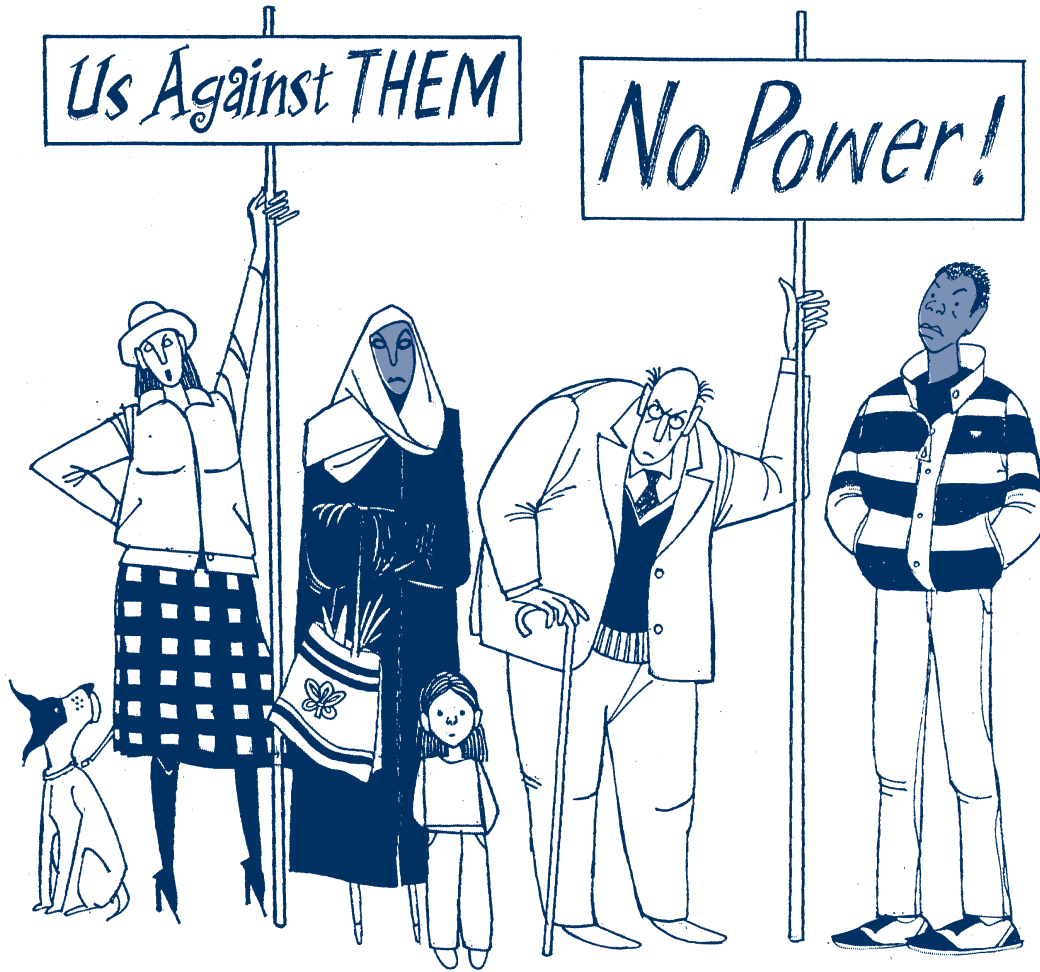


## Contents

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1. Introduction .....	3
2. Talks about talks .....	15
2.1 Clearing the ground .....	15
2.2 Establishing principles .....	21
2.3 Agreeing the question .....	27
2.4 Defining success .....	37
3. Getting started: preparing for the participation .....	45
4. Pulling it together .....	51



# 1. Introduction

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This guide is the first part of the Building Strong Foundations Toolkit, which is part of the support from the Scottish Executive to encourage greater participation by people who use health services and the public in the NHS in Scotland. It has been compiled by the Partners in Change project and draws on ideas and experiences contributed by many people across Scotland. We are grateful for their help.

The guide is designed for:

- people working in the health service who want to find better ways to involve, consult and work in partnership with the patients and the public they serve

and

- people who use the health service who are interested in shaping the way the service works - for themselves, for someone they know, for people in similar situations or for the community as a whole.

There are some people in the health service who think 'Involving people? Participation? It won't come to anything.'

There are some people in communities who think 'This isn't a partnership - they've got all the power, and it's us against them.'

But most of us, most of the time, genuinely want to work together, to listen and be listened to.

This guide is about working in partnership at different levels:

- Partnership between an individual, her friends and family, and the staff involved in her care and treatment.
- Partnership between the current (and future) users of a particular service and the people who work in and manage that service.
- Partnership between the wider public and the people who plan and manage health services.

Involving people takes time and energy. Sometimes it works well, and everyone benefits. Sometimes we put in a great deal of effort but everyone is disappointed with the result. This guide and the rest of the Building Strong Foundations Toolkit are to help us use our time and energy well.

4

Much of the toolkit is about 'set-piece' methods to involve people - where the communication is planned in advance around a specific issue, such as consultation about a new hospital.

But what makes most difference is the everyday, inconspicuous business of paying attention to people, providing information, giving feedback, treating them with respect and asking open questions.

If we are doing this work in the background, then the special efforts to involve and engage people will build on the existing culture. If we only listen to people when we are making a special effort, the gap between rhetoric and reality will soon show.

The ideas and practical suggestions in this guide are to help participation in all situations.



We like to get to know you as a whole person  
and develop a true partnership rather  
than simply  
treating  
the  
Symptoms



### Why is it good to talk?

In the old days, doctor knew best; the hospital manager knew best; health board planners knew best; and the government knew best.

Times have changed. People expect to be involved and consulted in all aspects of their lives; are more likely to ask questions and are less trusting of experts. There are more organisations of all sorts wanting to have a say in decision-making; and public authorities are more open to scrutiny and challenge.

The founding principles of the Scottish Parliament are openness, accountability, sharing of power and equal opportunities. These principles apply to all areas of public service in Scotland. The day-to-day dialogue between the people who use public services and the people who provide and manage them is part of the democratic process.

The health service has changed, too. The focus of the health service is no longer on acute disease but on helping people to maintain their own health and live well despite long-term illness.

*"When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. Now that chronic disease has become the principal medical problem, the patient must become a co-partner in the process."*

Holman and Lorig, BMJ



NHS Scotland is committed to achieving a culture change in the way the service interacts with the people it serves and the way services are delivered. Our National Health, which sets out the Scottish Executive's plan for improving the health of people in Scotland, describes participation by people who use the NHS and by the staff who work in it as an integral part of developing a modern, accountable NHS in Scotland.

*"It is no longer good enough to simply do things to people; a modern healthcare service must do things with the people it serves."*

So not involving people is not really an option. People expect to be involved, they have a right to be involved, and the health service is committed to involving people. But involving people is not just a fashion accessory; it can also deliver practical, measurable benefits for health.

9

At an individual level

- People find better ways to integrate their health with their life.
- People recover better from illness.
- People have less pain.
- People get care and support from a wider range of people.
- People are less dependent on formal services and more self-reliant.
- People feel better - more in control, more confident.
- Staff learn more from patients, and are able to pass this on to other patients.

At a service level

- Services are designed and adapted to respond better to people's needs.
- Staff time and skills are used more effectively.
- Service users' experience and knowledge is used to benefit others.
- New ideas and approaches are introduced.
- Services tap into the enthusiasm and energy of their users to get things done.
- Staff get more encouragement and support from service users.
- Changes stick because they make sense to everyone affected by them.

10

At a system/community level

- Major decisions are more transparent and therefore more acceptable.
- Better decisions are made because more people's views, perspectives and suggestions are heard.
- Communities take a greater responsibility for promoting health and well-being.
- Other resources within the community are used more effectively.
- Trust is built between communities and the health service.

The literature review by Scottish Health Feedback looks at the outcomes of involvement in more detail.

These benefits are never guaranteed: but they are more likely when we pay attention to:

- Clearing the ground
- Establishing principles
- Agreeing the question
- Defining success

As well as

- Processes, techniques and methods

Part two of the toolkit gives examples of processes, techniques and approaches for involving people in different situations, from discussions about what happens to one person to decisions about major health service change. It also has sources of further information for those people who want to follow up the processes and ideas.

11

This part of the toolkit looks at the other issues - some of the who and why and what rather than the how.

Sometimes, people seem to be much more interested in using the latest exciting method than in tackling the underlying issue. Or they use the method they know, because it worked last time. Or they don't think about which method they should use at all.

Bill is head of planning for Midross Health Board, who are planning to open a new hospital and move services away from the cottage hospitals in various outlying towns. He organises a meeting in one of the cottage hospitals to explain to local people the benefits of the new hospital - better equipment, single rooms, higher standards of care. It's not a great success.



It is worth spending a bit of time getting clear about the overall situation before choosing the method. Often the best way to do this is for two or more people with different roles - people who work in the health service, and people who use the service - to sit down and talk through the situation together.

It doesn't matter who makes the first move to get the dialogue started. The third section of this guide has some suggestions to help anyone - in the NHS or in the community - who thinks the partnership could be better and wants to do something about it.

### summary

- Talking together has benefits for everyone.
- Thinking about a few essentials beforehand will help the discussions be more productive.
- Anyone can make the first move.



## 2. Talks about talks

### 2.1 Clearing the ground

When we start putting in new plants or building something, we first have to clear the ground. When we are starting to think about getting strong, healthy participation, we often have to do our equivalent of clearing the ground.

We often pay a lot of attention to systems and structures and policies, and forget that working together starts with people. The context in which the talks about participation take place includes the people who are round the table, and what they bring. We have different roles in this situation, and we bring different experiences and perspectives. If we take the time to discuss and clarify these roles and experiences, we are more likely to do some fresh thinking and come up with a good process.

*"If you always do what you've always done, then you'll always get what you've always got."*

#### **The right people**

Even when we want the process that follows to be fresh and creative, we all usually start by getting in touch with the same people we always talk to.

#### **Who is round the table?**

- Who should be here but isn't?
- Who would bring some fresh ideas?
- Would it be good to get some help just for this stage?



### Past experience

We can bring some negative assumptions - which may or may not be based on previous experience of involvement in the health service - about what is likely to happen this time.

#### Is there any baggage we would like to check in before we start?

At the start of the discussions, it might be useful to tell each other about any bad experiences we have had around participation.

- What happened last time?
- Is there something we still feel angry about? Were we let down?
- What are we afraid will happen this time?
- What would help prevent this from happening again?
- If it goes well this time, what would happen? What would change?

Of course, we also bring positive experiences of things which have worked, so it might be helpful to share these now.

Briefly talk through the positive experiences of partnership working that people in this meeting have had:

- What has gone well before?
- What was particularly good about it?
- What would help make sure this happens again?

### **Authority and responsibility**

It is important to recognise our own and each other's authority and responsibilities in this situation. Once we acknowledge these, the conversation becomes less personal; we can see more clearly 'where the other person is coming from'.

As a patient, relative or community member, my authority might be:

- personal experience of living with this illness - it's my life
- being a friend or relative of someone who lives with the condition
- knowing many other people and families in similar situations
- extensive knowledge of research and practice relating to this condition
- knowing many people in the local community, and being widely trusted
- many years' experience as an activist
- being a formal representative of a consumer group or a community organisation.

The responsibilities that go with this might include:

- reflecting the experience of other people as well as my own situation
- checking back with the other people in my network.

As a member of staff, my authority might be:

- as a formal representative of the Board/local authority
- able to commit resources and to make decisions

- extensive knowledge of research and practice relating to this condition
- many years' experience of planning and managing change.

The responsibilities that go with this include:

- being accountable to the Board/Councillors/senior managers
- having to explain and justify my decisions and recommendations
- basing decisions on evidence, and taking as much evidence as possible into account
- balancing the interests of current service users with those of future service users
- making good use of public resources - resources I am directly responsible for and more generally
- keeping colleagues and other organisations informed
- taking account of the interests of staff and the wider public.

### **Why now?**

How we approach the situation will also be influenced by the timing.

Why do we need to have this discussion now?

For example, is this a crisis? Has there been a complaint/investigation? Is this exercise being required by an external agency/head office/the Scottish Executive?

It helps when the people involved are open about the reasons for the discussions, and about any timescales associated with them. But it also helps when everyone is willing to be flexible when possible.

The other reason for pausing to think about 'why now?' is that the background can colour how we approach the situation. If it is a crisis, we all tend to find it hard to stand back and be reflective. If it is a complaint, people will generally feel defensive and take a 'them against us' position. If we are doing this because we've been told to talk to people, we might be more concerned with whether the meeting happens than in listening to what people say once they are there.

Points to think about might be

- What do we need to tell each other about the reasons for these talks?
- Even if the timing is not of our choosing, what are our reasons for talking to each other?
- What can help these talks be as useful as possible?
- Do we want this to be a one-off conversation or part of an on-going dialogue?

20

*"I've been told we have to finish the consultation by March. But can we come back together and have a more detailed discussion over the summer about the next stage?"*

### summary

- Get the right people round the table.
- Let go of the past experience that gets in the way and use the experience that helps.
- Recognise your own authority and responsibilities, and respect other people's.
- Think about why you want to have the discussions, and why now.

## 2.2 Establishing principles

Effective talks are based on some principles, even when these aren't stated or obvious to the people involved.

When you are having talks about talks, it is a good idea to make the principles explicit.

### Values

The talks will be more useful when the values are clear, and are shared by all the people involved (as far as possible). The values in how you have the discussions need to reflect the values and aims you want the health services to reflect.

You might decide that the principles you are working to are:

- Genuine respect
- Inclusiveness
- Willingness to learn
- Openness/disclosure
- Give explanations/feedback on decisions

### Scope

The talks will also be more useful if people are as clear as possible about what the scope is.

What's negotiable? Is the discussion about how the new service will be organised really open, or has it already been decided that the staff will be based at the health centre and it will operate between 9 and 5?

Openness and disclosure might be one of our principles, but are there any limits to this?

Are we really asking the community for participation/joint decision-making? Or is this just consultation, where people are asked their views but the NHS will take the decisions and implementation alone.

Do we really want to be part of the solution, or is it easier to make comments and then leave the rest to other people?

How far can you go? Describing the problem? Coming up with solutions? Implementing the solutions?

### **What's in it for us?**

One of the reasons why some people - staff in the health services and people from communities - feel disillusioned about partnership working is that it feels as if they have put in a lot of effort to help move on the problems that someone else has raised, but have got very little for themselves.

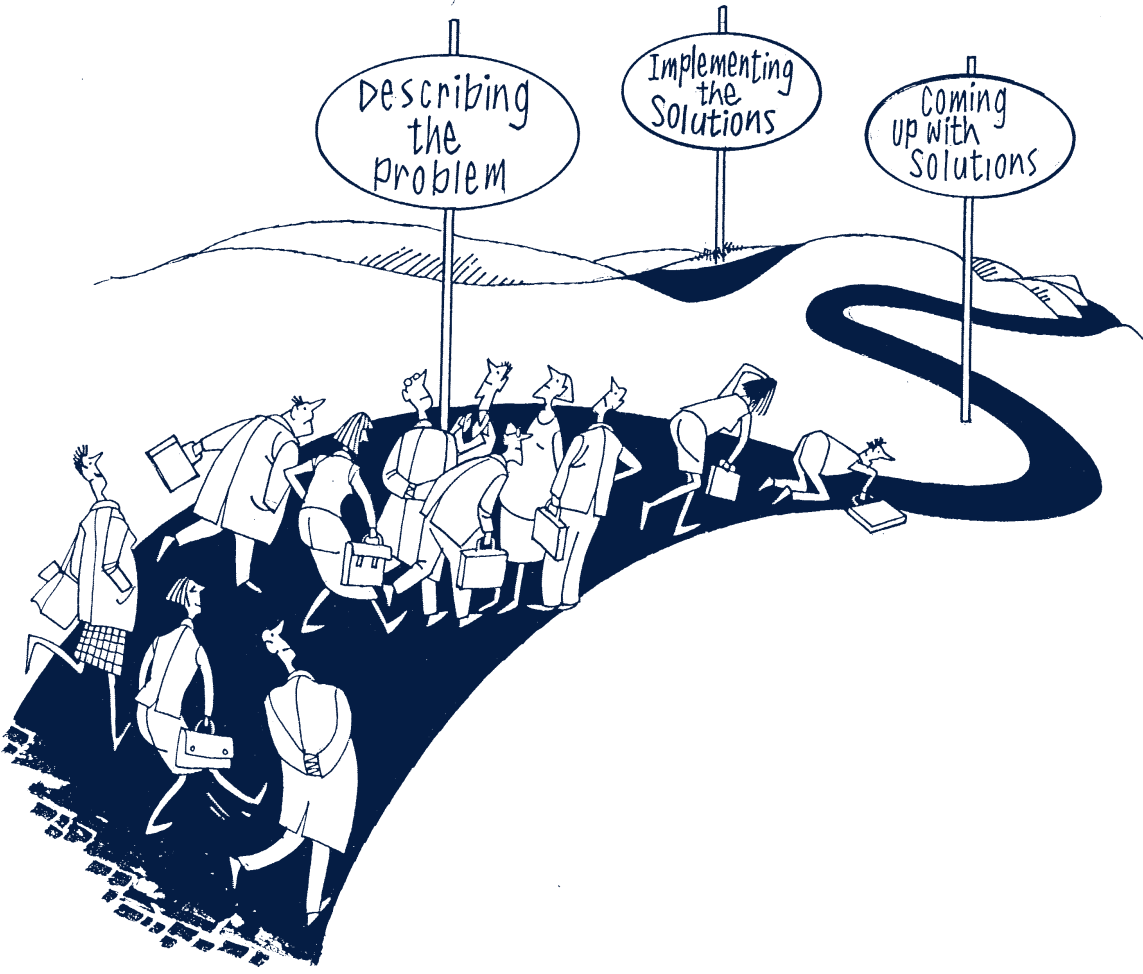
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- Are all the people or groups who are helping make the participation happen going to get what they need from the process?
- Can we do something to help one of the groups move on an issue that matters to them at the same time as we work together on the first issue?
- Is it balancing out in the long-term?

### **Inclusiveness**

Certain groups typically get left out of consultations and feel least involved in decisions about their own care.

- How much effort are we prepared to put in to tackle this in this process?
- If it will take longer to have a proper discussion with some people who are likely to get missed from the usual consultation methods, are the rest of us willing to wait?



### Information and knowledge

If people have only experienced what they have now, and don't know about any alternatives, how likely is it that they will come up with imaginative and practical options for change?

## Example

### Joint Futures planning

A joint health and social services manager asked people to come to a meeting to help her plan how services for older people in this town might be developed.

People were asked to think of this as a blank sheet of paper, and to be as creative as they liked.

The people who came along included older people and staff and volunteers from the services that worked mostly with older people. Most of the suggestions that people came up with were for a bit more or a bit less of the range of things that were already provided.

The people who were there said they found thinking with no limits to be quite difficult. When people talked it over afterwards, they mentioned still being aware of:

- the people who are using the services now may not like any changes
- anything we suggest is bound to cost a lot of money, and there won't be enough
- if they have to stop the current services to pay for the new ones, something might go wrong and the new services won't happen
- we don't know of any ways to do it differently
- the Councillors and people on the NHS Board will still want to play safe.

## Approaches that can make it easier for people to think differently

### Beforehand

- circulate ideas from other places - not just in Scotland, but from anywhere
- get ideas about how ordinary things that are already here are used by older people - shops, swimming pools.

### On the day

- start off with some 'games' to get people bouncing ideas off each other
- ask along some people who aren't old and people who don't work in special 'older people's services'
- start off talking about what makes a good life for anyone, before getting into talking about future services
- use graphics, drawing pictures - to help people see it differently.

Some of the approaches described in part 2 of this toolkit have been developed to encourage people to think differently.

## Move together to a new place

If the aim is to work together to find a new approach, or a new way to talk to each other, then we don't have to worry about defending the position we started out with.

What we are trying to get away from is:

- seeing any change as a compromise or a sign of weakness,
- if someone has won then someone else must have lost
- defending a position - right or wrong.

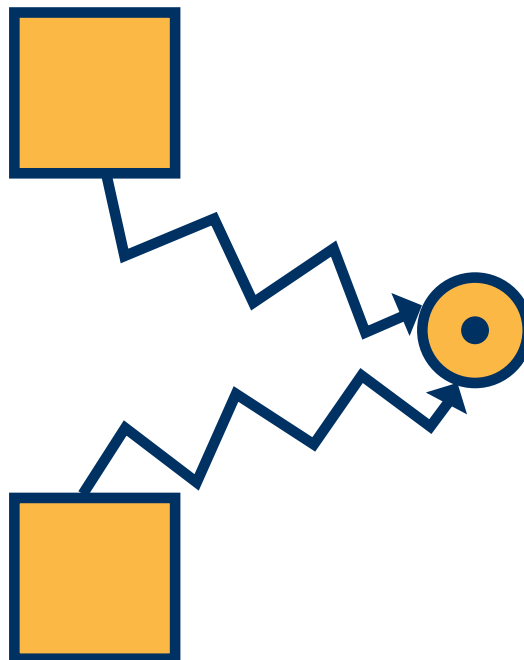
What we are looking for is:

- each person understanding the other person's situation better
- each person contributing to the new ideas
- looking for a place where we are both getting what we need.

instead of people moving to a compromise,



people respond to each other and move together to a new position that they share



### summary

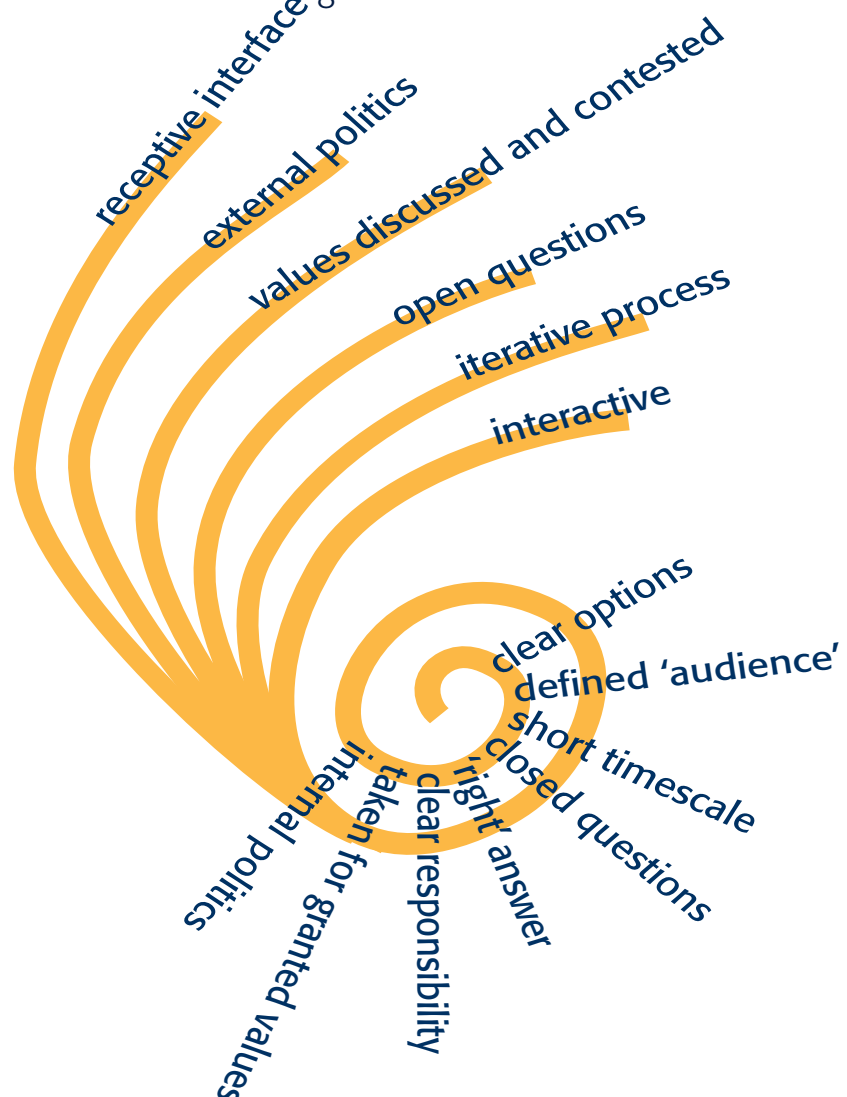
- Be open about the principles and values you want to work to.
- Recognise that working in new ways will involve some movement.
- Look for the advantages that come from working together.

## 2.3 Agreeing the question

If we are going to have talks that are productive, it will help if we are talking about the same things, and about the right things.

Some of the tensions that can happen are:

- One person looking for certainty while another wants to explore options.
- One person looking for the method that will produce the 'right' answer that will then stick for a long time, while another person is expecting that the whole context will have changed part-way through the dialogue.
- One person focusing on the internal concerns of their organisation, while other people are looking at how all the various organisations interact.



One way of thinking about it is a spiral, with one part a single strand and inward looking, and the other opening out to multiple strands. Points to remember are:

- Both parts of the spiral matter.
- Sometimes the questions we want to talk about are in the closed part and sometimes in the open part of the spiral.
- The people you need, and the types of methods you will use to have the dialogue, are very different in the 2 situations.
- It can be hard for individuals who are comfortable with one situation - perhaps because that is all they have known - to move to the other part.
- When the 2 people are in different parts of the spiral the dialogue is going to be difficult - so it will need longer and more checking out as you go.

The examples of people being in different parts of the spiral come up in all situations. And people from both the NHS and people from communities will be among those who are naturally comfortable in the closed and the open contexts.

- A GP who encourages her patients to make choices and take responsibility for their health might find that some patients like this responsibility while others still want her to make the decisions.
- Someone who wants to handle their illness in a particular way and get advice from several sources finds they are disagreeing with a clinical team who want to follow the 'best practice' guidelines.
- Two nurses are planning to start discussion groups with people who use their service: but one thinks the topic is 'should we hold the clinics on a Saturday?', while the other thinks the question is 'what is it like living with diabetes, and what can our service do to help you?'

- A manager thinks the consultation should be about a particular health service, because that is what is worrying a professional advisory committee within the NHS Board, while other people think the consultation is about exploring how people in a particular area use all sorts of resources.

The case examples in the rest of this section show some of the tensions that can arise when people are not clear about whether they are talking about the right questions, and how the methods used to have the dialogue can make a difference.

What can we learn from one person's experience, not how do we deal with this person's anger?

## Example Linda and David

David is in his 20s and has lived with a serious mental health problem for several years. He stays in a flat provided by a voluntary organisation, which also provides him with support, and he has care from a Community Mental Health Team. He often moves around - sometimes he will go to stay for a few weeks or months with his brother, or his mum, or various friends. During these times the services find it difficult to provide him with support.

Linda, David's mum, has been trying to get a better arrangement - some way of getting care from the same staff no matter whose house David happens to be living in. Linda has written letters to many different people and organisations. She has now written to the NHS Board, asking them to consult with people with mental health problems and their families to establish the need for a flexible home support service.

The manager at the NHS Board (Keith) is planning to tell Linda that they will not have this consultation. He thinks that she really wants to make a complaint about the Community Mental Health Team or about the voluntary organisation - neither of which are his direct responsibility. Or else she wants him to do something about the care of an individual person, which is also not appropriate.

Linda thinks that everyone she talks to in the system is missing the point. The people who David is in touch with are mostly good at their jobs, and she wants him to have more contact with them, not less. The system seems to say that the services cannot support David because he has a chaotic lifestyle. Linda knows of other people and families who are in the same situation - so maybe this is quite a common aspect of living with the illness, and the services should be planned around fitting in to how people live their lives, rather than expecting people to fit into how the services like to be organised.

Linda's list of the issues	Keith's list of the issues
<p><b>Is the issue about</b></p>	<p><b>Is the issue about</b></p>
<p>Individual people: not really. If the problem gets sorted it will help David, but it is about lots of people.</p>	<p>Individual people: yes. This is about the care for David.</p>
<p>What services are provided: yes. Or about getting the current services to work in different ways and probably some new ones.</p>	<p>What services are provided: no.</p>
<p>Quality of service: not really.</p>	<p>Quality of services: almost certainly, although it hasn't been presented as an complaint.</p>
<p>Strategy/service planning: yes. There is going to be an update of the joint mental health strategy in a year or so, and we all need to be thinking now about what support people really need. And they shouldn't just consult on whether people want more or less of the same things.</p>	<p>Strategy/service planning: it might feed in here. We are planning to do a consolation for the update of the strategy next year, but this hasn't been planned yet. Can this lady wait?</p>
<p>Links with the wider world: yes. Because if David had a wider network of friends, and people were more tolerant of mental illness, it would be easier for all of us to help support him without needing to fall back on the mental health services.</p>	<p>Links with the outside world: no.</p>

### Shared list of issues they end up with

#### The issues are

Individual people: yes, but it isn't an issue for this consultation.

Strategy/service planning and what services are provided: yes

Links with the wider world: yes

#### What will happen next

Keith will talk to the services to make sure they are asking individual clients about how they want their support to be organised, in case there is more scope to be flexible than people realise.

Linda and Keith will work with other people to plan discussions about what helps people get good support, and what would make a good service.

Linda will talk to staff in Health Promotion who are already planning work on challenging stigma, and offer help from her and other families.

What does Mrs Jones want to do with her life, not how do we organise care?

### Example Jean and Mary

Jean has lived on her own for many years, and wants to stay in her own house. She had a fall and hurt her leg, and let the home help persuade her to go to hospital to have it looked at. She's been in hospital for nearly a month, her leg is better now, and she wants to go home.

Mary is Jean's niece. She lives 60 miles away from the town where Jean lives. She's been visiting Jean every weekend, and agrees with Jean that they should be getting her home. She's had a phone call to say that the doctor wants Jean to move to a nursing home, and will she come to a meeting at 4.30 next day.

- For Mary, the main issues are how and where Jean wants to live, and being able to make those decisions for herself.
- For the doctor, the question is which nursing home will Jean go to.

The discussion between Mary and the doctor gets off to a bad start - partly because they are both rushed and partly because they seem to be having 2 completely different conversations.

Mary says she will phone next morning and arrange a meeting when they can discuss the matter properly. She now has to think about what can help her and Jean get the discussion to be about the questions that are important to them.

After phoning round some friends and people they suggested, the ideas Mary comes up with are:

- Talking over with Jean beforehand all the things that Jean wants in her life and what she doesn't want, and writing it up.
- Looking out photographs of Jean at home and activities she enjoys, to get the people at the hospital to think of Jean as a person and not just as a patient.
- Making a list of all the people who can help support Jean at home - such as the corner shop's delivery service, friends and volunteers from the church's home visiting group, as well as the formal services.
- Finding someone from the independent advocacy project to meet Jean soon and get to know her, in case it is useful at later meetings to have an advocate there instead of Mary.
- Getting a friend to come with Jean and Mary to the next meeting.

The other part of this toolkit have more information on some of the which help individual people to get plans that are centred on what is important to them.

How do we get the best outcomes for women with cancer, not how do we improve this unit?

## Example

### Citizen's Jury: East Sussex, Brighton and Hove Health Authority, February 1997

The background was that the Health Authority was trying to find a balance between having services that would ensure the best outcomes for women who have cancer, to implement a national report that made recommendations aimed at better clinical outcomes, and local access to services for women across the area. They also wanted to use a process that would seek views from a range of people - not just the current service users - and allow debate around a complex issue.

The question that was put to the Citizen's Jury was: Where should women with gynaecological cancer who live in East Sussex, Brighton and Hove be offered treatment?

They were asked to consider 3 options:

- To continue services in the current format - several smaller units and a main unit.
- To centralise services in Brighton.
- To refer women for treatment at specialist cancer centres outside the county.

The evidence that the jury considered included the views and advice of staff in the local units, the unit in Brighton and from hospitals in London; the experience of women who had cancer; and background information about the main gynaecological cancers, treatment and the evidence about outcomes.

The jury's final recommendation did not match any of the initial options.

In the long term, they wanted to see a centre of excellence at a new unit - not at the current site in Brighton.

They were unanimous in their recommendation that the Health Authority should centralise services, and made suggestions about how this should happen; develop a good interim cancer centre; and have good clinical care at the local units.

They made a series of recommendations to improve the current services in the meantime - including quality of the physical environment, access to information and counselling, training for staff, improving clinical practice.

*Source: Davies, S., et al (1998): Ordinary Wisdom: reflections on an experiment in citizenship and health: Kings Fund, London*

## summary

- Take time to agree what the right question is.
- Think about whether it is a closed, certain issue or an open, fuzzy issue.
- Give yourself and other people space and confidence to ask different questions and think in different ways.

## 2.4 Defining success

This section is about what's most important about the talks - working out what that is, and helping it to happen.

There are 2 ways of thinking about success here, and they are both essential.

The process matters - how the dialogue happens, whether people had their say, how people feel at the end of it. If the way in which we have one discussion is a success, it is more likely that future discussions will be successful too.

For most people, the outcome of the discussions matters even more - the changes that the health service then makes to services, the treatment and care that a person gets, how healthy people are in that community. Even if it is the most inclusive process in the world, if nothing changes as a result of people in the community talking to the NHS, people will have doubts about whether it is worthwhile doing it again.

The second part of this toolkit looks at the different tools or approaches to let you have a dialogue between the NHS and people who use services or the public, and shows how to select the tools that will work best in your situation. This stage is much easier when you already have a shared understanding of what you are aiming for - what you will regard as a success in your situation.

Some of the definitions of success are:

- Representativeness: is it important that the people who take part in the main discussions represent the views of the whole community?
- Gaining understanding: is it important to get an indepth view from a few people, even though they might not be representative of the community?

- Working with the people who are going to be most affected: is it important to understand the concerns of the people who depend a lot on particular services?
- Numbers of people involved: is it important that there is a large number of people involved?
- Drawing in people who tend to be marginalized: is the main priority to hear the views of people who tend to be missed out? Are there particular groups within the community whose views are particularly important in this situation?
- Clinical outcome: is our main priority here the health of individual people? So do we want to focus the discussions on the types of people who have the potential to gain most from any changes we go on to make to services? Do we want to focus on people for whom the clinical outcome at the moment is not as good as we wish it to be?
- Evidence base: is it important that we learn more about how services make a difference for people? Do we need to be able to link the points people raise back to what we already know makes a difference to people's health and well-being?
- Building capacity: do we want to have a process that has more people with more skills and confidence at the end of it - so that they can help lead the next round of discussions, for example?
- New ideas: are we more interested in getting new ideas and new perspectives at this stage than in checking out how many people agree with particular approaches?
- Agenda re-defined: is it important to check out what the agenda is, whether we are all talking about the right questions? Would it help to use these talks to move the agenda on - from 'where should the new building be?' to 'what types of services can help people live their lives?'

- Change implemented: is it important that the discussions move on the changes that happen? Would it help if the discussions also brought forward people who will then be part of putting the changes into effect - for example, as volunteers, helping to train staff, members of on-going Quality Panels? Is it important that staff are involved, so they can help explain the changes that emerge to their colleagues and to their patients?

The best way to check what will be a success is to ask the people involved.



## Example

### What is important to families?

This is a list of factors that some parents of children who have labels of special needs identified as important to them and other parents taking part in various consultation and partnership arrangements.

#### **How to make involvement work**

##### **Commitment**

There must be the belief not that involvement is only about political correctness. There is no point doing it because you have been told to do it or it is the latest 'thing'. The belief has to genuinely be that those who use services are the best placed to know what they need.

##### **Timing**

People must be involved in actual planning and policy formulation. There is no point producing a shiny document, on which the priorities and funding implications have already been decided - and asking what do you think of what we have done? There is usually no room for more than a comma or full stop - no wonder people do not respond.

##### **Empowerment**

Give people the training opportunities and they will be a huge asset for you. This is the role of Partners in Policymaking and similar opportunities. This way, all consultation and involvement is done with people and not to people - you may find that you ask completely different questions.

##### **The Right Questions**

Instead of asking 'what type of activities would you like us to provide in day centres?' - try asking 'how would you like to spend your day? Instead of asking 'what type of respite service would you like?' - try asking "what sort of supports would you need to live a normal family life?'

**Goal** - Be absolutely clear what you are trying to achieve from a consultation or involvement exercise. Do not ask people for their views unless you intend to respond / act on what they tell you - this will also decide the method you use.

### **Method**

It is important to believe that there are lots of ways to consult and all are legitimate and all need to be used appropriately. Inviting everyone to a public meeting to discuss a 40 page report is going to be impossible - but having a few key people in at the planning stage of such a report is much more feasible. Not everyone wants to be consulted or involved - different methods for different people.

- Genuine partnerships - users/carers etc as part of the team - working on policy and plans - Joint Commissioning Team membership.
- Workshop model - invite larger groups but give presentations and use facilitators to work in small groups - usually works best if done with specific topics and not too wide ranging.
- Consultation days - open meetings to discuss a range of issues or a particular issue.
- Use local champions - people will generally respond better to someone they know and trust.

### **Working with families**

#### **Key points**

- Commitment  
Based on a genuine belief that those who use services are best placed to determine what kinds of service they need.
- Timing  
Involving people in planning and policy formulation rather than consulting with them on documents that have already been written.

- Empowerment  
Giving parents training opportunities enabling them to become valuable and valued contributors to true partnership working.
- Clear Goals  
Being absolutely clear about the purpose of involving parents and children and being prepared to act on the contributions made by them.
- Method  
Using methods which are relevant and appropriate to the people you want to involve and being prepared to be creative.
- Right Questions  
Thinking carefully about the outcomes you wish to achieve...remember, asking the wrong questions will result in the wrong answers.
- Action  
Being prepared to implement suggestions to achieve tangible changes within a reasonable timescale.

*Source: Josephine Cochrane and Dorothy MacDonald: workshop at Child Health conference, 27 February 2002*

## summary

- Get a shared understanding of what you think is a success in this situation.
- What will be a success for the way the dialogue happens?
- What will be a success for people delivering and using real health services? What will be different for them?



## 3. Getting started: preparing for the participation

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Even when we recognise that the dialogue could be better between the NHS and the people who use services, it can be hard to start making this happen.

It is easier when everyone is able to make the first move - and doesn't feel that this is someone else's role. It is also easier when the practical aspects are right.

Many of the approaches that are described in the other part of this toolkit have more detailed suggestions about the practical aspects, but there are some basic elements that help in any situation.

### **Making the first move**

Sometimes people feel they want to talk to someone but aren't sure where to find the right 'other person'. Knowing who to talk to helps, but it is usually better to make contact with someone in the organisation, and ask them to bring in colleagues who should also be involved, than to take no action at all.

Possible starting points are:

- Many NHS Boards provide information of how the public can contact them.
- Staff such as public involvement workers will be able to help.
- The Health Council should be able to give advice.
- Community development workers and health promotion staff often have good networks among community groups and can put you in touch with colleagues in other departments.
- Volunteer co-ordinators in the NHS will know their way around NHS and community networks.

- Community Care Forums and Councils of Voluntary Service have contacts in many community groups.

### **What makes it hard to talk about health?**

Communication is always difficult when one or more of the people are:

- rushed
- angry, or frightened
- uncomfortable - thirsty, sitting in a cramped seat, tired
- worrying or thinking about something else
- not talking about the same thing
- out of his depth
- assuming that he or she knows what the other person is going to say
- not taking what the other person says seriously
- unable to find the language for what she or he wants to say.

Talking about health can be difficult for all those reasons, and it is also by its nature difficult.

- The subject is upsetting or worrying.
- Often several issues are intertwined.
- We want to talk about the feelings aspect of ill health, but most of the conversation is about tangible aspects - symptoms, treatment etc.
- The conversations often involve talking about other people - so get caught up in issues around confidentiality.
- People put a lot of personal effort and commitment into the service, and any suggestion about changes can feel like a personal criticism.
- There are big differences of power and knowledge.
- Conversations about health care are often against the backdrop of money, or politics, or both.

## Example

### Background to the meeting for Mary and Jean

When Mary went to the meeting about her aunt Jean, working out what the issue was that was being discussed wasn't the only problem.

The meeting was arranged at very short notice. Mary had to drive over 60 miles to get there.

By the time Mary got to the hospital, she was angry and upset. She didn't have a chance to talk to Jean about the suggestion that Jean go to a nursing home instead of getting back to her own house. It was hard to get away from work early, then the traffic was terrible and she got caught in the one-way system and was late.

The doctor had only seen Jean once and was working from Jean's notes and a brief conversation with his colleague, who had been called away to an emergency. He was being bleeped by the ward while talking to Mary.

When Mary arranges the second meeting, she wants it to include Jean and discuss the issues that matter to Jean. She also wants it to happen in a calmer setting.

### When and where?

Think about the discussion being in places where everyone will be comfortable and feel able to talk over the issues and ideas as equals.

Factors that get in way can be:

- Holding all the discussions in places that are clearly the territory of one person or organisation - such as someone's office, the board room.
- Using venues that are difficult to get access to - not suitable for people who have problems walking or getting up stairs, or for people who have a hearing loss.
- Having meetings at times that make it difficult for people to get there, or to concentrate (when is the last bus? will I be back for the children getting in from school? will I be away in time for my next meeting?).
- Places where one or more people will be interrupted with phone messages or by people wanting to speak to them.
- Places where people tend to think in predetermined ways.

Factors that can help include:

- using different locations
- finding a venue where you won't be disturbed
- setting aside a day or half day for longer discussions
- talking to each other by phone or email to keep the communication going between meetings
- making sure people have any supports or practical help they need.

### Other practical aspects

It is important to get the basic practical aspects right for the initial talks about talks as well as for the main dialogue.

- Enough time to have the discussions - on the day and allowing enough time between meetings for people to check out ideas with colleagues.
- Accessible information.
- Making sure that everyone is covered for travel costs and other costs like childcare or someone to stay with a relative.
- Access to interpreting and translation services - not just for people from minority ethnic communities but also for people who are deaf and people who do not use words to communicate.

The Partners in Change project has developed a set of Meetings Checklists, which have more suggestions on productive meetings which involve people from the community and staff.

Fair for All, which was launched by the Scottish Executive in early 2002, gives more policy advice and further contacts of making health services more accessible to people from minority ethnic communities.

### Facilitation

There are also situations where it can be useful to have another person to facilitate the meeting.

Circumstances where this can be useful include:

- Where it is likely that someone will be upset or angry.
- Where there has been a history of difficult discussions in the past.
- Where you know you will find it difficult to keep to the point - for example where there are a lot of interconnected issues.

- Where all of the people at the meeting want to contribute, so it is harder for any one person to take on the reflective or managing the meeting roles.

Points to think about around who can do it are:

- Is it better to have someone from outside any of the organisations or networks involved?
- Is it useful to have someone who knows the background and the context, but is not directly involved? - such as someone from another part of the NHS Board or a local authority, or one of the community networks; someone from another NHS Board or a community activist from another area.
- Have we any resources to pay for someone?: if not, look to colleagues from within your organisations or networks, or someone from another organisation who will do it on an exchange basis.
- Do we want to use or develop the skills of people that we know?
- Are we looking for a particular type of facilitation, such as graphic facilitation - because that will help the people at this meeting to contribute or reflect on what is emerging?

Even when you do use a facilitator, it may be useful to bring in this support at key stages, such as the first few meetings or if discussions get a bit fraught, rather than have them there all the time.

### summary

- Start talking to someone and ask for introductions, rather than delay until you find the 'right' person.
- Think about how to make the communication easier.
- Pay attention to the practical details

## 4. Pulling it together

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By this point you will have worked through most of the issues and practical aspects that will let you have a healthy discussion about the type of participation you want to see happen, and how this can take place.

### **Main stages to having talks about talks**

Define the problem.

Define how you will organise the discussions between the community and the health service (or with other people).

Consider who is the right person to lead the discussions from this point on. The person who first instigated the talks about talks can end up with all the work when it would be better to hand it on to someone else.

Accept that as soon as you do go out and the dialogue between the community and the service starts, other people will bring other ideas and issues.

Identify which tools you are going to use: the other parts of the toolkit are useful here.

### **Begin the dialogue**

Try it, start your plan.

Reflect

- Is it a success in terms of the process? Are people having a say? Are you reaching the right people?
- Is it a success in terms of the likely outcomes? Are the changes to the way someone gets a service going to happen, or is there something else that needs to be tackled?

Revise your definition of the problem, or how you are tackling it, as need be.

Listen to what people are saying.

Reflect - what action is needed, and who is doing it?

**Continue with the talks about talks**

Do people still want or need to be involved in working with the NHS on this matter? What is the issue now, and how are we going to work together to get people be involved?

**For each situation write down:**

What the issue is

What the values are that you agree are important here, and that everyone will try to put into practice

Write down the plan of how you are going to take it forward

### **Making the participation happen**

This section has 3 examples, to show how the talks about talks, choosing helpful methods and working to make changes happen can all come together. Like all the case examples in this guide, they are based on real situations.

#### **Example**

#### **Midross Health Board and the Cottage Hospital: trying again and opening the discussions**

Bill was the manager at Midross Health Board, who found that the public were not as impressed as he was with the plans to replace the cottage hospital.

Bill had decided hold a few meetings in each of the cottage hospitals that were going to be closing. He invited representatives from the Health Council and a few other bodies, and mentioned that members of the public could also come along. One reason was that this was how the Health Board usually handled consultations. Another was that the changes affected services that were used by various groups of people, and he felt that if he talked especially to one interest group he would have to talk to all the others.

The first public meeting was angry and difficult. Many more people turned up than Bill had been expecting - so the room wasn't big enough. People accused the Board of trying to hide the decisions - it was supposed to be a public meeting, but it hadn't been advertised in the local paper, etc. They said the Board did not really want to listen, and was making it hard for the people who were most affected to have a say.

Afterwards, Bill and some colleagues met with some local people. This meeting took place at the local library. Most of the first meeting was about what had gone wrong that time and on some other occasions, and also what had gone well with previous consultations and discussions.

The new consultation plan was arranged around:

- Going to places where older people (who were the main users of the services affected) would be, or could come along.
- Taking longer to explain to people what the changes would mean in practice.
- Getting people's ideas about other ways to make life easier for people who used these services - so also bringing in discussions about local authority services and community resources.
- People going to see the new facilities and fact-finding visits to similar hospitals that had replaced cottage hospitals in other places.

The approaches that were used included:

- A series of open meetings at libraries, community centres, community health projects, etc.
- Sessions at places such as lunch clubs, Women's Guild meetings.
- People having discussions with graphics and photographs of what they liked and what they wanted to change around the current services.
- Focus groups of people who were younger and who also used these services a lot.
- Meetings, focus groups and interviews with people from the minority ethnic communities, who tended to use the current services less often than other people: the new hospital was being planned in ways that were aimed at better reflecting the preferences of this group of people.
- Individual people sending in comments and suggestions.
- A series of discussions with the staff who worked in the cottage hospital.
- Having public meetings in the evenings and afternoons, but towards the end of the process to both check out and feed back on what was emerging so far.
- People from the local community leading many of the discussions - being the facilitators, going to meetings in a pair with Bill or another person from the Board.

## Example

### Sam and Jill: more participation for one person leading to changes for other people

Sam has had a lot of health problems since he was a baby. He lived at home with his mum (Jill) and dad, with support from health services and from other services organised by the local authority. Eventually Sam's mum and dad were persuaded that Sam needed too much support, and that he should go to a residential school. Sam was not happy, and neither were his mum and dad.

Every time there was a review about Sam, Jill asked if he could come home, and was told this wasn't possible. Jill began finding out about different ways in which children like Sam could be supported at home. This included ideas from other parts of Scotland and further afield. She also found other people who could help her work to get Sam home. The next time there was a review, she said the question ought to be not 'can Sam come home today?' but 'what will it take for Sam to be able to come home?'

It took nearly 2 years and a lot of hard work by people who worked in services as well as by Jill and people who were helping her. By then there was a voluntary organisation which was willing to try to provide Sam and his family with the kind of support the new assessment said that Sam would need to be at home. The local health services were also willing to try some things they had not done before in quite that way. And the senior managers were supporting the new arrangements.

Sam came home. It hasn't been easy all the time, but overall it has worked even better than anyone had expected. So the outcome has been good for Sam, Jill and the rest of his family and friends.

After the services were in place for Sam, the voluntary organisation, health services and other local services

looked at the way the support was working, and began providing more flexible types of care and support as part of the range of things they did. So changes began to happen at the level of these services, and this meant more choices for other people who now have more opportunities to be involved in planning what happens to them.

The discussions that Sam's situation had started continued after Sam's arrangements had been agreed. Most of the agencies in that area are looking at what they do. The question now is 'how do we support people in the way they want to live?' These discussions will go on for some time and will include consultation with other people and families on the ideas that are emerging about types of support and how people can make choices.

Some of the approaches that have been used to make these discussions and changes possible have included:

- Individual planning with Sam and his family, especially the use of Essential Lifestyle Planning.
- Advocacy for Sam and sometimes for Jill.
- Circles of friends around Sam, to help him continue to be able to make choices and to be an on-going safeguard for him.
- Large-scale facilitation using PATH (one of the other person centred planning methods) when all the local agencies began reviewing how families can best be supported.
- Presentations on the support for Sam and what has happened in other places, to let people think about options that are not available in their local area.

The approaches that are going to be used in the next stage include:

- Consultation methods such as interviews, focus groups, for other families.
- Consultation with people who before have tended to be left out, because they communicate in different ways from most other people.

## Example

### Quality Panel review of Cardiac Services: involving people in improving current services and planning for the future

The Cardiac Unit at a hospital wanted to look at the quality of their services from the point of view of the patients and their families, as part of a wider rethink of how services could be organised in future.

Some members of the Patients' Reference Group at the Trust volunteered to help, and worked with people who had been in the cardiac ward the previous year. They talked to patients at the outpatient and inpatient services, some families, and to staff. The report made suggestions about how the quality of the current services could be improved and ideas for longer-term changes.

Some suggestions were acted on almost immediately; some got fed into the review of Cardiac Services; and some were taken up by the Patients' Reference Group because they could apply to most people who came to that hospital.

The quality team had developed a list of points that people and families thought made a good quality cardiac service. Staff began using this list in discussions with individual patients to help make sure each person was getting the care and information they wanted, and people are now routinely more involved in planning their own care.

One of the points raised by the quality team was that many of the people who came to the cardiac unit were older people, but there did not seem to be any connection between making life easier for people who had heart problems and planning for all older people in that area. The next stage of the follow-up action will include making these links.

The Patients' Reference Group and the Trust had talked before about having a Quality Panel, but this was the first time people from the community had taken on this role. The Patients' Reference Group is now recruiting more people to join a Quality Panel for services across the Trust.

The approaches that were used for the initial quality team were:

- Building on the Patients' Reference Group.
- Advice and training from a Mental Health Users Group that had experience of user-led research on how to do surveys, and some advice from a researcher.
- The team gathered information through focus groups, face-to-face and telephone interviews and a small-scale survey, and through their own observations.

The approaches used to take forward the results and make the links with wider planning included:

- Some people joining the Cardiac Services Redesign Group as lay members.
- Taking some of the issues on through the Older People's Joint Strategy group.

## Reading list

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Holman, H. and Lorig, K. (2000) Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *BMJ (BMJ (Clinical research ed.))*, 320(7234), 526-7

Partners in Change (2001) Checklists for meetings (series of four booklets). Edinburgh, Partners in Change. Available from <http://www.shstrust.org.uk/publications.html>

Scottish Executive (2000) Our National Health: A plan for action, a plan for change. Edinburgh, Scottish Executive Health Department. Available from: <http://www.scotland.gov.uk/library3/health/onh-00.asp>

Scottish Executive (2001) Fair for All: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland. Edinburgh, Scottish Executive Health Department. Available from <http://www.scotland.gov.uk/library3/society/ffar-00.asp>

Scottish Health Feedback (2002): User and Public Involvement in Health Services: a Literature Review; Partners in Change

