The design

In July 2002 three of the research team (Rebecca Rees, Jonathan Shepherd and Sandy Oliver) met twice to identify ways in which the advisory group should be managed. While these researchers managed most of the work related to the advisory group over the course of the review, there was no explicit allocation of responsibility within the research team for this work. There was no budget specifically allocated for the advisory group's work.

These researchers identified the following issues as important:

- The advisory group's role would be primarily to help prioritise topics upon which the review should focus.
- The group might also help to:
    > identify studies
    > publicise the review to colleagues and associates
    > incorporate its findings into their work

Example 2 **User involvement in systematic reviews**

> ensure that the review was sensitive to sexual and HIV prevention politics (for example that it used appropriate terminology).
- There would need to be clear terms of reference for the group.
- The group would meet at three key decision-making points in the review (see Figure 2.1): during initial discussions over the conceptual framework for the review, when deciding on criteria for including studies in the review, and to help interpret the review's findings.
- These meetings would be semi-informal, would last around two hours and would be held at the EPPI Centre in London.
- Recommendations made by the group would be recorded and summarised by the chair at the end of each meeting.
- Advisory group members should bring together the following kinds of experience:
  > providing health promotion services in the statutory sector
  > providing health promotion services in the voluntary sector
  > representing users of health promotion services
  > developing/implementing Department of Health policy
  > developing/implementing voluntary sector policy
  > researching health promotion for MSM

Previous experience of working together

The advisory group's work was able to build upon already existing relationships. None of the research team had worked previously with either of the advisory group members from service user groups. However, several other advisory group members had worked previously with a member of the research team. All advisory group members were familiar with each other's work prior to the first advisory group meeting. Four of the group, including both members from service user groups, had worked with each other as part of the Community HIV and AIDS Prevention Strategy initiative mentioned above.

The stages that users were involved in

Advisory group tasks are detailed in Section B1 below. As Figure 2.1 illustrates, advisory group members were involved from an early stage in this review, through to production of the final review report.

A2. Background to participants

Who we aimed to involve and their potential interests in this work

In this review, we worked not with individual service users but with organisations that campaign and provide services for men who have sex with men. We aimed to involve organisations set up by users that also identified themselves explicitly both as working for such users and as involving them in the organisation's decision making. By inviting representatives of organisations we aimed to tap into these organisations' networks of communication and information sharing. This approach was chosen in order to access a range

of perspectives and help us communicate the study's findings. This approach contrasts with methods that work solely with individuals who are not aligned with any one organisation.

The two user organisations involved in this review, the Terrence Higgins Trust (THT) and Gay Men Fighting AIDS (GMFA), have features in common but they are also quite distinct. Both are campaigning charities that aim to provide advocacy, advice and information alongside health promotion services. Both have a focus on conducting and commissioning research.

We invited senior staff from both organisations. We anticipated that these organisations might be interested in being involved in our review as a way of potentially influencing health policy and the research agenda at a national level.

The research team

The roles and relevant experience of the three researchers involved most closely with the review's advisory group are as follows:

- Rebecca Rees worked in research in the voluntary sector and for a campaigning charity before joining the EPPI Centre.
- Jonathan Shepherd had previously led an evaluation of a sexual health intervention for men who have sex with men. He was selected to chair the advisory group because his previous work meant that he was known to some advisory group members.
- Dr Sandy Oliver has been working in the area of user involvement in research for 18 years, first as a service user and later as a researcher.

Other participants in this work

In addition to representatives from the Terrence Higgins Trust and Gay Men Fighting AIDS, the advisory group included people from the following organisations:

- Sigma Research. This organisation is a partner in the Community HIV and AIDS Prevention Strategy initiative. As well as other in-depth studies of the social aspects of HIV and the lives of men who have sex with men, Sigma conducts an annual survey to examine socioeconomic variation and trends in behaviours, beliefs and attitudes.
- The National AIDS Trust (NAT). The National AIDS Trust campaigns on policy issues so as to address HIV both nationally and internationally.
- The National HIV Prevention Information Service (NHPIS). At the time of the review the NHPIS was collating and assessing research on HIV prevention as part of the Health Development Agency (HDA). The NHPIS has recently completed a review of reviews of evaluations of HIV prevention. The Health Development Agency has since been subsumed into the National Institute for Health and Clinical Excellence.
- The MRC Social and Public Health Sciences Unit, University of Glasgow. This unit is a recognised centre for epidemiological and social research on HIV and other aspects of sexual health.

Example 2 **User involvement in systematic reviews**

- The Department of Health. One representative from the DH was managing the department's strategy on sexual health and HIV at the time of the review. The second Department of Health representative was managing the EPPI Centre's contract for this programme of work.

A3. Methods for involvement

How were users selected, recruited and briefed?

When selecting participants from service user groups we looked for people known to have had previous involvement in research and policy development.

The research team drew up a shortlist of potential advisory group members and an invitation letter was sent to each in September 2002. The letter was accompanied by an outline of the proposed work and some information about systematic reviews of effectiveness (two pages of A4 in total).

We worked on the basis that all advisory group members would all have at least a basic familiarity with research methods and would be used to contributing to meetings relating to either research or policy. No training or one-to-one support was provided during the project, either to group members or to researchers.

What roles were taken in the interaction?

The research team devised the agenda for the first meeting. The agenda was shared after this point to some extent: towards the end of the first and at each following meeting, the advisory group were asked what steps they felt the group should take next.

Members of the group were asked to contribute to discussions and to help shape decisions as follows. After introductions, each meeting started with a presentation by the research team outlining their work to date and seeking questions of clarification. Then a further presentation outlined decisions that needed to be taken at that stage in the review. At this point the group was asked to respond, through an open discussion, to a set of questions set by the research team. At the end of each meeting the chair listed the main suggestions he felt had been made by the group and asked for confirmation.

In addition, at the second meeting, the research team asked the advisory group to take sole responsibility for a decision that would then be used as part of the review's methods (see the selection of priority outcomes for synthesis in Section B1 on page 25).

What methods were used with the aim of supporting involvement?

Steps taken to facilitate the involvement of all advisory group members included:

- preparation of a glossary of research terms, which was circulated at the second meeting
- development of terms of reference for the group, which included:
  > the aims of the advisory group
  > descriptions of the range of experiences brought to the group by different members
  > tasks that members would be expected to undertake
  > other expectations of group members (that they would be familiar with health issues for men who have sex with men, that they should be aware of, and be able to present in discussion, a range of views pertinent to group tasks)
  > clarification that discussions would be conducted in both plain English and technical language, that group members would be refunded standard travel expenses and that they would be acknowledged in review reports
- postage of information well in advance of each meeting
- full introductions at the start of each meeting
- provision of handouts of PowerPoint presentations at meetings with detailed tables printed in a readable font size
- structuring some of the interactions to record views and priorities in two rounds of voting
- seeking feedback from group members after the first meeting about their hopes for and experience of participation
- producing detailed minutes of the discussions and suggestions made at each meeting
- following up members who were unable to attend specific meetings with a letter outlining the main discussion and decision points from the meeting and a request for advice
- sending a draft copy of the final report or the review to each advisory group member for comment.

Accountability and ownership

Several of the methods mentioned above, including the chair's seeking clarification over the main points raised in meetings, the use of detailed minutes and the circulation of a draft of the final report, were used in order to improve accountability of the research team to the advisory group.

However, ultimate responsibility for the review lay with the research team. The research team needed to seek the agreement of the manager of the EPPI Centre's contract at the Department of Health if the team wished to change the plans outlined in the original proposal for the review.

At the first meeting one advisory group member from the DH sought clarification of the status of DH representatives on the group. They were named at that point as having observer status. At the second meeting's prioritisation of outcomes for the review, all group members voted, including those from the Department of Health.

Example 2 **User involvement in systematic reviews**

B. What happened?

B1. Processes, tasks and resulting issues

Selection, recruitment and attendance

All those invited to join the advisory group accepted the invitation but not all members were able to attend all three meetings. While there was always someone from a service user organisation present at each meeting, one was unable to attend the first meeting and the other was unable to attend the second and third meetings.

Interaction and engagement

Minutes of meetings record that all members present participated. The extent of participation varied, however. The meeting minutes attribute the vast majority of contributions to discussion to four of the seven members, none of whom was from a service user group. The lead researcher's notes from one meeting record her concern that one of the members from a service user organisation did not say very much.

As mentioned above, the advisory group chair wrote to all of those unable to attend the second meeting to request further input. No response was received from the service user group member who had been unable to attend. Neither individual from service user groups made contact with the research team between meetings.

No responses were received to the request for an evaluation of experiences of the first advisory group meeting. No second request for this information was sent out.

The prioritisation of outcomes described immediately below required all members to leave the table and place votes on a flipchart. This activity provided a welcome break and brought a more informal and communal atmosphere to the meeting.

Tasks conducted by the advisory group

The two main tasks were to make recommendations about the scope of the review through open discussion and to select priority outcomes for the review's data synthesis stage independently of the research team.

Early in the first meeting, the research team presented its ideas for the review and asked group members to discuss whether they thought important aspects would be covered.

At the second meeting, the research team presented the findings of the systematic map. This map described the range and number of studies found, but not study findings. The group was then asked to identify which interventions, and which sub-groups of men who have sex with men seen in the map, should be a priority for the review's syntheses.

A formal consensus development exercise to identify the outcomes that were considered a priority by the most group members was also held at the second meeting. The procedure for this exercise was as follows:

- The research team presented a list, on flipchart paper, of over 15 different outcomes they had identified from intervention evaluations.
- The group was asked to look at the list, suggest additional outcomes they thought were important and suggest categories that should be collapsed together. They were asked to talk about the value of different outcomes.
- Since group behaviour often leads to early closure of decisions, the research team ensured that the group considered the list of outcomes to be exhaustive before moving on to the second stage of consensus development.
- Each group member was given two sets of stickers: 15 green stickers and five yellow stickers.
- Participants were asked to vote with their green stickers for the outcomes they thought should be a focus for the review. They were advised that they could allocate their stickers as they liked: all against one outcome, or more evenly spaced.
- When all had placed their votes, the group was asked to examine the results of the vote and hold an open discussion.
- The group then voted again with the yellow stickers.
- The most popular outcomes and the outcome with the greatest number of votes were minuted.

Example 2 **User involvement in systematic reviews**

Figure 2.2. Outcomes identified and prioritised by the advisory group using formal consensus development methods

Outcome*	First round of voting	Second round of voting***
Knowledge/awareness	9	4
Attitudes/motivations/intentions	4	0
Beliefs/perceptions	6	2
Psychological well-being	5	0
Skills	11**	Skills (general) 1 Practical skills 2 Interpersonal skills 4
Unprotected anal intercourse (UAI)	3	0
Sero-discordant or unknown status unprotected anal intercourse (sdUAI)	11	5****
HIV incidence	10	4
Incidence of other sexually transmitted diseases	9	2
HIV test use	6	2
Condom failure	5	0
Structural outcomes (e.g. provision of a new service, condom distribution)	11	4

Key

*   A subset of the outcomes discussed are presented here (those voted for in either the first or the second round).
**   After the first round, the group decided to split this outcome into three types and vote separately for each.
***   All outcomes receiving a vote in this round were selected for study in the review
**** This outcome became the priority outcome for study in the review and received most emphasis in the review's write-up.

The advisory group was also asked:
- to examine lists of identified studies to identify relevant studies missed by the review team
- how the review's findings could best be communicated to a variety of audiences
- to comment on a draft report of the review.

Influence

When writing up the final report of the review, the research team agreed that the advisory group as a whole had influenced the review in a number of important ways:

- In discussion at the first meeting group members advised against focusing on the epidemiological concept of 'risky sexual behaviours'. They advised instead that the research team frame the review around the idea of men who have sex with men gaining control over their own health. Control could be gained, group members argued, by having knowledge and a range of skills or through improvement of personal circumstances. These included being well informed, for example, or having the skills to negotiate sex, or not being subjected to discrimination because of sexuality or HIV status. This focus on control demands that health promoters aim for empowerment through information and support, rather than condemning any particular behaviour. This discussion led the research team, in consultation with the Department of Health, to revise the conceptual framework of the review to be centred on control over their sexual health by men who have sex with men.
- Open discussion at the first meeting also identified an important threshold date for the review. Group members advised that the widespread introduction in the developed world of Highly Active Antiretroviral Treatment (HAART) in 1996 is likely to have changed attitudes to HIV and sexual behaviour. The group recommended that the review focus on studies conducted after this date. As a result, the review's map of research and all three syntheses were restricted to studies where data were collected in or after 1996.
- At the second meeting, group members also discussed sub-groups of men who have sex with men that should be a priority for study. The team proposed that the review focus on UK studies of groups of men who have sex with men vulnerable to reduced control over their sexual health. The group singled out HIV positive men who have sex with men and young men who have sex with men as being particularly important. The review team subsequently interpreted vulnerability quite broadly and sought studies of the following sub-groups of men who have sex with men (although studies were found for only the first six categories):
  > HIV positive men who have sex with men
  > young men (aged 16 to 25) who have sex with men
  > men who have sex with men selling sex
  > working class men who have sex with men
  > black and ethnic minority men who have sex with men
  > disabled men who have sex with men
  > men who have sex with men who inject drugs, have a low income, have lower educational achievement, do not identify as gay/bisexual or are in some other way socially excluded.

Example 2 **User involvement in systematic reviews**

Arguably the most direct form of influence of this group, however, was enacted through the prioritisation of outcomes (see Figure 2.2). The results of this process were as follows:

- In the initial identification round, the group identified an outcome that the research team had overlooked. In addition to unprotected anal intercourse (already identified by the research team) the group emphasised the importance of sero-discordant or unknown status unprotected anal intercourse (sdUAI). This is unprotected anal intercourse where one partner is positive for the HIV virus and the other is negative, or when one does not know their HIV status. This outcome is when exposure to HIV is most likely.
- All the outcomes that received a vote in the second round were selected for study in the review. The outcome that received the most votes (sero-discordant or unknown status unprotected anal intercourse) was given the most emphasis in the review's write-up. Figure 2.2 shows all the outcomes receiving votes in the first or second rounds.
- As Figure 2.2 shows, there was a range of outcome preferences within the group. In discussion, some group members emphasised the value of HIV incidence since it measures risks to people without HIV. Others stressed the importance of knowledge or awareness, partly because they were easy to influence.

The advisory group as a whole has been influential in other ways. Its work is now described in the manual for reviewers undertaking reviews as part of the International Cochrane Collaboration (www.cochrane.org/resources/handbook/). The review itself has been cited by a number of authors and the Department of Health stated that it would be used to develop policy to address stigma and HIV.

Accountability or ownership

The choice of outcome focus of this review would appear to be the part of the review that is most owned by its advisory group, and it is an important one. This prioritisation framed the review's findings about intervention effectiveness in a completely different way from other existing systematic reviews of HIV. Previously these had measured any type of sexual behaviour, or unprotected anal intercourse, regardless of whether it also involved knowledge about HIV status.

The chair's summing up of the recommendations from each meeting was designed to check that points of agreement in open discussions were recorded. However, this approach does not ensure that all points of view are taken into account. After the review was finished, one advisory group member revealed concern about the review's focus on particular sub-groups of men who have sex with men. While the groups selected can all be seen to be particularly vulnerable to 'reduced control over sexual health' ('Section B1 'Influence'), this member was concerned that other groups of men who have sex with men were vulnerable in other ways that the review had not addressed. This distinction between different perspectives and the development of consensus within a group highlights the importance of seeking a wide range of perspectives in the first place.

B2. Barriers to participation

We have identified a number of barriers to user participation in this work:

- The research team's approach of working with staff from organisations could be judged to have excluded men who have sex with men but who do not have such affiliations.
- The research team's lack of a budget for advisory group work and the way in which staff time was not allocated explicitly to management of the advisory group also potentially had an impact on participation of service user groups. Lack of a budget could have been problematic for service user groups with limited income. In addition, greater efforts at following up those who did not attend meetings might possibly have increased their contributions outside meetings.
- There was also limited time at meetings to address potential differences in understanding of terminology used to describe different research designs and methods.

B3. Methods that helped in overcoming those barriers

To have worked with men who have sex with men and who were not aligned with a specific organisation, although potentially valuable, would have required a completely different approach to involvement. Such an approach might include more dedicated staff time to recruit, brief and support users and the use of additional methods, such as small-group work for eliciting the engagement and interaction of users. Within the approach used, participation could possibly have been improved if we had been able to refund participants from service user groups for their time.

The glossary of research terms that was distributed at the second meeting may have helped reduce differences in understanding of the terms being used by the research team to describe different research designs and methods.

B4. Resource issues

As mentioned above, limitations in financial resources and time were potential barriers to user participation.

Relationships and good will were possibly a more central resource for this review, however. The advisory group was able to build upon several existing relationships. Often these had been forged through collaborative work. Members may also have felt more at ease at the group's first meeting because of being with people they already knew and had worked with. The research and policy focus of the advisory group work was not dissimilar to aspects of the Community HIV and AIDS Prevention Strategy partnership's work, for example. Group members worked hard to cover a large amount of ground, possibly because they saw the work as a further development of work previously done.

Example 2 **User involvement in systematic reviews**

B5. Feedback loop to users

While all group members were asked to comment on the draft report of the review, we received no input directly from those from service user groups. The review's findings were presented at the Community HIV and AIDS Prevention Strategy partnership's annual conference for health promoters and campaigning groups, where they were well received.

C. Learning points for the future

To support service user involvement in future reviews we would consider:

- planning for a sufficient budget and additional time a) to enable effective follow-up of advisory group members who have had less of an input into discussions and decision making, and b) offering payment to members of not-for-profit groups for time spent at meetings
- ensuring that one member of the research team is explicitly allocated the role of managing the advisory group.

Example 2 **User involvement in systematic reviews**

D. Conclusions, discussion and recommendations

This advisory group work was worth doing. It had an impact on the focus of the review.

The model used, depending mainly on input from participants at group meetings, requires relatively few resources. Our allocation of minimal resources may however have resulted in less input from those from service user groups where time and financial resources were most precious.

Structured consensus development techniques for eliciting ideas and setting priorities can be helpful for allowing equal input to decision making. The techniques appeared to be very easy to engage with. Using them helped to identify important distinctions between different outcomes for men who have sex with men. Group members were then able to produce a list of outcomes ranked in importance through individual votes. This approach does, however, require work up front to identify a starter list of topics for discussion. The process encourages focused discussion of reasons for different perspectives. However, it does not ensure that all participants' perspectives are represented in final decisions.

It is worth noting that this could be an unusual topic and advisory group. Research has been a central issue in the gay community since the appearance of HIV in the early 1980s and the Community HIV and AIDS Prevention Strategy initiative in particular has meant that there is a great deal of engagement in research among the user groups that campaign for and support men who have sex with men. Additional work might be needed in other research areas to encourage an interest in the idea of reviewing research among service users and groups that represent them.

This report is limited in that it consists of reflections solely by the research team and, because of constraints on time, has not been compiled in consultation with members of the advisory group. We have also used minutes to measure the extent of participation of users and need to note that, despite being very detailed, these were not designed primarily to record the full extent and subtleties of different participants' contributions to meetings.

We recommend that resources be made available to enable more formal prospectively designed evaluations to be conducted to examine the roles and influence of service users in such groups. Rigorous study of user involvement in advisory groups is needed before specific recommendations can be made to support users and ensure that they can help improve the relevance and uptake of review findings.

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EXAMPLE 3

An example from newborn screening

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This work was planned and executed by a research team. Nevertheless, in places the work is reported in the first person to reflect the personal tone adopted when working with service users.

Example 3 User involvement in systematic reviews

A. Background

A1. Background to the systematic review

Using evidence to inform policy and practice

This report describes user involvement in a programme of research and policy development. It is an unusual example in that it includes systematic review **and** use of evidence to inform policy and practice. This work includes innovative examples and valuable experiences for those conducting systematic reviews.

We used elements of explicit consensus development methods (Murphy, Black, Lamping, McKee, Sanderson and Askham, J. 1998[1]) described in section A3.

The focus of this work

In the UK the bloodspot programme screens around 700,000 babies each year. With parents' consent, spots of blood are collected from babies' heels when they are a week old. These spots are tested for four serious but rare conditions. While phenylketonuria (PKU) and congenital hypothyroidism have been tested for decades, national screening for sickle cell disorders and cystic fibrosis is being introduced now. Screening for at least one additional condition is currently being piloted.

The inclusion of new conditions, developments in technology and new expectations for parent choice led to the recognition that national standards and resources were needed.

In 2002 the Great Ormond Street Hospital NHS Trust, the Institute of Child Health and the Social Science Research Unit, Institute of Education, University of London were funded to develop evidence-informed policy for newborn bloodspot screening. Known as the UK Newborn Screening Programme Centre (UKNSPC), this collaboration worked to bring together a range of evidence and knowledge to develop evidence-informed, relevant and realistic policies and resources, under the strapline 'UKNSPC, quality through partnership in newborn blood spot screening'.

The evidence included in this work

This work included drawing together:
- research knowledge (published and unpublished, primary studies and systematic reviews)
- knowledge and experiences of:
    - > practitioners
    - > policy makers
    - > parents (users).

The flowchart in Figure 3.1 illustrates how this evidence was gathered and used to inform policy development.

User involvement

This report describes user involvement (in this case the parents of babies who are screened) in the collection of evidence and the development of evidence-informed policies and resources from 2002–05. It culminated in the publication of:

- policies and standards (UK Newborn Screening Programme Centre, 2005a[2])
- implementation guidance (UK Newborn Screening Programme Centre, 2005b[3])
- parent information leaflets (UK Newborn Screening Programme Centre, 2005c[4])
- a handbook for health professionals (UK Newborn Screening Programme Centre, 2005d[5])
- training resources for health professionals (UK Newborn Screening Programme Centre, 2005e[6]).

Users were involved largely in the interpretation and implementation of review findings.

The work was funded by the Department of Health (DH) for England on behalf of all four UK countries, with a budget for user involvement of around £20,000.

The design of user involvement in this work

The aim

The aim was to ensure that policies and resources were relevant to parents, taking into account their experiences and views.

Initiating involvement

Involvement of parents in the programme was initiated by the team at the Social Science Research Unit (by Ruth Stewart, in particular).

The design

Policy and resources were developed by 12 multi-disciplinary expert groups. Parents were included in these expert groups to share experiences and join discussions.

Previous experience of working together

There was no intention to select participants for the groups with previous experience of working together, nor did we aim to recruit parents with whom we had worked in the past.
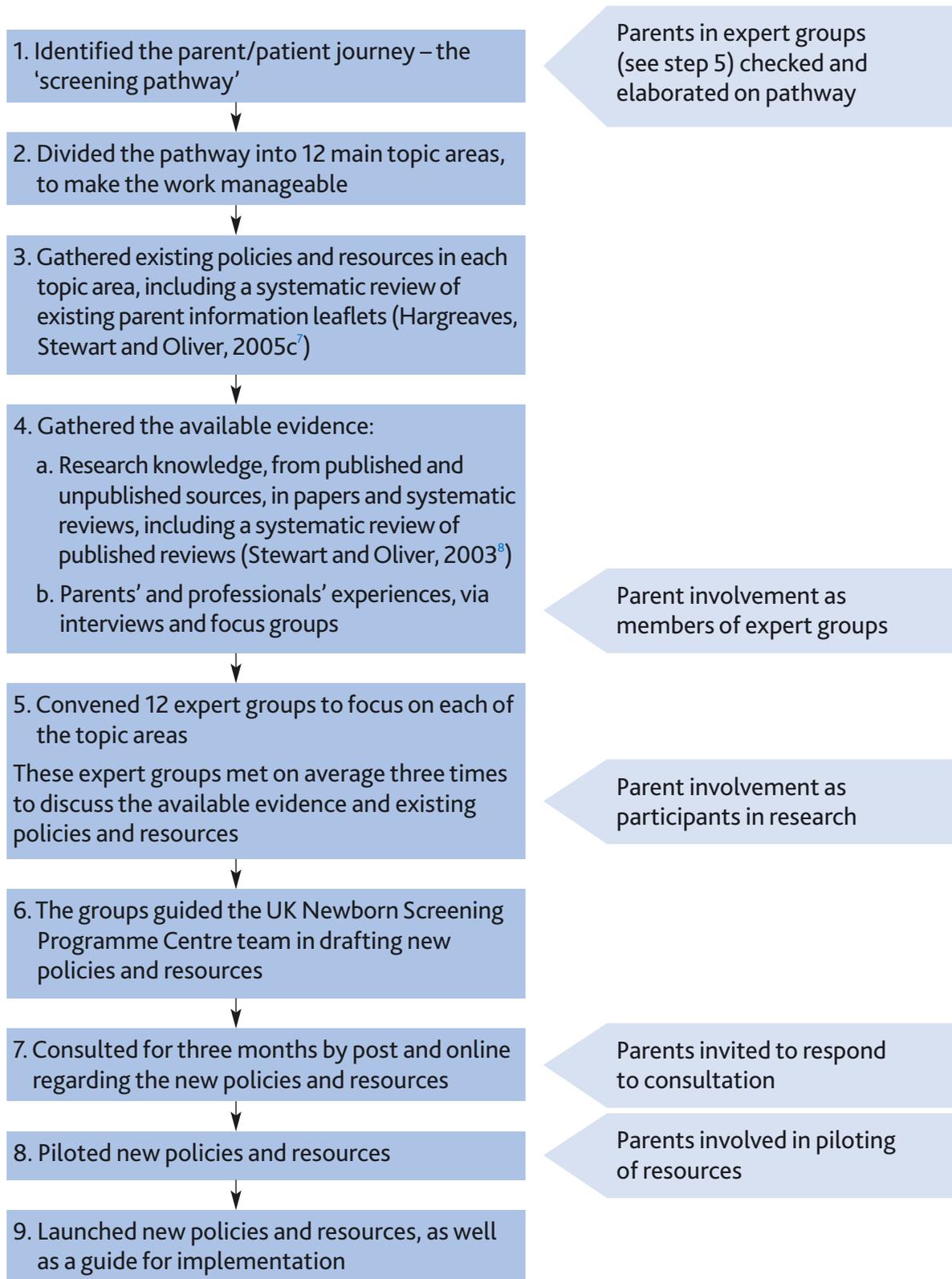
Example 3 User involvement in systematic reviews

The stages that users were involved in

Twenty-two parents were involved in the multi-disciplinary expert groups (steps 5 and 6 of Figure 3.1). Within these groups they helped with:

- describing the parent journey (reviewing step 1).
- interpreting collected evidence, for example contributing to discussions of evidence presented by the researchers
- clarifying parents' needs and priorities, for example discussing when to offer parents the choice to have their babies screened
- guiding detailed development of policies, for example discussing the protocol for if/when parents refuse screening for their babies
- guiding detailed development of parent information, for example deciding how to describe to parents the severe disability caused by some of the conditions
- providing feedback on policies and resources, for example responding to the public consultation on version 1 of the resources (step 7) and taking part in the piloting of resources (step 8).

In addition, 47 parents and 35 health professionals contributed as research participants in the interview and focus group study (step 4). A summary of this study's findings was presented to the expert groups to inform them of the views of this wider group.

Figure 3.1. Flowchart illustrating the stages involved in this work

1. Identified the parent/patient journey – the 'screening pathway'

> Parents in expert groups (see step 5) checked and elaborated on pathway

2. Divided the pathway into 12 main topic areas, to make the work manageable

3. Gathered existing policies and resources in each topic area, including a systematic review of existing parent information leaflets (Hargreaves, Stewart and Oliver, 2005c[7])

4. Gathered the available evidence:

   a. Research knowledge, from published and unpublished sources, in papers and systematic reviews, including a systematic review of published reviews (Stewart and Oliver, 2003[8])

   b. Parents' and professionals' experiences, via interviews and focus groups

> Parent involvement as members of expert groups

5. Convened 12 expert groups to focus on each of the topic areas

These expert groups met on average three times to discuss the available evidence and existing policies and resources

> Parent involvement as participants in research

6. The groups guided the UK Newborn Screening Programme Centre team in drafting new policies and resources

7. Consulted for three months by post and online regarding the new policies and resources

> Parents invited to respond to consultation

8. Piloted new policies and resources

> Parents involved in piloting of resources

9. Launched new policies and resources, as well as a guide for implementation

Example 3 User involvement in systematic reviews

A2. Background to participants

Who we aimed to involve and their potential interests

We aimed to involve people with experiences of newborn screening (see Box 1) who were confident joining in discussions and committed to attending three meetings over 6–12 months.

> **Box 1: Definition of service users**
>
> - Service users were defined as parents whose babies had been screened, preferably within the last five years.
>
> - Efforts were made to include parents whose babies had received the full range of possible screening results.

We aimed to include parents with varied experiences of newborn screening results:

- Parents of unaffected babies remembered the midwife taking some blood from their babies but often hadn't received the results and didn't think any more about it. The challenge was to interest them sufficiently in this programme of work to engage their involvement.
- In contrast, the lives of parents of babies with the conditions changed completely following newborn screening: they remembered the screening programme, in particular receiving the results, and were heavily involved in the ongoing care of their children. The challenge with this group was to focus on the screening programme rather than their everyday concerns about their children's health.

We had no expectations that parents had any experience of research or evidence-informed policy prior to their involvement in this work.

The research team

Ruth Stewart and Sandy Oliver were involved in the design and implementation of user involvement in the work of the UK Newborn Screening Programme Centre.

- Dr Sandy Oliver has been working in the area of user involvement in research for 18 years, first as a service user then as a researcher. She has long experience of engaging service users in discussions about the design and conduct of research, and the interpretation and implementation of research findings.
- Ruth Stewart has experience of working with mixed groups of stakeholders in conducting systematic reviews for policy and practice in HIV prevention. Her

volunteer work with small-group teaching, and mother and baby groups, meant that she was well placed to facilitate user involvement in this work.

We drew on experiences and resources developed for user involvement in a related systematic review (Oliver, Dezateux, Kavanagh, Lempert and Stewart, 2004[9]; Oliver, Lempert, Stewart, Kavanagh and Dezateux, 2004[10]). We also adapted a glossary developed for the advisory group for that project. We prepared job descriptions and person specifications for recruitment based on similar work originally for the NHS Health Technology Assessment Programme, and this has since been recognised as good practice by INVOLVE (www.invo.org.uk).

Other participants in this work

The UK NSPC team included collaborators at Great Ormond Street NHS Trust and the Institute of Child Health: researchers, midwives, paediatricians, epidemiologists, health service managers and administrators.

Other relevant professionals working in newborn screening were invited to take part in the multi-disciplinary expert groups: health professionals who deliver screening, for example midwives who take the blood; paediatricians; laboratory directors; lawyers; ethicists; Department of Health staff; and members of research bodies, such as the Medical Research Council.

Most expert groups included two parents, around 10 other relevant professionals and five members of The UK Newborn Screening Programme Centre (UK NSPC) team.

A3. Methods for involvement

How were users recruited and selected?

A pool of potential users was recruited via parent networks by posting adverts in newsletters and on message boards of support organisations, including organisations for families affected by the conditions and broader parenting groups. We also distributed a leaflet to support organisations appealing to parents to get involved. Some of the parents recruited through support groups took part to some extent as representatives of those groups, although we did not require them to do so. These parents gave us access to a wider body of opinion through at least one social network.

I (Ruth Stewart) also contacted health professionals we knew and asked for their help. We only used this route for recruitment when all other channels had been exhausted, as we didn't want to put parents under pressure to take part.

I briefed by telephone everyone who assisted us with recruitment to ensure a clear understanding of what was expected from parents.

Example 3 **User involvement in systematic reviews**

All parents who responded to initial recruitment were sent an invitation pack containing background information and a job description, outlining what we could offer and what we expected from them (see appendix 1). This was followed up with a telephone call, in order that:

- parents could ask questions
- I (Ruth Stewart) could gain an understanding of the parents' experiences of newborn screening

This information helped us allocate parents to the different groups. It helped us identify parents who had lived through difficult emotional experiences and reflected on these sufficiently to draw on them and engage with our collective task. Parents who still seemed overwhelmed by their experiences were not included, although the expert groups were informed of particularly negative experiences, however rare.

- we could check parents' availability for the meeting dates.

Parents were matched to the different expert groups on the basis of their babies' screening results (see Box 2).

> **Box 2: Examples of how we allocated parents to the groups**
>
> - We included parents of babies unaffected by the conditions on the blood sampling group because we felt that parents whose babies are found to be affected by the conditions might be distracted by their own specific and rare experiences.
> - We included parents of babies who were unaffected and parents of babies who were affected by the conditions on the consent group, because while the vast majority of parents have babies who are unaffected by the conditions, only parents of affected babies tend to appreciate the importance of the tests.

How were users contacted and briefed?

Once we had allocated parents to groups, we contacted them to confirm their invitation to take part. Where possible communication with parents was now by email, although for some contact continued by telephone and post.

Background papers for the meetings were sent out by the central UK Newborn Screening Programme Centre office. I (Ruth Stewart) checked all letters sent to parents to ensure that the language was appropriate.

Finally, I contacted all parents a week before each meeting to check that they had received the background papers, to answer questions they may have and to confirm their attendance.

The content of background papers was reviewed in presentations during the meetings to allow members to see, hear and ask questions about the information.

Were users provided with any training or introduction in systematic reviews?

Parents were not offered any formal training in systematic review of the evidence or the use of this evidence to inform policy, although they were briefed informally in advance, as described above. I (Ruth Stewart) met with parents for pre-meetings (coffee before meetings), sat with parents during the meetings, and phoned and emailed parents after each meeting. Pre-meetings allowed parents to meet one another, so that they always knew me and at least one other member of the group before the formal meetings began.

Were researchers or others provided with any training or introduction to working with users?

A few weeks before the first parent information group meeting, the research team attended a training session on interactive teaching. The trainer for this session, Sally Crowe of Crowe Associates (crowe-associates.co.uk) encouraged us to use practical, interactive activities for the groups rather than formal committee procedures.

The chair of each expert group started each meeting by saying that it was important to keep language non-technical and to take into account the different views and experiences of all group members.

What roles were taken in the interaction?

During the meetings, in principle, parents were included as equal members of the expert groups. Like other members of the groups, parents were expected to play a role:

- contributing to discussions
- shaping decisions.

What methods were used to support involvement?

Steps taken to facilitate user involvement included:

- preparing a glossary of terms circulated to all parents and published through the project website
- developing job descriptions and person specifications for each group

Example 3 User involvement in systematic reviews

- posting information in advance of each meeting to give parents time to read it through and ask questions
- briefing service users over the phone before and after each meeting and in person before each meeting; I (Ruth Stewart) usually initiated this, although occasionally parents phoned with a query
- considering attendees at the meeting: reserving seats for myself and the parents before joining parents for a pre-meeting coffee
- contacting parents after meetings by telephone and email to enable them to ask questions and make additional contributions which they may not have thought of during the actual meeting, or may not have felt able to voice
- giving parents further opportunities to contribute their views via consultations and piloting of resources
- reimbursing parents for their involvement (see Box 3).

> **Box 3: Payments**
>
> We paid:
>
> - parents' travel expenses to and from meetings
> - for coffee at pre-meetings
> - honoraria for parents equivalent to £17 per hour at each meeting, given in gift vouchers*: this came to £75–£100 for each meeting
> - a fee to organisations that assisted with recruitment, in recognition of the support these organisations provided to parents. The fee was either £8 per hour of meeting attended by their members, or later, because this became too difficult to administer, a one-off £50 fee per parent recruited.
>
> *The use of gift vouchers to pay honoraria reduced the risk of volunteers' welfare benefits being jeopardised due to this additional income

Accountability or ownership

We aimed to be accountable to all those involved through transparent reporting of decisions. Each meeting reported and built on discussions at the previous meeting so that members had a chance to correct minutes and reconsider decisions. Because parents had opportunities to input later in the development of resources through consultations and piloting, they could see and comment on the final decisions made by the UK Newborn Screening Programme Centre team. In writing reports of meetings and of policy and resource development we tried to be explicit about decisions and the reasons behind them (Stewart, Hargreaves and Oliver, 2004[11,] 2005[12]; Hargreaves, Stewart and Oliver, 2005[13], 2005[14]).

B. What happened?

We (Ruth Stewart and Sandy Oliver) considered each of the topics addressed above and report below what actually happened.

B1. Processes and roles

Recruitment and selection

Recruitment and ongoing contact with parents required dedicated time and consistency of staffing. I (Ruth Stewart) worked in the role of parent support research officer, the first and continuing point of contact with all parents over the three years of the project.

In general parents of children affected by the screened conditions were more interested in getting involved. Recruitment of parents whose babies were not affected proved more difficult and we had to resort to inviting parents we already knew, something we had hoped to avoid. Two of the six parents of unaffected babies who took part in groups were previously known to us. All recruited parents attended meetings except two, who did not turn up and never contacted us again.

Most commonly mothers responded to invitations, although two fathers did take part in the expert groups. One couple attended a group together, on their request.

Despite hoping to avoid using health professionals in parent recruitment, it was difficult to access parents whose babies had congenital hypothyroidism, as no specific support organisation currently exists in the UK. As a result of health professionals helping with recruitment, we had two instances where parents were members of the same groups as a health professional who had treated their child. In these cases I (Ruth Stewart) contacted the parents and health professionals concerned in advance to forewarn them. This prior relationship did not appear to prevent parents participating in the meetings.

On one of the expert groups, unknown to the research team, there was a laboratory director who had years before informed the parents on the group that their children had cystic fibrosis. The laboratory director told us that she felt uneasy about the possibility that the parents might perceive her as the source of all their bad news. The parents on the group described being shocked when they initially made the connection. However, after a conversation with the laboratory director concerned, the parents said they understood better what her role had been, and viewed her in a better light.

Contacting and briefing

I (Ruth Stewart) built relationships with the parents, the majority of whom were responsive, returning phone calls and chatting about the meetings. A few engaged less, discussing only essentials such as the time and place of meetings.

Example 3 User involvement in systematic reviews

Introduction in systematic reviews for users

Before their involvement in this work most parents had very little or no experience of systematic reviewing or evidence-informed policy. One mother had been involved in supporting a systematic review in her professional capacity in the past, on a different subject completely.

At the first meeting of one expert group that met three times, members participated in an interactive learning activity focused on research design and the role of systematic reviews in informing policy decisions.

Roles

We found that parents and the team took on a range of roles. Often parents were more willing to share details of their experiences informally with me (Ruth Stewart) than in the meetings. This was true of both parents who were 'stay-at-home mums and carers' and parents in high-ranking occupations. To an extent I became friends with the parents over the course of this work. Some parents still send Christmas cards years later.

We found ourselves providing support to parents in ways we had not expected. Examples included looking after children while parents participated in meetings, acting as an introduction service for isolated parents who wanted to meet others with children with the same rare conditions, getting advice from a paediatrician for a parent who was expecting a second baby and was having difficulty getting the necessary specialist advice, putting parents in touch with their local newborn screening laboratory so that they could find out more about their baby's tests, and generally finding out information for parents about the conditions their children have. Through the process of involving parents in our work, we also became involved in their lives.

Level of engagement

From my own observations parents all took part in discussions at the meetings. At first they tended not to join in discussions until asked by the chair or another member of the group, but by the second and third meetings parents were more comfortable talking in the group.

The parent information group included more parents than the expert groups (four rather than two) and focused on parents' interactions with the screening service. Parents at this meeting tended to contribute more than parents on the other groups, perhaps partly due to the use of practical activities rather than formal committee procedures. Activities included noting personal roles on a screening time line that stretched the length of the meeting room wall, sorting topics on cards to prioritise issues, and scribbling amendments to text displayed on the meeting room wall. Even the simple requirement of getting up and walking around the room to participate in these activities made the atmosphere informal and encouraged one-to-one and small-group exchanges.

Parents' contributions to the meetings appeared to be shaped partly by other individuals. Some non-user members of the groups were particularly friendly and made an effort to chat to parents. Others made less effort and tended to dominate discussions. On at least one occasion parents commented after the meeting (to Ruth Stewart) that they had felt intimidated by a member of the group who had used technical language, or openly challenged others' contributions.

Influence on decisions

We believe that parents' views influenced decisions made in the groups. For example, on the group developing parent information, parents' views guided decisions about: the level of detail to include in the leaflet and the inclusion of the word 'death' on the front page of the leaflet.

User involvement in the expert groups also appears to have had a wider influence. As well as being involved in other research projects at the Social Science Research Unit, one parent has since been involved in groups for the National Institute for Health and Clinical Excellence, **an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill-health.**

Other group members reported learning from the parents' experiences and said they would be changing their practice as a result of what they had learnt. For example, one parent explained a useful trick for getting newborn babies to take thyroxine, something which is apparently very difficult.

Accountability or ownership

Despite attempts to be accountable to the members of the expert groups (including the parents), the team also had obligations to the funders to deliver work on time with limited resources. In addition, gatekeepers within the NHS were influential in the final decisions. For example, laboratory directors have been responsible for preparing and distributing much of the parent information relating to newborn screening and needed persuading that the new national leaflets were sufficiently detailed.

B2. Barriers to participation

We have identified a number of barriers to parents' participation in this work, as follows.

Potential to be recruited
Some parents, particularly those who did not belong to support organisations, were very unlikely to receive or access invitations to take part in this work.

Example 3 **User involvement in systematic reviews**

Childcare

Involving parents of sick children is particularly challenging. We had to contend with last-minute apologies and alternative input by telephone or email, and needed huge commitment by parents and the research team for families to attend meetings.

Childcare costs

Paying for childcare in order to attend meetings meant that some parents were not able to join groups. While the £17 per hour honoraria covered some costs, parents with more than one child felt this was insufficient. Similarly, the fact that the meetings were held in London meant that some parents had to leave home early and arrive back late, often causing additional difficulties with dropping off and picking up school-age children.

Travel

Delays on the roads and the public transport system meant that some members of the groups arrived late. While this problem was not unique to the parents in the groups, it did prove problematic if parents were already nervous about taking part and then missed the introductory sessions of the meetings.

Language

Despite attempts to avoid technical terms, language was still a barrier. Some parents found the names of the conditions screened for difficult to pronounce. To different degrees parents at the meeting would ask the chair the meaning of terms, or speak to me (Ruth Stewart) during or after the meetings. An example of language causing some confusion is the use of 'positive' and 'negative' to describe screening results. These words led to several confused discussions until we realised that some parents view a 'positive' result as meaning good 'positive' news, i.e. no condition detected, whereas health professionals use the term 'positive' to mean that the condition has been detected. We subsequently avoided using these terms whenever possible.

B3. Methods that helped in overcoming barriers

The following methods were implemented with the aim of overcoming barriers to involvement.

At the recruitment stage

As outlined in section A3, we conducted a lengthy recruitment and briefing process which included several contacts with parents before they attended any meetings. Immediately before they attended the main meeting, I (Ruth Stewart) supported parents in pre-meetings. I then supported them in the main meetings and followed up with a phone call and email a few days later.

Preparing for the meetings

The meeting room was prepared in advance to ensure that participants would be comfortable, would be able to see presentations clearly and would have room for their working papers.

Meeting for coffee beforehand was particularly helpful, as it provided a chance to introduce parents to one another, run through the agenda for the meeting ahead and go through the list of attendees so that parents knew something about others at the meeting.

Distributing information for meetings in advance is commonly held as good practice. This allowed parents time to read through the papers, refer to the glossary and ask questions before the meetings.

Parents particularly appreciated the care we had taken to collate their background papers and stationery in labelled folders large enough to add to at each successive meeting.

During the meetings

During the meetings themselves certain steps were taken to try and overcome power imbalances and language barriers. These included sensitive chairing of meetings, the use of first names rather than titles and the use of a range of activities through which people could share their views. These included small-group discussions, opportunities to vote for certain decisions, the use of a wall chart to guide and illustrate discussions, and use of flipcharts and coloured paper and pens.

Structured participation

The interactive learning activities structured participation so as to encourage contributions from quieter members. Consultation by email, telephone and post when finalising work formalised contributions, providing equal opportunities for contribution and influence.

General

I (Ruth Stewart) kept careful records of communication with parents. This informed decisions about which parents to include on each group and proved helpful in remembering details about parents and their families, such as the names and ages of their children.

Example 3 User involvement in systematic reviews

B4. Resource issues

The user involvement aspect of this programme of work was labour intensive over 18 months, during which it took approximately one day a week of my time (Ruth Stewart).

Additional resources included the time to develop links with the parent organisations and health professionals who assisted with recruitment, time to set up the room before each meeting, the development of a glossary, and time spent at meetings to support parents. Costs were also incurred for parents' travel expenses and honoraria.

Although difficult to quantify, the parent involvement benefited from my role in the research and policy development aspects of the project (my involvement was broader than the parent involvement work alone). These benefits included my knowledge of the conditions and of screening. For example, I was able to anticipate parents' concerns about congenital hypothyroidism and brief parents on the uncertainties about the condition before they attended the meetings.

B5. Feedback loop to users

Feedback to parents took place through informal ongoing contact I (Ruth Stewart) made with parents. More formally, parents were sent drafts of the resources and reports resulting from the work and were invited to give feedback through piloting and a consultation.

Along with other group members, parents were invited to the launch of the new national polices and resources for newborn screening in December 2005. Several attended this launch and celebration of our work.

Parents were sent the full pack of newly developed resources and successive annual reports to keep them up to date.

C. Learning points for the future

C1. Any learning points arising

We will be taking a number of points into account when planning future user involvement in our work and we hope these will be helpful to others.

Recruitment

- Recruitment takes longer than expected. It can help to try and anticipate whether any particular groups will be difficult to recruit, for example people with 'average' experiences who are not aware of any reason why their experiences are important. Users who have a clear interest in the topic are much more likely to volunteer.

Payment

- We now have a policy of offering parents £17 per hour spent at meetings for users involved in our work. We pay this in gift vouchers. We have sometimes asked parents to chose which vouchers they would like (for example vouchers to spend at Marks & Spencer or Boots) but to avoid spending hours shopping for vouchers, it is best to specify which vouchers you are offering.
- Although not raised as an issue in our work, volunteers can jeopardise their welfare benefits if they accept financial honoraria. This needs to be taken into account when making decisions about the amount and type of honoraria offered.
- Buying large amounts of vouchers is difficult, particularly as shops are reluctant to accept company cheques. It is important to consider who will buy vouchers as the amounts can total hundreds and even thousands of pounds.
- We have been recommended to buy general high street vouchers via the internet that are redeemable at a range of stores.
- There is also often a need to have cash available, for example to pay for coffee for an informal meeting in a café, or to pay for a taxi so that a user can catch a train in time to meet children from school.
- Pay honoraria for attending meetings afterwards, not in advance. We once paid in advance for three meetings and the users did not turn up after the first meeting.

Involvement in people's lives

- In inviting users to get involved in your work you are also getting involved in their lives. You need to be prepared to 'go the extra mile' to support them in a range of ways.

C2. Further analysis

It has not been possible to conduct further analysis of the user involvement in this programme. This report is based on reflections of Ruth Stewart, with input from Sandy Oliver.

Example 3 **User involvement in systematic reviews**

D. Discussion and recommendations

Did we achieve our aims?

The aim of involving parents in this work was to ensure that the policies and resources developed were relevant to parents, taking into account their experiences and views. It is difficult to assess the extent to which this was achieved. However, we observed that parents did shape the decisions that were made at the meetings (Stewart, Hargreaves and Oliver, 2005[12]). Initial piloting and consultation took place before the policies were launched in December 2005. More formal evaluation of the developed resources will be undertaken during 2006–07. This will shed light on what parents and health professionals think about the policies and resources developed.

This report contains the reflections of those involved in designing and implementing the user involvement in this programme of work. It would have benefited from input from the parents involved, but unfortunately this has not been possible.
We would recommend that in the future funding is set aside to evaluate user involvement during the project itself and believe that more formal evaluations of user involvement in research are needed to help address questions about the processes and impact of user involvement. As it is, we appreciate the opportunity from SCIE to write up this report.

We had prepared a generous budget for user involvement as a central part of the original funding proposal. As a relatively large programme of work, we were able to put considerable effort and resources into recruiting and supporting parents. We would encourage funders to put more money into this important aspect of research.

Appendix: Job description and invitation letter

Parent with experience of newborn screening

This group member will:

- be familiar with the Newborn Screening Programme
- have an understanding of the perspectives of parents of newborn babies in the UK
- be aware of, and able to present in discussion, **a range of views** pertinent to parents' perspectives of newborn screening
- be a member of a support network where they can discuss issues relating to newborn screening and the Programme Centre's work
- have **personal experience** of at least one of the following:

  > being offered newborn bloodspot screening
  > having their baby screened for phenylketonuria (PKU), congenital hypothyroidism, cystic fibrosis or sickle cell disease
  > receiving results of newborn screening
  > receiving counselling about newborn screening.

Each group member will:

- attend up to three meetings during the lifetime of this group
- attend a parent support meeting once during the year
- read papers in advance of meetings
- read and comment on the minutes of group meetings
- respond in writing on particular issues when requested at meetings
- be available for occasional one-to-one discussion with the team by telephone, email or post
- advise on disseminating findings through their own networks
- declare any potential conflicts of interest.

This generic job description was amended slightly for each of the expert groups.

DATE

Dear ……………........,

Do you remember when your newborn baby had their heel pricked and some spots of blood taken for testing? Every baby in the UK has some spots of blood taken from their heel when they are about a week old.

These are used to test for a number of rare conditions, which can be treated if picked up early. The majority of babies are not affected by the conditions and parents often never hear anything more about the test.

I work as part of a new national centre which has been set up by the Department of Health to set quality standards for these tests. This includes everything from what information is given to parents to how the midwife takes the blood spots and when parents receive the results.

We want to make sure that parents have a say in the decisions that are made, and would like to involve parents in the work of the Centre in a number of ways:

• By inviting you to come and sit on one of our working groups. These working groups meet in London every couple of months (usually three times in all) to discuss and make decisions on different aspects of the newborn screening test. For example, we have a group looking at choices for parents, and another developing information resources for parents. We can pay your travel expenses and a small fee to help cover childcare. We've drawn up a 'job description' for parents who want to be involved on our working groups and can discuss this with you if you are interested in taking part.
• By speaking to you more about whether you were given any information about your baby's test, and whether it answered your questions. We will be holding some discussion groups later this year with groups of parents to find out more about parents' views and experiences of the communication process.
• By asking for your feedback on the parent information leaflets we developed at the end of 2003. We will want feedback on whether they are easy to understand and whether they contain the right level of information.

We shall work alongside all parents involved with the centre to make sure that you are well supported.

If you'd like to help with this work please contact me, Ruth Stewart, on

……………………........…, or by email at ……........……………………………………………

I'd love to hear from you.

Yours faithfully,
Ruth Stewart

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