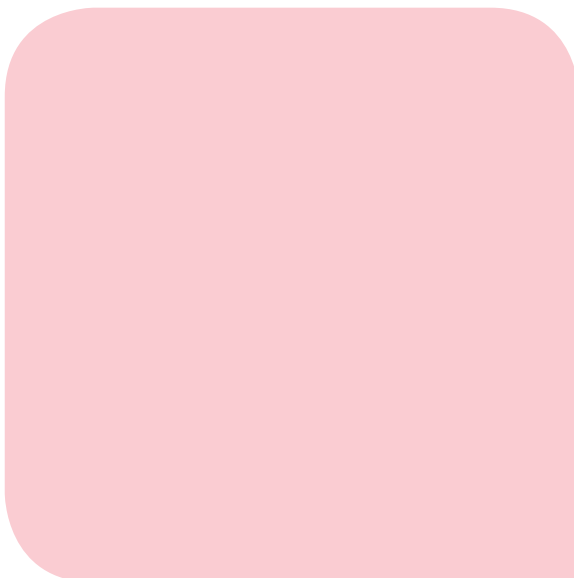
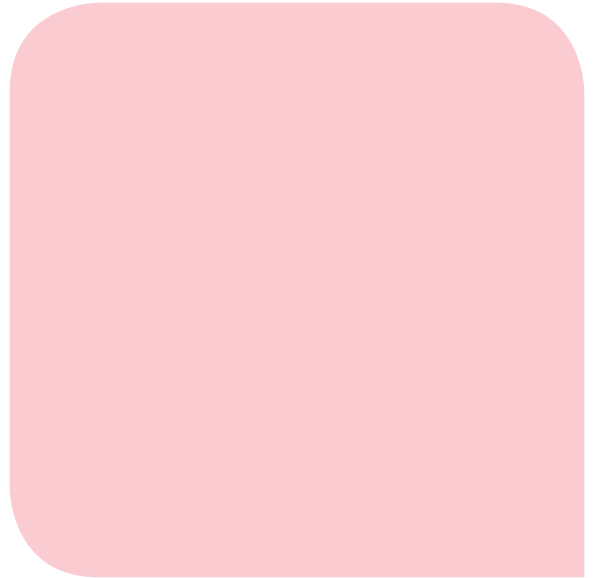


# Participation: finding out what difference it makes



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# Participation: finding out what difference it makes

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# Participation: finding out what difference it makes

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# Summary

## Introduction

This guide is based on research commissioned by the Social Care Institute for Excellence to develop measures that can be used to help evaluate the impact of service user and carer participation.

With service user and carer participation firmly on the agenda, there is a need to find out what *difference* service user and carer participation is making. No matter how *right* participation is, we also need to know how we can measure the differences that it is making. Whilst the service user participation movement has achieved much in terms of the principle, it is less clear what changes have resulted in practice.

## Purpose

- To find out what ways service user and carer participation is being evaluated.
- To suggest ways of finding out what difference service user and carer participation is making to social care services.

## Methodology

The research that informs the guide focuses on three main areas:

- What does the available literature tell us about how participation is being evaluated?
- What can we learn from examples of service user and carer participation (the 'practice sites')?
- Are there 'toolkits' that can help individuals and organisations to find out what impact participation is having?

The literature review built on the work of SCIE Position Paper 3 (2004), *Has service user participation made a difference to social care services?*, so searches were conducted electronically and manually of reviews from 2001. Studies were excluded if they simply reviewed service user involvement without any evaluation of the participation. Thirty key reviews met the criteria for inclusion and these were analysed using a standard pro-forma developed by the team of academic and service user researchers.

In order to access the 'grey literature' and to identify ten practice sites as examples of evaluation of participation, 1599 social care organisations were contacted across England, Wales and Northern Ireland in the summer of 2006. Thirty responses were received and from these and other 'snowballing' techniques, ten practice sites were

selected. These criteria were used to help the selection: geographical spread; client group spread; recency of evaluation; variety of evaluation methods being used.

From the literature review, the practice survey and informal methods, twelve toolkits were studied in more detail.

An Advisory Group of service users and carers was facilitated by a service user researcher and gave advice to the research group about specific elements of the research.

## Findings

The research pointed very clearly to a gap between participation of service users and carers (considerable activity) and systematic evaluation of what difference this is making (relatively little). This gap can be seen both in the literature and in practice, and is probably one of the reasons for the very low return rate from the practice survey.

In part, this gap between participation levels and evaluative activity can be explained by the barriers. If we understand these barriers, we can begin to overcome them in order to make evaluation an essential part of participation. The main themes are listed here.

- Power differences between professionals and service users can make honest evaluations difficult to achieve; power is also important in terms of who sets the stage for the evaluation (who decides what will be evaluated and how?).
- Expectations about what will be evaluated might be unclear; for example, is it the process of participation or the outcomes or, more likely, both? Intrinsic benefits of participation (the value of participation in itself) are linked to, but also separate from, extrinsic benefits (the results of participation).
- Evaluation needs to be built in from the beginning, along with the resources to conduct it. Although project funding might include evaluation, often it does not include evaluation of participation.
- Participation is like breathing for many organisations that are led by service users and carers, so it can be hard to know what aspects to evaluate.
- It is difficult to know whether 'A' caused 'B'; in other words, did this participation here cause that difference there?
- Commitment to the principle of participation can make it difficult to be objective about the difference it is making or, indeed, whether it is making any difference at all.
- Effective evaluation might require training (e.g. for service users to become research interviewers) or support (e.g. to ensure that the experience of evaluation is constructive and not hurtful).

- The culture in an organisation, including staff attitudes, can be hostile to evaluation. There may be fears, real or not, about what evaluation of participation will discover.
- It can difficult to include people who are seldom heard in the evaluation.
- Tokenism occurs when an organisation feels satisfied that it has ticked the boxes, yet the reality is experienced very differently by service users and carers.
- There are different timescales for service users, carers, workers, managers and researchers. One reason for the low response rate to the survey in this research was probably the fact that the timescale was too tight for most service user-led organisations that would want to consult with all their members.

There are different kinds of evaluations for different kinds of purpose. Some of the evaluations included in the practice survey were on-going and these fell into two categories: those that had a continuing commitment to evaluation as part of a 'quality loop', or those that had moved into a new phase of evaluation, building on the learning from the first phase. Some of the sites involved the evaluation of a specific, time-limited project or one project moving into another, in which evaluation had been built into the terms of the project and, importantly, its budget.

### Making use of the findings

It is not possible to declare which methods of evaluation are best for what kinds of participation. However, 'nine big questions' did emerge from the research findings, along with a list of twenty pointers. If individuals and organisations ask themselves these questions and address these pointers, they will be helped to develop the most fitting approach to evaluating the difference that participation is, or is not, making.

The 'nine big questions' are outlined in detail in Section 2 of this guide. The twenty pointers are listed in Section 3. With responses to these questions, individuals, groups and organisations will be better equipped to develop measures to evaluate the effectiveness of service user and carer participation.

# Section 1

## About this guide

### Who is the guide for?

This guide is written for any individual, group or organisation wishing to find out whether service user and carer **participation** is making a difference.

### Finding your way around the guide

#### *Section 1*

The first section tells you about the purpose of the guide. The research that informs the guide is briefly described. We consider the nature of **evidence**; in other words, what might show that participation has made a difference. We look at the idea of success and how this is not as simple as it seems. Any words in **blue** are listed in the fourth part of Section 1, with further explanation.

#### *Section 2*

We suggest that there are 'nine big questions' that have to be answered, or at least asked, when you are finding out whether service user and carer participation has made a difference. Each 'big question' is discussed in turn, with a summary and two boxes. The **Findings box** lists what the research suggests can help begin to answer the 'big question'. The language in the Findings boxes is, therefore, sometimes more formal than in the rest of the guide. The **Ideas box** aims to make the process of answering the big question more creative and involving.

#### *Section 3*

There is a checklist of twenty pointers to help you find out whether participation is making a difference. Also in this section is a list of **research reviews** and **toolkits** that you might like to refer to, as well as a description of the **practice sites**.

## Participation and evaluation

There are many ways of being involved in social care:

- as someone who uses services
- as someone who cares for a service user
- as a worker
- as a manager
- as a researcher
- as a policy maker.

Social care might be provided by service users and carers, by volunteers or workers, or a combination of these. The services might be provided in the state, charitable or private sectors. Social care is a big part of our lives and, like health and education, it is something that everybody is likely to have some contact with during their lives. In recent years the people who use services and their carers have had a greater say. This *service user and carer participation* is meant to improve services by listening to what people want and by acting on this information. In some cases, service users are now organising their own services too. Most people think that participation is a good thing, but:

- how do we know whether participation makes a *real* difference?
- what are the costs and what are the benefits?
- what are the *best* ways to find out whether participation is making a difference?
- what can we learn from the way that other people have done this?

This guide has been written to help answer these questions. It is based on research to discover what is already known about the evaluation of participation.

## About the research

### Purpose of the research

We wanted to find out what is already known about the difference that service user and carer participation can make and how people have gone about investigating this. We were especially interested in *how* the difference was being measured.

When you ask a question such as 'how do you find out whether participation is making a difference?' you find yourself asking even more questions rather than providing one short answer. So, the guide is not so much about answers but about making better sense of the questions. To do this, we will present 'nine big questions' that the research suggests are important to ask when finding out whether participation has made a difference.

### The research methods

In order to find out what is already known about this topic, we:

- searched for reviews of this topic (the work that other researchers have done to compile knowledge about evaluation of participation)
- read and digested 30 [reviews](#) in total
- reviewed twelve practice guides to evaluating participation, which we call [toolkits](#)
- sent a short questionnaire to 1,599 different social care organisations in England, Wales and Northern Ireland (we had 30 replies)
- issued a press release about the research (we received 12 responses)

- interviewed key people at ten **practice sites** where they had done or were doing **evaluations** of participation
- were steered by an **Advisory group** of eight service users and carers, facilitated by a service user–researcher.

### Understanding the research findings

We discovered that much more has been written about how people participate than about how we find out what difference participation makes. Even so, some of the methods used to help people participate can also be used to help find out what difference it has made. We have collected all of this information into the 'nine big questions', which you will find in Section 2 of this guide. We hope this will help both to understand the findings and to make practical use of them.

Crawford *et al* (2002, **R08**) 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, they can take a substantial amount of time to become evident, and the link with the participation of services users and carers can be difficult to prove. These can be **barriers** to evaluation (see big question 2). As a result, evaluations tend to use short term **indicators**.

Crawford (2003: p79 **R01**) developed four categories of outcome, where these have been evaluated:

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

Evaluations can be usefully considered as focusing on 'voice', 'choice', and 'change' (**R09**). 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?' Our research suggested two kinds of benefit from participation – **intrinsic** and **extrinsic**. Intrinsic benefits come from the **process** of participation itself, such as improvements to self-esteem and changes in attitude. How much these intrinsic benefits are valued varies, with Truman (2005: p572 **R14**) 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'. So the intrinsic value of service user participation might also have an impact on extrinsic changes; for example, increased self-confidence gained via the process of participation (intrinsic gains) might be necessary before people have confidence to campaign for specific changes to a service (extrinsic gains).

An example of an intrinsic benefit of participation is: 'children have said that having a say is more important than getting what they want' (R07).

An example of an extrinsic benefit of participation is: 'new services were developed and costs of care were reduced' (R09).

Open **communication** is a crucial part of the process of evaluation, but the **power** to provide a service (and stop providing it) makes it difficult to have an equal relationship between service users, carers and professionals. This is why the question of who does the finding out (who evaluates) is so important (see big question 5).

Although there are many different methods that can be used to find out what difference participation is making, we do not yet have enough evidence to know which method is best for which situation (see big question 6). **Networks**, whether service user and carer or professional, are important in providing strength and support, but it is also necessary to reach out to people who are not part of a network or group ('seldom heard' people).

## What is evidence of success?

### Different views of success

We are expected to look for evidence of what works well and to use this. This is called *evidence-based practice*. 'That's how we've always done it' is not good enough; we should know what evidence there is to support what we are doing. However, there are a lot of things we do not have much evidence of, and most situations are very complicated, so the evidence is not simple. Taking the following everyday example of a house extension, what might be the evidence that it was *successful*?

- The people living in the house might say it is a success if it gave them the extra space they had hoped for.
- The person owning the house might think it is a success if it was built on time and within the agreed price and it increased the house's value.
- The builder might judge it a success if it has made a profit.
- The architects might see success if their plans have been followed exactly.
- The local planning office might judge success if the extension meets all the regulations and planning laws.
- Neighbours might sense success in an extension that doesn't shade their garden.
- People across the street might see success in an extension that is in keeping with the neighbourhood.
- Family and friends of the people living in the house might feel success if it gives them a comfortable spare room to stay in when they come to visit.

From this example we can see that evidence of success needs to take account of many different views. Also, an opinion might change depending on when it is asked for. During the building of the house extension you might feel positive because the builders are involving you in making decisions. Or you may feel unhappy because the builders' work is very messy. Evidence of success is not just about what happens in the end (outcome) but it is also about how we all got there (process).

### The meaning of successful participation

The answer to the question 'how do we know whether being involved has made a difference?' is not easy. It depends on:

- who we ask ... and who does the asking
- when we ask the question
- how we ask it
- what we ask about
- how we feel about being asked (what has our past experience been?)
- whether we think it will make a difference if we bother to answer
- whether we feel we can be honest
- the different power of the people involved
- what 'being involved' has been like in the past.

### Terms used in the guide

Some of the words used in this guide are explained in more detail here.

#### Advisory group

The group of eight service users and carers who helped to advise the research and the production of this guide.

#### barriers

What gets in the way of finding out what difference has been made by taking part and joining in.

#### benchmark

Finding out exactly how things are now, so that you will be able to know whether anything has changed later on.

#### communication

Communication is the way we understand what other people mean and let them know what we mean; it needs to be open and honest.

#### evaluation

The term used for finding out how something is working, whether it has led to any changes and what kinds of difference these changes have made.



**evidence**

Proof that things have changed; examples of the differences that participation has made.

**extrinsic**

A benefit that arises from some identifiable end result or outcome. It is usually specific and is something that is evident.

**findings box**

The main messages from the research are given in these boxes (for each of the big questions in Section 2). Follow up the reference numbers in blue.

**grey literature**

This term is used to describe reports, toolkits and other documents that have not been published but are very useful.

**ideas box**

Suggestions to help you evaluate the difference that participation makes (one box in each big question).

**indicators (milestones)**

Signs to show that there is progress being made and that changes are beginning to happen. These might be different for different people.

**intrinsic**

A benefit that arises from the process of participation itself. It may not be evident except to the person who feels the benefit.

**involvement**

Another word for taking part, though involvement is not always seen as quite so active as 'participation'.

**network**

Networks are strong links between groups of people. They can link many different groups of people together, which can give them more power by acting together and sharing information.

**outcome**

The results of taking part. The outcome is the end result and is usually specific and planned.

**participation**

The general word for getting actively involved, joining in and taking part.

### power

Power can come from many sources, and it helps you to do what you want to do. Differences in power (for example between service users and paid workers) can stop participation from being successful if the differences are not changed.

### practice sites

The organisations that were contacted as part of the research for more details about the ways they were evaluating service user participation. References to the practice sites are in blue, e.g. (P01), and listed in full in Section 3.

### process

The outcome is the end result and the process is the way you get to the result. Sometimes that journey can be as important as the arriving, so the *experience* of participation is part of the evaluation.

### research reviews

These reviews collect the findings from many other studies on a similar topic and usually make comments on them. References to the reviews are in blue, e.g. (R01), and listed in full in Section 3.

### stages of participation

Adaptive and transformational (see T7 for further explanation).

### toolkits

Toolkits are handy 'how to' guides with practical ideas about doing evaluations. References to toolkits are in blue, e.g. (T1), and listed in full in Section 3.

## Section 2: Nine big questions

### Big question 1: Why bother to evaluate?

*Are there good reasons for finding out whether and how participation is making a difference?*

#### Summary

The reasons for evaluating participation are likely to influence the way in which it is conducted. Do you want to 'prove' that participation works or to describe what the process was like? What would be the result of *not* finding out whether participation has made a difference, and how will findings be used to make changes?

What is the likely balance of costs and benefits from finding out whether participation has made a difference? It is important that services learn from the experiences of those who use them, so that they can become more responsive.

#### *Findings box 1*

- Service user and carer participation might be an end in itself (R14) linked to broader issues of citizens' rights and democracy (R15).
- The question '*why evaluate participation?*' is not the same as '*why involve people in the first place?*' (R16). The two questions are linked, especially where the main aim has been service user involvement in research and evaluation (P09) (P10).
- Taking time to evaluate indicates the value of a service by gathering reliable and valid information in a systematic way (R18).
- As well as the value to service users and carers, it is worth considering the potential benefits to social care workers, such as feeling energised (P08).
- Evaluation is about communication – a dialogue in which people come to the table to talk about 'that which is of value, merit, worth or significance' (T4, p112).

### *Ideas box 1*

How important might each of the following potential benefits be for your organisation – and therefore, how might they help make the case that evaluating service user and carer participation is worth the effort?

- Improved access to services
- Improvement in the quality and responsiveness of services
- Better informed planning and development
- Evidence of more accountability
- Energised staff experiencing more job satisfaction
- Increased opportunities for service users and carers to share both their frustrations and their appreciation
- Service users and carers feeling more valued and more confident
- Service users and carers feeling they can make a difference
- Improvement in the relationship between service users, carers and the wider community
- Funders have a better understanding of the service's strengths and weaknesses and what to do about this

(Adapted from [T2](#), p7)

## Big question 2: What stops us from finding out whether participation makes a difference?

### *What are the barriers to evaluation?*

#### Summary

There is more information about what stops people from participating, than what stops people from evaluating (R15). The findings point to differences in power between service users, carers, workers and organisations as a barrier to evaluation. Consider which people are likely to have the most power in the house extension example in Section 1 and how that might exclude some people from defining 'success'.

Evaluation takes time, commitment, skills, resources and systematic planning, and if any of these are not available it is likely to prevent the evaluation from happening or from being successful. Evaluations need to be planned from the beginning, and costed into any proposals.

#### *Findings box 2*

- Differences in power can be a barrier to honest evaluation (R19) (R20) and evaluating means being prepared to accept findings that might change the power balance and may be contrary to current policies (R17).
- Real or perceived fear of the costs of evaluating can be daunting, along with concerns about additional costs that might be indicated by the findings (R17).
- Timescales may be different for different groups – service users, professionals, organisations, researchers.
- The main focus of evaluation may be elsewhere, e.g. driven by the terms of the project's funding, which may not have specified evaluation of service user and carer participation (P02) (P03) (P04).
- Poor motivation to get involved in evaluation, perhaps because of ill health or past experience of it not making a difference (R02).
- Attitudes of staff may be hostile or unsupportive to evaluations (R05)
- The culture in the organisation is hostile or not supportive to evaluating participation (R06).
- It is difficult to prove that that *this* change is due to *that* participation (R08).
- Practical matters can prevent thorough evaluations, such as lack of transport in rural areas (Branfield *et al*, 2006).
- Psychological issues, such as seeing participation as something that you ought to do, whatever the result, so why evaluate it, can be a barrier. If participation is a requirement or a right what is the point of evaluating it? (R02) (R21).
- The tick-box mentality (if the box is ticked it feels like it has been done).
- An insufficiently clear plan for participation and evaluation means that there is nothing tangible to measure.

*Ideas box 2*

What lies behind these quotes? How might they prevent you from finding out what difference participation has made, if they are not confronted?

Nobody ever asks the paid workers if their views are 'representative' ... can you imagine asking that in the middle of a meeting?

Things are slow to change, but it's getting better.

If you complain they say 'don't threaten me'.

If you're taken seriously it makes you feel good.

I'm the only voice.

It took me a year to get the gist of the meetings – then I could contribute, but by then it was time to leave.

Without good information we can't make the choice which would suit us best.

When there are too many pages I can't be bothered, so I put it in the bin.

People don't go to McDonald's to cook their own burgers.

That's how it is in all organisations.

### Big question 3: What do we mean by making a difference?

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

#### Summary

Evaluation is like opening up the 'black box' that aeroplanes use to track what happens, though in social care the story of how the project or agency has been working is more complex (T4; Baum *et al*, 1998) since finding out what differences have resulted from service user and carer participation is also about finding out *how* the participation has been making a difference. The participation might have been about service users having a voice (being listened to), about having a choice (more control over what the services they receive) or about making changes to the services as a whole. How people feel about the way they participated can be as important as the results of their participation.

#### *Findings box 3*

- There is a difference between finding evidence about the *process* of participation and reviewing the *outcomes* of participation (R06).
- Taking part can have its own benefits apart from any specific changes that come about as a result of participation. More studies focus on process rather than outcome (R02).
- There can be confusion over what is being evaluated (R05). It works better for outcomes to be realistic, measurable and specific (R06, p44).
- What is measured must be *meaningful*. Number crunching approaches such as admission and discharge rates or financial activity were not favoured (R05, p22).
- There is a close relationship between the method of participation, the degree of satisfaction and the extent of change. Processes and outcomes are not divorced from one another (R07).

### *Ideas box 3*

This Ideas box can be used by all the people involved in evaluating participation. It will help to show whether you are more likely to be interested in outcomes or processes, intrinsic or extrinsic benefits, or a combination. Giving specific examples of the kinds of changes that are wanted or expected is designed to develop self-awareness, which is important in sharing expectations and avoiding disappointment.

I want to be listened to

I want to see results soon

I want to see changes

I want to see lasting changes

I want to have choice

I want practices to change

I want to feel involved

I want policies to change

Complete these sentences as a way of starting a dialogue about how you and others can begin to know whether participation is making a difference.

An example of a change that is important to me would be ...

I would know things were changing when I noticed that ...



An example of me being listened to would be ...

What I get most out of taking part is ...



## Big question 4: When do we decide to find out whether a difference is being made?

*Is the timing right? Have things had time to develop?*

### Summary

If you do not know where you have started from you cannot know how far you have travelled. Finding out where you are at the beginning of the process is called a **benchmark**. A plan with time limits and deadlines also reminds you when to take measurements. This will indicate how far you have travelled. In the house extension example in Section 1 of this guide, we imagined that people might measure progress in their own different ways and at different times. Some of these indicators can be used quite soon, whilst others might have to wait a long time before we could use them to measure success.

#### *Findings box 4*

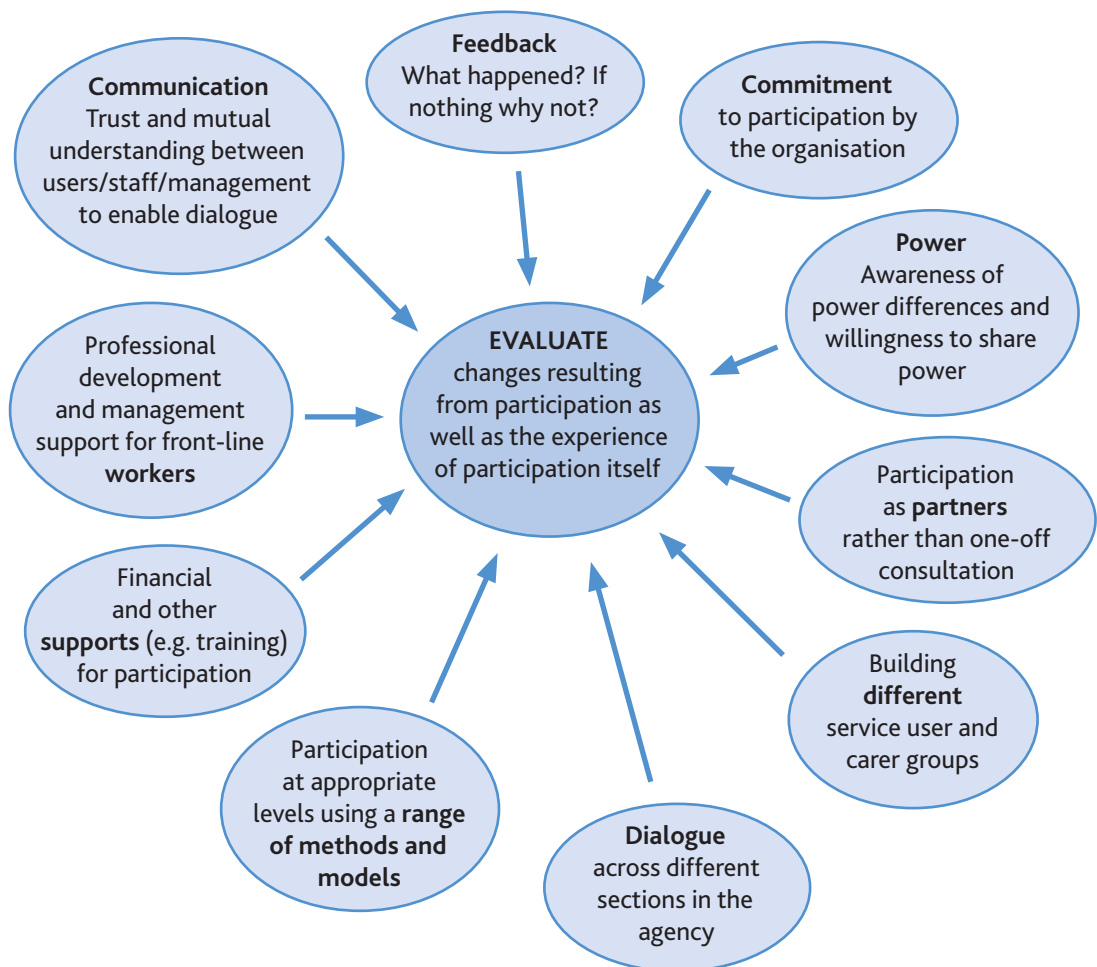
- Many of the changes that we might expect to see as a result of service user and carer participation take a long time (sometimes called 'a long horizon'). This can lead people to focus on the short term before the changes have accumulated (**R06**).
- Although a long term view is sometimes needed, it may be difficult to keep evaluation going over a long period (**R06**).
- Evaluation, like participation, can be occasional rather than continuous.
- A successful outcome might be less about change for the better and more about keeping things from getting worse (**P07**).
- We need to find out more about how the methods used to evaluate participation might need to be different depending how far advanced the participation is (**R06**).
- The 'when' question helps to recognise progress because you have to develop indicators along the way (sometimes called 'intermediate outcomes') (**R08**).
- The Rickter evaluation model focuses on distance travelled rather than outcomes (**P01**) (**T8**).

#### Ideas box 4

You have choices about *when* to evaluate. You can use the user-centred model of participation below to consider at which stage it would be best to find out whether participation is making a difference. Given resources are limited what would your priorities be?

(Adapted from T7, p51)

#### User-centred model



Although this is a user-centred model, it can of course be used by all those involved in evaluating service user and carer participation – workers, managers, and policy makers as well as service users and carers

## Big question 5: Who says?

### *Who does the evaluating? Will everyone get a say?*

#### Summary

Who is involved in the evaluation and who will do the evaluating? How independent will they be from the services they are evaluating? Who decides *how* to find out whether participation has made a difference? Service users and carers should participate in making decisions about who will be doing the evaluation and how it will be conducted, but differences in power can affect this if they are not faced openly. Care must be taken that evaluations are not felt to be destructive or hurtful and that they are conducted in a safe way. Most of all, people who are 'seldom heard' must be included.

#### *Findings box 5*

- Power is central to the question of who evaluates (R19) and power issues underlie the majority of identified difficulties with effective user-led change (R02).
- Whoever commissions the evaluation has a powerful voice both in *what* will be evaluated and *how*, so participation by service users and carers in the decision to evaluate is central to the participative process (R10) (R16) (R22) (P02).
- If service users and carers are involved in developing indicators to measure progress, this could lead to definitions of quality that are more meaningful to service users (R17).
- There is evidence that service users and carers are more likely to engage in research that arises from their own questions and requests (R13) and response rates may be improved.
- Who does the evaluating is important. It should be decided what competencies are necessary and, therefore, what training in evaluation should be available (R06).
- You need to think about whether evaluation should be independent and who it should be independent from (P02) (P03). Is it appropriate for service providers to evaluate their own services?
- It is important to consider who owns and who acts on the evaluation findings. When written feedback was provided, it was invariably provided to parents rather than to children (R04, p3).
- Consider who is responsible for the way the evaluation will be managed. Coordinate the consultation with any others taking place at the same time or covering similar topics or sections of the community (T3, p16).
- The participation initiative and the evaluation of it must have support from 'the top' (T4).

*Ideas box 5*

Make it easier for people to join in and to find out what difference this is making by:

- holding events during the day, during the evening and/or at weekends
- providing a crèche
- providing transport
- making sure the location is accessible
- assisting people with hearing difficulties (induction loop system and/or signers)
- assisting people who do not speak English (such as using interpreters)
- writing information in different forms, such as large print, Braille, tape, Easyread and other languages
- finding out what food people can eat and want to eat
- making payments for people's participation.

(Adapted from T1, p47)

## Big question 6: How do we find out?

*What methods might be used to find out whether participating has really made a difference?*

### Summary

There are many different ways of finding out what the results of taking part have been. The choice should be based on why the evaluation is taking place (see Big question 1), who will be involved in the evaluation, what skills and resources are available and the nature of the activity.

If several methods are used you can be more confident that the evaluation will be accurate. Researchers put their findings to more than one test to try to make sure that they are reliable. Using different methods might help different people to take part; some people are more confident writing, others better at speaking. Children might prefer drawing, for example, as a way of expressing themselves.

#### *Findings box 6*

- There is currently no best method of evaluating participation (T01).
- There is limited guidance, tools and knowledge about how services and organisations can review the outcomes of participation (R06, p50).
- Where a toolkit is used it is important to know how it has been tried and tested (Telford et al, 2004).
- The way the evaluation is done should reflect the values of participation (R06).
- Using a range of methods helps make sure that the evaluation paints a faithful (valid) picture (R18). See Ideas box 6.
- Partnership approaches in which service users and carers join in the evaluation (co-evaluators) (R10) or when they are the evaluators, can lead to more honest feedback (R09).
- The way in which the evaluation is conducted, and how the information is collected, should be relevant to all the people who have an interest in the evaluation (P05).
- The creative arts can be used to involve people who are not very verbal or whose English is limited (T5). These methods can be helpful where an evaluation involves expression of feelings.

The costs of evaluation might mean that a sample is needed (that is, a smaller number of people who are likely to represent the larger number). It may be necessary to seek expert assistance to know how best to use sampling techniques. Try the local university or research and development section of the statutory services for assistance.

*Ideas box 6*

**Different ways to find out whether participation makes a difference**

- Group interviews and discussions
- Individual interviews and telephone conversations
- Story telling
- Committees and forums
- Observation (of participation)
- Questionnaires
- Drawings/cartoons
- Computer packages
- Photos
- The creative arts
- Complaints
- Suggestions box

The methods used to find out what difference joining in is has made should encourage people to join in even more.

## Big question 7: What tools and resources do we need?

*What is going to help us to find out whether participation has made a difference? How do we make sure it is meaningful?*

### Summary

Think about the resources that will be needed to make a successful evaluation of service user and carer participation. For example, what kind of support and training might people need to take part in the evaluation or to conduct it themselves? Support might come best from joining together in groups or networks to 'flex your collective muscle' (Branfield *et al*, 2006) whether this is networks of service users, carers, workers, managers or policy makers, or perhaps networks between all of these groups.

The evaluation might take place at different levels. What is needed for a one-off event will differ from on-going evaluation. Finding out about how service users participate in their own care plans will need different resources to finding out about their participation in strategic planning.

#### *Findings box 7*

- There is no evidence in the available literature of any systematic attempt to make the link between methods of evaluation and models of participation, such as Arnstein's ladder (R16) and Tresedar's circular model (R06).
- Different stages of participation might lend themselves to different evaluative approaches (T7).
- Differences in the size of the changes might suggest different kinds of evaluation. Policy makers may be looking for the impact of participation at a strategic level whilst service users may be more likely to focus on developing measures to evaluate the impact on their day-to-day experience of services.
- Involvement at a higher strategic level is rare and so, presumably, is evaluation of this level of participation (R04) (P01) (P04).
- How might people join in by joining together? Research suggests that service user organisations and individual service users are often isolated and that the development of service user networking is critical to making user involvement work (Branfield *et al*, 2006).
- 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).

*Ideas box 7*

What might be needed for a successful evaluation?

**Skills**

negotiating

interviewing

facilitation

communication

questionnaire design

groupwork

sampling

analysis

writing

presentation

**Training**

For above skills

**Physical**

equipment

rooms

transport

access

**Personal**

confidence

trust

commitment

persistence

strength

honesty



## Big question 8: What about differences?

*How will differences be handled? What if there are conflicts?*

### Summary

Service users and carers are not one group. Although they have some things in common, there are also many differences. When you are finding what difference participating has made, how will you take account of these different groups and the different kinds of evaluation that might be needed? And how might differences within groups be evaluated? What conflicts might there be during the evaluation?

There are power differences within groups and between them (for example, between service users and professionals). Has participating made a difference to the power relationships and how will you know if that is the case?

### *Findings box 8*

- In one study, self-advocates reported that they felt strongly that the process of change needed to slow down; so evaluative approaches with self-advocates might need to proceed at a different pace (R02).
- Finding out about children's involvement needs particular skills and approaches, both with the children and any workers who are supporting them (R03) (R21) (P06) (P07).
- Evaluating young people's participation requires particular consideration (T11)
- Approaches to evaluation should take different cultures into account and make sure that black and minority ethnic groups are fully involved (R17).
- Differences between generations need to be considered (R03).
- Issues for lesbian, gay and transgender people need to be considered.
- Measures to find out what difference participation is making must be careful to include people who are seldom heard (R11). How can information be made accessible to different sections of the community?
- How might different views and outlooks be included? For example, one study found that service users identify higher levels of unmet need than service providers (R12).
- There are many different kinds of organisation in social care: those led by service users and carers; substitute and complementary services; statutory, voluntary or independent, etc. How will these differences affect the evaluation? And are there differences between new and established services? We were reminded by our advisory groups that it is the day-to-day experience of services that counts (R17, pii).
- The outcome of participation should not be fixed ahead of time. It is unpredictable, so that there will be some results that were not expected, but which may be welcome even so. How will surprises be handled (T4)?
- Do the funders have the same idea about what should be evaluated as the people who use and provide the service?

*Ideas box 8*

- Which groups of people or individuals might you have to make extra efforts to reach (Shaping Our Lives, 2007)?
- Why might there be barriers to this group of service users (for example, the barriers might be carers or people who believe that service users are incapable of speaking for themselves)?
- What other barriers might there be?
- How might it be possible to work with these barriers in order to reach the service user?
- How could you help to dismantle barriers to participation for people who have not been involved before?

## Big question 9: What happens next?

*How is the information from the evaluation collected and made sense of? Let's have some 'for instances' of changes. How will we get feedback? Who owns these findings and what will happen as a result of them?*

### Summary

It is important to consider who is responsible for the evaluation, who decides what will happen to the findings and how people are going to get to know about them. It should be clear who will make sure that recommendations are acted on, so that the evaluation makes a difference.

The results of the evaluation should be shared with the people who have been taking part. With their permission, the findings can be shared with other networks of services users and carers so they can learn from the experience, too. However, people's privacy needs to be respected.

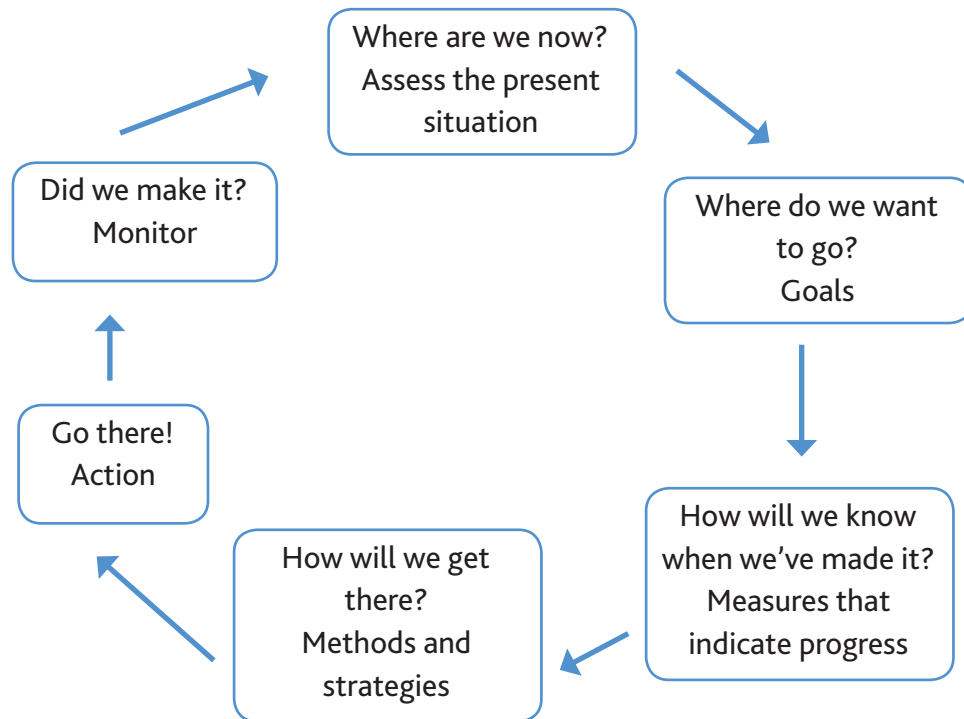
Participation should not come to a finish with the evaluation, but can carry on in the way that the findings are shared and acted on.

#### *Findings box 9*

- Findings need to be participative (T7), be presented creatively and in ways that are relevant, interesting and visible to the audiences for whom they are intended (P05) (P06).
- Feedback to people who have taken part is crucial to prevent cynicism (R02) and to maintain interest (T2). People should be involved in deciding how feedback will be provided (R06).
- Who has the responsibility to make sure that the findings from the evaluation will be implemented? Who will make sure that you continue to find out the difference participation of service users and carers is making?
- How might wider publicity be given to the findings, for example through websites (P04), so that others can use your experiences of evaluation (R09)?
- What are the implications of the evaluation? Are there broader, political implications?
- Research suggests that a properly resourced national user-led network could support the networking that is crucial for positive participation (Branfield *et al*, 2006).
- A third of the initiatives in one review (R04, p3) were not providing any feedback.

*Ideas box 9*

How might evaluation needs and methods differ depending on where you are in the cycle?



(Adapted from T4)

## Section 3

### Checklist of pointers

#### A quick checklist to help your evaluation of service user and carer participation

1. **PURPOSE:** Are you clear about the purpose of the evaluation? Why is service user and carer participation being evaluated?
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?
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?
6. **SKILLS:** What skills are needed to make an evaluation of participation?
7. **TRAINING:** What kinds of training are needed to help people to evaluate the effects of participation? Is this training available?
8. **RESOURCES:** What resources are needed to evaluate participation? Are resources such as budget available (e.g. for payments to service users and carers involved in evaluations) and, if not, how might they be found or creatively substituted?
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?
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?
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?

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?
13. **TOKENISM:** How will you avoid tokenism? In other words, how will you evaluate whether the participation has been real and meaningful?
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?
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)?
17. **FEEDBACK:** How do people find out about the results of the evaluation of service user and carer participation?
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?
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?

## Numbered references

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- R02** Carr, S. (2004) *Has service user participation made a difference to social care services?* London: SCIE
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- R04** Franklin, A. and Sloper, P. (2004) *Participation of disabled children and young people in decision-making within social services departments in England*, Social Policy Research Unit, York
- R05** Young, A. F. and Chesson, R. A. (2006) 'Stakeholders' views on measuring outcomes for people with learning disabilities', *Health Social Care in the Community* 14 (1) 17–25(9)
- R06** Wright, P., Turner, C., Clay, D. and Mills, H. (2006) *Involving children and young people in developing social care*, London: SCIE Practice guide 6
- R07** Cashmore, J., 'Promoting the participation of children and young people in care', *Child Abuse and Neglect* 2; 26(8)
- R08** Crawford, M.J., Rutter, D., Manley, C., Weaver, T. and Bhui, K. (2002) 'Systematic review of involving patients in the planning and development of health care', *British Medical Journal* 325 (7375)
- R09** Langton, H., Barnes, M., Haslehurst, S., Rimmer, J., Turton, P. and Langton, H. (2003) *Collaboration, user involvement and education: a systematic review of the literature and report of an educational initiative*, *European Journal of Oncology Nursing* 7(4): 242–252
- R10** Simpson, E. L., House, A. O. (2002) 'Involving users in the delivery and evaluation of mental health services: Systematic review', *British Medical Journal* 325 (7375): 1265–1268
- R11** Taylor, S. *et al.* (2005) *Widening adult participation in learning: a systematic review of strategies: research report*, London: Learning and Skills Development Agency
- R12** Thornicroft, G. and Tansella, M. (2005) 'Growing recognition of the importance of service user involvement in mental health service planning and evaluation', *Epidemiologia Psichiatria Sociale* 14(1):1–3



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- R15** Barnes, C. and Mercer, G. (2003), 'Health/Research Review on User Involvement in Promoting Change and Enhancing the Quality of Social 'Care' Services for Disabled People'
- R16** CCNAP (2006) *Asking the Experts. A Guide to Involving People in Shaping Health and Social Care Services*, Community Care Needs Assessment Project (CCNAP)
- R17** Janzon, K. and Law, S. (2003) *Older People Influencing Social Care – Aspirations And Realities. Research Review On User Involvement In Promoting Change And Enhancing The Quality Of Social Care Services*, London: SCIE
- R18** Salmon, N. (2003) 'Service Evaluation and the Service User: a Pluralistic Solution', *The British Journal of Occupational Therapy* 66(7)
- R19** Williams, V. et al (2003), *Has anything changed?* Norah Fry Research Centre
- R20** Bentley, J. (2003) 'Older people as health service consumers: disempowered or disinterested?', *British Journal of Community Nursing* 8, 181–187
- R21** Ackerman L., Feeny T., Hart J. and Newman J. (2003) *Understanding and evaluating children's participation: A review of contemporary literature*, Plan UK/ Plan International
- R22** Kirby P. and Bryson, S. (2002) *Measuring the magic? Evaluating and researching young people's participation in public decision making*, Carnegie Young People Initiative (see T11)

## Toolkits and further references

Most toolkits, guides and models focus on participation rather than specifically on evaluation. However, the examples below all include sections on evaluation, and the tools they describe to facilitate participation are also useful for evaluation. They are intended to cover many different kinds of evaluation in different settings.

- T1** The Darlington Toolkit – Y. A. Harrison (2004) *Patient Carer and Public Involvement Staff Toolkit*, Darlington Primary Care Trust

This is a toolkit for staff and is based on the requirement of Section 11 of the Health and Social Care Act (2001) for PCTs (Primary Care Trusts) to progress patient and public involvement in a systematic and coherent way. A section on *Recruiting participants* suggests ways of reaching groups who are seldom heard. The aspects

specifically relating to evaluation are on pp51–2. The toolkit considers the way in which results are presented and who they are presented to. It suggests a series of questions that staff should consider and includes an example procedure for securing patient and public presentation on committees, groups and panels. There is useful further reading and websites. Ideas box 5 is adapted from this toolkit.

- T2** Cathy Street and Barbara Herts (2005) *Young Minds, Good Practice: Putting Participation into Practice*, [www.youngminds.org.uk](http://www.youngminds.org.uk)

A guide for practitioners working in services to promote the well-being of children and young people. The central focus is on participation. Of most relevance to the question of evaluation is a sub-section on involving young people in research and evaluation. This usefully reminds us of the ethical issues involved in evaluating. The authors note that 'there has been a general move away from large scale survey approaches towards methods that more actively involve service users in research about mental health services'. The guide includes case studies and tools for developing participation. Stage 3 of this process focuses on feedback, in which a strong message is the need to ensure that participation and evaluation are part of the planning cycle and not just an 'add-on'. The guide looks at the advantages and disadvantages of different methods of gathering information from young people, families and carers. There is a comprehensive list of references.

- T3** Waltham Forest Council (2004) *Public Consultation Toolkit*

This focuses on consultation as one aspect of participation. A checklist on consultation (p16) includes 'Make it clear who will manage the process and ensure that contact details are available' and 'Coordinate the consultation with any others taking place at the same time or covering similar topics or sections of the community'. The evaluation of the consultation exercise is available at: [www.lbwf.gov.uk/comp-pub-cons.pdf](http://www.lbwf.gov.uk/comp-pub-cons.pdf)

- T4** Department of Public Health (2000) *Improving Health Services Through Consumer Participation: a resource guide for organisations*, Flinders University and South Australian Community Health Research Unit

Looking outside the UK context, this provides a useful list of toolkits in the Australian context. Again, it is primarily concerned with participation *per se*, but Section 5 (pp 111–4) concerns evaluation. The notion of a participation cycle has been incorporated into Ideas box 9. The authors introduce the idea of evaluation as *dialogue*, so that service users and carers can come to the table to talk about what is of merit, value, worth or significance to *them*. This toolkit has a useful Evaluation checklist (p113) and an alphabetical 'Frequently asked questions' section (pp115–127).

- T5** Lewisham Primary Care Trust (2003) *A guide to involving public, patients, users and carers in developing Lewisham Primary Care Trust*, written by Marion Gibbon

Although this focuses more on getting people to participate, rather than evaluating the effect of the participation, this is a useful guide to participation at a community level. See: [www.lewishampct.nhs.uk](http://www.lewishampct.nhs.uk)

**T6** Appreciative Inquiry (AI) (<http://www.aipractitioner.com>)

Not so much a toolkit as a methodology for exploring the strengths in organisations. It takes its evaluation from this strengths perspective.

As the term implies, *Appreciative Inquiry* focuses on appreciating and then giving leverage to an organisation's core strengths, rather than seeking to overcome or minimise its weaknesses. It focuses on exploration and discovery of moments of excellence in the organisation through deep inquiry, and an openness to seeing new potentials and possibilities from that collective knowledge. 'Organizations grow in the direction of what they repeatedly ask questions about and focus their attention on.' Most of us have grown up in organisations that were comfortable (some addicted to!) identifying and analysing problems. AI suggests that there is another, more powerful model for organisational change, that treats organisations as mysteries to be embraced rather than problems to be solved. This alone is a powerful shift in thinking.

For more information contact: Julie Barnes [julie.barnes@yahoo.co.uk](mailto:julie.barnes@yahoo.co.uk) or [lesley@mooreinsight.co.uk](mailto:lesley@mooreinsight.co.uk)

**T7** McGinn, P., (2006) *Assessing the Impact of Service User Participation in the Southern Area*, Lurgan: Southern Health and Social Services Council, available from: [www.shsscouncil.net/pdfs/Assessing%20Service%20User%20Book.pdf](http://www.shsscouncil.net/pdfs/Assessing%20Service%20User%20Book.pdf)

This is more of a review than a toolkit, but it is a useful example of an evaluation of service user participation in terms of its impact. The review explains the terms of reference for the review, the methodology used, includes a literature review and an overview of the policy context. The process and impact of service user participation are illustrated with case examples. A user-centred model is presented to promote participative practices (this has been adapted in Ideas box 4), with specific examples of evidence from practice. The review concludes with some helpful guidelines.

**T8** Hutchinson, R. and Stead, K. **The Rickter Scale**® [info@rickterscale.com](mailto:info@rickterscale.com)

This tool is used by one of the example Practice sites (P01). It has been created for practitioners by practitioners, with a minimum of recording documentation. It measures 'distance travelled': the 'soft' outcomes that people achieve, such as dealing with barriers to employment, training or education, by overcoming limiting beliefs, and gaining confidence and self-esteem. The Rickter Scale® is essentially a colourful plastic board with sliders on scales that read from 0 to 10. It is non-paper based, with the specific intention of providing an experience that appeals to different senses and learning styles.

It is a participative tool which can be used to evaluate participation. Ready-made questions are available for a number of different situations (available on the website); these could be adapted to measure the impact of participation.

The Rickter Scale® helps people to make informed choices and set goals which are realistic and achievable, and to take responsibility for their own action plan and determine the level of support they require. It is designed to enable people to take up new perspectives which reflect their capabilities, beliefs, values and sense of identity. The significance of people keeping their fingers in contact with the Rickter Scale® during the questioning is related to what is known in neuro-linguistic programming as 'anchoring'. At the second or subsequent use of the Rickter Scale®, comparison is made with this first 'profile' and thus 'distance travelled' is measured.

**T9** Gwynneth Strong and Yvonne Hedges and Welsh translation by Emyr Huws Jones (2000) *Too Many Pages: SCOVO's Guide to Involving Service Users to Make Better Services*

This accessible guide is written in English and Welsh is dotted with cartoons and illustrative quotations ('if there's too many pages, I can't be bothered, so I put it in the bin'). Its main audience is the learning disability sector, but it is relevant to other sectors, too. Like the other guides and toolkits we have mentioned, its main focus is on participation and involvement, but there are also useful ideas about feedback and evaluation.

The guide squares up to issues such as representation, for example 'nobody ever asks the paid workers if their views are 'representative'. Can you imagine asking in the middle of a meeting "Are you sure Mr/Mrs Social Worker that the views you are giving are representative of every employee in social services?"' Ideas box 2 is adapted from this toolkit.

**T10** W. K. Kellogg Foundation (2004), *Using Logic Models to Bring Together Planning, Evaluation, & Action: Logic Model Development Guide* ([www.wkkf.org/Pubs/Tools/Evaluation/Pub3669.pdf](http://www.wkkf.org/Pubs/Tools/Evaluation/Pub3669.pdf))

Like AI (T6), Logic models are not so much a toolkit as an aid to planning and evaluation. They set out the logical relationships between needs, goals, services and outcomes. They provide a structure for understanding the process of change, whether for projects or for individual work. Typically, a logic model will focus on the problem and what is wanted as the end result, identifying that as the goal, but noting also a series of mini-goals or milestones towards achieving the goal. Indicators that will show whether each mini-goal has been achieved need to be made specific – in other words 'how will we know if change has occurred?' Logic models measure *results* (the progress at the end of the project or piece of work) and they also measure *outcomes* (the progress at a later stage which shows whether the effects have been sustained). There is increasing experience of using logic models at individual and service level.

A closely linked method is task-centred practice, which is a highly participative method of practice in social work and social care (Marsh and Doel, 2006).

- T11** Perpetua Kirby with Sara Bryson *Measuring the Magic: Evaluating children's and young people's participation in public decision making*  
London: Carnegie Young People Initiative ISBN 0-900259-47-7 ([www.carnegieuktrust.org.uk/files/main/Measure%20the%20Magic.pdf](http://www.carnegieuktrust.org.uk/files/main/Measure%20the%20Magic.pdf))

This publication reviews approaches to participation of young people in decision making and provides guidance on the best practice to follow. The publication details the problems and pitfalls in processes used in participation and provides a range of useful sources of materials (see R22).

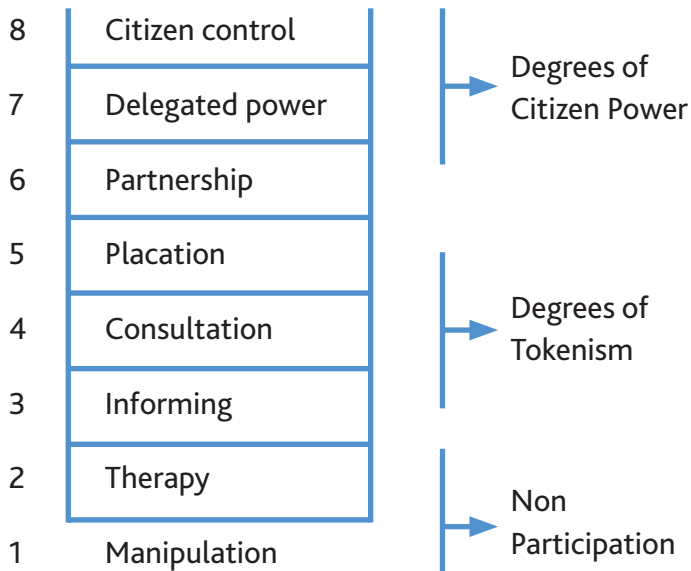
- T12** *The Evaluator's Cookbook* (2005) National Evaluation of the Children's Fund ([www.ne-cf.org](http://www.ne-cf.org))

This resource contains 25 'recipes' for participatory evaluation exercises for use with children and young people. Interactive versions of a number of these exercises are available on the NECF website. The Cookbook now includes 'templates' for a number of the exercises.

The Cookbook is designed as a resource for anyone working with children to use – either as part of an overall evaluation of children's services/funds or as a tool for evaluating particular activities (play schemes, single sessions, etc.). Although primarily a resource for those working with 5–13-year-olds, all the exercises have also been piloted for use with adults.

## Arnstein's Ladder of Participation

Although this ladder is about participation rather than evaluation, and it was first developed in 1969, it is still frequently referred to and so we reproduce it here.



### Other website-based toolkits include:

Worcestershire County Council:

<http://worcestershire.whub.org.uk/home/wccindex/wcc-con/wcc-con-toolkit.htm>

Bournemouth Teaching Primary Care Trust:

<http://www.bournemouth-pct.nhs.uk/involvement/toolkit.htm>

### Other references

Baum, F., Cooke, R. and Murray, C. (1998) (see T4 references)

Branfield, F. and Beresford, P. with Eamon J. Andrews, Patricia Chambers, Patsy Staddon, Grace Wise and Bob Williams-Findlay (2006), 'Making user involvement work: supporting service user networking and knowledge', Joseph Rowntree Foundation (download free from [www.jrf.org.uk](http://www.jrf.org.uk)).

Marsh, P. and Doel, M. (2005) *The Task-Centred Book*, London: Routledge/Community Care

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### Additional references: difference and diversity

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## Practice sites

Ten 'practice sites' were included in the research as illustrations of evaluation of the difference participation has made. All of these are included below, with detailed accounts from nine of them.

### **P01 NIUSE SEA project (Northern Ireland Union of Supported Employment, Supported Employment in Action project)**

#### **1 Characteristics of service users ('beneficiaries') involved**

Service users are called beneficiaries in the project and they are disabled people with physical, learning, sensory or hidden disabilities, or a combination of these.

#### **2 How service user participation within the project is ensured**

The SEA focus group consists of 13 service users who have accessed employment-focused services across Northern Ireland. The project aims to strategically review services for disabled people – more specifically the gap in employment service provision. Participation in the project gives disabled people access to policy review through focus group and conference activities run by disabled individuals.

#### **3 What policies on service user participation has the project formulated?**

The beneficiary focus group has contributed to the review of employment-focused services in Northern Ireland. They will have valid input into key policies effecting disabled people accessing, maintaining and retaining paid employment. Through the research methodology it is hoped the project will impact or influence future policies related to service user participation.

#### **4 How are service users (beneficiaries) supported?**

Service users are supported with transport, accessibility, follow-up contact, member organisations and consent issues.

#### **5 How are the effects of participation monitored, audited, and evaluated? Who carries out the evaluation?**

The evaluation of participation is taking place from individual to policy levels using focus groups, life histories, case studies and photography projects. The Rickter motivational assessment tool has been deployed in a group format to further the evaluation model used (this measures distance travelled) (T8).

An external evaluator is involved and the final evaluation is expected in summer 2007. Beneficiaries (service users) are involved as participants in the research.

## 6 A particular example of participation making a difference

Disabled participants now have the capacity to form opinions on their individual lived experience, identify their difficulties and relate this to structural barriers.

At a strategic level, this group using the information they have produced on structural barriers now engage with senior government personnel and other key stakeholders making recommendations for change.

This project is still on-going and the impact of service user participation is still to be determined and will continue beyond the completion of the project in December 2007.

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## P02 The Skillnet Group

### 1 Characteristics of people involved

The Skillnet Group is an organisation where learning-disabled people and non-disabled people work together equally.

### 2 How participation is ensured

Self-advocates have control in all aspects of the Skillnet Group. Participation is about 'voice', 'choice' and 'change'. Self-advocates' participation includes:

- team and training days (each project or service)
- planning meetings (new projects, services or ideas)
- communication days (all employees – includes learning-disabled people)
- internal reviews

- Speaking Up Network
- a board of trustees
- funding bids
- recruitment
- policies, procedures and risk assessments – everyone involved
- website – message board, suggestions/new ideas area, emails.

### **3 What policies on participation has the organisation formulated?**

Participation began at the beginning, with the attempts to seek funding for the project. The Skillnet Group has developed Steering groups and a 'Decision team' to embed participation throughout the organisation; these groups have members who are learning disabled and members who are not. A website is used to feedback findings as well as feedback forms. Each project/service produces its own action plan every year – everyone works on these together. These feed into the overall three-year plan (monitored by the Decision team) which is composed of about 20 people, ten of whom are self-advocates.

### **4 How are people supported?**

The Skillnet Group directly supports about 150 self-advocates and 300 others indirectly to become more independent in all parts of life, including; learning, work, housing, health, money, transport, leisure and relationships. People are supported to develop their own person-centred plans and to make sure their plans are put into action and taken seriously.

### **5 How are the effects of participation monitored, audited, and evaluated?**

In addition to the activities already mentioned, two evaluations have been conducted by self-advocates from another project, the most recent was completed in December 2006. Self-advocates were part of the evaluation team.

### **6 A particular example of making a difference**

Self-advocates have always made the decisions about staff recruitment and this has been a significant step.

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## **P03 People First Rhondda Cynon Taff (RCT)**

### **1 Characteristics of service users involved**

People First is a service-user led organisation for self-advocates (people with learning disabilities). There are about 200 members.

### **2 How self-advocates' participation within the organisation is ensured**

There are meetings of self-advocates once a month in each of three counties. An over-arching Executive Committee includes self-advocates. A participation guideline has been developed to guide local statutory services.

### **3 What policies on self-advocates' participation has the organisation formulated?**

There is participation at all levels from individuals to a three-county strategy. Self-advocates receive training to participate in interview panels. There has been a recent bid, jointly with a local university, to undertake research, in which self-advocates will participate as co-researchers.

### **4 How are self-advocates supported?**

The self-advocates support each other. Staff offer support on a group basis.

### **5 How are the effects of participation monitored, audited, and evaluated?**

Evaluations are undertaken as part of the terms of the funding for various projects within People First. An independent evaluation was conducted in 2004 and another is due, though it is not specifically evaluating participation. The AGM and annual report are important for public audit of the project and the effects of participation. There are occasional questionnaire surveys. However, self-advocates generally say they prefer group discussions to writing things down.

There are tracking forms to see whether all parts of the learning disabled community are participating – to understand whether some of the 'seldom heard' groups are being included, too.

### **6 A particular example of participation making a difference**

Training around participating in interviews has been important and has made self-advocates' participation more meaningful. RCT train people with learning disabilities to become co-tutors which enables them to deliver disability equality awareness training.

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## P04 Sandwell Visually Impaired Group (SVI)

### 1 Characteristics of service users involved

SVI serves adults with visual impairments in the Sandwell area of the West Midlands. It is a service user-led partnership with the local authority. Currently (March 2007) there are 200 members of SVI, which is 12% of all visually impaired people in the borough.

### 2 How service user participation within the organisation is ensured

The purpose of participation is enhancing the quality of lives of the visually impaired people living or working in Sandwell and to help members to become self-advocates. SVI's mission is the full implementation of the RNIB 16 standards as laid out in 'Progress In Sight', which the council have also pledged themselves to implement. There is participation on council committees and service provider teams (Sensory Impairment) as well as job interviews for professionals.

### 3 What policies on service user participation has the organisation formulated?

Participation takes place at all levels except research. At the policy level, the council have undertaken to develop a Sensory Impairment Booklet and SVI are engaged in this process. SVI members have joined two council Scrutiny Panels (Equality and Diversity; and Culture and Community) and sit on the Disabled Equality Project Board.

### 4 How are service users supported?

Users of Sandwell's Vision Services are supported by the endeavours of the SVI Management team to secure the delivery of an improved service. To this end SVI have established two strategic sub-groups. Both groups meet frequently and not less than monthly. As community peers, with expertise, SVI are advocates for the less confident.

Social support is provided by SVI publishing a quarterly newsletter that is distributed to all 1,700 named on Sandwell's register of visually impaired people; the launch of an interactive website; and the holding of quarterly entertaining 'Open meetings'. The well-attended AGM (110 people in 2006), also provides another friendly forum for the community.

## **5 How are the effects of participation monitored, audited, and evaluated?**

Internal evaluations are undertaken, but there is no independent evaluation. Evaluations are not specifically about the effects of participation, but focus on the 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). A regular newsletter and the SVI website and AGM are used to help monitor participation.

## **6 A particular example of participation making a difference**

Four of SVI's committee members now have input into job applications. Initially this was confined to posts within Vision Services this is now broadening to embrace the wider council service.

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## **P05 CHILYPEP (Sheffield Children and Young People's Empowerment Project)**

### **1 Characteristics of service users involved**

The Sheffield Children and Young People's Empowerment Project (CHILYPEP) is a registered charity that has worked with children and young people across Sheffield for over five years. The purpose of the work is to support children and young people in communities with high deprivation indicators to be actively involved in decision-making processes that affect their lives.

### **2 How service user participation within the organisation is ensured**

The project is designed as a peer research project. Participants develop questionnaires, which are analysed by staff but with reports written in consultation with young people. Feedback is provided through area conferences to key public services.

### **3 What policies on service user participation has the organisation formulated?**

The organisation's purpose is to develop participative consultation with children and young people in key areas of Sheffield and to promote and facilitate the application of findings of consultation exercises with public services.

### **4 How are service users supported?**

A paid worker coordinates the peer research projects and supports the young people to develop neighbourhood youth forums to take forward issues raised in the research findings. A professional researcher ensures that the design and analysis of data collection uses the themes and issues suggested by young people.

### **5 How are the effects of participation monitored, audited, and evaluated?**

The process is self-auditing with clearly defined outcomes to each episode of participatory work.

### **6 A particular example of participation making a difference**

A Peer Research Project was undertaken to find out the views and ideas of young people. This piece of research was also assigned to inform the Youth Strategy for this area. The Community Forum will be responsible for the implementation and review of the strategy, with support from partners within the Youth Strategy Group. The Delivery Plan will cover a 12-month period, and will be reviewed and updated through quarterly meetings. An evaluation event is planned (March 2007), which will work to inform how this project is developed further. The project was also aimed at supporting young people to develop new skills in research and consultation, and to gain a wider understanding of how to influence decision making and have their voice heard.

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## **P06 Cornwall Young Carers' Project**

### **1 Characteristics of service users involved**

Service users are young people who have a caring role for a parent or grandparent who suffers from a long term illness, disability or have a dependency on alcohol or drugs.

### **2 How service user participation within the organisation is ensured**

The project works to ensure that the young people who have a caring role have quality time to enjoy leisure activities, that schools are sensitive to the issues that face them, and all service providers are aware of problems that occur for these young people on a daily basis. Young people are involved in decisions about individual and group work within the project. They have also been closely involved in the design and development of project evaluations.

### **3 What policies on service user participation has the organisation formulated?**

The project operates from a participative framework in which young people are encouraged and enabled to take part in shaping the direction of the project as a whole and the direction of individual work they may be involved with.

### **4 How are service users supported?**

Two project workers and an administrator are funded to work on the project. They help with advice and information, practical support, liaison with professionals, personal support, outings and leisure activities and arranging time off.

### **5 How are the effects of participation monitored, audited, and evaluated?**

Evaluation has been a major focus of the development of the project. There have been two major independent evaluations, the second of which built on the findings of the first. Findings from the first evaluation pointed to the need for development of administrative systems to support further evaluative work. Young people are closely involved in the design, delivery and dissemination of the evaluation. Evaluation uses an action research approach but recognises that this does not easily capture the cumulative benefits of the project.

### **6 A particular example of participation making a difference**

The emerging evaluation strategy has been able to demonstrate the need for an on-going action research approach to the project while also recognising that impact is cumulative for many young people. Many of the young people have presented at conferences locally and nationally about the Project's success.

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### **P07 The Visiting Advocacy Service in Secure Children's Homes (VOICE)**

#### **1 Characteristics of service users involved**

Young people in secure children's homes.

#### **2 How service user participation within the organisation is ensured**

VOICE (formerly Voice of the Child in Care) operate a visiting advocacy service within a number of secure establishments to provide independent support to young people who wish to raise concerns about their care or make representations. Advocates visit on a regular basis either weekly or fortnightly and become familiar and trusted persons, seen as independent of both the secure units and social services departments. A key feature of their involvement with the young people is a high threshold of confidentiality.

#### **3 What policies on service user participation has the organisation formulated?**

It is important to distinguish between the policies in the secure establishments and those of VOICE itself. VOICE has an overall 'blueprint for activity' which aims to:

- focus on the child in everything we do
- promote good relationships with family, friends and professionals
- recognise that children and young people are competent and have the capability to work in partnership with adults
- argue that the bureaucratic processes that have become associated with the care system have to be minimised and adapted, if we are to serve children as individuals, and promote their sense of identity.

#### **4 How are service users supported?**

The secure advocacy project provides advocacy visitors for young people who are in secure accommodation, supporting interventions on their behalf.

## 5 How are the effects of participation monitored, audited, and evaluated?

The service has developed an exit interview as an approach to evaluating the advocacy service, as well as reviewing the young person's experience in the unit. In theory all young people are able to contribute to the exit evaluation, although unforeseen moves or releases from custody at court appearances mean that not all young people participate. The exit interviews operate in three secure units at present and developments in other locations are underway.

## 6 A particular example of participation making a difference

Representations to the visiting advocacy service resulted in a substantial change in policies regarding telephone contact in one establishment. The managers saw the process primarily as one part of the unit's involvement of young people in the service they receive.

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## P08 Mersey Care Trust

### 1 Characteristics of service users involved

All users were mental health service users and carers. The evaluation asked why service users wanted to become involved in services. The most common reasons were to 'change and improve services', 'to give something back' and 'to have something meaningful to do'.

### 2 How service user participation is ensured

Activities and methods that ensured participation described by service users included:

- recruitment and selection of staff
- open space events
- provision of information
- involvement in a user forum
- positive achievement awards.

### **3 What policies on service user participation have been formulated?**

The Trust has a strategy which states the importance of user involvement/ participation. In the survey of staff members 58 out of 73 said they were personally responsible in involving services users.

### **4 How are the effects of participation monitored, audited, and evaluated? Who carries out the evaluation?**

The evaluation of participation was undertaken in the form of a survey of 201 people who had participated in services and who were held on a user participation database.

### **5 A particular example of participation making a difference**

Both service users and staff were asked in the survey how participation made a difference.

**Service users:** 44 out of 93 said it made a lot of difference to their lives, 34 out of 93 said it made some difference, and 8 out of 93 said it made no difference.

**Practitioners:** 32 out of 73 a lot of difference, 34 out of 73 some difference, and 6 out of 73 said it made no difference.

### **6 Contact details**

The evaluation report for Mersey Care Trust can be found at: [www.mersecare.nhs.uk/Library/service\\_user\\_and\\_carer\\_involve/Involving\\_S\\_&\\_C/SUCReportColourUpdate2.pdf](http://www.mersecare.nhs.uk/Library/service_user_and_carer_involve/Involving_S_&_C/SUCReportColourUpdate2.pdf)

## **P09 The TRUE Project**

### **1 Characteristics of service users involved**

This case study is the evaluation of the experience of user participation as co-researchers on a research project. The evaluation report is called 'A Story of Colliding Worlds'.

The TRUE (Training in Research for Service Users Evaluation) Project was undertaken to scope training provision in the UK relevant to consumer involvement in research: to identify what elements are effective, and to develop a good practice guide.

The co-researchers in the TRUE Project were adults who were mental health service users. All user-researchers were members of CAPITAL (Clients and Professionals in Training and Learning), a mental health service user organisation.

## **2 How service user participation within the organisation is ensured**

The project was a three-way collaboration between Worthing & Southlands Hospitals NHS Trust, CAPITAL and the University of Brighton.

## **3 What policies on service user participation has the organisation formulated?**

The evaluation focussed on user involvement in research.

## **4 How are service users supported?**

The TRUE team comprised seven service users (members of CAPITAL, a mental health service user organisation), three project supervisors and a project coordinator. The three supervisors represented the three organisations involved in the collaboration: one researcher from Worthing & Southlands Hospitals NHS Trust, one researcher from the University of Brighton, and the third being the Director of CAPITAL.

## **5 How are the effects of participation monitored, audited, and evaluated?**

The 'Colliding worlds' evaluation took place at the end of the TRUE Project. The TRUE research team requested the opportunity to reflect on their experiences of being involved in the project. This evaluation explored the experience of user participation as co-researchers and the purpose of the evaluation was to improve good participation of service users in research.

A one-day event was arranged at the end of the project to bring everyone together in order to reflect upon the project. Five service users and three researchers attended. This was facilitated by an independent researcher.

A second half-day was organised for those people who wished to take part in a further opportunity to share their views in more depth. Four people (one researcher and three service users) attended and one further service user submitted a response in writing.

## **6 A particular example of participation making a difference**

The TRUE team produced an action pack that has been tried and tested. This pack was downloaded 9342 times in the first year.

## **7 Contact details**

The TRUE project can be found at: [invo.org.uk/pdfs/TRUE%20final%20report130404.pdf](http://invo.org.uk/pdfs/TRUE%20final%20report130404.pdf)

Capturing the experiences of those involved in the TRUE Project: A Story of Colliding Worlds can be found at: [www.invo.org.uk/pdfs/colliding%20worlds.pdf](http://www.invo.org.uk/pdfs/colliding%20worlds.pdf)

## **P10 London Primary Care Studies programme**

This was a commissioned evaluation of the impact of service user involvement in research across a wide range of settings within primary care. Service users were involved in interview design, revising questionnaires, finding new ways to collect data and increasing number of participants. They contributed to interpretation of data and to dissemination of findings through their own networks. Service users and 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. Service users and carers who felt more remote from the senior researchers were more likely to report a mixture of positive and negative experiences of their participation. Methods used included regular telephone contact and easy to understand language. There was a 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. The report provides guidance on best practice in service user involvement in evaluation.

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## Participation: finding out what difference it makes

The Social Care Institute for Excellence has commissioned this guide to help users, carers and professionals design evaluations of service user and carer participation. The principles of service user and carer participation is well established, by evaluating this we will be able to see what impact this involvement is having on social care services.

This publication is available in an alternative format upon request.

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