

Chapter 3

Engaging and Involving Individuals and Communities

Before we start thinking about why and how we should engage and involve patients, service users and carers, it is worth noting that there is some real ambiguity about the terms that people use to describe both those involved in these kinds of activities, and the activities themselves. For a start, it is difficult to agree a common term to describe someone receiving a health or social care service – are people patients, service users, clients, consumers or customers? In some cases, people who have had a disease, or condition, refer to themselves as survivors, so there are stroke survivors, cancer survivors and mental health survivors. Those looking after people in need of care are generally referred to as carers, but may also be referred to as care-givers.

When it comes to the activities we are going to talk about in this chapter, they are variously described as, amongst others, involvement, engagement, participation, collaboration, co-production and lay representation, or by the abbreviations PPI (public and patient involvement) and PPE (public and patient engagement). People are described as exercising their right to choice, voice and exit strategies in their interaction with health and social care, and we gather their experiences, we ask them for their evaluation of services, we empower them, and we measure their satisfaction. We also provide patient-centred care, person-centred care, individual care planning and negotiated care, and we expect people to self-care and to self-manage!

It can all become a bit of a minefield, but the important thing is to think carefully about what role someone is in at any point of time, what it is they are doing at any point in time, and to be consistent in your own use of terminology.

In this book we use the term ‘service user’ to refer to someone actively in receipt of a health or social care service, regardless of the nature of that

service, and ‘citizen’ to refer to someone who is not actively in receipt of a service but in all likelihood has been at some point in time and may be again at some future point. We also use the term ‘carer’ to mean anyone either actively involved in the act of non-paid care-giving to an individual, or with responsibility for the welfare of an individual, such as a parent or guardian.

We use the term ‘engagement’ to refer to the process by which people are encouraged or facilitated to be interested in health and social care services, and their own health and wellbeing, and ‘involvement’ to mean their active participation in a specific activity.

We now come to the thorny issue of representativeness in engagement and involvement. There is a frequent argument used by some that an involvement activity isn’t legitimate or credible because it isn’t ‘representative’, or the participants themselves aren’t representative. Concerns about representativeness are sometimes used to marginalise or discredit people’s voices, especially when they are challenging the status quo. But what do they actually mean when people say something isn’t representative?

They often mean that the people involved don’t reflect the demographics either of the local community, or of service users in a statistical sense. For example, if you held an event that was specifically intended to gather the views of older people using day care services, of course you would want people there who were older who might use the service, but it might not be as important to have participants who statistically reflected the gender and ethnicity of the local older age community.

Whether those who are participating are representative of the group or community as a whole in a statistical sense is a contested concept – services might emphasise demographic correspondence, but service users themselves might emphasise the importance of empathy, shared experiences and local connections as being more important than statistical representativeness.

In any case, does statistical representativeness guarantee that the full range of views and experiences will be offered? For example, regarding older people’s views on day care services, you might want to ensure that there are people there who have used the services for a while, people who have chosen not to, and people who have used them but who have stopped going, so you can understand the reasons for each scenario. You might also want to ensure that there are people there with and without disabilities, those living alone, and those living with others.

Is it also reasonable to expect a small number of individuals to fully represent all others? We know that service users often report feeling uncomfortable about this. Some argue that it is not representation of individuals that is important, but representation of the range of discursive positions within society, and therefore diversity and inclusion are better goals than representativeness per se.

Now we have covered some of the minefields in terminology, the rest of this chapter covers the following themes:

- Why do we engage and involve service users, carers and citizens?
- What activities do we engage and involve service users, carers and citizens in?
- What are the barriers to engaging and involving people in integrated initiatives?
- Which factors enable engagement and involvement?
- What are the key stages of involvement?

Why do we engage and involve service users, carers and citizens?

Engaging and involving service users, carers and citizens in health and social care have become key policy objectives internationally over the last few decades. This policy direction started with debates about empowerment for people with mental health problems and people with learning and physical disabilities in the 1980s and early 1990s, and continued through the 1990s, with debates about delivering health and social care services that would meet the needs of service users rather than meeting the needs of those who worked in them or ran them.

Over the intervening time, many policies have been introduced to encourage greater engagement and involvement of service users, carers and citizens in both health and social care services, and to encourage people to become fully engaged in their own health and wellbeing. Various organisations have been established to support active public involvement in health and social care. These policies and organisations facilitate the development of health and social care services where people have a far greater range of choices, and of information about services to enable those choices; and for a service that has better and more regular sources of information about people's preferences and opinions on the care and services they receive.

A whole range of reasons is given for engaging and involving people, and evidence supports many of these reasons, although the quality of that evidence is sometimes limited. In essence, however, there are two main reasons: the first is that engagement and involvement is ‘an end in itself’ – this refers to the rights-based argument and is concerned with people’s self-determination and autonomy over their own health and wellbeing. This view of engagement and involvement challenges the traditional primacy of the professional by equalising power imbalances.

It is also suggested that involving citizens in decisions about which services are funded and how they are delivered means that such decisions will be better, fairer, more transparent and more democratically legitimate. This kind of involvement requires that citizens take some responsibility for decisions that affect society as a whole, particularly where there are difficult decisions to be made around ethical dilemmas, such as choices between funding services for one group of people over another. It is also suggested that there are educative benefits in this kind of involvement as it promotes more realistic public expectations about how much services cost and what can be afforded.

The second reason is that engagement and involvement is a ‘means to an end’ – this is based on the view that it leads to improved services that are more responsive to users’ needs and are of a higher quality. This second reason is also recognised as leading to better outcomes for individuals, such as better compliance with medication or treatment regimes, and care decisions and treatment plans that are more appropriate and acceptable for the individual, through the sharing of knowledge and understanding amongst all parties. This kind of involvement can lead to improved psychological outcomes too, such as increased confidence in care recommendations, higher levels of satisfaction with the care received and better psychological adaption to illness or life circumstances.

The first reason is described as the ‘democratic approach’, where the focus is more about improving people’s lives, by people having more say over the services they use and more control over their lives in general, whilst the second reason is often referred to as a ‘consumerist approach’, where the focus is the service system, the objective of which is to get service user, carer and citizen input to inform services and provision. It is, of course, possible that engagement and involvement activities may satisfy the needs of both democratic and consumerist approaches concurrently. However, for convenience, this chapter focuses on the second of these models, the consumerist approach, and Chapter 6 subsequently considers the first model, the democratic approach.

It is important to understand whereabouts on the spectrum between these approaches you are pitching your engagement or involvement activity, as this will determine whom you engage with and how you go about involvement. It is also important at the outset to match people's expectations to whereabouts on the spectrum their input is going. Whichever approach you are tending towards, though, it is important to remember that the activity must be meaningful for people and should make a difference, either to the individual or to the experience of receiving a service.

What activities do we engage and involve service users, carers and citizens in?

It is helpful to think about these kinds of activities occurring at different levels – for example, are we asking people to be involved in activities that will affect them as individuals, or are we asking people to be involved in providing their views on national policies and developments? Building on the micro, meso and macro framework introduced in Chapter 1, involvement can be thought of as occurring at the following levels:

- *Micro* – the involvement of the individual service user for their own benefit.
- *Meso* – the involvement of a group of service users for the benefit of a service.
- *Macro* – the involvement of the community, or citizens more widely, at a strategic level, whether across a whole system or at a national level.

It should also be recognised that an involvement continuum exists across these levels, but for the sake of simplicity, Table 3.1 shows what kinds of activities might occur at each level.

Although all organisations will be doing some form of engagement or involvement activity, many will not be doing this systematically, and probably most organisations would say they found engagement and involvement activities challenging.

Common concerns include how much it will cost to do properly, how to select people to take part, what methodologies or approaches to use, how to use the data that is gathered from these activities, and how to demonstrate that the activity has had any impact on the organisation, or for the individuals involved. These are all legitimate concerns and need

careful thought, but before an organisation begins to involve service users, carers or citizens, it needs to take a step back from the overwhelming urge to ‘do something’ and think about the purpose of involving people. It is only in identifying the purpose of engagement and involvement that organisations can answer all the other questions above.

Table 3.1: Engagement and involvement activities at different levels

Micro	Meso	Macro
Self-management	Governance of services	Establishing values and ethical principles
Evaluation, e.g. feedback	Quality assurance of services	
Safety, e.g. prompting hand-washing, or raising awareness of allergies	Developing policy	Developing policy
Research	Consultation on plans for major service change	Consultation on plans for major service change
Shared decision-making and care planning	Allocating resources locally	Allocating resources strategically
Exercising choice – of provider, location, etc.		
Co-production	Co-production	

What are the barriers to engaging and involving people in integrated initiatives?

We cannot talk about engagement and involvement without introducing the concept of power, as this helps explain the nature of the relationship between individuals and the state and statutory organisations more widely, but also between individuals and health and social care professionals or systems. It also helps us think about why things don’t always work as we had hoped they would.

Power theories help us to understand who is ‘allowed’ or not ‘allowed’ to be engaged or involved, and what the parameters of that activity are. For example, are people able to make their own decisions, or has a decision about something already been made and people are just being asked to support it? Are people offered a choice but only from a limited range of options pre-determined by someone else? Do people even believe they have a legitimate right to be asked for their view or opinion about something in the first place?

These different manifestations of power are likely to be apparent in all involvement or engagement activities and at all stages, from the initial idea that perhaps people ought to have a say in what is happening to the means by which the outcomes of the activity are publicised and promoted. One of the most obvious ways in which an organisation or individual professional can exercise power is to claim that people are not interested in being involved in decisions that may affect their lives. It is therefore appropriate to consider why this attitude prevails.

Do people want to be engaged and involved?

When asked about their motivations, people often say that they have become involved in providing feedback, or attending meetings, because they want to make a difference, or that they want to change things for the better or to give something back to a service that has helped them or those close to them. However, in spite of this altruistic desire from many people to be involved, surveys and other research suggest that actual involvement is lower than the amount of involvement people say they would like. There are a number of reasons why this might be the case.

The first, and most important reason is that people think their involvement will not make any difference to what happens. It's the 'Why bother? They won't take any account of what I've got to say and they'll do what they want to do anyway!' response, which we've probably all heard said to us, and probably all said ourselves at some point about giving feedback or our opinions on something. This perceived lack of influence relates directly to the power theories discussed previously – if people think they have no power to change anything, why would they bother to spend their time and effort getting involved?

The second important point to come out of these surveys and research is that people want decisions about the provision of health and social care services to be more open and accountable, but when it comes to complex decisions, people are more willing to give responsibility to professionals to make these decisions. This might be particularly the case where there may be trade-offs to make between the benefits of centralising some very specialised services to ensure expertise in these services, but the disbenefits of people not having a local service. And even when people feel they are not best placed to make the final decision, they still want their opinion to be taken into account.

The third point to note is that people often need practical support to be engaged and involved. This might mean that people need more

information to help them make decisions, but it also means that they might need someone to take them to meetings, or they might want to attend events at different times to suit their personal circumstances. Practical support may mean that people have their travel expenses paid or costs of a child minder, or carer, covered whilst they are taking part in some activity.

'Professionalisation' of participants

The 'professionalisation' of participants is another issue that crops up again and again when talking about involvement. At the heart of both this and the concern over representativeness lies the issue of the 'typicality' or 'ordinariness' of those taking part. You will have probably heard the phrase 'the usual suspects', which means that the same people keep coming along to involvement activities. It is often used quite pejoratively in a way that suggests these individuals have some kind of involvement compulsion or are 'hangers-on'. At the same time, participants in involvement activities might be criticised for lacking particular knowledge or understanding of a clinical or technical issue. There is therefore a real tension between asking someone to take part in something because they have a level of expertise on a particular subject, that is, they have been caring for someone with a mental illness for years, or because you want the view of 'Joe/Jo Public'. Are you therefore looking for 'experience-based experts' or publically legitimate representatives?

It is also worth raising here whether it is actually feasible for someone to be completely objective or impartial about an issue, because we all have a particular view on life as a result of our personality, our experiences and the influence of people around us. This idea of complete impartiality is a contested subject and underlies debates about the partisan nature of participants in involvement activities. However thoughtfully you go about involvement, there remains the likelihood that you will leave out someone or some group.

Other barriers to effective involvement

Apart from those issues mentioned, a range of other issues might prevent people from wanting to take part in an engagement or involvement activity, or might make it more difficult for the activity to be meaningful to people, or for it ultimately to have some sort of impact and to make a difference.

These can include the real or imagined existence of a paternalistic culture in health and social care services, which might either actively discourage involvement, or might affect people's underlying assumptions about what will happen if they 'make a fuss' about something they are not happy with or that hasn't gone right for them.

Trust is an important aspect of engaging and involving people, and both sides have to learn to develop trust in each other to make the relationship work well. It is all too easy for service users, carers and citizens to lose trust in an individual or an organisation when things go wrong. It's often the little things that frustrate and annoy, and when taken together can lead people to disengage. For example, if someone arrives for a meeting and no one is expecting them because someone has forgotten to put their name down on a list, it creates an immediate barrier. If a service user needs wheelchair access to attend an event but this hasn't been picked up, it creates another barrier.

There may also be some very unrealistic expectations from both sides about what an engagement or involvement activity is likely to achieve. An organisation might think that it is reasonable to ask people to give their opinions about complex service changes without providing them with the right kind of preparation, or people might think they are able to design a new building when all they are being asked to comment on is the colour of the walls. If expectations aren't dealt with at the outset, it is likely to lead to frustration from both sides, which ultimately will affect how the next activity is viewed and whether people will want to take part.

If the environment is financially challenging, then individuals and organisations will need to make decisions about what activities they prioritise. It is likely that the delivery of services will be prioritised above other activities, and that activities such as engagement and involvement will be seen as 'nice to do', rather than 'need to do'. There is an assumption that these kinds of activities cost a lot of money, and, of course, some activities can take a lot of time and resources, but other activities need not break the bank if they are well thought out and well planned and are systematised. For example, it is worth investing in some software and training to design online questionnaires as this might be used many times over, and other organisations such as charities might sponsor events if they are able to have a stand and some promotional literature available on the day. Difficult operating environments should lead to creative solutions, rather than being a reason to stop doing things.

You may also have to be creative in how you work with people in different ways. It is quite likely that at times service users may not be well

enough to take part in activities, or may not feel ‘up to it’ for whatever reason. Recognising that this is a consequence of the environment, and not the individual, and being flexible enough to adapt your plans, is important. As well as people’s health and wellbeing affecting their ability to engage and get involved, people’s level of health literacy can be seen as a barrier to accessing activities. In simple terms, you might need to think about how to provide people with materials in a range of languages, easy-to-read versions or braille, or you might need a signer to help at events or meetings. But you will also need to take into account the specifics of health and social care language – will you be using terminology that people will understand, will you be using jargon or acronyms that are obvious to you but not a lay person, or will you be talking about concepts that are difficult for most people to grasp, such as their risk of developing a particular disease or condition, or what randomisation in a clinical trial means?

Which factors enable engagement and involvement?

We’ve talked a lot about the barriers to engaging and involving people, so now it’s time to think about what facilitates engagement and involvement. The CLEAR framework (Lowndes, Pratchett and Stoker 2006) is a really helpful and simple way of thinking this through (see Table 3.2), and sets out what is required from organisations and individuals for each factor.

Table 3.2: The CLEAR framework

Can do	Have the resources and knowledge to participate	Capacity building, training and support
Like to	Have a sense of attachment that reinforces participation	Building visibility, trust, relationships
Enabled to	Be provided with the opportunity for participation	Investing in infrastructure, groups and networks
Asked to	Mobilise by official bodies or voluntary groups	Opportunities that are appealing, engaging and appropriate; getting the ‘ask’ right
Responded to	See evidence that their views have been considered	Feedback on how decisions were made and views were considered

We have already talked a little bit about the ‘Can do’ by providing people with the practical support to be involved, whether this involves providing information or addressing logistical challenges. As regards the ‘Like to’, we mentioned earlier that people become involved with activities for a

number of reasons, but building relationships and trust is crucial. Seeing involvement as a ‘one-off’ activity and only asking people to participate in something when you have a problem to solve, or a regulatory requirement to meet, will probably make some people feel rather used, so try to ensure that your involvement activity is something regular, continuous and systematised. Following on from this, involvement should be something that people enjoy doing and see a value in. The ‘Asked to’ suggests that people need to be ‘mobilised’ and to see a purpose in what they are being asked to do – this goes back to the point about involvement activities being meaningful. We consider the ‘Enabled to’ and ‘Responded to’ in more detail in the next section that looks at different stages in the process of involvement.

What are the key stages of involvement?

Stage 1: Determining the purpose of involvement

Before you jump in and start organising a workshop event, or start designing a questionnaire, be really clear about why you are doing this. You might intuitively think it’s a good idea to do some involvement work (and it is!), but if you’re not clear about the purpose, you won’t know what the best approach is, who to involve and how, what to tell people about why you are asking them to do something for you, and what you will do with the answers you get or the data you gather (see Case example 3.1).

Asking yourself a series of questions as follows should help:

- Who will be using the information you collect? Will you be sharing the information with policy-makers and professionals, or service users, carers or citizens?
- At what level are you looking for involvement? Are you looking to involve people at the micro, meso or macro level? Do you want to know about strategic or operational issues?
- Whose issues are you asking for information on? Are you asking people to give you information to meet your agenda, or are you asking people what their agenda is?
- How will information be analysed? Do you have the analytical skills to analyse complicated quantitative data from surveys, or have you got software to help you? Do you have the time to analyse lots of qualitative information, and how will you draw together and analyse information from lots of different sources

such as post-it notes, flip charts or drawings from a workshop event, for example?

- Will the information be summarised or aggregated? Depending on the answer to this, will the information still be meaningful to everyone you will share it with if it is summarised?
- How will decisions subsequently be made? Do you know what the process is by which the information you gather will affect decision-making?
- Is the involvement instrumental or symbolic? (The above questions and prompts generally assume that the involvement activity is instrumental and designed to meet a specific purpose. However, there may be a symbolic element to involvement, and that this is a means by which people's views are seen to be valued, or there may be some therapeutic value attached – 'tell us what has happened to you and it will get it off your chest'. If the purpose of involvement is either of the above, proceed with extreme caution. Symbolic gestures may make the organisation feel good, but if there is no tangible outcome for participants, it could do more harm than good in terms of your long-term relationship with service users, carers and citizens.)

Case example 3.1: Commissioning support services in Edinburgh

The City of Edinburgh Council, NHS Lothian, carer organisations and carers came together through a working group to redefine their strategic approach to commissioning support services for carers. The development of a three-year joint carers strategy for 2014–17 involved a consultation with carers on their priorities and the support they required. The approach set outcomes for carers at the centre of the new strategy.

To produce the strategy, the working group used the Wisconsin Logic Model¹ as a planning and evaluation tool. This approach brings detail to broad goals, helps identify gaps in strategies, is outcomes-focused, and makes underlying assumptions explicit. In order to ensure that all members of the working group knew how to work with the model, specific training was given to bring everyone up to the same level of

1 See www.uwex.edu/ces/pdande/evaluation/pdf/lmcourseall.pdf

knowledge and understanding about its application. The working group discussions were also independently facilitated.

Once six priority themes were agreed, the working group identified a set of questions under each theme on which it sought feedback from carers, including suggestions as to what type of support was needed under each heading. Written and online questionnaires were developed, and a number of consultations were held. The feedback from these events was fed directly back into the development of the strategy.

What does this case example tell us?

- » The purpose of the involvement activity was clear to all those involved – it was to develop a new carers strategy, focused on carers' own priorities.
- » The use of any specific tool or mechanism within involvement activities must be carefully thought through, with the development needs of all those involved in the activity appropriately addressed.
- » Even though the working group involved carer organisations and carers, it recognised the benefits of consulting more widely to allow for a broader range of perspectives to be considered and for the emerging priorities to be confirmed.

Stage 2: Determining who is the focus of involvement

Again, it might be useful to ask yourself a series of questions, to be clear who is the focus of involvement – individuals or groups. There is also the scenario whereby people may offer their opinions and ideas informally, i.e. outside of any formal kind of involvement activity such as a survey exercise or a consultation event. A service user might provide you with feedback whilst you are visiting them at home to undertake an assessment, or as part of another professional contact. You will need to think about how you capture this information and ultimately how it is used. Otherwise, think about the following points:

- Do you want to target specific groups of people as 'experts by experience', or do you want participants who represent a broader range of experiences and perspectives?
- Is statistical representativeness an issue?

- Who are the seldom-heard groups or individuals in the area you are exploring?
- Is it going to be important for respondents/participants to be anonymous, and do you need to maintain confidentiality about their involvement?
- Will participants have the competence and capacity to take part? (Put simply, ‘competency’ refers to the mental ability and cognitive capabilities required to execute a specific task rationally, whereas ‘capacity’ refers to an individual’s psychological abilities – specifically, their ability to understand, appreciate and manipulate information and to form rational decisions.)
- How can you ensure you are accessing participants who are likely to be supportive and challenging? (Be sure to not just seek the inclusion of people who are likely to tell you what you want to hear.)

It is also important in many instances to understand the views and experiences of people who do not access or use services. If you involve people who are not service users but who are eligible to be, and have chosen specifically not to do so, you will get very different views from those who do use the service in question. It is, of course, more difficult to identify who these people are, and will require a more creative approach to engagement. It is quite possible that people choose not to access or use a service because they do not have a sense of attachment to the organisation providing the service, or may actively choose not to identify as a service user – this means you will have to work first to establish trust.

Stage 3: Which engagement or involvement approach to use

So, let’s imagine that you are clear about the purpose of your involvement activity and you know who you wish to involve. You now need to turn your attention to the approach and methodology. Table 3.3 provides a simple example of three approaches to engagement and involvement – the provision of information, consultation and participation – and examples of different methods you could use, such as information leaflets, surveys and citizens’ juries.

Table 3.3: Three approaches to engagement and involvement

	Information	Consultation	Participation
Flow of information	One-way	One-way	Two-way
Purpose?	Letting people know and raising awareness about a change to an existing service	Getting a snapshot of people's views on proposals for a change to an existing service	Engaging in dialogue or negotiation to change national policies on paying for services
Who?	Service users of the specific service	Members of the local community	Citizens
How?	Leaflets, websites, local media, roadshows, noticeboards, newsletters	Surveys, focus groups, public meetings	Opinion polls, discussion forums on social media, petitions

There is, of course, a whole range of methods by which you could engage and involve people, and there are advantages and disadvantages to them all. Table 3.4 sets out the main methods and their strengths and weaknesses to give you a sense of when it might be appropriate to use them. Generally speaking, of course, an organisation will be using a range of methods all the time, as there is no one method that is acceptable, or appropriate, to all people, in all circumstances, and at all times; a range of methods is required to maximise response rates, increase representation of a range of experiences and viewpoints, and to avoid bias. Think of it like a toolbox of methods, and choose the one(s) that you think fits best with the 'why', 'what' and 'who'.

It is also worth bearing in mind that people can sometimes feel overwhelmed by requests for information or involvement, and so it is important not to bombard service users, carers and citizens with multiple requests. This is especially important when you are working in an integrated care setting, and a number of organisations might want to lead these kinds of activities. It is important therefore that you are clear which organisation, team or department has responsibility for these kinds of activities, so that energy and costs are not duplicated, and goodwill is not jeopardised.

Table 3.4: Main methods of engagement and involvement, and their strengths and weaknesses

	Approach (e.g. information, consultation, participation)	Volume reach	Provision of quantitative data	Provision of qualitative data	Speed of response	Real-time information	Low-cost	User-friendly	Reporting of sensitive information
Roadshows	Information	✓	✓	✓				✓	
Leaflets	Information	✓	✓	✓				✓	
Newsletters	Information	✓	✓	✓				✓	
Public meetings	Information Consultation		✓	✓	✓	✓			
Self-administered questionnaire/ survey (not online)	Consultation	✓	✓✓	✓			✓	✓	✓✓
Comment/ feedback cards	Consultation	✓		✓	✓	✓	✓✓	✓✓	
Hand-held devices	Consultation	✓✓	✓✓		✓✓	✓	✓	✓	
Touch-screen kiosks	Consultation	✓	✓✓		✓✓	✓	✓	✓	
Online questionnaires	Consultation	✓✓	✓✓	✓	✓		✓✓	✓	✓✓
Telephone interviewing	Participation			✓	✓			✓	
Depth interview (service user story)	Participation			✓✓	✓			✓✓	✓
Peer researchers	Participation			✓✓				✓✓	✓
External websites (NHS Choices, Patient Opinion)	Consultation Participation	✓		✓	✓		✓	✓	
Focus group	Consultation Participation			✓✓				✓	
Online communities	Information Consultation Participation	✓		✓	✓		✓	✓	
Social media – Facebook	Information Consultation Participation	✓		✓	✓		✓	✓	✓
Social media – Tweets	Information Consultation Participation	✓	✓	✓	✓✓	✓	✓	✓	
Citizens’ juries	Information Consultation Participation			✓					
Experience-based design/ co-production	Information Consultation Participation			✓				✓	

Whatever method(s) you choose to use, good practice dictates that you test it out first. This means that if you ask people to complete a survey, ‘pilot’ the questions first – do your pilot respondents understand what information they are being asked for, and will they interpret things in the same way as the person who has designed the questionnaire? The same will be true if you are using a topic guide in an interview. It is also worth thinking about the increasing use of technology as a proxy for human contact – what you might gain from convenience and speeding up the process, you might lose in engagement and developing rapport with some groups of people.

There are also advantages and disadvantages in collecting information from people at the point at which they are receiving a service – ‘real time’ – and collecting information some time after they have received a service – ‘retrospective’. It has been suggested that collecting information in ‘real time’ gives the organisation and its staff more motivation to act, because the information is fresh and it is easier to determine cause and effect. It is therefore easier to prevent issues from becoming problems and to improve the overall experience for others. There are, however, disadvantages in seeking ‘real-time’ feedback, partly because reflection is an important element of giving feedback on an experience, but also because there is a phenomenon called the ‘positivity of response bias’, which means that some people may provide more positive feedback during an episode of care because there are inherent difficulties in talking about poor experiences and a concern that negative feedback will affect ongoing care, as they will be viewed as troublemakers, or as difficult people to deal with. Also, however, some people have a deep-rooted psychological need to remain optimistic, and do not want to contemplate that things might not be going as well as they could.

Roadshows, leaflets and newsletters need to be engaging – remember that involvement, in whatever guise, should be a pleasurable experience for people. This also means that events should not be intimidating or overwhelming, thus preventing people from wanting to contribute. Public meetings, and in particular, formal public meetings, can be very bound by procedures and rules, making them very user-unfriendly. But if this is the means by which you are required to involve people on occasions, try to think about how the meetings can be made to feel more inclusive – perhaps by arranging the seating in a semi-circle, away from desks or tables, or by ensuring that the chair of the meeting is very skilled at making everyone’s voices heard.

When it comes to methods such as postal questionnaires or surveys, response rates can be variable according to demographics, though in general, response rates to postal surveys are declining. Anonymous questionnaires can lead to the disclosure of more sensitive information than you might otherwise receive, but the fact that they are anonymous means that people cannot be followed up for additional involvement, where this might seem appropriate.

Methods such as comment or feedback cards can provide extreme views, so that you are only told if someone has had a very good or very bad experience. A survey using electronic means such as hand-held tablets, or touch-screen kiosks, can provide a more nuanced set of responses, but the number of questions generated is nonetheless quite limited in number. However, the results from these kinds of devices are analysed automatically, which can save time, and negates the need for a specific set of analytical skills.

Online questionnaires or involvement activities involving social media can be used creatively, and the nature of online engagement often means a reduction in self-moderation and the disclosure of more sensitive information, which might be beneficial. People can also dip into and out of activities, as convenient. In addition, an interactive website can enable organisations to engage in a more participatory way with people, though this sort of dynamic interaction would require more management of the activity. And a further word of caution – in spite of the growth in home internet access, any online method will still disadvantage certain demographics such as older people and the socially disadvantaged, in terms of access, so think carefully about these methods.

Deliberation events are based on egalitarian principles, but it is important to be realistic that participants themselves may not always follow these principles in practice. Small group discussions tend towards the majority view, and power and professional and hierarchical status can influence the underlying assumptions of the group. An example of this kind of involvement activity is illustrated in Case example 3.2. The same can be true of focus groups, so it is important to consider sampling of participants carefully.

Face-to-face interviews and their subsequent analysis are the most inclusive method of involvement, but they are time-consuming to undertake and require skill to do well. The presence of the interviewer can also have a moderating effect on responses, so that participants may not always feel able to be as candid about their experiences, or their

opinions, as they might be through other means. However, it is clear that people appreciate the human dynamic of this kind of interaction. These same kinds of issues are also relevant for telephone interviews, although powerful visual clues to what someone is really thinking or feeling will often be lost.

Case example 3.2: Review of Jersey's mental health services

When the State of Jersey's Department of Health and Social Services (DHSS) began its review of mental health services on the island in 2014, it made a conscious decision to involve citizens at the outset in its review, rather than wait until decisions had been made before consulting them. The methodology used was a citizens' panel that was managed and facilitated by external and independent experts. Vouchers were offered as incentives to people to take part, and the costs of childcare, travel, etc. were reimbursed.

It was essential to the success of the project that a diverse group of people was recruited to take part. This involved the distribution of 1000 letters inviting people to take part, randomly generated by the island's postal service. Invitations were also distributed through local organisations such as Mind Jersey and the Jersey Alzheimer's Association. Seventy people expressed an interest in taking part, from which 25 participants were purposively sampled to ensure variation by gender, ethnicity, age, geographical location and experience of using Jersey's mental health services. Thus the final sample included people who described themselves as using the services currently, those who had in the past, and those who had never used the island's mental health services.

The panel convened on four occasions across two weeks, meeting for two-and-a-half hours on a weekday evening. The first two sessions enabled people to think about the current system of support and what was working well and what was not working so well, and to share their life experiences. The third session drew on the expertise of mental health professionals to explore the evidence about what was known to work well in the delivery of mental health services elsewhere. The fourth session allowed participants to develop the building blocks they agreed were important for the development of a new strategy for the delivery of mental health services in Jersey.

What does this case example tell us?

- » Members of the public were involved from the outset in the review, which demonstrates a commitment from the DHSS to equalise the power dynamics between the state and citizens.
- » Although people were invited at random to take part, people self-selected in volunteering to take part. It is possible that this approach means that the voices of the most disadvantaged and least able to take part because of the level of support required to participate were not heard. However, including the charitable organisations and other local groups in the recruitment potentially went some way to mitigate for this.
- » The scheduling of the sessions and the financial support offered were helpful in enabling people to participate.
- » The activities at each session allowed people to contribute equally and meaningfully.

But whatever method you use, such as collecting information and data from people, or involving them in a citizens' jury (or panel) or co-production exercise, the act of involvement is only as good as the resulting action, which leads us nicely into the next section – how the organisation responds to the outputs from involvement.

Stage 4: How to respond to involvement outputs

Responding appropriately to involvement activities requires a willingness to be open and transparent and to be committed to the principles of involvement – for example, individuals and organisations will need to be able to respond objectively so that credence isn't only given to what the organisation might want to hear, but to everything that is being said.

Responding appropriately often also requires some specific insights and skills. The organisation may require some technical expertise to analyse data or information gathered to help interpret the outputs of the activity, and therefore translate these into outcomes. It is important to think at the outset whether the outputs of your activity are likely to be actionable. So, does your organisation have the capacity and capability to design, collate, analyse, interpret and act on engagement and involvement activities? We have already seen that the enthusiasm of people to be

involved is related to their ability to change or to improve things for others. To maintain that sense of engagement, it is crucial to have some means by which you can tell people what difference their involvement has made (see Case example 3.3).

Case example 3.3: National Voices and the development of 'I' statements

The development of a narrative around what integrated care is from a user perspective is a good example of how participants were able to see the difference their input was making. In 2012, the NHS commissioned National Voices to work with it to co-produce a new definition of integration, taking the user perspective as the organising principle.

In order to do this, National Voices first reviewed its own set of 'I' statements that had previously been developed based on evidence and feedback from members of the organisation. These statements illustrated what good care might look like from the service user's perspective, that is, 'I don't want to have to repeat my story every time I see a different carer.' A workshop was then organised to test these statements out with health and social care professionals, policy-makers and individual service users and representatives from service user organisations. A second version of the statements was drafted and circulated to attendees. After further revision these were made public and additional feedback was sought. A second workshop in March 2013 reviewed all the feedback and agreed a third and final version in May 2013. Key revisions emphasised the service users' need for autonomy.

This narrative has become the source of measurement for people's experiences of coordinated care and is being used by NHS England to develop new questions for national surveys. It is also being used to develop measures for success for local commissioners.

What does this case example tell us?

- » The involvement process allowed for iterative versions of the narrative to be developed based on participant feedback. This was a clear and transparent process.
- » The exercise has had a visible impact nationally, and has been publicised by organisations such as The King's Fund.

Stage 5: Reviewing and improving the impact of involvement

It is a sad fact that we know very little about the achievements of involvement. The evidence base for demonstrating impact from engagement and involvement activities is limited and of poor quality in the main. Few studies define what they mean by involvement, and there is an absence of robust measurement of impact. In reality, there is a lack of valid, reliable instruments to measure impact and persistent issues with attribution, so that it is not always possible to isolate the effects of an involvement activity with the effects of another policy initiative. The literature is also weak in reporting the cost-effectiveness of engagement and involvement activity. Unfortunately, it becomes a vicious circle, for the fewer studies that describe the benefits of engagement and involvement on the delivery of services, the less likely organisations may be to give service users, carers and citizens a bigger voice in these matters.

There are a number of ways in which you can measure the impact of your own activities. These might include surveys, interviews or focus groups. They might also include documentary analysis – this could be of board or other meeting minutes to see how the outputs of involvement activities play into these decision-making fora, or observation of meetings to capture opinions about the difference engagement and involvement has made. Of course, impact can be felt in the short and longer term, or across different time points, and you will therefore need to use methods that recognise this. To add to the complexity, the impact of activities could be felt by participants, the organisation or third parties, the identity of whom might not be known either in the short term, or at all. This would be the case, for example, if an experience-based design (EBD) event led to improvements to services that would be felt by future service users.

So, what kinds of impact are we looking for from engagement and involvement activities? The list below is not exhaustive, but is designed to give you a sense of what you might be looking out for:

- development of trust between organisations and the people they serve
- changes to organisational culture and professional attitudes to service users and carers – this might include fostering better dialogue between parties and better shared decision-making opportunities

- services that better reflect the needs of patients, service users and carers
- changes to how people think, feel and behave in relation to their own health and wellbeing and the use of services
- development of new skills and confidence for patients, service users and carers
- development of new skills and confidence amongst staff.

Whatever impact you are hoping to achieve and whatever measures you use to assess whether it has been achieved, someone has to take responsibility for this final aspect of engagement and involvement on behalf of the organisation.