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# Developing measures for effective service user and carer participation

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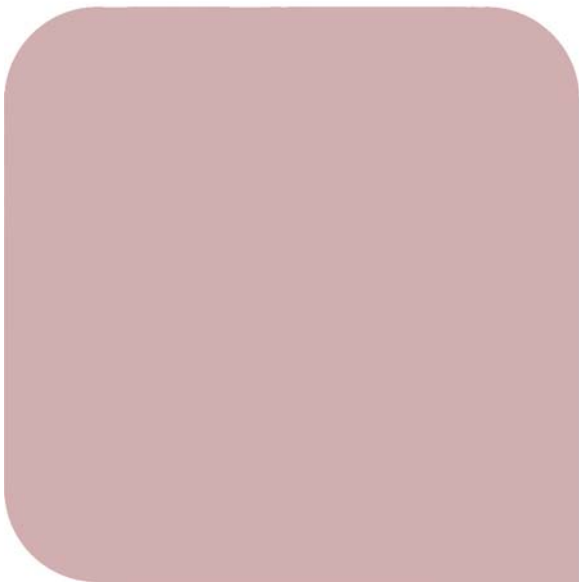
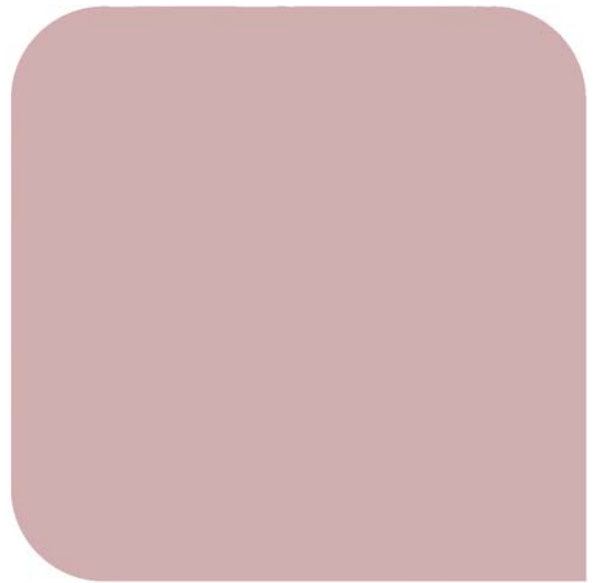
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# Developing measures for effective service user and carer participation



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NB References to the key reviews (Appendix 1) are prefaced by '#' (e.g. #10) and references to practice sites (Appendix 5) are prefaced by ‡ (e.g. ‡07).

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## Introduction

The purpose of this report is to present the process and outcomes of research commissioned by SCIE. The audience for the report is primarily SCIE, since the findings and recommendations from the report will be presented in an accessible format in a Resource guide designed to have wider appeal. The Resource guide will be of direct use to organisations, groups and individuals concerned to develop their own measures to evaluate the effectiveness of service user and carer participation.

## Background

Service user and carer participation is firmly on the agenda, in large part through the efforts and energies of service user and carer movements and organisations dissatisfied with many aspects of the services available and the failure to consult when planning new services or restructuring existing ones. This, coupled with a vision of how improvements can be made, has ensured that service user and carer participation has become central to social care services.

The research reported here builds on SCIE Position paper 3 (*Has service user participation made a difference to social care services?*), which based its analysis on six reviews of practice in different domains. Whilst the service user participation movement has achieved much in terms of the principle, it is less clear what changes have resulted in practice. This current research project was charged not with evaluating the impact of participation, but with scoping what is known about it and how evaluations are being conducted. With this knowledge, the project aimed to suggest ways in which individuals, groups and organisations can develop measures to evaluate the effectiveness of service user and carer participation.

Systematic evaluations of the impact of participation are critical if we are to develop models that can be tried and tested to help providers and users of services understand the ways in which participation is making a difference.

## Approach

The research consisted of three components. The first was a scoping review building on SCIE's (#03) earlier review in order to identify the key reviews of evaluation of service user and carer participation and to extract the data from them. The second was a mailing/emailing to 1600 social care organisations, both to access 'grey literature' and to survey ten practice sites in more detail. (A pre-requisite was a scoping exercise of organisations in Wales and Northern Ireland to add to the

England database). The sites were chosen using criteria agreed with SCIE in the research tender. Further grey literature was added using 'snowball' techniques, including some specific evaluative 'toolkits'. The third component continues to be the advice and deliberations of an advisory group of eight service users and carers, drawn from a small geographical area but from a broad experience of services, and also the resources within the research team, which included two service user researchers.

The data and experience from these components has been synthesised into a set of 'key factors', presented in the conclusion to the full report, with a tentative list of 'pointers' to help organisations, groups and individuals to help measure effective participation. We see the key factors and pointers as the bones of the Resource guide.

## Component 1: Scoping review

### Scoping method, strategy and results

This is a scoping review. Studies were included if they fulfilled all of the following criteria:

- reviews, systematic reviews
- descriptions or assessments of tools evaluating service user consultation, participation or involvement
- service users included all users of health, care, housing and social care services
- 2001 to 2006 (with the assumption that reviews and systematic reviews would encompass significant materials from before 2001)
- English language only.

Studies were excluded if they simply reviewed service user involvement/participation projects without any evaluation of the project. The search was limited to material from 2001 onwards because a SCIE review has been published on a similar topic recently (Carr, 2004 #3). By looking for literature from 2001 onwards, the current review seeks to capture all recent research and reviews not covered by this previous review.

The electronic databases searched were Applied Social Sciences Index and Abstracts (ASSIA) (2001–2006), British Nursing Index (BNI) (2001–2006), Cochrane Database of Systematic Reviews (Cochrane Library, Issue 3, 2006), CENTRAL (Cochrane Library, Issue 3, 2006), CINAHL (2001–2006), EMBASE (2001–2006), Educational Resources Information Center (ERIC) (2001–2006), International Bibliography for the Social Sciences (IBSS) (2001–2006), Medline (2001–2006), NHS DARE (Cochrane Library, Issue 3, 2006), NHS EED (Cochrane Library, Issue 3, 2006), NHS HTA (Cochrane Library, Issue 3, 2006), PsycINFO (2001–2006), Social Science Citation Index (2001–2006), Science Citation Index (2001–2006), Urdadoc (2001–2006). Searches were also made of the following websites and grey literature sources: DH-Data (2001–2006), HMIC (2001–2006), Joseph Rowntree Foundation (2001–2006), King's Fund database (2001–2006), the National Research Register (2001–2006), and SCIRUS (2001–2006).

To identify relevant reviews, this report used a validated three-line search strategy for identifying reviews (Montori *et al*, 2005). This was combined with truncated terms and synonyms for the principal elements of the research question: service users, involvement and evaluation. Earlier, more sensitive scoping searches were conducted using additional terms also, such as consumer, client, customer, engagement, perspective, voice, attitude, view, preference and opinion. However, the team decided that insufficient time and resources were available for sifting and

reviewing the large number of citations generated by these more inclusive searches and, as a result, a more specific, focused search strategy was used, employing fewer terms and generating fewer, but more highly relevant hits. The chosen terms were used both as free-text and database keywords, where they were available. The search filters were modified for different databases to take account of the thesaurus and limitations of each database. There were no limits of language. An example search strategy is given below:

### Search strategy

Database: Ovid MEDLINE(R) <1996 to August Week 5 2006>

Search strategy:

-----

1. meta-analysis.mp,pt. (18724)
2. review.pt. (682447)
3. search.tw. (49601)
4. or/1-3 (724821)
5. (carer\$ or caregiver\$).tw. (12036)
6. (service\$ adj2 user\$).tw. (773)
7. 5 or 6 (12722)
8. (effectiv\$ or measur\$ or model\$ or evaluat\$ or indicator\$).tw. (1695808)
9. (involv\$ or particip\$ or consult\$).ti. (53755)
10. 4 and 7 and 8 and 9 (13)

The limitations of searching only electronic databases to identify relevant studies for review are increasingly being recognised (Wade *et al.*, 2006; Greenhalgh *et al.*, 2004; Rothstein *et al.*, 2004; Grayson and Gomersall, 2003). This is especially the case in the field of social science, which lacks the traditions of a stable, controlled vocabulary and structured abstracts, which are found in the area of medicine and health (Grayson and Gomersall, 2003). Therefore, additional methods of searching for and identifying relevant studies were also used. During data extraction, reference lists were checked for further relevant references, which were then checked against the inclusion criteria. Informal sources of knowledge were also exploited, such as the personal knowledge and databases of members of the project team and communications from colleagues, to supplement those studies found by the searching of electronic databases and reference tracking.

Chris Carroll performed the searches, imported the results into reference management software and deleted duplicates. Titles and abstracts were screened by Susan Nancarrow using the inclusion/exclusion criteria to identify potentially



relevant publications. In cases where there was insufficient information in the title or abstract to make a judgment on inclusion, the full publication was retrieved.

## Results

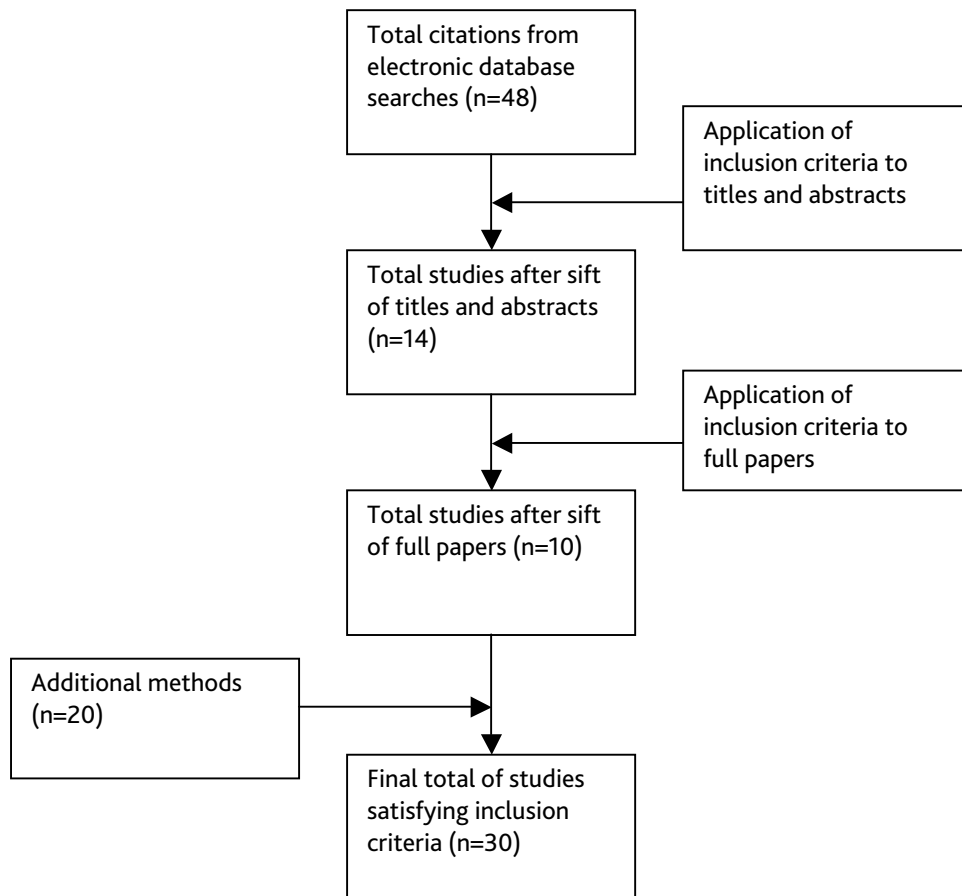
The QUORUM flowchart (Moher *et al*, 1999) in Figure 1 explains how many studies were rejected and at which stage, and the means by which included studies were identified. After the removal of duplicates, a total of 48 reviews were identified by the searches of the electronic databases and grey literature sources. The titles and abstracts of retrieved studies were then screened using the stated inclusion and exclusion criteria. The result was 14 potentially relevant reviews, four of which were ultimately rejected after examining the full paper because they were found not to satisfy the inclusion criteria. Ten reviews were therefore included from these sources (#10, 12, 13, 14, 15, 16, 17, 19, 20, 21). Informal sources identified another 20 reviews. Overall, therefore, 30 reviews were identified which satisfied the inclusion criteria. However, amongst those that remained in the review, very many provided only a limited review of evaluation of participation, with most typically focusing on participation or involvement rather than evaluating their effects.

## The process of reviewing the literature

Data extraction was performed on references selected for inclusion using a form developed for this review and piloted on a sample of the studies. The pilot extraction was conducted by four reviewers (MD, JC, AH and SN) to test the data extraction form and to assess inter-rater reliability. The template was developed through an initial review of the literature undertaken by one member of the team in consultation with the project team. This drew substantially on the model devised by Crawford *et al* (ref #01, SDO review: *User Involvement in Change Management: A review of the literature*). Consensus was reached on the details of data extraction and a revised form. Given that this is only a scoping review, which seeks to capture any and all findings of potential value to this emerging field, there was no formal process of quality assessment for the included studies.

The 30 review studies were distributed amongst reviewers from the research team, who used the standardised template to extract data from each of the documents. Secondary analysis of six papers was undertaken as a process of verification. See Appendix 1: Key reviews; Appendix 2: Standardised table for key reviews. The summaries of each of the papers can be made available as a separate addendum if requested.

**Figure 1 The means by which key reviews were identified**



### Findings from the scoping review

Table 1 shows the range of service user, carer and other groups covered in the key reviews. We have also extracted the various purposes of evaluation indicated in these reviews and the range of approaches identified.

**Table 1 Summary of stakeholder groups, principle purposes and evaluative methods**

Attribute	Details
Stakeholder group(s)	Adult learners (#17) Cancer patients (#8, 13) Children and young people (#4, 5, 7, 9, 35) Learning disabilities (#6, 32) Mental health service users (#15, 18, 20, 21, 30)

Attribute	Details
	<p>Older people (#25**, 26, 34)</p> <p>Physical disabilities (#22)</p> <p>Service providers (#12)</p> <p>Trainers/educators (#13, 14)</p> <p>Mixed (#3, 10, 27)</p>
Purpose of evaluation	<p>Adult participation in learning – widen (#17)</p> <p>Clinical practice guidelines (#27)</p> <p>Curriculum development for training nurses (#14)</p> <p>Developing health care policy and research (#26, 27)</p> <p>Own care (#6, 9, 35)</p> <p>Patient information material (#27)</p> <p>Statutory requirement/policy directive</p> <p>Monitor service quality or feedback on aspects of the service (#7, 22, 26)</p> <p>Priority setting (#7, 20, 22)</p> <p>Research (#4, 8, 20)</p> <p>Services – increase uptake; impact on service delivery, design and decision making (#7, 22)</p> <p>Service planning and evaluation (#22, 26)</p> <p>Specific question about consultation (#34)</p> <p>Strengthen local or participatory democracy of users (#22)</p>
Evaluative approaches	<p>Accessing people through existing networks (#20)</p> <p>Arts based/visual (#5)</p> <p>Audits involving patients (#10, 14)</p> <p>Care delivery (service users involved in) (#15)</p> <p>Citizen advocacy (#10)</p> <p>Citizens' juries (#10)</p> <p>Consultant groups (#10)</p>

Attribute	Details
	Drawing and posters (#4) Goal attainment scaling (#6) – but was unsuccessful with people with learning disabilities Interviews (group/individual) (#4, 5, 10, 14) IT linked (#4, 5) Journals (#4) Mapping (#4) Meetings (#10) Observation (#4) Patient forums (#10) Patients employed as consumer advocates (#10) Patients involved in decision making and teaching (#14) Photos/videos (#4) Project development (#26) Questionnaires (#4, 6, 10, 14) Research (by service users) (#15, 26) Research proposal consultation (#20, 26) Role playing/story telling (#4) Training, planning, implementation and evaluation of curriculum (involvement in) (#14, 15)

### Different approaches

We do not have sufficient evidence or conceptual clarity to make judgements about what kinds of evaluative approach would work best with which kinds of service user and carer participation. However, this should provide a guide for the future, since (as Table 2 illustrates) there are a wide variety of goals with which service user and carer participation are undertaken, and we can assume that this will have some bearing on the evaluative methods that would be used. These participative goals include guiding service planning and evaluation, increasing service uptake and developing policy and research, as well as more personal participation in terms of choice and control over one's own service. A wide range of stakeholder groups are involved in participatory approaches and, again, we might speculate that different evaluative methods might

serve different service user groups better, though the evidence base is just not available to make these judgements.

Crawford (#01: p30) provides one of the more useful conceptualisations of the different approaches and philosophies to user participation, but this remains limited to methods of service user involvement, as opposed to evaluations of the effectiveness of participation. The findings of our survey suggest that Crawford's (2003, #01: p14) recommendation that 'independent evaluation should be undertaken of the impact of changes based on implementing the views of service users, including quantitative comparative research and economic evaluation of the costs and benefits of different methods of involving users' has yet to be acted upon. Crawford's (2003, #01: p79) conclusion that 'most of the reports that we identified did not describe the outcome of user involvement' remains true three years later. Where outcomes have been evaluated, or at least discussed, Crawford (2003, #01: p79) suggests they fall into one or more of these categories:

- increased satisfaction with services
- promotion of further user involvement initiatives
- improved management
- changes to service priorities.

Service user and carer participation is undertaken with a number of different goals in mind, such as the development of services, identification of priorities, monitoring of service priorities. These goals will influence the methods used to evaluate, though the literature does not give any clear indication of which kinds of method might suit which kinds of purpose.

### Conceptualising the outcomes of service user and carer participation

Crawford *et al* (2002, #10) point out that the ultimate goal of service user participation should be the promotion of health, quality of life, or overall user satisfaction with services. However these outcomes are often difficult to measure, can take a substantial amount of time to become evident, and be difficult to attribute to a specific participatory intervention. As a result, evaluations tend to use short term or intermediate indicators or proxy outcomes, and no published studies definitively report on the longer term outcomes in terms of benefits to quality of life.

Additionally, within the service user and carer participation literature, it is well recognised that the process of participation itself can bring benefits to the participants themselves (including staff and service users/carers), such as improvements to self esteem and changes in attitude. The extent these intrinsic benefits are valued varies, with Truman (#21, 2005: p572) suggesting that 'User involvement should not be seen as an end in itself but rather it is a means of enabling people to make choices and have control over their daily lives'. However, the intrinsic

value of service user participation might also have an impact on the extrinsic changes; for example, increased self-confidence gained via the process of participation (implicit gains) might be a necessary prerequisite to campaign for specific changes to a service (explicit gains). Table 2 provides a summary of references to different kinds of outcome in the key reviews.

**Table 2 Intrinsic benefits and extrinsic results**

Attribute	Details
Intrinsic benefits of participation	Attitudes (of staff, organisational culture) (#10; 15) Familial relations improved (#35) Feedback, participation and change at an individual level (#3) 'Socialisation' of children – being part of decision making process Learning, social contact, increased confidence to criticise services, improved confidence (elderly service users) (#1) Process (of participation – evidence) (#7) Rewarding for staff (#10) Satisfaction (with the process of participation) (#1, 10) Self-esteem (improved in patients) (#10, 35)
Extrinsic results of participation	Accessibility of services increased (#10) Changes to services, activities (leisure), information provision, décor, best value recommendations (#5) Changes at strategic or care planning level (#6) Costs reduced (in cost of care) (#13) Future independence enhanced (#9) Gaining qualifications, obtaining a job, skills acquisition (#17) Information material and sources developed and improved, more accessible (#1, 10, 27) New services and initiatives (#1, 10) Organisational commitment and responsiveness (#3) Research priorities identified (#20)

Attribute	Details
	<p>Research response rates and satisfaction scores improved (#15)</p> <p>Research satisfaction surveys improved with user interviewers (#27)</p> <p>Scope of services changed (#10)</p> <p>Stability of placements for children (#9)</p> <p>Staff training and selection (#6)</p> <p>Support (identified) needed to enable service users to provide services (#15)</p>

The outcomes of service user and carer participation can also be considered in terms of timescale; are the outcomes to be evaluated in the short, medium or longer term? Intrinsic outcomes are more likely to be immediate; extrinsic outcomes may have a 'long horizon' and, therefore, be more difficult to measure.

Wright *et al* (2006, #7) refer to outcomes that need to be:

- realistic: development of effective participation is time consuming, so organisations need to acknowledge how much change is possible within the timeframe
- measurable: need to identify what change will improve as a result of participation and should be measurable to evidence that change
- specific: outcomes need to point to clear proposals for change.

This is very similar to research into the kinds of goal that are most likely to be successfully achieved in one-to-one work in participative social work practice (Marsh and Doel, 2005) and, therefore, more susceptible to evaluation.

The conceptual map that the research team developed during the course of the research is presented as Appendix 3.

### Barriers to evaluation

Although the identification of barriers in the literature was primarily concerned with barriers to participation, these same barriers can also be inferred as restricting or preventing evaluations of participation. Table 3 summarises the range of barriers identified in the key reviews. To these, we might also add the lack of knowledge about the best ways in which to implement an evaluation of participation.

**Table 3 Barriers to evaluation of participation**

Attribute	Details
Barriers	<p>Attitudes of staff entrenched, hostile, not understanding (#32)</p> <p>Awareness of support mechanisms needed to facilitate user involvement lacking by managers (#22)</p> <p>Communication between staff and service users is poor (#21)</p> <p>Diversity missing in service providers – do not reflect the users (#3)</p> <p>Eligibility criteria undermine meaningful user participation (#22)</p> <p>Funding: lack of core funding for these initiatives; financial priorities that do not include service user involvement (#22)</p> <p>Information not made available to service users limits options and possibilities (#32)</p> <p>Organisational capacity and resources lacking or limited – affects ability of the organisation to implement change (#26)</p> <p>Organisational entrenchment of interests of service system (#32); organisational culture is hostile (#3)</p> <p>Policy direction (local and/or central) may work against what users want (#26)</p> <p>Power imbalances not addressed (#32)</p> <p>Lack of support for service users with impairments can be a barrier to engagement (#22)</p> <p>Unresponsiveness of agencies to respond to the messages from users (#21, 26)</p> <p>Tick-box approach: government demands for agencies to include user participation can become an exercise rather than embedded in organisational practice (#3)</p> <p>Tokenism: service user participation initiatives become consultation exercises to approve of service planning and policy approvals rather than enabling service users to be key partners in their formulation (#3, 10, 22)</p>



Attribute	Details
	<p>Training, or appropriate kind, not available (#21)</p> <p>Unsystematic, so there is a failure to embed evaluation of participation – need to develop a whole-systems approach (#7)</p>

#### Power: whose evaluation is it?

One of the barriers to participation and, by inference, to developing measures to evaluate participation, is the failure to recognise issues of power, more specifically imbalances of power. Although it is infrequently mentioned in the key reviews (indeed, perhaps *because* it is infrequently mentioned), these imbalances and the different kinds of expectations and worldviews of organisations, professionals, service users and carers, has a large impact on the effectiveness of participation and the perspective on its evaluation.

Since the participation process has an impact on a wide range of different people (service users and carers, service providers and policy makers), it is important to consider whose perspectives need to be considered in evaluating participation and how these different perspectives can best be accommodated. If tokenistic participation is to be avoided, it seems that all parties must work at understanding and acting on these differences.

## Component 2: Practice survey

### Accessing the 'grey literature'

A key part of the scoping strategy was to identify as much of the 'grey literature' as possible. Our principle method was to email and mail all of the social care organisations (1,599) on the existing database of a member of the research team. Many of these were service user or carer-led organisations, and all were concerned with social care services and the people who use them, across all service user groups. An additional scope of Wales (40) and Northern Ireland (87) was undertaken to extend the original database. The result was that:

- 945 emails were sent to a wide range of groups, including 211 children's organisations
- 654 Easyread press releases with covering letters were mailed out to social care organisations, including 117 newly scoped organisations in Wales and Northern Ireland. The press release and covering letter were sent out by Disability Wales to 162 member groups.

In addition to the press release, information was placed on Disability Research and Danmail email group lists. Information also went out in VOICE UK magazine.

Thirty (0.58%) responses were received, some beyond the deadline date, though the project responded as flexibly as it could to late responses. One of these respondents could not be included because they wished to mail out the information to their members and then wait for responses and the project timetable did not allow for this. The differences in timescale between funders/commissioners, researchers, social care organisations and service users and carers are an important finding. We anticipate that many more organisations, especially service user-led ones, would have responded if timescales had been less restricted.

From these responses and other snowballing techniques we contacted ten sites to include in the practice survey.

### Possible reasons for the low response rate

- Organisations and groups are not funded specifically to carry out evaluations and are unable to do so from their core funding. There are not, therefore, the resources (in time and money) to prioritise this area.
- The press release could have been clearer regarding the information being sought.
- The timescale of the project meant that the press release was sent out during July/August when many people are away from work on annual leave.
- The project timescale did not allow enough time for responses, especially from organisations that might need more time to consult with members, etc.

- It seems clear that monitoring participation, in terms of the effectiveness of user participation initiatives, projects, events, etc. is very rarely built into the methodology of the actual work being undertaken. This is, in itself, an important finding from the project.

## Toolkits

From these and other contacts ('snowballing'), other grey literature emerged, such as Northern Ireland's (2006) *Assessing the Impact of Service User Participation in the Southern Area Health and Social Services Council*. This informal literature has been incorporated into the ten key factors and the pointers in the conclusion to the report. In addition, a number of 'toolkits' for evaluation emerged. In particular, findings from the practical application of models such as Appreciative Inquiry ([www.aipractitioner.com](http://www.aipractitioner.com)), the Rickter model (#01), the Logic Model (McLaughlin and Jordan, 1999) and Telford *et al*'s (2004) model for evaluation. These will be included in the Resource guide.

## Introduction to the practice survey

The practice survey covered ten sites across England, Wales and Northern Ireland (see Appendix 5). As we note in the next section, our initial survey found comparatively little formal evidence of evaluation of participation, though the tiny response makes any general comment difficult. Of those where evaluation had taken place, we selected the sites for the practice survey with the aim of balancing geographical spread with coverage of the major service user and carer groups. This has provided rich data about the practice of evaluating participation, with messages that are both general and specific to service user groups and to particular settings. These specific groups and settings point to the need for diverse, and sometimes divergent, approaches to evaluation. This report reviews the overall findings from the practice survey before turning to the specific issues raised by particular settings and user groups. A protocol was developed to guide the enquiry with each practice site (Appendix 4).

## The nature and scale of evaluation of service user participation

The distinction between participation *per se* and evaluation of participation has not always been easy to discern in this survey. The concept of working in partnership or participatively is axiomatic throughout social care and is central to the values of social work. We have chosen to focus on projects with a specific remit to develop participation and we defined that as relating to the key constructs of 'voice', 'choice', and 'change' (#13). Each of these constructs lends itself directly to an evaluatory question: 'did they listen?', 'did I get what I wanted?' or 'did the service change?' Without completing the 'loop' of service delivery by seeking answers to these

questions, whether formally or informally, it is difficult to see how the currency of participation may be maintained. From our wider survey there is no doubt that many projects may well have reflected on these issues. The timeliness of this project is, however, reinforced by the finding that while there are relatively few organisations that have completed a detailed evaluation of the impact of participation, there are many who are seeking a route map for such activity.

Some of the evaluations included in our survey were on-going and these fell into two categories: those that had a continuing commitment to evaluation as part of a 'quality loop' (¶07), or those that had moved into a new phase of evaluation, building on the learning from the first phase (¶05). Some of the sites we selected involved the evaluation of a specific, time limited project (¶08) or one project moving into another (¶03), in which evaluation had been built into the terms of the project and, importantly, its budget. In other cases, an evaluation component had been added into the project which could itself be either time limited or mainstream. This raises an issue regarding service evaluation that is current across social care projects in respect of innovatory practice. Much developmental work takes place within the framework of short term project grants and the focus of any evaluative process that accompanies such grants will determine the nature and style of the evaluation (¶03). In general, project evaluations in our survey appear to focus on three distinct areas:

- the achievement of intended goals or outcomes
- the user experience
- the potential for 'mainstreaming' the project's work.

This can be distinguished from the evaluation of projects with an indefinite life span where the focus is likely to be on:

- refining goals and outcomes
- service improvement/extension
- service development.

### Deciding to evaluate participatory work

As noted above, the decision to evaluate the impact of participation can be seen as a natural part of practice development, be it through the 'quality loop', the concept of reflective practice (Schon, 1983) or the 'Assess, Plan, Intervene, Review' model to name three standard approaches to practice. The increasing interest in evaluating participation may be connected with what Corby (2006) identifies as the increasing shift in UK social work research towards outcome-focused research, but this begs the question of whether this has been triggered by the turn to short term development work through 'project funding' approaches. Patton (1981) has suggested that evaluation has to be systematic, may have many purposes but fundamentally must be *used* by someone if it is to be effective. Newburn (2001:10) throws further light on

this by suggesting that 'the most important purpose of evaluation is not to prove but to improve'. Within the framework of participatory and emancipatory research, evaluation can take on a further dimension.

The decision to evaluate was, for most sites, an explicit aspect of commitment either within the agency/project itself, or within the wider organisational structure, to the concept of participation. Thereafter, motivations varied according to the type of project. At one extreme there was an inherent experimental design in the project's work, while at the other, there was a more informal taking stock of progress.

We found that the most frequent motivation to evaluate came from doing something innovatory, where the motives of both proving and improving were combined. In these cases the evaluation was integral to the project design as a whole, i.e. from its inception. The most formal of these was the CSI Study (#09). This was a longitudinal study of the outcomes of an intervention with mental health service users and was established as the first CSI outcomes study involving a three-stage review of service users as compared with a non-equivalent control group. The POPPIE project (#08) involved the development of a range of different activities across European partner agencies. These investigated the training requirements needed (of both service providers and old people themselves) to ensure that older people feel confident and have the necessary skills to work in partnership with in a range of public services across Europe. Although many of the sites in our survey had involved service users and carers in the evaluation, one group of sites specifically focussed on the involvement of service users in developing participation (#05, 10, 11, 12). The last two of these projects had a research focus and had involved training service users and carers in research methods to a level sufficient for them to be able to undertake research independently, rather than as adjuncts to 'professional' researchers.

By the criteria for inclusion in our survey, all the sites that we surveyed had decided to evaluate participation (though some (like #04) were far from formal and were 'thinking on their feet'), so they do not provide direct evidence about the barriers to undertaking evaluation. They were able to point to difficulties they had overcome that might prove to be barriers elsewhere. The CHILYPEP Project (#05) found that their first evaluation was limited by inadequate research design and therefore decided to develop a more robust approach the second time round, employing a trained researcher to enhance the quality of the evaluation. A lack of research expertise and confidence within participation projects may be a disincentive to undertaking evaluation. The Cornwall Young Carers' Project's (#06) first phase evaluation found that a lack of detailed record keeping had limited the data available to the evaluation. The evaluation report recommended changes to routine data collection that made the second evaluation more effective. This lack of routine data may also point to a barrier to evaluation. The third barrier would appear to be

funding, which may be either inadequate or non-existent, unless careful consideration is given at the project design stage.

The decision to evaluate is not always initiated within the target group for evaluation. VOICE (formerly Voice of the Child in Care) (07) is a national organisation providing advocacy for looked after children and young people. VOICE initially developed their participatory work with one secure children's home out of discussions between their Visiting Advocacy Service (a service level agreement with a number of secure children's homes) and a single unit manager. They then offered the system to other units, as an extension of their existing advocacy role, and negotiated an extension to their service level agreement accordingly. As the process grew, it incorporated a feedback dimension and the evaluation developed as one that was on-going.

### Evaluation approaches used

Research about participation, whether primary research or evaluative research, has a particular relationship with both the political and the therapeutic concepts of partnership outlined by Howe (1991). Bennett's (2004) study of participatory research on poverty notes that participatory research can itself add value by, for example, improving research and leading to policies which make sense to those affected as well as by bringing direct gains to the participants, not just in terms of personal confidence but also as learning and skills development. She also considers that participatory research embodies 'the right ... to influence images ... and public debate' with the potential to develop a fuller notion of citizenship. Applying this to the evaluation of participation would mean that the service users engaged in participation should at the very least have some control of the outcomes of the participation, and of the means by which their achievement was evaluated. To be judged as emancipatory research, Oliver (1996) would go further, adding to control over the research process the necessity to control the resources to do the research.

The evaluations within the sites surveyed used a wide range of approaches. In some cases an external contractor was invited to propose an evaluative framework. These evaluations are variously described as 'independent' (02, 03, 06) or 'external' (01). The VOICE project (07) appears to have elements of action and research, and was designed by an agency external to the direct service providers. The CSI study (09) was conducted by external academic researchers and, as noted above, had an experimental design. That the independence of the evaluation is seen as a defining factor is noted by a project that had undertaken internal evaluation but reported that they had never had an independent evaluation (04).

Other sites chose evaluation approaches that were a reflection of the holistic approach to participation within the project itself. In the SkillNet Project (02), 'self-advocates' participate, indeed have control, in all aspects of the project. Their

decision to commission an evaluation by self-advocates from another project is participatory. A further creative approach to evaluation was noted in the TRUE project (#09), which had developed a 'colliding world' model of evaluation involving a reflexive approach. This had involved training of service users in research methods so that when these users' responses were themselves the focus for evaluation the respondents were 'research aware'.

Only one evaluation attempted a controlled trial approach. The Participation in Consumer/Survivor Initiatives (#09) compared the outcomes of participants within the CSI project to a non-equivalent control group who had not used the service. This was a longitudinal study, focussing explicitly on outcomes for service users at baseline, nine- and 18-month intervals.

Techniques such as focus groups, life histories and photographic projects are both means of achieving participation as well as a means of evaluating it. Conference environments are now being used as an evaluation approach (#03). Training and preparation for service user involvement in, or leadership of, evaluations is central and significant but may be assisted by drawing on experiences in other areas of the project's life (#10). Whether service users are interviewing, or being interviewed, preparation will be a significant factor in the quality of the data.

Asking the right questions is central to the quality of the evaluation. The NIUSE SEA project (#01) used a 'Rickter model' to develop a measure of distance travelled to project goals. Liaising with stakeholders about their knowledge needs is also important. The Chilypep Project (#05) canvassed a wide range of public service organisations to establish what they needed to know about young people in the area in order to develop participatory services.

The regular collection of basic administrative data is also central to effective evaluation. Patterns of attendance at projects, interest in particular activities, the project's 'reach' (#04), who is using the service and how they came to be there, all provide important data for both formative and summative evaluation.

### Levels of participation

All of the survey sites represent attempts to develop participation by service users and/or carers, but the goals and the means of participation varied widely, as did the level of control over the processes of participation. The VOICE project (#07) was initiated as a means of beginning to develop the first stages of participation by young people held within a secure environment. The concept of participation in this context, albeit warmly embraced by some of the managers interviewed in the study, is necessarily limited when compared to many of the other sites in the survey. At a superficial reading it verges on tokenistic participation, concerned as it is with topics such as food, visits, telephone calls, etc. The researcher suggests, however, that in

this environment the fact that some items of concern could be fed back to managers and acted upon generated considerable enthusiasm. More generally, Howe (1991) has described partnership as being broadly in two categories: political and therapeutic. In many of the survey sites, both these elements were reflected in the participatory practices. The level of participation in the evaluation was, however, more varied. Where the projects had an element of service user control, for example on management committees, or, as in the case of SkillNet (02) in all aspects of the project, then the evaluation appeared to have a more participatory focus. In the TRUE project (09) the prior experience of service users as researchers led to a reflexive response to being evaluated.

### Dimensions of participation

The dimensions of participation, as revealed by the practice survey, are particularly complex. Within our survey we found some evidence of a mirroring between the participative culture of the organisation and the extent to which the evaluation was also participatory. First is the question of the organisational culture, not just for the fostering of participation but also for the support for evaluation. This has been recognised in some of the evaluation toolkits where it is recognised as essential to prepare not only service users but also staff for the evaluation experience. In two of the secure units covered by the VOICE study (07) there had been obstacles in responding to the real concerns about food and it was noted that the relevant staff may not have shared the commitment to participation.

### Who evaluates?

In considering who undertakes the evaluations, the survey considered Oliver's (1996) key criteria of control over both the research process and the resources to do the research. It seems to be clear that where research had been commissioned from an external agency, a degree of control would be lost by participants in a project. In two cases (02, 03) self-advocates from another project had been used to undertake the evaluation of the survey site. Findings in (02) had been fed back through 'decision teams' and a website. The extent of reciprocity, or the potential for it, is unclear in this arrangement, although it is an attractive concept. On the other hand, the same project had taken as its original funding proposal targets as the outcomes to be measured by the evaluation, rather than considering the focus on self-advocate participation that had become the dominant theme in the project.

There are clearly some important messages for professional/academic researchers who engage with participative evaluation about who defines the terms and rules of play and whether these embrace the participative paradigm.



### Processes and outcomes

The current trend towards a focus on outcomes has been noted above. This does not preclude an evaluation combining both formative and summative measures. What may be central here is ensuring the right fit between the stage of evaluation (i.e. formative or summative; adaptive or transformative) and the approaches, methods and focus of dissemination that are used. The VOICE project (07) feeds back to unit managers on a six-monthly basis but is now aggregating two years of findings from three units with a view to using the report to persuade a wider range of units to engage with the process.

### When to evaluate

Evaluation as a concept remains, to some degree at least, a contested term (see for example Newburn, 2001), incorporating a wide range of approaches as observed in this survey. If the goal of projects is to increase voice, choice and influence it seems that it must combine both formative and summative approaches if the project is to approach a social justice model of functioning. Perhaps the more pertinent question here is when to commit to evaluation, to which the answer would be at the inception of a project. For on-going services, the goal should be to strive to embed both participation and evaluation of its impact, so that it is not seen as a one-off occasional 'extra'. Service user-led organisations (like 02, 03 and 04) have an advantage in this respect, since 'participation is like breathing'. However, this does not automatically mean that the impact of participation will be evaluated.

### Diversity: evaluating different kinds of service

There remain issues of capability, capacity and external perceptions in involving service users in evaluative activity. Central to effective evaluation is the environment and culture of the organisation concerned. The projects surveyed have all had participation as their major goal, but the environments and cultures have differed. It is inevitable that a project for young people within a secure environment is likely to be different in at least some dimensions from a community-based service for adults. At the same time the impact of the evaluation is subject to very similar constraints: the culture and commitment of all those engaged in the project to hear and act upon the evaluation. An early success in the voice project (07) related to arrangements for telephone calls, because the manager was committed to participation, had control over the telephone system and was prepared to take the matter up as a priority. Changes to the food in two units have so far not been possible, either because of disinterest or lack of capability or control.

Different kinds of service are likely to require different kinds of techniques and methods of evaluation. Creative approaches have been developed to explore views about services with very young children and have been central to participative

evaluation of Sure Start and Children's Fund activities. Similar creativity also operates in participative evaluation with people who have learning disabilities, physical disabilities and mental health problems. Central to the application of methods and techniques is the understanding that identity and self-esteem play an important part in the ability to participate in research.

### Publicising and disseminating the evaluation

Four of the sites in our survey had evaluations that could be said to have 'completed' (#06, 08, 09, 10). In addition, three other sites (#03, 05, 06) had completed earlier evaluations. Of the completed studies, three (#06, 09, 10) had published reports, and one (#06) has been the subject of academic journal publications. Two sites (#05, 06) had used conferences to present findings to stakeholders, and one (#01) plans to (as opposed to (#03) which used a conference environment to conduct their evaluation). Two sites (#02, 04) use websites to disseminate findings.

## Component 3: The advisory group

The advisory group has had just one meeting since the interim report, so much of the text of the interim report is included below. This third meeting used small groups and full group discussion of an early draft for the Resource guide. Significant suggestions for changes were made (see Appendix 4). A fourth and final meeting of the advisory group will be held in late January to discuss the final draft of the text for the Resource guide.

### Planning

The facilitator of the advisory group was recruited only two weeks before the first meeting (because of the changed circumstances of the original facilitator), so did a particularly good job to recruit members to the group in the time available. It did limit the kind of preliminary contacts we would have liked to have taken place. Ideally, the facilitator would have preferred to have recruited from a wider source.

It is obviously quicker and easier to rely on existing contacts, though there is a danger that this approach will involve those individuals who may already be over-involved in initiatives and may, as a result, be experiencing 'involvement fatigue' (Barnes *et al*, 2003). The approach also makes it harder to recruit people with a wide range of perspectives and experiences.

### Recruitment

Three members had already been recruited before the facilitator became involved with the project and all three had experience of services for people with physical impairments or disabilities. This reduced the remaining places to five.

The facilitator was asked to recruit members who would 'represent' a range of circumstances and interests. It is unrealistic to expect one person to be typical or 'representative' of any particular group (Hanley *et al*, 2004; Faulkner, 2003; Entwistle *et al*, 1998; Beresford and Campbell, 1994). Therefore, members were instead recruited to provide a range of perspectives to the group. Despite the short timeframe a wide spectrum of people were recruited:

- both users and carers
- an older person
- someone with mental health difficulties
- someone with a learning difficulty
- someone with experience of using services as a child
- people with physical impairments/disabilities.

In addition, issues of equality and diversity were considered in order to involve communities or groups of people that are traditionally excluded from research and participation (Beresford, 2005a; Hanley, 2005; Hanley, 2000). The people recruited have a wide age range (21 to 88), three are male and five female, and two are members of black and minority ethnic communities. The facilitator was also asked to recruit people who had experience of participation and/or research as well as those who had none. This was also achieved.

When initially contacting prospective members, the facilitator asked for some brief background information, including their experience of social care services and demographic information as above. SCIE's definition of social care services was used:

All interventions provided or funded by statutory and/or independent agencies which support older people, younger adults and children in their daily lives, and provide services which they are unable to provide for themselves, or which it is not possible for family members to provide without additional support. They can be provided at home, in day centres or on a residential basis, including substitute family care and care home.

(Waine *et al*, 2005: p1)

It was important to explain and discuss this at the initial stages to ensure the recruitment of members with appropriate experience. All members had experience of using social care services except for one of the three people who had already been recruited when the facilitator joined the project.

When recruiting people it was important to use language and ideas that people were familiar with (Hanley, SCIE, 2005; Hanley *et al*, 2004). The topic of the research study was understandably unfamiliar to several of the group members and was quite complex in itself. For example, the concept of the 'evaluation of user and carer participation' was completely alien to one member.

## Meetings

The facilitator asked everyone in advance if they had any particular needs in order to enable them to attend the meetings, whether they would be bringing a personal assistant or supporter, if they had any dietary requirements, etc. Several guidelines were followed in this respect (Social Care Institute for Excellence, 2005; Shaping Our Lives, 2003).

The dates for the four meetings of the advisory group were set in advance at the very start of the research project. The advantage of this was to check out dates beforehand with people and to make sure they were in the diary; the disadvantages were that the frequency of the meetings might not match the needs of the research. A better approach is for the group to meet at certain key stages of the project and to

negotiate the dates of the meetings as the project progressed, as successfully adopted by other advisory groups and vital to avoiding tokenism (Hanley *et al*, 2004; Rhodes *et al*, 2002).

The first meeting focused on helping people to get to know one another and introducing people to the project and the likely issues. The facilitator recognised the need to provide the advisory group with specific tasks to focus the discussion in the second meeting and also to break the larger group into three smaller ones. This was done successfully.

The third meeting, planned for early November, did not fall at a relevant time in terms of the progress of the research and, with the agreement of the Chair of the advisory group, was postponed until December, when there was a clearer focus on the first drafts for the Resource guide for the group to advise on. This also enables the fourth meeting to be held in late January, when the group will be able to advise on a final draft of the Resource guide.

### Payments

All advisory group members were paid a fee of £75 to attend each meeting. This undoubtedly contributed to the full attendance of members during the first two meetings and all but one of the eight in the third meeting. There have been difficulties experienced when some members did not have bank accounts or a NI number and this took up additional time for the facilitator. These difficulties are being investigated so that we can follow good practice guidance (Department of Health, 2006; Involve, 2006). A member of the support staff at SHU attended the third meeting and this helped to ease the process.

### Roles

The members of the advisory group asked for clarity regarding their role and they requested set tasks to carry out, both at the meetings themselves and in between meetings. Set tasks were discussed and recorded at the second meeting and the third and fourth meetings will provide more focused tasks on the progress of the research. Focused tasks are particularly important for those members who have less experience in either participation or research activities and in fact, this request has come mainly from those more inexperienced members. Often people are not able to contribute at all if they do not know what is expected of them (Minogue *et al*, 2005; Hanley *et al*, 2004; Paterson, 2004; Telford *et al*, 2004).

The facilitator is an academic user researcher, which is often an advantage in this role (Griffiths *et al*, 2004; Ochocka *et al*, 2002). Also attending the meetings is a service user member of the research team and the research project lead, who have

facilitated the small groups as needed. To encourage ownership, the research team has encouraged a member of the advisory group to chair the meetings.

### Resources

It is well documented that there is a need for support and training, in particular for those people who are less experienced in participation and research (Beresford, 2005a; Hanley, 2005; Hanley *et al*, 2004; Telford *et al*, 2004). The short time between award of the contract and the first meeting of the group meant that this could not take place. We will be in a better position to evaluate this at the end of the project, but it has to be recognised that four meetings is not many, especially since setting up such a group takes time and effort (Howe *et al*, 2006; Paterson, 2004; Rhodes *et al*, 2001). The inclusion of users and carers with such a wide variety of experiences further increases this need (Steel, 2005).

### Power dynamics

There are usually issues of power present in user and carer participation initiatives. In this project, it is important that the power differentials, both between the research team and advisory group and between members of both groups, are examined to encourage greater participation (Tew *et al*, 2006; Beresford, 2005b; Ochocka *et al*, 2002).

The facilitator has made a start at resolving difficulties by the use of small group work in the second and third advisory group meetings. Each of the three groups was carefully chosen, considering in particular each person's level of participation and ability to work with others in an enabling manner. The small groups were very successful, in that the quieter members, who have not contributed at all in the main group discussions to date, were able to fully participate in this environment.

### Conclusion

The research team considers the advisory group to be an important element of the project and the review of the group, carried out for this interim report, has provided a useful opportunity to improve both the functioning and purpose of the group. The facilitator is to be congratulated on taking the reins so quickly and for understanding the dynamics and needs of the group and acting on this.

We also recognise that it would be fitting and extremely valuable to carry out an evaluation of user and carer participation within this project. This has been done to great effect in other similar research studies (Minogue *et al*, 2005; Faulkner, 2004; Rhodes *et al*, 2002).

## Conclusions, key factors and pointers for the Resource guide

### Summary

Overall, the evidence base is generally weak in the area of evaluation of user and carer participation. Few papers examine the outcomes of user participation for the various stakeholders and the actual outcome measures are poorly conceptualised. This is an area that needs much more work and it is essential that funders and commissioners of services ensure that their money is being spent effectively. Of course, attributing the outcomes to the participatory intervention is also a difficulty that is perhaps impeding more work in this area (Crawford, 2003, #01: p151). There are very few good quality reviews in terms of their transparency (i.e. which literature they included and why) and few adopt a systematic approach to the review process. Many documents that purport to be reviews are actually opinion pieces, discussion documents or practice guides in which the evidence base is unclear. The situation seems much the same in health as well as social care, as Nilsen *et al* (2006, #27: p10) make clear: 'The effects of involving consumers in developing healthcare policy and research, clinical practice guidelines and patient information material remain largely unevaluated'.

In addition to this weak evidence base, the diversity of the stakeholders and the goals of participation make it very difficult to provide a single 'magic bullet' approach to the measurement of effective service user and carer participation.

Having stressed the weak evidence base, there are nevertheless indications that help begin to develop measures. Below, are ten factors for consideration. These are gleaned from the key reviews, the practice survey and from discussions in the advisory group. In the final part of the research process they will also be refined by considering some existing models of evaluation, such as Appreciative Inquiry (AI). These ten factors provide the skeleton for the Resource guide which will be the concluding element of the research.

### Ten key factors to consider when developing measures for effective service user and care participation

Below are ten key factors which should underpin any measures to evaluate effective participation. The supporting documents are referenced in brackets to key reviews (#) and practice sites (‡) (see Appendices 1 and 3 for the full references). In each factor we raise a number of questions which are designed to trigger responses that we hope will be helpful to those engaged in evaluating service user and carer participation.

(Please note that the first draft of these factors was brought to the December 2006 meeting of the project's advisory group for discussion. The outcome of the service user and carers' discussions and the changes they made are presented in Appendix 4, Parts 1 and 2, which should be read in conjunction with what follows.)

## 1 Why evaluate? (#07)

### Why find out whether participation makes a difference?

What is the rationale for evaluating the effect of service user and carer participation? It may be a question of finding out what kind of participation works best in which kinds of circumstance, rather than 'proving' that participation does or does not work.

Is user involvement an end in itself (#21: p572)? Is user participation linked to broader issues of participatory democracy (#22)?

It is important to remember that the question 'why evaluate participation?' is not the same as 'why involve people in the first place?' (#25), though the two are linked, especially where the main aim of the participatory project has been service user involvement in research and evaluation (#09, 12).

Evaluation emphasises the value of a service by gathering reliable and valid information in a systematic way (#29).

It is worth considering the potential benefits to practitioners, such as feeling energised, as well as the value to service users and carers (#13).

## 2 Barriers to evaluation of participation

### What gets in the way of finding out whether participation makes a difference?

Although there are many sections on *barriers to participation* in the literature (e.g. #22), this is conceptually different from *barriers to evaluation of participation*. With the exceptions of initiatives such as Shaping Our Lives, the influence of service user participation on transforming services has not been the subject of any major UK evaluative research study (#03), so what prevents systematic enquiry into what difference participation is making?

Evaluation might not be a priority for the following reasons.

- An ethical matter: participation is perceived as the *right* thing to do, an ethical issue not an empirical one, so why evaluate something that is so self-evidently *right*? There is an untested 'optimism about the values of participation' (#03).
- A requirement: participation is seen as a policy or legal requirement, so why evaluate something that you have to do anyway? 'Generally, the reviews reveal



there is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off rather than an embedded and powerful organisational practice' (#03: p18).

- A right: participation is seen as a right, thereby combining ethical rightness with legal requirement. From both points of view, it might result in a perceptual barrier to the need for evaluation (#35).
- Perceived costs: scarce resources mean that the costs of evaluation are hard to find and evaluating participation is not as highly prioritised as the participation itself. There might also be fears about the additional costs that an evaluation might suggest are necessary to promote effective participation (#26).
- Power: evaluation might not give the answers wanted, or be contrary to central and local policy direction (#26). Evaluating means taking risks, for example that the need for radical changes is indicated. Also, local service users may not be empowered or lack existing networks to assert the need for an evaluation (#20). Power differentials can be a barrier both to participation and to evaluation. People with learning difficulties often report that they are controlled by their own service staff and their power to be influential in change is limited by (#32: p9):
  - 1 their lack of information about options and possibilities (Swindon People 1<sup>st</sup>, 2000)
  - 2 the attitudes of staff towards self-advocacy (Palmer *et al*, 1999; Williams, 2002a)
  - 3 the entrenched interests of the service system (Dowson, 1997; Aspis, 2002b).

'Older people ... may be excluded from active participation (and, by inference, from evaluations) through illness, being housebound or through a lack of consumerist ethos' (#34: p42).

- Timescales may be different for different groups – service users, professionals, organisations, researchers
- Focus of evaluation is elsewhere: organisations' evaluations are driven by the terms of their funding, which may not have specified evaluation of service user and carer participation (#02, 03, 04).
- Motivation of service users: poor motivation to get involved will reduce the chances of an effective evaluation (since there is little to be evaluated) '... little is known about why young people choose not to be involved, or why they get excluded' (#03: p31).
- Attitudes of staff: goal attainment scaling was intended to be used with individual people with learning disabilities, but not achieved 'because frontline staff believed meaningful involvement of service users was not feasible due to limited levels of patient understanding' (#06).
- Organisational culture: the culture in the organisation might be hostile to evaluative procedures in particular and participation in general (#07). For example, Kirby *et al* (2003) found that there were four common reasons why organisations

often failed to evidence outcomes resulting from children and young people's participation:

- 1 Organisations believe that they are too early on in the process of participation to be able to evidence change.
  - 2 Organisations provide descriptive accounts of what they have done to involve children and young people, rather than what has changed as a result of their involvement.
  - 3 Organisations find it difficult to evidence possible outcomes of participation – such as young people's increased self-esteem.
  - 4 Organisations find it difficult to attribute change specifically to the involvement of children and young people as there may have been other factors that contributed to the outcomes (#07: p44).
- Complexity: how do you know that changes are a direct result of participation (#10)? In the social world it is not possible to state with certainty that x caused y, so it is very difficult to prove a link between this participation and that change. These uncertainties can be a psychological barrier.

### 3 What to evaluate: processes and outcomes

#### **What goes on during participation and what changes as a result of participation?**

Is there evidence that children and young people have been actively listened to?

Is there evidence of change as a result of listening to children and young people?

(Wade (2003) in #07: p48)

There are two separate, but related, issues when considering the question of what to evaluate. The first is the *process* of taking part, which might bring intrinsic benefits quite apart from any specific changes that come about as a result of participation. The second is the *outcome*, the particulars of the changes that occur as a result of participation. 'More studies focus on process rather than outcome' (#03).

One way of looking at processes and outcomes is to consider the intrinsic benefits of participation and the extrinsic results (see Table 2, page 10, for a summary of these as noted in the key reviews). The former tend to be more subjective and general, the latter more objective and specific.

#### **Examples of the intrinsic benefits of participation**

- Young people who do engage in good participatory work benefit in a number of ways – confidence, self-belief, knowledge, understanding and changed attitudes as well as skills and educational attainment. Many also report having fun and making friends. There is little evidence on the views of those who do not participate (#36).
- Children have said that having a say is more important than getting what they want (#09).

- The development of personal and collective empowerment and knowledge development (#26).

### Examples of extrinsic results of participation

- New services developed (#1, 10).
- Costs of care are reduced (#13).
- Gaining qualifications, obtaining a job and skills acquisition (#17).

There is evidence of some confusion over what is being evaluated – intrinsic benefit or extrinsic change. 'Identifying suitable user- or carer-based outcomes can be problematic because the aim of social care may not be to improve end-state welfare. The main focus of the intervention may be on for example, risk reduction, preventing exploitation or managing deterioration.' (#06: p18)

One way in which this confusion can be lessened is for 'outcomes to be realistic, measurable and specific' (#07: p44). This certainly makes them easier to evaluate, though they must also be *meaningful*. This indicates a difference between *evidencing the process* of participation and *reviewing the outcomes* of participation (#07). A scepticism about targets and league tables suggests that this issue of meaningfulness is very important. 'Respondents raised questions regarding achieving meaningful measures of outcome. Overall "number crunching" approaches such as admission/discharge rates or financial activity were not favoured.' (#06: p22) We need to consider whether the evaluation will focus primarily on qualitative or quantitative factors. For example, the *quality* of decision making by young people has been the subject of few evaluations (#36).

Decisions about what will be evaluated are made the more complex because there is likely to be a relationship between the method of participation, the degree of satisfaction and the extent of change, so that processes and outcomes are not divorced from one another (#09).

There has been little research to date on how services are influenced by users' involvement. What would effectiveness in user involvement look like? What you would be measuring is change:

- 1 Within participants themselves (service users becoming more confident, practitioners feeling less fearful).
- 2 Within the nature of the relationships between the participants (is there a more equal distribution of power?)
- 3 In attitudes and working practices.
- 4 In efficiency (the best result that can be obtained from the resources used) for example, by providing the services that make a difference to people's lives.
- 5 In effectiveness (services that do what they were intended to) measured in terms of service users' quality of life. (#25)

## 4 When to evaluate?

### When should we find out whether participation is making a difference?

Forty-four per cent of projects indicated that there had been changes to services as a result of disabled children and young people's participation. For the majority of the other respondents, it was *too early* in the process to indicate any outcomes. (#05, our emphasis)

In order to evaluate what difference participation has made, it is necessary to have a benchmark against which change can be measured and a schedule to help decide when to review for changes and how to recognise progress. If there is a time limit to the participation, a post-participation review should also be conducted. The long horizon for many of these changes (for example, the participation of service users and carers in social work education) can lead to a focus on the short term, when many of the potential differences are not yet in evidence. Moreover, longer term participation might struggle to sustain evaluative approaches (#07), just as participation can often be occasional rather than continuous (N.I. 2006). A successful outcome might also be less about change and more about maintenance or a slowing in deterioration, if this is what was indicated by service users and carers in the participative exercise, or about cumulative impact (#07).

How might the evaluative approach link to the stage of participation in any organisation or group (#07)? The question is asked, though with few indications of the answer:

You need to know what you have got to start with – some sort of measurement of organisational culture, and then introduce participation and carry on measuring and hope that things change. (#07: p49)

The 'when' question is an important trigger to develop signposts to recognise progress (or lack of it). Developing these indicators helps to clarify what it is that is being evaluated and to develop intermediate outcomes (#10).

## 5 Who evaluates?

### Who should be involved in evaluating?

There are two fundamental questions wrapped up in the issue of who evaluates: 'who does the evaluating?' and 'who owns the evaluation'? Both concern the central issue of power.

Effective interaction within a consultation can only happen when there is:

- an attempt to redress the power balance between managers/policy makers and people with learning difficulties

- accessible written information
- a good, clear communication strategy (#32: p2)

Who commissions the evaluation? Whoever commissions the evaluation has a powerful voice in what will be evaluated and how, so participation by service users and carers in the decision to evaluate is an intrinsic aspect of the participative process (and could, itself, be evaluated). Users highlighted that what was important to them was different to the priorities identified by the research team (#15). By contrast, in The Impact Project (#25: p124), the topic was identified and prioritised by service users, working on the study in partnership with managers, clinicians and researchers. Report #20 noted that users are more likely to engage in research arising from users' questions and requests. Response rates may be improved, and the data richer and more relevant. Participation in the process of developing measures to evaluate might lead to definitions of quality that are user-centred and user-derived (#26, #02).

Who evaluates? To what extent are, or should, service users and carers participate in the evaluation process itself, as co-evaluators, for example? What competencies do the evaluators need (#07: p42) and, therefore, what preparatory training should be available? How 'independent' should the evaluation be, and independent of whom? The appropriateness of those who deliver services carrying out user participation and then evaluating that participation is questionable.

Who owns and who acts on the evaluation findings? Once an evaluation is completed, who owns the information derived from the evaluation and whose responsibility is it to act on the findings from the evaluation?

Power issues underlie the majority of identified difficulties with effective user-led change (#03). 'When written feedback was provided, it was invariably provided to parents rather than to children. A third of the initiatives were not providing any feedback' (#05: p3). The position of children needs particular consideration in terms of their preparation for evaluation and also the preparation of the staff to support the evaluation process (#04, 35; #06, 07, 08).

## 6 How to evaluate

### **What approaches can you use to find out whether participation is making a difference?**

Among the literature, there is a lack of guidance, tools and knowledge about how services and organisations can review the outcomes of participation. (#07: p50)

Table 1 summarises the evaluative approaches that were identified in the key reviews. We use the term 'approach' in recognition that the research did not provide

evidence to develop 'models' as such; indeed, some of these approaches were extrapolated from participative approaches, since most reviews focused more on approaches to participation than approaches to evaluation. We might ask, then, 'can the approaches which are used to facilitate participation also be used to develop measures for evaluation?' To what extent should the evaluative approach be congruent with participative approaches, in the sense that it reflects the values of participation (#07)? A not very participative example:

Overall, 62 (85%) of respondents identified staff appraisal as a method of evaluating [services] and 52 (71%) identified registration and inspection. (#06, p20)

A more creative example:

Written, verbal, visual, computer/IT and arts based methods were being adopted to involve disabled children and young people. (#05)

The choice of approach will be influenced by the other factors detailed later in this section, such as the goals of the evaluation and who 'owns' the evaluation. Other considerations concern how to make the evaluation cost effective. Sampling may be necessary to cut down on costs. In order to achieve good sampling techniques, it may be necessary to seek expert assistance.

Pluralist approaches, in which a number of different methods are used, can help to ensure that the evaluation is broad-based and has internal validity (#29). Partnership approaches in which service users and carers are co-evaluators (#15) and user-led approaches where service users are the evaluators can lead to more honest feedback (#13). Advisory groups of service users and carers can comment on the proposed approaches (#25). The evaluation approaches and data collection tools need to be relevant to the stakeholders (#05).

## 7 Levels and stages of participation and evaluation

### How might the level of participation influence the model of evaluation?

A number of models of participation have been proposed ('Models That Describe Levels Of Involvement', #25: p16) such as Arnstein's ladder and Tresedar's circular model (#07: p9) and Beresford's distinction between consumerist and democratic models. We might ask, therefore, whether there is any relationship between model of participation and model of evaluation? And might different stages of participation, such as adaptive and transformational (N.I. 2006), lend themselves to different evaluative approaches? There is no evidence in the available literature of any systematic attempt to make this kind of link. However, if 'different levels of participation are valid for different groups of children and young people' (#07: p9),

what implications might this have for the approach to evaluation? Again, the review of literature allows us only to raise rather than answer this question. If the level of participation is at shared decision making rather than consultation, what impact would this have on our approach to evaluation (#13)? If 'there is some indication in the review findings that user participation initiatives can become consultation exercises to approve of service planning and policy proposals, rather than enabling service users to be key players or partners in their formulation' (#03: p26), how might an effective evaluation begin to demonstrate what differences a more profound partnership could have made? Involvement at a higher strategic level is rare (#05: p1; #01, 04) with a focus largely on individuals' participation in their own care rather than policy or service level participation (#06).

## 8 Dimensions of participation and evaluation

**What might people participate about? What, therefore, are the goals of the evaluation?**

Notions of the 'level' of participation and evaluation suggest an unwanted hierarchy of higher and lower levels, yet each has its own value, equal to the others. Perhaps it is more accurate to consider different 'dimensions' of participation and evaluation. In order to encompass all dimensions, a whole system approach is suggested, such as individual treatment, service delivery systems and policy; or voice, choice and change (#13) and culture, structure, practice and review (#07):

- **Culture:** the ethos of an organisation, shared by all staff and service users, which demonstrates a commitment to participation. How might this best be evaluated?
- **Structure:** the planning, development and resourcing of participation evident in an organisation's infrastructure. How might this best be evaluated?
- **Practice:** the ways of working, methods for involvement, skills and knowledge, which enable children and young people to become involved. How might these best be evaluated?
- **Review:** the monitoring and evaluation systems which enable an organisation to evidence change affected by people's participation. How might these best be evaluated? (#07)

Some practice methods and planning approaches have evaluation built in to their methodology, both short term results and longer term outcomes, though it is rare to have a systematic analysis of the findings from these experiences (Marsh and Doel, 2005; McLaughlin and Jordan, 1999).

## 9 Diversity and difference

**Is 'making a change' different from one service to another? What kinds of difference might an evaluation discover?**

... we were reminded by our advisory groups that it is the day-to-day experience of services that counts. (#26: pii)

While in general children are increasingly involved in decision-making, growth has been slower in respect of disabled children and young people. (#05: p2)

There are several issues to consider in respect of diversity and difference when developing measures to evaluate participation.

- 1 Are different approaches relevant to different groups of service user and carer? In one study, self-advocates reported that they felt strongly that the process of change needed to slow down and, by inference, evaluative approaches with self-advocates might need to proceed at a different pace (#03). There are different ethical and practical issues when children are research participants (#04, 35). Evaluative measures should be culturally appropriate and ensure that black and minority ethnic groups are fully involved (#26). Generational differences also need consideration (#04).
- 2 How can measures ensure that people who are seldom heard can be included in evaluations (#17)? In what formats should the necessary information be available to ensure participation by marginalised groups and individuals?
- 3 How might the perspectives of different people (service users, carers, professionals, managers, etc.) be reflected in the evaluation? For example, one study found that service users identify higher levels of unmet need than service providers (#19). How, too, can differences within groups be properly reflected? It is a mistake to assume that service users can, do or should speak with one voice; differences within service user groups need to be reflected sensitively within evaluations of participation.
- 4 Are evaluative approaches relevant for different forms of service organisation, be it service user led, substitute and complementary services, statutory, voluntary or independent? Is it a new service or an established one and what difference might this make to the evaluative approach?
- 5 Are there differences in the *size* of the changes that are being evaluated – and does this matter? Many policy makers may be looking for the impact of participation at a strategic level whilst many service users may focus on developing measures to evaluate the impact on their day-to-day experience of services.

The understanding of diversity is crucial. Whether services are delivered in a domestic or a residential setting, the voice of the individual needs to be able to be heard on a day-to-day basis. Again and again, we were reminded by our advisory groups that it is the day-to-day experience of services that counts. (#26: pii)



Reviews should recognise that it is as important to identify the small changes as well as the larger ones ... [Reviewing our outcomes] has highlighted a lot of really quite small and subtle changes in practice, but really important ones. (#07: p49)

## 10 Publicising the findings from evaluations

### How do people find out about the difference that participation makes?

There are two central issues in this question, the first concerning feedback to participants about the difference *their* participation has made or is making, and the second on the wider dissemination of the findings from evaluations. In both cases, you need to consider how changes are going to be recorded (#07: p44).

Feedback to participants is crucial if we are to combat evidence of cynicism after involvement in consultation that is tokenistic (#03). It is important to consider how feedback will be provided in participative ways (N.I. 2006) and to involve people in these decisions. 'Children and young people should be asked how they would like to receive feedback, and any feedback should be produced in a child-friendly format' (#07: p33; #05, 06).

In terms of wider dissemination, perhaps to people who are not yet involved, websites seem to play an important role in disseminating research and having an impact (#04). Findings need to be presented creatively and in ways that are relevant, interesting and visible to the audiences for whom they are intended. Just as participation champions have been found to be effective (#07) so there is perhaps also a need for 'evaluation champions' who provide leadership and enthusiasm in this topic.

How might this factual finding be presented in a more creative way? Forty-four percent of projects (31 of 70 different initiatives) indicated there had been changes to services as a result of disabled children and young people's participation (#06: p21).

What is being claimed? How do we know that the difference being claimed is a result of the participation? There may be a reduction in costs, but how do we link these reductions to the impact of participation (#13)? Does the evaluation indicate whether the changes are sustainable?

Once we have developed discrete models to evaluate participation, we can compare them systematically, so that we can start to answer the question – in which circumstances are which approaches more effective? We have some way to travel.

## Pointers

Pointers to help develop measures to find out whether participation is making a difference.

1. PURPOSE: Are you clear about the purpose of the evaluation? Why is service user and carer participation being evaluated? (#01, 06)
2. CHANGE: What kinds of change might you expect service user and carer participation to have made and at what levels is it expected to make a difference – individual experiences, staff attitudes, agency policies, local or national strategies?
3. TIMING: When will you measure these changes? Are you looking for short term results, longer term outcomes or both? Do you have indicators of progress?
4. PROCESS OF PARTICIPATION: How might the experience of participation be evaluated? (#03)
5. SUPPORT and SUPPORTERS: What kinds of support might be needed to make the evaluation an effective and independent one? What part might supporters and facilitators play in evaluating the results of participation? (#05, 04, 35, 36)
6. SKILLS: What skills are needed to make an evaluation of participation? (#07)
7. TRAINING: What kinds of training are needed to help people to evaluate the effects of participation? Is this training available? (#05, 36)
8. RESOURCES: What resources are needed to evaluate participation? Are resources such as budget available and, if not, how might they be found or creatively substituted? (#07; #02, 03)
9. ORGANISATIONAL CULTURE: How open to participation is the organisation or group? Does the climate or culture in the organisation support participation and how do you find out about this? (#07)
10. PRACTICE: How participative is *practice* in the organisation or group? How do you evaluate the way service users and carers are involved in practice? (#07)
11. STRUCTURE: Is evaluation of participation a regular feature of the organisation or group? Is it part of the *structure*? How might evaluation help it become part of the structure? (#07)
12. POWER: What differences in power are there between the people involved (service users, carers, professionals, managers, etc.)? How might these affect the evaluation? What can you do to change these differences in power? How will you involve people who are seldom heard? (#36)
13. TOKENISM: How will you avoid tokenism? In other words, how will you evaluate whether the participation has been real and meaningful? (#36)
14. THOROUGH AND FAIR: How will you make sure that your evaluation listens to the negative messages as well as the positive ones, taking note of disadvantages of participation as well as advantages?
15. LINKING PARTICIPATION TO CHANGES: How might you find out whether any changes are indeed a result of participation and not something else? (#10)

16. OWNERSHIP: How will service users and carers participate in deciding what will be evaluated and how? Who will undertake the evaluation and how independent should they be from the process? Who will own the information gathered? Are there any other ethical issues that you will need to consider (for example, about confidentiality)? (#04)
17. FEEDBACK: How do people find out about the results of the evaluation of service user and carer participation? (#05)
18. IMPLEMENTATION: How are the findings from the evaluation to be used? Who will implement recommendations? What further changes should you expect as a result of the evaluation? (#07)
19. CONTINUITY: Is evaluation a one-off event or an on-going process and part of the way the organisation or group works all the time?
20. PUBLICITY: How do other organisations and groups learn from your experience of evaluating the difference that participation has made? (#01)

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Please see Appendix 1 for the full list of key reviews.

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## Appendices

### Appendix 1: Key reviews

Ref no #	Full references (* indicates refs from electronic database searches.)
01	Crawford, M. (2003) <i>User Involvement in Change Management: A Review of the Literature</i> , SDO
02	Carr, S. (2004) <i>Has service user participation made a difference to social care services?</i> London: SCIE
03	Coad, J. and Lewis, A. (2004) <i>Engaging children and young people in research</i> , Literature review for the National Evaluation of the Children's Fund (NECF), London
04	Franklin, A. and Sloper, P. (2004) <i>Participation of disabled children and young people in decision-making within social services departments in England</i> , Social Policy Research Unit, York
05	Young, A. F. and Chesson, R. A. (2006) 'Stakeholders' views on measuring outcomes for people with learning disabilities', <i>Health Social Care in the Community</i> 14 (1) 17–25(9)
06	Wright, P., Turner, C., Clay, D. and Mills, H. (2006) <i>Involving children and young people in developing social care</i> , London: SCIE Practice guide 6
07	Cashmore, J., 'Promoting the participation of children and young people in care', <i>Child Abuse and Neglect</i> 2; 26(8)
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16	CCNAP (2006) <i>Asking the Experts. A Guide to Involving People in Shaping Health and Social Care Services</i> , Community Care Needs Assessment Project (CCNAP)
17	Janzon, K. and Law, S. (2003) <i>Older People Influencing Social Care – Aspirations And Realities. Research Review On User Involvement In Promoting Change And Enhancing The Quality Of Social Care Services</i> , London: SCIE
18	Salmon, N. (2003) 'Service Evaluation and the Service User: a Pluralistic Solution', <i>The British Journal of Occupational Therapy</i> 66(7)
19	Williams, V. et al (2003), <i>Has anything changed?</i> Norah Fry Research Centre
20	Bentley, J. (2003) 'Older people as health service consumers: disempowered or disinterested?', <i>British Journal of Community Nursing</i> 8, 181–187
21	Ackerman L., Feeny T., Hart J. and Newman J. (2003) <i>Understanding and evaluating children's participation: A review of contemporary literature</i> , Plan UK/Plan International

22	Kirby P. and Bryson, S. (2002) <i>Measuring the magic? Evaluating and researching young people's participation in public decision making</i> , Carnegie Young People Initiative (see T11)
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## Appendix 2: Standardised table for key reviews

<b>1 Author and date</b>
<b>2 Who are the stakeholders?</b>
<p>Service users</p> <p>Carers</p> <p>User groups (informal or constituted)</p> <p>Carer groups</p> <p>Community/public</p> <p>CHCs</p> <p>Staff/professional</p> <p>Special constituencies (minority ethnic, women, substance users, homeless, acute, older people, children, families)</p>
<b>3 Who is the review likely to have relevance to?</b>
E.g. sector such as health or education, or the list of stakeholders above.
<b>4 What is the purpose of the evaluation/consultation with service users/carers?</b>
E.g. priority setting, impact on service delivery and decision making, feedback about particular aspects of the service
<b>5 Which services are involved?</b>
<p>Health, social care</p> <p>Statutory, voluntary, private</p>
<b>6 What methodology has been used for the evaluation/consultation (including the methods, principles and paradigms)?</b>
E.g. consumerist/citizenship models; principles of training service users and providers; use of questionnaires/focus groups, etc.
<b>7 What is the level of participation in user/carer involvement?</b>
E.g. user led or user controlled participation or service led/service controlled

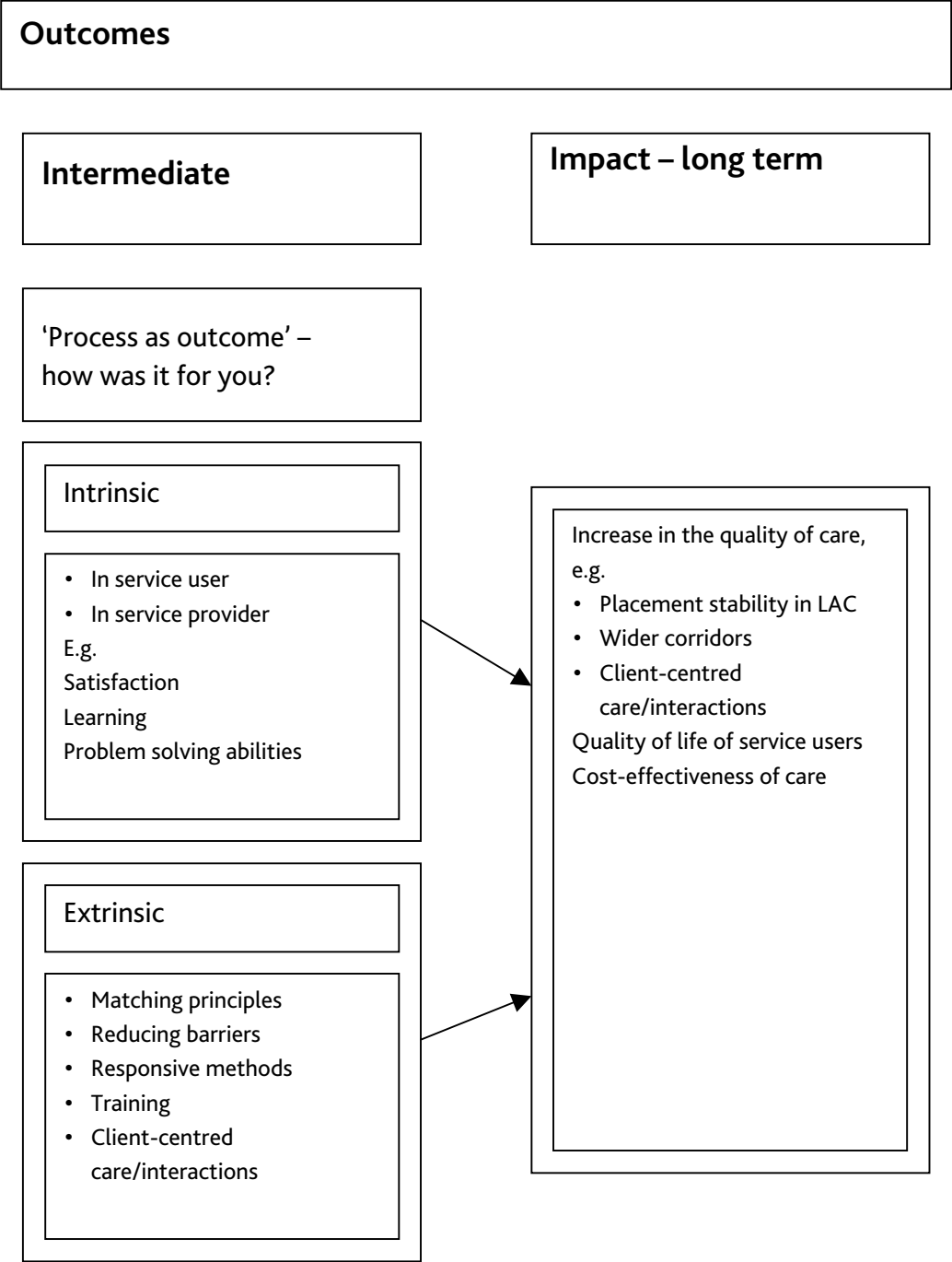
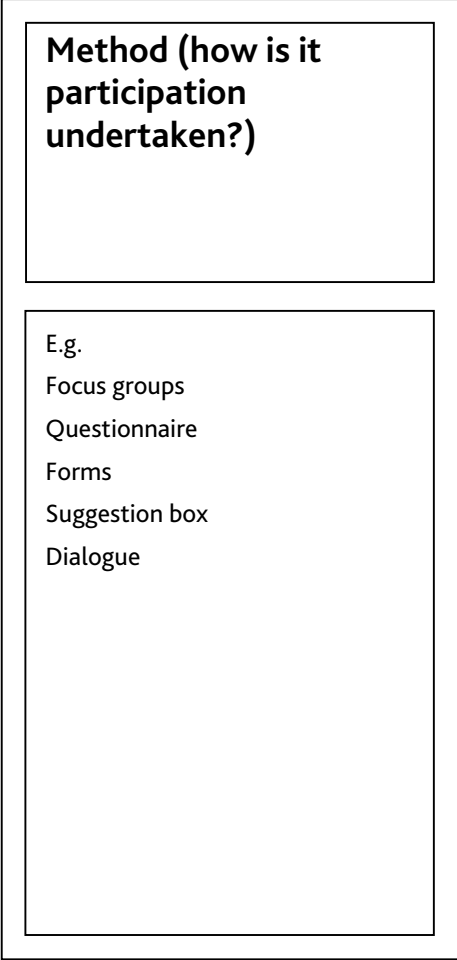
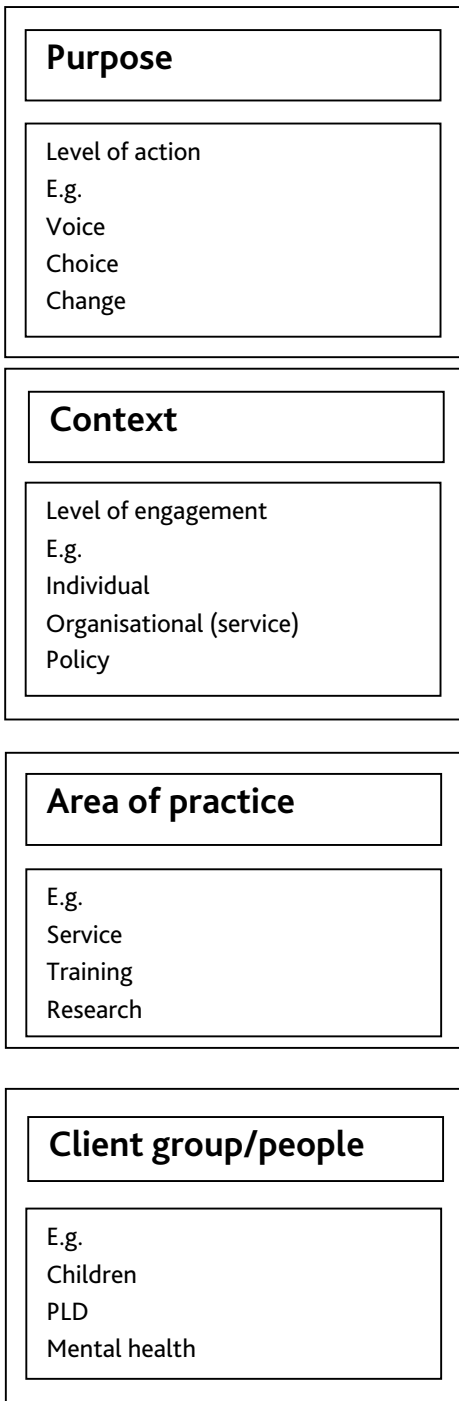
<b>8 Focus of user participation/involvement</b>
Individual service Local service National service/policy Non-specific
<b>9 What are the outcomes of evaluation/consulting with service users and carers?</b>
Include here how the outcomes are described, captured and measured
<b>10 Country</b>
UK US/Canada Europe Australia/New Zealand Other (specify)
<b>11 Who is the target audience for this study?</b>
Academic Professional Users/carers
<b>12 Publication type/source</b>
E.g. Journal article, commissioned report, unpublished report, on-line source
<b>13 Type of literature</b>
E.g. Review, original research, survey, other
<b>14 Other issues</b>
E.g. barriers/facilitators to user or carer involvement; issues of reward or reimbursement; any other issues that are relevant to the review

**Useful quotes:**

**Possible messages for the Practice guide:**

**Other points:**

**Appendix 3:  
Conceptual map for  
evaluating participation**



## Appendix 4: Protocol for enquiry with the ten practice sites

### Part A: Background questions about participation

1. What is/was the purpose of the participation (e.g. service user voice, choice, change, etc.)?
2. At what level did the participation take place (e.g. individual, organisation, policy)?
3. What was the area of practice that the participation was designed to influence (e.g. service delivery, training, research)?
4. What client group was included in the participation (e.g. children, disability, mental health, adults)?
5. Who carried out the evaluation (e.g. internal or external to the organisation)?
6. When did the project take place and over what time period (i.e. longitudinal or short term)?
7. How was the participation/process of evaluating the participation funded?

### Part B: How the methods and processes of undertaking the participation are evaluated

1. What were the processes or methods used to undertake the participation (e.g. focus groups, questionnaires, forms, suggestion box, dialogue, etc.)?
2. How was this method or processes decided upon (i.e. did service users/carers have any say in the process of developing the method)?
3. What happens to the information elicited from the participation process (e.g. is it fed back to the participants; how is it used to inform practice)?
4. Do you find out what people feel and think about the experience of participation?
5. If yes to 4, then what happens to the information?
6. Were participants paid for their work?
7. What monitoring of participants took place (e.g. capturing demographic details, equal opportunities, barriers to participation)?
8. What was the level of participation? How many participants were involved and to what extent did they participate?

### Part C: How the outcomes of participation are being evaluated

1. Were clear outcomes identified at the start of the project?
2. When are the outcomes of participation measured (at what stages in the participatory process do you take stock)?
3. Were the outcomes achieved? If not, why not?
4. What specific examples are there of service user and/or carer participation making a difference?
5. What was the change and how was it linked to the participation?
6. Are particular elements in the participatory processes or the organisation of the participation considered to be more effective than others?
7. Do you have any evidence that service users are now more satisfied with services as a result of the changes made?



Appendix 5: Ten practice survey sites (brief summaries – for full summary breakdowns please refer to *Resource guide 7 Participation: finding out what difference it makes* p42–54)

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range)  Comments:
01	<b>NIUSE SEA project</b> (Northern Ireland Union of Supported Employment; Supported Employment in Action project)	Northern Ireland	Current: ends June 2007	Disabled people (physical; learning; sensory; hidden)  13 statutory and voluntary services	Evaluate participation from individual to policy levels using focus groups, life histories, case studies, photography projects.  Rickter model used (measures distance travelled).  External evaluator involved – evaluation not complete yet.  'Beneficiaries', the project's name for service users, are involved as participants in the research.
02	<b>SkillNet</b>	East Kent	Current: five years old	Learning difficulties	Self-advocates have control, in all aspects of the project. An evaluation was conducted by self-advocates from another project (People First); another is due in Dec 2006.  Steering groups, 'decision teams' and website used to feedback findings.  Evaluation focuses on the funding proposal targets rather than specifically on effects of self-advocates' participation.

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
03	<b>People First</b>	South Wales	Current: 2003–06; 'Changing Lifestyles' will run 2006–09	Learning difficulties  Service user led	Independent evaluation was conducted two years ago. Not specifically evaluating participation.  Participation at all levels from individual to three- county strategy.  Conference to evaluate participation – how user led was the organisation? AGM important.  Training around participating in interviews is important.
04	<b>Sandwell Visually Impaired Group (SVI)</b>	West Midlands	Current: two years old	Visually impaired adults  Service user led partnership with local authority	Internal evaluations undertaken, but no independent evaluation. Evaluations are not specifically about effects of participation, rather to RNIB's 'Progress In Sight', which is regarded as the benchmark. Membership figures are seen as a good indication of the success of participation (and these are increasing dramatically).  Newsletter, website and AGM used to help monitor participation.  There is participation on council committees and service provider teams (Sensory Impairment) as well as job interviews for professionals.

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
05	<b>Chilyep (Sheffield children and young people's empowerment project)</b>	South Yorkshire	Current: ongoing	Children and young people in communities with high deprivation indicators	<p>Participants developed questionnaires, analysed by staff but reports written in consultation with young people.</p> <p>Feedback through area conferences to key services.</p> <p>Issues about the difficulties in hearing findings at a local level, although strategic response positive.</p> <p>Findings limited by basic research design and need for more expertise in research design recognised in appointment of professional researcher for next phase of work.</p>
06	<b>Cornwall Young Carers' Project</b>	Cornwall	Current: 1999–2001 and 2002–2004	Young carers, parents, service providers, project leads	<p>Second phase of evaluation built on an earlier study and, because of that, incorporating detailed record keeping.</p> <p>Used focus groups, interviews and questionnaires.</p> <p>Also evaluated the extent to which recommendations about evaluating participation from first phase of the study had been implemented.</p> <p>Findings from both studies have been presented to national audiences by the young people concerned.</p>

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
					Recommend use of an ongoing action research approach to continue evaluation but warn that some aspects may not lend themselves to this approach, e.g. where impact is cumulative.
07	<b>The Visiting Advocacy Service in Secure Children's Homes (VOICE) (formerly Voice of the Child in Care)</b>	National	Current: 2004–06, ongoing	Children and young people in secure accommodation – involuntary services users	<p>A cumulative, ongoing programme of participatory evaluation of young people's experiences in secure children's homes. Built around exit interviews undertaken by advocates, or through independent completion of evaluation forms.</p> <p>Feedback to individual secure homes on a six-monthly basis.</p> <p>The interviews/questionnaires are designed to collect only that information which participants wish to share. Current estimates suggest 30%–40% of target population engage with the study; partly influenced by sudden departures of those on remand.</p> <p>Although the participants do not directly benefit from changes, the exit interview/process of completing a form generates interests among all residents and is beginning to have an impact on cultures of participation among residents.</p>

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
					<p>Changes resulting from the programme are not always easy to implement because they often depend on staff who are not part of the care culture.</p> <p>Feedback goes to individual homes and aggregate feedback is shared among all secure children's homes.</p>
08	<b>Mersey Care Trust</b>	Merseyside	2005	Mental health service users	<p>External evaluation by SURE (Service User Research and Evaluation), a user led organisation supported by a Service Governance support team.</p> <p>They used a questionnaire survey to capture views of service users about the experience of participation rather than the impact, though impact was also explored. This was a user led evaluation with summative and formative elements, e.g. information seeking element and an action orientated approach.</p> <p>A pluralistic approach included capturing the thoughts and experiences from both sides of the participation partnership, which enabled triangulation of users and managers views.</p>

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
09	<b>The TRUE project (Training in Research for Service Users Evaluation)</b>	West Sussex	Published 2004	Adults who had mental health problems – wide ranging	<p>The evaluation was on service user training for, and involvement in, research, so that when their responses to the project were evaluated they were 'research aware participants'.</p> <p>Used a one-day event to evaluate and conclude the project ('Colliding Worlds').</p> <p>Findings stress the need for time for developmental work with service users and the financial implications. The project was most successful when users were engaged with 'real' research tasks and able to fully participate in creating research, rather than simply responding.</p> <p>Positive spin-offs included greater confidence among service users and a greater understanding of research issues. Service users learned new skills (computer and project work, telephone interviews, analysis, focus groups, role play), met new people and networked, increased career options and choices. Negative issues surrounded payment for service users' time.</p>

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
10	London Primary Care Studies Programme	London	2004–05	Children, mental health, learning disabilities, communication difficulties (as well as project in orthodontics, falling, unmet health needs, tuberculosis screening and self-management)  Both users and carers	<p>A commissioned evaluation of the impact of service user involvement in research across a wide range of settings within primary care. Service users involved in interview design, revised questionnaires, found new ways to collect data and increased number of participants.</p> <p>They contributed to interpretation of data and to dissemination of findings through their own networks.</p> <p>Users/carers changed services based on the research findings and measured the impact of those changes. There was a direct relationship between the level of engagement and positive feelings about it.</p> <p>Users/carers who felt more remote from the senior researchers were more likely to report a mixture of positive and negative experiences of their participation.</p> <p>Methods used included regular telephone contact, easy to understand language. Need for respect for service user knowledge and insights and a strong commitment from everyone to use involvement to improve research and service delivery. In projects not achieving this level of partnership, participants reported the use of jargon by researchers and clinicians.</p>

	Site name	Criterion 1: Geography	Criterion 2: Recency	Criterion 4: User group(s)	Criterion 3: Approach (range) Comments:
					The report provides guidance on best practice in service user involvement in evaluation.



## Appendix 6: An example of the work of the advisory group

### Part 1: Suggested headings for different sections in the Resource guide

When SCIE asked us to put together the Resource guide, these are the audiences they saw using it:

- all social care stakeholders
- service users and carers involved in participation initiatives
- officials of service user and carer groups
- social care service managers
- senior social care managers.

Below are the suggested headings for different sections in the Resource guide at this stage of our research. We would like your advice on the Resource guide and, in small groups, we will be asking you to consider these questions:

- Are the headings in the Resource guide suitable?
- Are there any other headings or issues you would like to see included?
- How would you like to see the guide presented (e.g. text, pictures, etc.)?
- How would you like to be able to get hold of the guide?

*(These headings differ slightly from those in the full report because they have been through a number of iterations since being presented to the advisory group.)*

#### **1. Why evaluate?**

Why find out whether participation makes a difference?

#### **2. Barriers to evaluation**

What gets in the way of finding out whether participation makes a difference?

#### **3. Approaches to evaluation**

What ways are used to find out whether participation makes a difference?

#### **4. Levels of participation**

How might people participate at individual, group, organisation and national policy levels?

#### **5. Dimensions of participation**

What might people participate about? The 'culture' in an organisation, the structure of the organisation, individual practice, and reviewing participation.

## **6. Who evaluates?**

Who should be involved in evaluating?

## **7. Processes and outcomes**

What goes on during participation (the process) and what changes as a result of participation (the outcome)?

## **8. When to evaluate?**

When should we try to find out whether participation is making a difference?

## **9. How to evaluate**

What different methods can be used to find out whether participation is making a difference?

## **10. Diversity: evaluating different kinds of service**

Is 'making a change' different from one service to another, from one group of people to another?

## **11. Publicising evaluation**

How do people know about the difference their participation has made? How do other people get to know about this?

## **12. What kinds of differences might an evaluation discover?**

Examples of changes that participation has made.

## **Part 2**

At the advisory group's third meeting in December 2006 it was felt that the language in these headings could be improved and made much more accessible. Following two small group and one full group discussion, one member of the advisory group (Alan Meadows) took the group's recommendations away and came back with these suggested alternatives which will be discussed at the January meeting of the advisory group:

Joining in. Getting involved. It sounds good. It feels right. But does it get results? Does it bring real improvements? Improvements that can be pointed at and measured? Does it have a real value? And do we bother to find out whether it does or not? That's what people mean by 'evaluation' and here are some of the questions that arise about it.

**1. Why bother?**

Are there good reasons for finding out – for 'evaluating'?

**2. What stops us finding out?**

Are there any barriers to evaluation?

**3. What do we mean by 'results' anyway?**

Can all improvements be easily measured? If we just 'feel better' or 'understand more', is that a result in itself?

**4. How do we find out?**

What methods might be used to find out if joining in has real value?

**5. How wide and how deep does it go?**

Can people 'join in' a little, or a lot? Independantly, or in groups? And will they be taken seriously by everyone? Or will they just be 'humoured' by some?

**6. Who says?**

Who does the evaluating? Will everyone get a say? And when are the best times you do it?

**7. What will we look at?**

Will we look at every possible kind of service? And will we think about whether 'change' might mean different things in different places?

**8. Will we hear back?**

After we've 'joined in', will we get some feedback? If we've helped to 'get a result', will everybody hear about it? And who owns these results anyway? All of us? Or just some of us?

**9. Give us a 'for instance'**

Can you show us examples of where joining in has brought changes? Can evaluation show us how getting involved has 'got a result'?