



*Modernisation Agency*



Learning from patient and carer experience

# A guide to using Discovery Interviews to improve care





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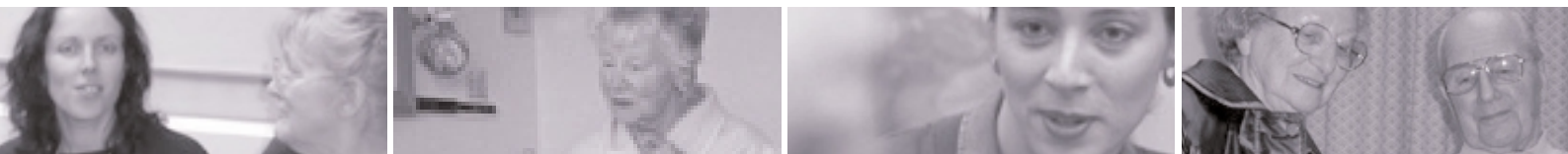
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# section one

## Introduction and overview

### i. Introduction to the Guide

This Guide is intended to give information and guidance on how to use Discovery Interviews to improve care by understanding patient and carer experiences better and by gaining insight into their needs. Discovery Interviews are only one of a number of possible approaches to involving patients and carers in improving care. They are particularly useful when clinical and other practice based teams want to directly learn about patients' needs and use this understanding to stimulate improvement ideas that they can test out in their services.

Very positive feedback has been received from staff about improvements in care following the use of Discovery Interviews. Some staff have also reported an increase in team and individual confidence as they have planned improvements on the basis of what they have learned from patients and carers.

Clinical team members have also discovered that hearing patients' and carers' stories creates knowledge that influences their own individual practice and is very useful to keep in mind even though it may not lead directly to specific improvements in services.

The Guide has been informed by the learning from the first phase of Discovery Interviews which involved the national Coronary Heart Disease (CHD) and Critical Care Collaboratives and which has been used to revise the original Toolkit prepared by the CHD Collaborative. A Resource File containing additional information, specific guidelines and documentation to support implementation is available as an additional aid and to facilitate consistency in using Discovery Interviews across different settings. This can be found on **[www.modern.nhs.uk/chd](http://www.modern.nhs.uk/chd)**

The contents of the Guide are divided into sections representing major elements of the Discovery Interview process, from thinking about undertaking them to planning and monitoring improvements that arise from their use. Fig 1 outlines these elements and includes tasks that must be undertaken to make the process go well. Advice for undertaking these tasks is included in the appropriate section of the Guide. Where detailed guidance is already available from other sources links for these are included.

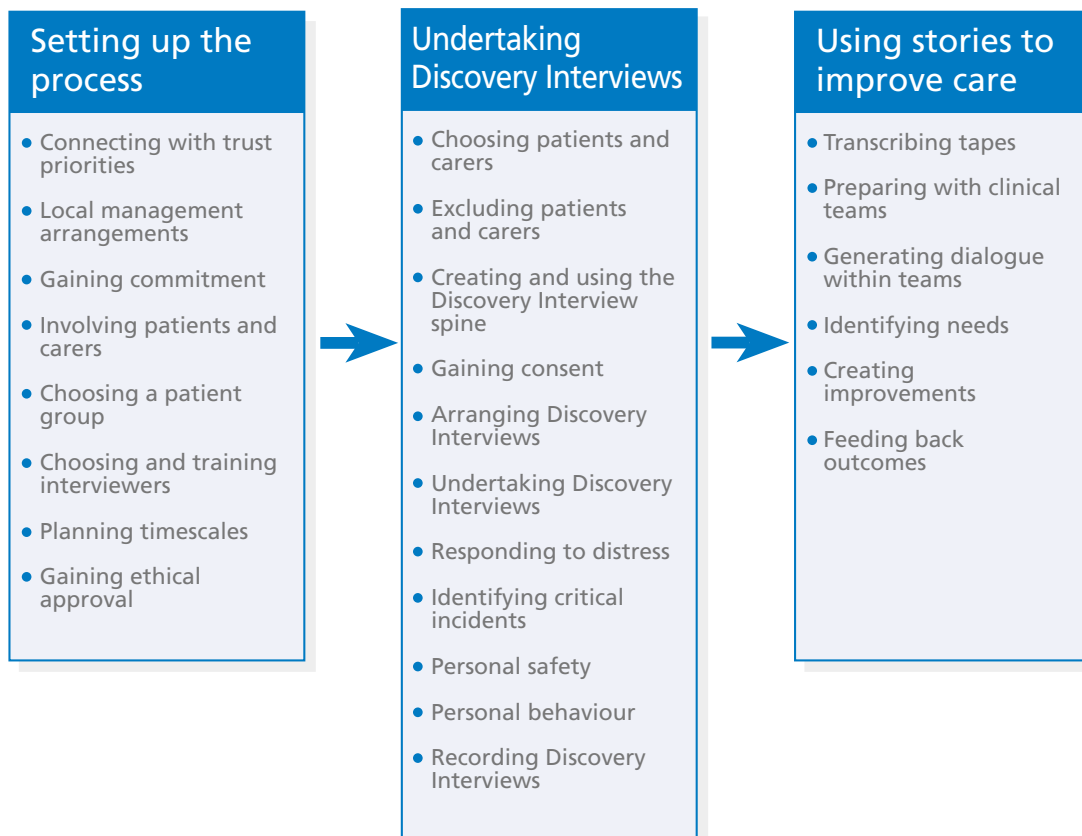
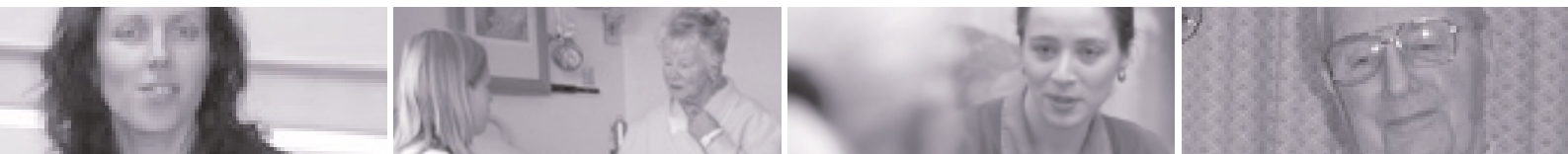
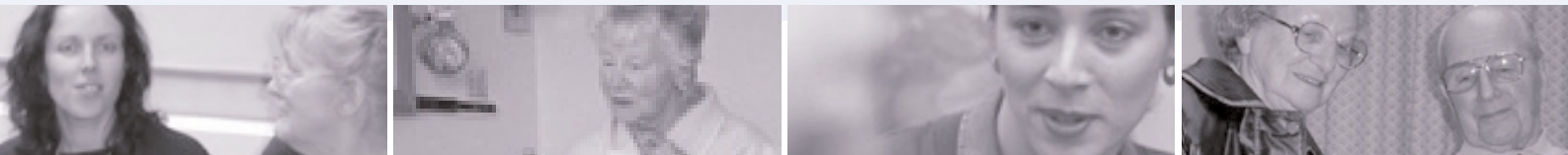


Fig 1: Outline of the Discovery Interview process for improving care



## ii. The importance of learning from patient and carer experience

Broadly speaking the Modernisation Agency's goal for the national Collaboratives was:

- To improve experience and outcomes for patients and carers by optimising care delivery systems across the whole integrated pathway of care.

The work of the CHD and Critical Care Collaboratives also provided a unique opportunity to explore one of the most important challenges in healthcare today. How can we learn directly from our patients and their carers about ways to improve the services we provide so that we meet their needs better? This is one of the underpinning principles of continuous quality improvement, ie that improving services is about improving the way we meet the needs of those who depend on us.

It has proved difficult to learn about patients' and carers' needs using traditional approaches that have often asked questions from a service point of view rather than asking what is most important to them. Yet unless we know about the latter it is hard to see how we can improve the way we meet the needs of those who depend on our services. However, experience suggests that explicit questions about 'your needs' are difficult to answer.

## iii. The early work of the national Collaboratives

From December 2000 small-scale pilots were set up to learn about how to use patients' and carers' stories to improve care. The results of this work were used to write the original CHD Collaborative's "Toolkit for Learning from Patient and Carer Experiences". The Toolkit was subsequently used by the Critical Care Programme which has provided further rich experience. More recently it has been employed by other national Modernisation Programmes who wanted to use the Discovery Interview approach, eg the 'Action-on ENT and Orthopaedics', Access-Booking-Choice Programme (ABC) and Ideal Design of Emergency Access (IDEA). There is now a substantial amount of experience of their use in practice.

This experience has been used to produce this Guide. It is expected that learning from experience of using Discovery Interviews will be a continuous process and arrangements to support this are suggested in section 4vi/5iii+iv of this Guide. In addition it is hoped that continuing experience will be used to keep the Guide updated and helpful.

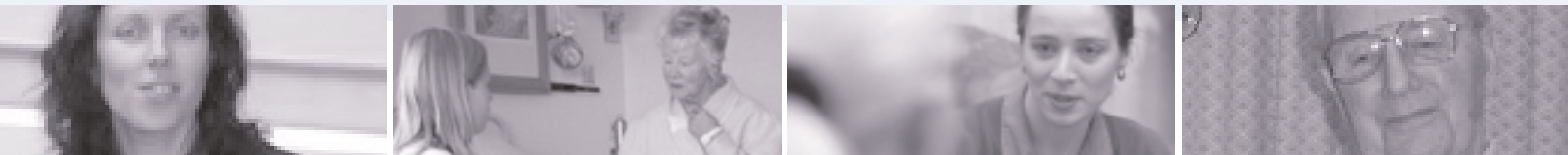
## iv. Using the Discovery Interview process to improve care

The CHD and Critical Care Collaboratives built upon innovative work exploring ways to learn what it is like to be a person (rather than a patient), or carer of a

person, with a particular illness or condition. The aim was to explore, and learn from, the impact of the illness on people's everyday lives. Evidence has emerged that taking this approach produces knowledge about needs that may have a significant impact on recovery and wellbeing.

One underlying principle is that the area patients and carers understand best is the impact of their illness or condition upon their lives. It is difficult for them to make value judgements, which require an understanding of their illness itself, or how services are run. Those delivering their care are acknowledged to be the experts in the illness and service provision. Thus they can use their own clinical and professional knowledge and experience to interpret what they hear from patients and carers to create better or new ways of meeting their needs.

Opportunities were therefore created for patients and their carers to provide information that was not constrained by thinking 'in the box' of their previous experience of care. In other words to shift the focus of enquiry from asking them service focused questions to encouraging them to talk about themselves. Discovery Interviews provide opportunities for patients and their carers to directly tell the story of their illness or condition using a framework (referred to as a 'spine') that guides them through the key stages of their experience.



Using the spine encourages a natural discussion about experiences that triggers significant memories and thoughts. This will provide the information that local teams can then use to identify needs and plan improved ways to meet them as mentioned above.

The process is very much viewed as one of joint discovery and hence the interviews are referred to as “Discovery Interviews”.

## The essence of the Discovery Process

The Discovery Interview process is used by teams to improve the way that they meet the needs of their patients and carers. . .

. . .through listening to their stories about the impact of their illness or condition on their everyday lives, and linking what they learn with their own professional knowledge and experience.

## v. Using Discovery Interviews with staff

Obtaining the views of staff is also important and encouraging them to tell stories in a similar way, eg using a care pathway, will equally reveal information that is not obtained through traditional methods.

A small amount of pilot work has been undertaken using Discovery Interviews with staff. However there is not yet enough experience of using them in this context to offer guidance about how to tackle it. Two main purposes have underpinned thinking about the importance of staff Discovery Interviews. These are:

- To learn from them about how services may be improved;
- To learn about their own needs and how these may be met better (the Retention and Recruitment Initiative plans to carry out small scale pilots during 2003).

## vi. Numbers of Discovery Interviews that need to be undertaken

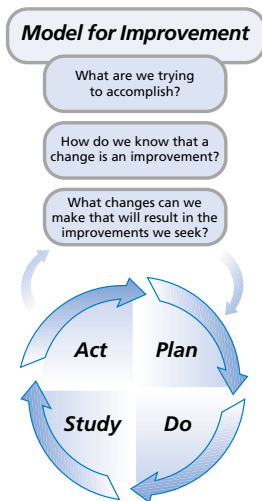
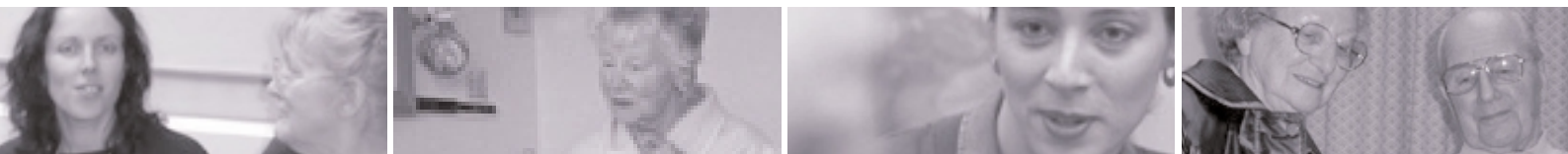
Learning from experience has shown us that it is not the number of interviews conducted that is important but the opportunity to hear detailed stories from a small number of patients and carers from across the whole patient journey. One story may provide many ideas for improvement, and teams need to concentrate on the quality and number of improvements rather than completing a specified number of interviews.

## vii. The link to Continuous Quality Improvement

Continuous Quality Improvement (CQI) is a set of principles and methods that enable people to improve the processes and systems within which they work and is the core business of the Modernisation Agency.

At its centre is the use of knowledge to identify changes for improvement, plan a test and learn from the results. It is a framework to improve the match between the services professionals provide and the needs of the people who depend on them.

Experience with inter-professional clinical improvement teams demonstrates that they benefit from having clear frameworks to guide them through their efforts. One that has received much attention is the ‘Building Knowledge for Improvement’ framework developed by Tom Nolan and colleagues. It presents a systematic way for building changes into improvements and is widely used across the NHS. (See Fig 2). It draws on an action learning approach. This is fundamental both to CQI and to the use of Discovery Interviews. It allows for small changes to be quickly implemented and tested. Feedback measures are built into each small change and used to plan next steps.



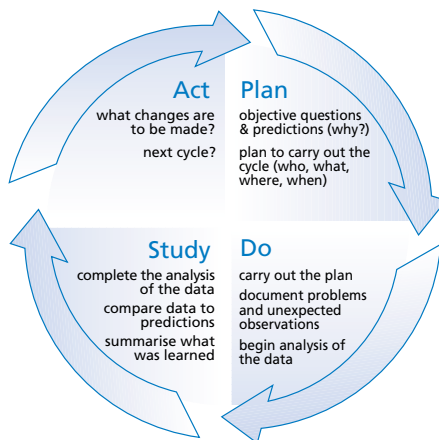
**Fig 2: Building Knowledge for Improvement framework** Reference: Langley G, Nolan K, Nolan T, Norman C, Provost L, (1996), *The improvement guide: a practical approach to enhancing organisational performance*, Jossey Bass Publishers, San Francisco

The focus on small steps with rapid feedback also ensures that movement in the 'wrong' direction is detected quickly and reduces risk. Improving care in this way is seen as an ongoing learning process and in practice is achieved by using the 'Plan - Do - Study - Act (PDSA), framework to help turn improvement ideas into action. Larger improvements are realised by the cumulative effects of small step, 'rapid improvement', PDSA cycles.

There are four stages to a PDSA cycle (see Fig 3)

**Plan:** plan the change to be tested or implemented;  
**Do:** carry out the test or change;  
**Study:** study data before and after the change and reflect on what was learnt  
**Act:** plan the next change cycle or plan implementation.

A PDSA cycle involves testing the improvement ideas on a small scale before introducing the change. By building on the learning from the test cycles in a structured and incremental way, a new idea can be implemented with greater chance of success. We have found that barriers to change are often reduced when many different people are involved in trying something out on a small scale before implementation.

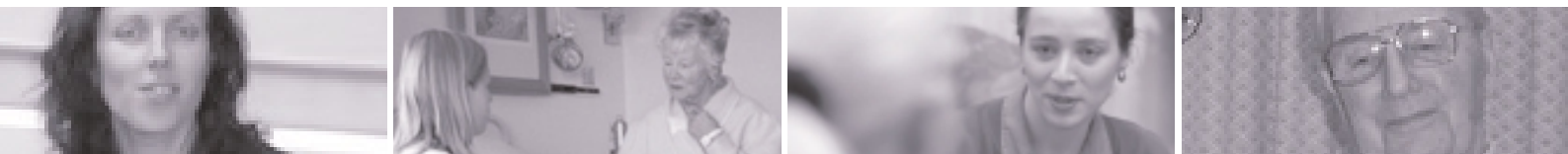


**Fig 3: The PDSA cycle to test a change idea** (©IHI)

This model of learning for improvement underpins the work of all the Collaborative Programmes supported by the Modernisation Agency across the NHS.

Within the context of Discovery Interviews the aim is to generate improvement activities (ie PDSA cycles), that are inspired by hearing patients' and carers' stories. When making their decisions about what action to take, teams must be sure that changes will add benefit to patients and carers and that there is no obvious risk. Using the PDSA method of implementation will itself contribute to achieving both these aims.

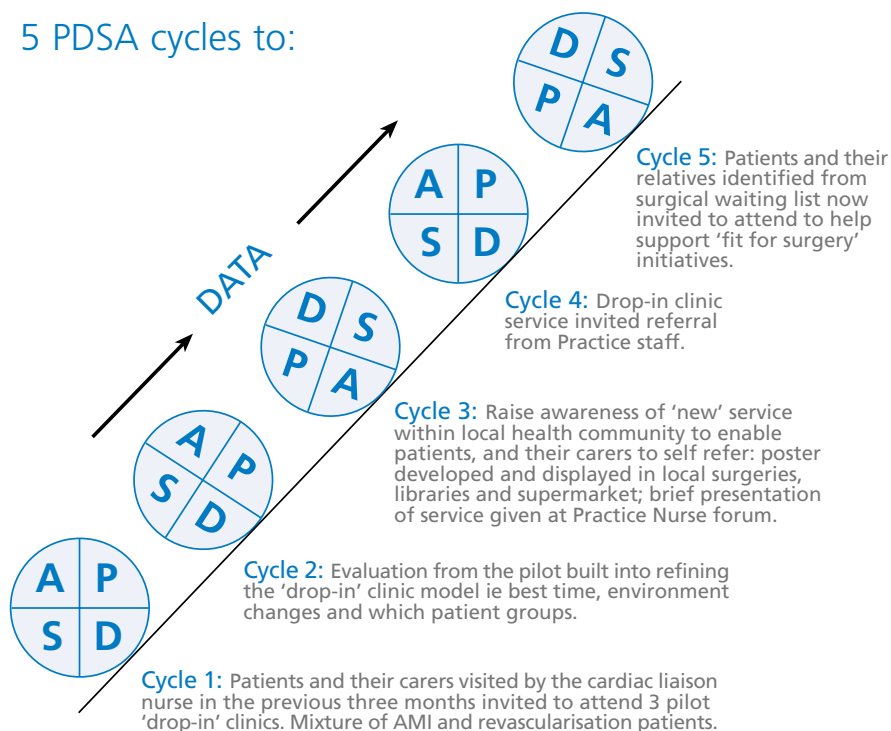
(Further information about improvement methodology can be found in the Modernisation Agency's Improvement Leaders' Guides published in 2002. See [www.modern.nhs.uk/improvementguides](http://www.modern.nhs.uk/improvementguides)). An illustration of using the model for improvement can be seen in fig. 4 on the following page.



### Issue identified from Discovery Interviews:

Discovery Interviews with patients and carers sampled across the patient's journey highlighted a perceived lack of social, emotional and professional support in the period between discharge from hospital to follow up. Carers reported feeling invisible and neglected whilst patients often felt abandoned during these early weeks.

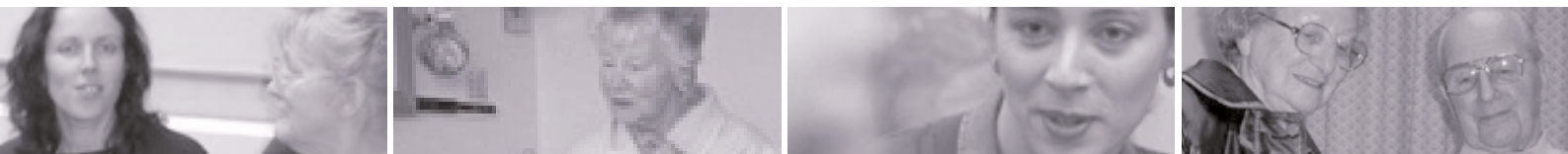
### 5 PDSA cycles to:



### Outcome:

The cardiac 'drop-in' clinic is now a regular weekly event, hosted by the British Heart Foundation Cardiac Liaison Nurse. The patients together with their informal carers, lead the sessions either independently or in groups, supported by the nurse who offers advice, information and support with living with their cardiac problem or issues related to readjustment /recovery. Additional features of the service are wound care management, suture removal and monitoring of blood pressure helping to reduce 'hand-offs' and delays in the patients' experience. A variety of health promotional and educational resources, including leaflets and videos, are available at the clinic for patients and their carers to access.

Fig 4: **Testing process:** To pilot a health centre based 'drop in' clinic for patients and their carers during the early period post discharge from hospital providing a forum in which individuals may access information, advice and support.



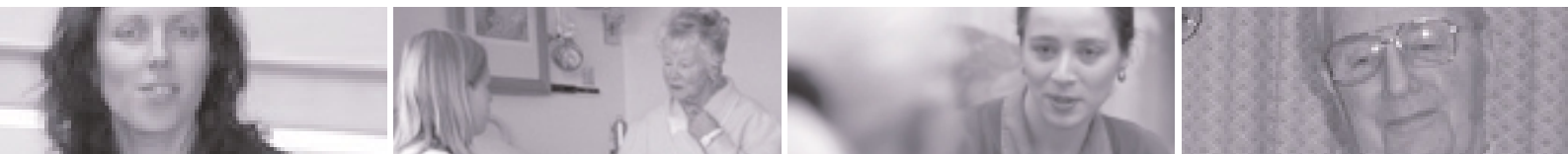
### Further reading

If you would like to read more about aspects of using patient narratives there is a list of useful references on [www.modern.nhs.uk/chd](http://www.modern.nhs.uk/chd)

## Touchstones for Discovery Interviews

When people use Discovery Interviews well to improve care they:

- i. Ensure that senior managers and clinicians in health care organisations are aware and supportive, and necessary connections across services and departments are made so that stories are used to improve care across the whole patient's journey;
- ii. Involve different patients and carers in their planning and implementation and use their experiences to improve care. (ie other than those being interviewed, see the Improvement Leaders' Guide to Involving Patients and Carers for further ideas [www.modern.nhs.uk/improvementguides/patients](http://www.modern.nhs.uk/improvementguides/patients));
- iii. Make sure that members of the teams involved have expressed a desire to use them to improve care and that protected time is planned for them to jointly listen to the stories;
- iv. Ensure that people undertaking them have been properly selected and trained, are supported in practice and maintain a reflective learning journal of their experiences and that quality is monitored;
- v. Appropriately identify and inform patients and carers about their purpose and implications and obtain written consent to involve them;
- vi. Undertake them at a time and in a venue chosen by the patient and carer, usually in their own home;
- vii. Actively use the stories to generate demonstrable improvements in the way patients' and carers' needs are met;
- viii. Ensure feedback of the outcomes of using Discovery Interviews to all the patients, carers and staff involved.



# section two

## Setting up the Discovery Interview process

### i. Connecting with Trust priorities - the strategic context

Section Eleven of the 2001 Health and Social Care Act places a duty on all health and social care organisations to consult and involve service users in all aspects of service planning, delivery and scrutiny. Each Trust will therefore need to take a strategic approach to patient and carer involvement. Discovery Interviews should be planned in this context and appropriate resources must be made available to undertake them as part of everyday activity.

Patient participation may occur at a number of different levels of contact ranging from individual treatment to groups of patients involved in strategic policy making. The table above shows three broad modes of participation: informing, consulting and partnership.

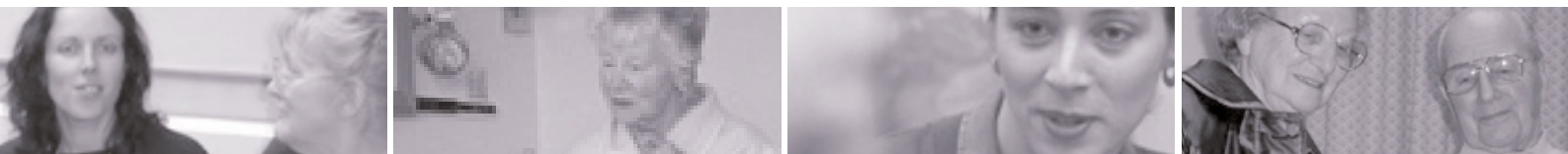
The Discovery Interview focus fits into the shaded elements in the model above, which is around service development and treatment. Our emphasis is on active partnership leading to jointly designed and implemented improvements in these two areas.

	Strategic Policy Making	Service Development	Treatment Processes
Informing			
Consulting			
Partnership			

Discovery Interviews should not be established as stand alone activities. They should be part of local service improvement plans and quality improvement activities and should fit into wider organisational strategy and priorities. Learning that emanates from them might well feed into, and inform, Trust strategic planning. (see the Improvement Leaders' Guide to Involving Patients and Carers, Section 2, for further insights into linking patient involvement and service improvement: [www.modern.nhs.uk/improvementguides/patients](http://www.modern.nhs.uk/improvementguides/patients))

In the future, it is likely that approaches such as Discovery Interviews will be used across different departments and services

within a local 'health community', ie reflecting the patient's journey rather than simply specific organisations or departments. All the relevant healthcare organisations including Hospital, Community and Primary Care Trusts within a local community will require co-ordination. This may be achieved through their modernisation leads or through those with responsibility for patient and public involvement. Strategic Health Authorities may be able to provide such co-ordination.



## ii. Local management arrangements

The early Discovery Interview work was mainly within Modernisation Agency Programmes and Collaboratives that currently sit outside mainstream management arrangements. As their use develops it will be crucial to involve senior staff in healthcare organisations who have appropriate responsibilities. In particular Trust Chief Executives and Medical Directors and Clinical and Nursing Directors, as appropriate, must be informed.

Part of this will depend on building them into Trust/StHA strategy to ensure that support is made available as part of key business priorities and that the Discovery Interview process fits into the Trust's patient participation strategy. Primary Care Trusts, as well as Hospital Trusts are likely to be involved.

As mentioned earlier Section Eleven of the 2001 Health and Social Care Act makes patient and public involvement mandatory and should help to support the use of Discovery Interviews within Trusts.

The sustainability of Discovery Interviews in practice will depend largely on local management involvement. Individual managers need to be able to offer everyday support to facilitate their implementation and their use to improve care by the teams within their sphere of responsibility.

## Key local management responsibilities

- ensuring that necessary support is provided to undertake Discovery Interviews;
- making connections between the different services involved in a patient's journey, both to prevent duplication of invitations and to make sure that stories are heard by the necessary services;
- ensuring that interviewers are appropriately chosen and trained, and that monitoring arrangements are in place;
- ensuring that necessary resources to undertake Discovery Interviews are available, as well as including the time needed to type transcripts and protected time for teams to listen to stories;
- ensuring that stories are used to implement improvements in care;
- dissemination of improvements.

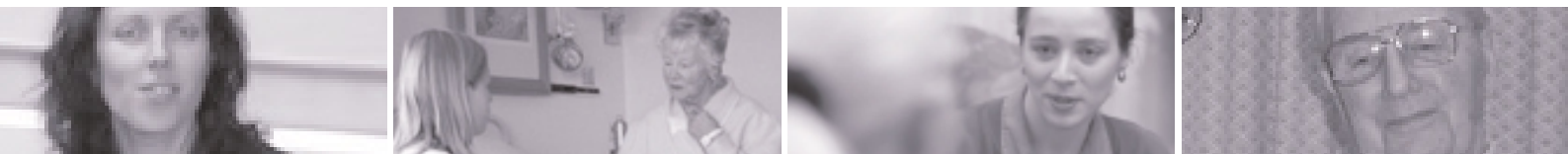
## iii. Gaining commitment within the service

Discovery Interviews should always be undertaken by teams who are interested in using them as part of an improvement process. It is therefore important to make early contact with clinical, managerial and support staff. This means discussing the ideas, and potential benefits as well as resource implications, in advance with teams and other related providers who contribute services to the patient's journey. Unless this is done they are unlikely to be enthusiastic to use the stories to improve the care they provide.

Letting teams initially hear a story from another part of the country is a good way of helping them gain insight into the process before they begin. There are a number of stories available that can be used for this purpose and some are included in the Resource File.

It is important to gain the commitment of all clinicians whose patients may be approached and they should have the implications for them and their patients explained. They have an important role in helping to choose the group of people from who interviewees will be randomly selected and also need to be able to respond appropriately should a patient tell them that they have been interviewed.

Further information about involving clinical and other practice teams is included in section 4 of the Guide.



#### iv. Involving patients and carers in the Discovery Interview process

Patients and carers should be involved at all stages of the Discovery Interview process including planning and designing improvements once stories have been obtained. In order to preserve confidentiality people who have provided Discovery Interview stories should not be explicitly included.

More detailed guidance about how to involve patients and carers in service improvement is included in the Improvement Leaders' Guide to Involving Patients and Carers (see: [www.modern.nhs.uk/improvementguides/patients](http://www.modern.nhs.uk/improvementguides/patients)).

#### v. Choosing a patient group

##### a. Sampling

For improvement purposes we do not need to be constrained by using approaches such as stratified sampling to provide a representative picture of all the users of a service. The approach is based more upon qualitative enquiry where exploration of ideas allows choosing a particular group of patients who are the focus of the enquiry. They are likely to be a subgroup within the range of patients seen by the team involved and may be chosen in order to inform a particular purpose.

The aim is to identify a small number of people, which should include men and women, who are typical rather than an exactly representative sample.

Finding out what other patient involvement activity is underway is important in order to avoid 'patient involvement fatigue' ie more activity going on than can be reasonably supported by staff and patient time.

Discovery Interviews have not so far been used with samples including young people under eighteen or children.

##### b. Involving people from vulnerable groups

###### People from ethnic minorities

Special arrangements may need to be made for people from ethnic minorities. Those who use services but who do not speak English must be interviewed in their own language by a person who is socially and culturally acceptable and the tape must be translated during transcription. Others may not yet use the services, or may experience particular difficulties in accessing them for cultural reasons. Planning processes must identify the most appropriate ways to identify them and the best ways to make contact with them. Additional resources are also likely to be needed. This will require separate ethical approval.

A pilot project to explore the benefits of using Discovery Interviews with people from local Vietnamese and Punjabi communities is being planned for 2003.

###### People with specific difficulties

Special arrangements must also be made for people who have particular difficulties such as illiteracy, who are blind or deaf or who have learning disabilities.

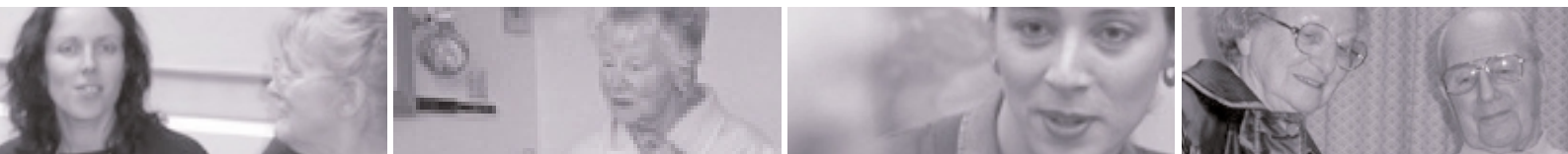
Work is currently being planned to test ways to use Discovery Interviews with people who are experiencing difficulties with their mental health.

#### vi. Choosing and training interviewers

###### Skills and qualities of interviewers

The experiences, skills and qualities of interviewers are essential components to be considered. Interviewers must understand both the process and purpose of the Discovery Interviews within the context of improvement and know exactly what is expected of them.

The frequency with which interviews are undertaken will influence the skills of the interviewer, and this should be taken into account when deciding how many to undertake, and by whom. As a rule of thumb three or four interviews a quarter per interviewer seems an appropriate number to maintain skills. The availability of peer support meetings will also play an important part in maintaining skills. (See section 5 iii). It is important to the success of the Discovery Interview process that people undertaking them are enthusiastic and local managers need to be involved in identifying them.



### Training in undertaking Discovery Interviews

The Discovery Interview process is neither traditional research nor audit although some of the principles of both qualitative research and audit are embodied within it. The term 'interview' may conjure up pictures of a questioning process. However the most important aspect within the actual 'interview' part is listening to patients and carers. The most critical skill is the ability to gently encourage interviewees to continue telling their story.

It is essential that Discovery Interviews are conducted well; both from the point of view of safeguarding patients' and carers' wellbeing and to obtain the rich information that will inform improvement efforts. Discovery Interviewers need to be familiar with the three main components of the Discovery Interview process even though they may only be involved with gaining patients' and carers' stories: ie

- setting up the Discovery Interview process;
- undertaking Discovery Interviews;
- using stories to improve care.

Interviewers have come from a variety of backgrounds and with a range of different types and depth of experience. They have included nurses, midwives, a physiotherapist, a radiographer, audit staff and PALS (Patient Advice & Liaison Service) staff as well as interviewers who have been specially employed. However interviewers must not have been involved in the clinical care of the patient being interviewed.

### Key issues in undertaking Discovery Interviews

- training in listening to patient and carer stories;
- careful preparation by the interviewer;
- ensuring that interviewers are familiar with the relevant patient pathways;
- awareness of important aspects of the particular service whose patients are being listened to.

A certain amount of training is needed and one of the conditions of ethical approval was that anybody wishing to conduct a Discovery Interview must have attended a training workshop and/or demonstrated in practice that they have the necessary skills.

### Crucial skills for undertaking Discovery Interviews

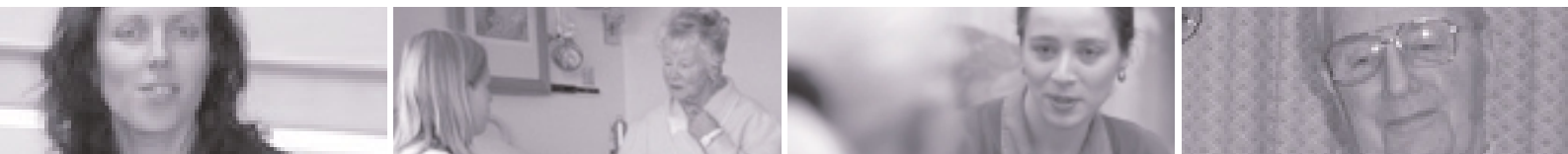
- active listening and ability to engage interviewees;
- ability to put interviewees at ease and to make them feel safe;
- ability to encourage interviewees to stay on track without leading them down particular paths;
- an understanding of the improvement context so they can explain their purpose clearly;
- personal robustness to be able to listen to people describing difficult and distressing stories on occasion.

Local managers must follow the guidelines for training interviewers which are included in the Resource File and satisfy themselves that all those involved match the skills criteria below.

Specific training is provided for interviewers followed by assessment in practice. This will primarily be provided by trainers who are undertaking Discovery Interviews themselves to maintain their skills and credibility and to ensure that they can offer training based on practical experience.

Learning from the early sites has shown that being an experienced interviewer in other contexts may not necessarily mean that a person has the appropriate experience or particular skills needed to undertake Discovery Interviews well.

Regular workshops for interviewers will be run and funded by the Modernisation Agency during 2003 to support the development of the Discovery Interview process on a local basis.



## Every new prospective Discovery Interviewer will be required to:

- meet the requirements of the person specification (see Resource File);
- attend a training workshop which can be accessed through the NHS Modernisation Agency;
- successfully complete a practice interview in their work setting and then have their third interview 'assessed' by a designated person;
- have tapes of interviews 'assessed' at regular intervals by a designated person. The current recommendation is for every fifth tape to be assessed;
- attend local interviewer support meetings.

As programmes unfold more experienced interviewers will be available to conduct interviews across different patient groups. The use of PALS as a resource could also be considered although the place of Discovery Interviews within their portfolios of work should be clarified.

### Supporting interviewers

The first phase of interviews has shown the importance of supporting interviewers, particularly when an interview has been difficult, or the patient/carer appeared unhappy with the process. In some places a 'buddy' system has been used to debrief and support interviewers.

### Maintaining a Learning Journal

Interviewers are encouraged to keep a log of their own experiences, thoughts and feelings about the interviews in a Learning Journal. (See section 5 i).

Local interviewer support meetings will be held in different parts of the country for all those involved in conducting interviews to meet on a regular basis to provide peer support and challenge in the process. (See Section 5 iii). Anonymised transcripts may be used at these meetings to help interviewers reflect on practice.

## vii. Planning the timescale for the Discovery Interviews

### a. Lead-in times

The time taken to conduct this type of work can often be longer than expected. Patient/carer interviews should ideally be planned for several weeks before the actual interview needs to be conducted. Six weeks is probably the minimum comfortable period for planning an interview.

### b. Timing of interviews

The timing of the interview is important. Patients should not be interviewed immediately after discharge from hospital nor in the middle of a course of treatment. It is equally important that patients and carers are not interviewed too long after their contact with the service has ceased.

The timing needs to be relevant to the condition or illness of the patient group. For example this will be different for longer term conditions where it is desired to listen to patients at different stages of the pathway.

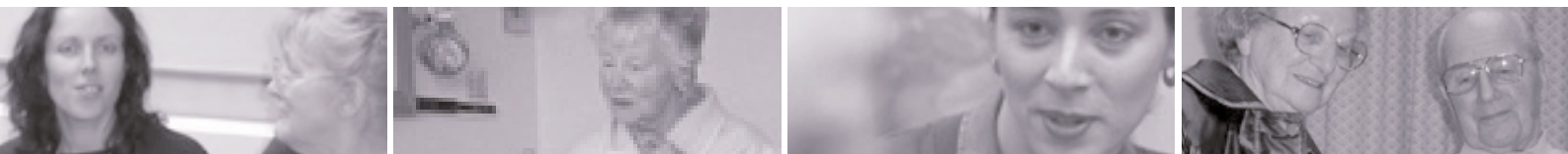
## viii. Gaining ethical approval

It is essential to gain ethical approval for undertaking Discovery Interviews. This may take some time so it is important to plan ahead.

Research Ethics Committees exist across the country and vet proposed research projects to check that they will not cause harm to patients or staff, either physically or mentally. All patient contact that is not clinical is currently considered to be within the province of the new Research Governance guidelines for which ethical approval must be obtained. Discovery Interviews come within this category.

The National CHD and Critical Care Collaboratives both obtained Multi-site Research Ethics Committee (MREC) approval but it is still necessary for local sites to apply to their Local Research Ethics Committee (LREC) to approve local arrangements. These differences must also be notified to the lead 'researcher' identified on the MREC application.

Documentation from the successful CHD and Critical Care applications for MREC approval is provided in the Resource File.

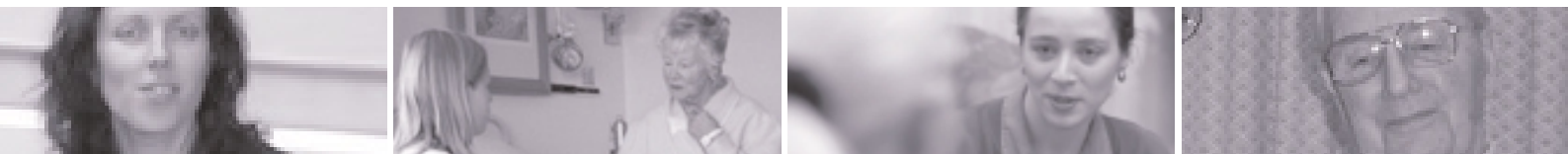


The North West MREC has agreed to act as the national focus for multi-site ethics approval applications and will be able to draw on their previous experience when vetting them. This should expedite applications although it is important to understand that it is still necessary to obtain LREC approval to ensure that local circumstances are taken into account. Services that cover more than one LREC should speak to the LREC Chairs to check procedures for gaining approval in such circumstances.

Obtaining LREC approval is the responsibility of the local manager leading the initiative, and it will be necessary to prepare a local implementation plan highlighting where local arrangements differ from the MREC approved application.

## ix. Equipment

Interviewers have used a variety of different audio-cassette and mini-disc recorders, often with external microphones. Before purchasing such equipment it is advisable to seek the views of those who have previous experience. Interviewers should make sure that they are familiar with the equipment they are using and that it is in working order before they attend an interview.



# section three

## Undertaking Discovery Interviews

Once the patient group has been identified and relevant service teams have agreed to participate, arrangements must be made to undertake the interviews and ensure that they are used to improve care. The process map overleaf (Fig. 5) describes the key steps in achieving this. Sections Three and Four provide further guidance about implementation.

### i. Choosing patients and carers to be interviewed

#### Identifying specific people

Patient confidentiality means that it is not possible to approach healthcare organisations to directly obtain the names and addresses of patients and their carers. Therefore several routes were used during the first phase of interviews to obtain a broad pool of patients and carers. These included:

- Asking GPs to recruit patients on their lists. These patients need to be properly selected - e.g. patients who have received treatment between certain dates and who are still alive.

- Approaching patients and carers before discharge from hospital to see if they would be interested in being involved at a later date.
- Approaching local patients' support groups for volunteers to be interviewed.
- Asking local GP surgeries, rehabilitation classes and follow-up and out patient clinics for patients and their carers to place advertisements seeking volunteers.

One underlying principle, however the lists are prepared, is that the final selection of people to interview will be random and will not involve the service team. Rather than have the clinical team choose the actual patients to be involved, with the possibility of bias being introduced, it is suggested that they identify all relevant patients and that a random selection is then made from this group.

#### Seeking volunteers

Responses to requests for volunteers to be interviewed have usually been very good with many patients expressing a desire to be involved. This may lead to its own problems since it will then become necessary to select from a large group and sensitively let others know that they will not be interviewed, and why.

More importantly there is a danger that seeking volunteers will create a pool of self-selected people and may miss others with important stories to tell. Generally speaking it is advisable to use routes that involve clinicians directly in choosing patients from whom the final, random, selection may be made.

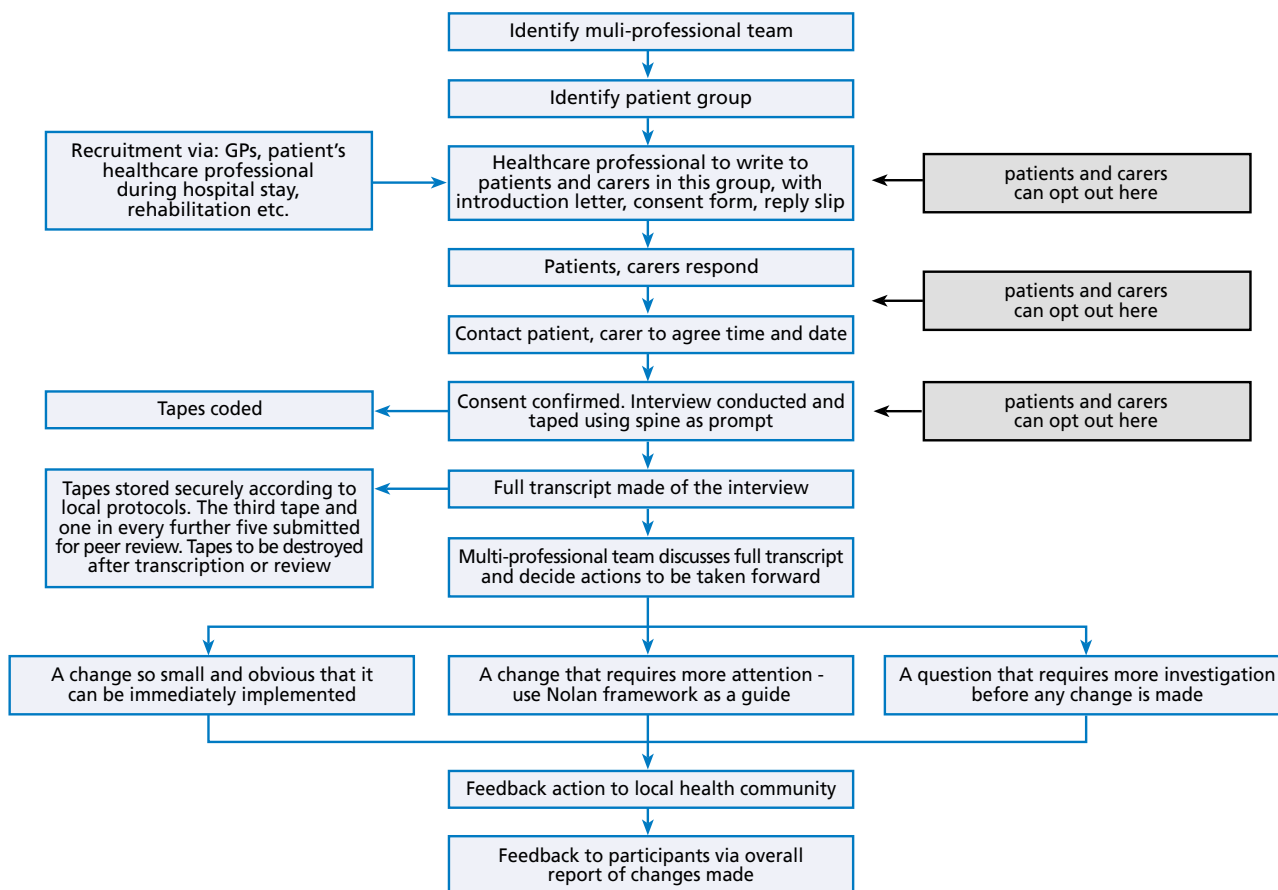
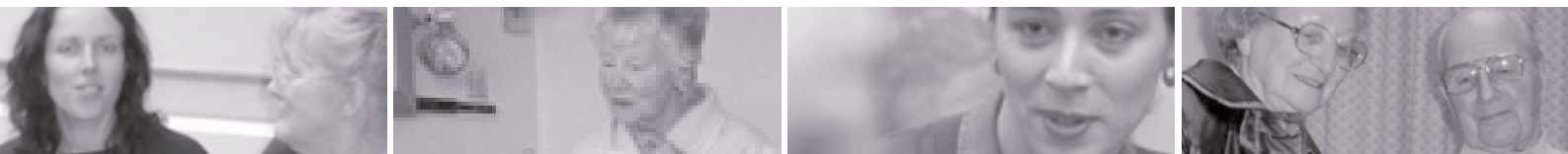
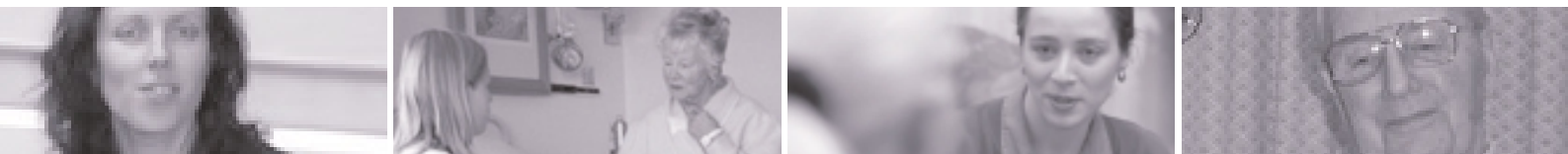


Fig 5: **The Discovery Interview Process** (see Sections Three and Four)



### Using Discovery Interviews across patient pathways

Conducting interviews across the breadth of the patient's journey allows health care teams to use the findings to improve services for patients and carers across different services. Patients' experiences do not acknowledge the arbitrary divisions that we organise into services since they necessarily have to cross them. Thus individual stories are relevant to a number of different services or departments and remind teams of the importance of patients' and carers' experiences before and after the care that they provided.

### Routes used by the CHD Collaborative to identify patients and carers at suitable points in the care pathway:

- patients with a diagnosis of heart failure randomly selected from the heart failure registers in primary care;
- patients attending the rapid access chest pain clinic with a confirmed diagnosis of angina;
- patients admitted for coronary angiography;
- patients visited by the cardiac liaison nurse following MI or surgical revascularisation in the first week of discharge;
- patients attending post myocardial infarction clinics;
- patients attending cardiac rehabilitation phase 3 classes;
- patients attending for CHD monitoring in primary care.

The CHD Collaborative made efforts to obtain a reasonable spread of patients and carers from across stages of the illness journey bearing in mind that their condition at the time of the interview will emphasise different aspects of the service.

### To obtain a reasonable spread over time interviewers should plan to:

- cover the whole spectrum of the condition being considered (eg for CHD include different types of CHD, heart failure, angina, rehabilitation and surgery, for Critical Care include both elective and emergency patients);
- interview both patients and carers - and also include some patients who do not have carers. Consideration could also be given to interviewing close family members who are not direct carers as such;
- interview both newly diagnosed patients and people with long term conditions bearing in mind that the time interval will greatly influence the nature of the interview and its content.

It may also be appropriate to select a group of patients whose stories will be relevant to a particular service priority or to learn about a specific aspect of interest. For example patients with long term conditions, those receiving long term care and those with progressive illnesses.

### ii. Excluding patients and carers from the Discovery Interview process

#### Patients and carers who refuse to give consent

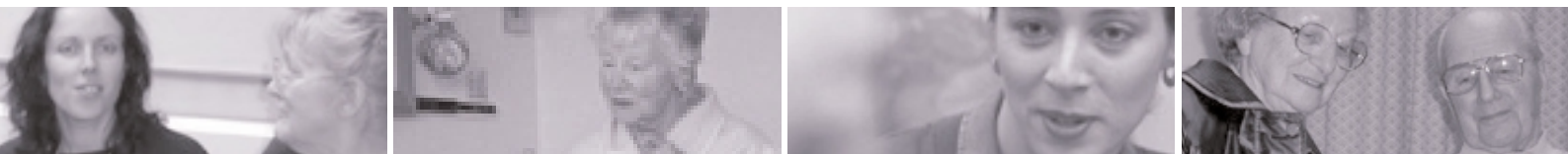
Patients who either refuse, or who are unable to give explicit consent, and carers who refuse to give explicit consent must not be included whilst at the same time being reassured that it will make no difference to their treatment.

#### Patients or carers who have made a complaint

Patients or carers who have initiated a complaints procedure against a Trust must also be excluded whilst their complaint is still in progress. Once it has been completed there may well be benefits in offering them the opportunity to participate.

#### Patients and carers who may not be able to cope

When preparing lists of patients to interview, a certain amount of pragmatic screening will be needed to avoid causing distress and wasting people's time.



It may be appropriate to exclude very elderly people, those considered too vulnerable for both physical and emotional reasons and those unable to communicate for whatever reason. However, it should be borne in mind that all these people have a story to tell and wherever possible arrangements should be made to offer Discovery Interviews to them. This is a matter for local judgment and will be influenced by the specific purpose of the Discovery Interviews.

### iii. Creating and using the Discovery Interview spine

#### Creating a Discovery Interview spine

A standardised 'spine' is used to offer guidance to patients and carers whilst telling their story. It describes the key chronological stages of the patient's and carer's journey through their illness or experience and serves as a trigger for significant memories. It is referred to as a 'spine' because it provides the barest minimum of prompts around which the patient or carer can build their story.

'Spines' are illness/condition specific and need to be generated for each patient group, if possible involving patients and carers in the process. There is often a spin-off benefit in that it heightens awareness of the clinical team about the whole journey of care within which they play different parts.

This will involve meeting with the team at an early stage before any interviews are undertaken. It has also been found useful to work with teams to clarify the patient's

journey as they understand it eg by using process mapping. This will enable a spine to be developed to provide the structure for the interviews and will also provide the background knowledge interviewers need before beginning.

Working with teams in this way begins to generate a sense of ownership and involvement, and they are more likely to look forward to hearing the stories.

Spines are therefore an important part of the Discovery Interview process. Examples of the spines used by the CHD and Critical Care Collaboratives are shown below. The Resource File contains illustrations of stories that were obtained through using the appropriate spine.

#### The Critical Care Spine

First realising something was wrong  
Getting to the Critical Care Unit  
Being in the Critical care Unit  
Leaving the Critical Care Unit  
Being on the ward  
Going home  
At home

#### The CHD Spine

Thinking something was wrong  
Seeing someone in the NHS  
Having tests to find out what was wrong  
Being told what was wrong  
Receiving treatment  
Getting better  
Living with your condition  
Being followed up

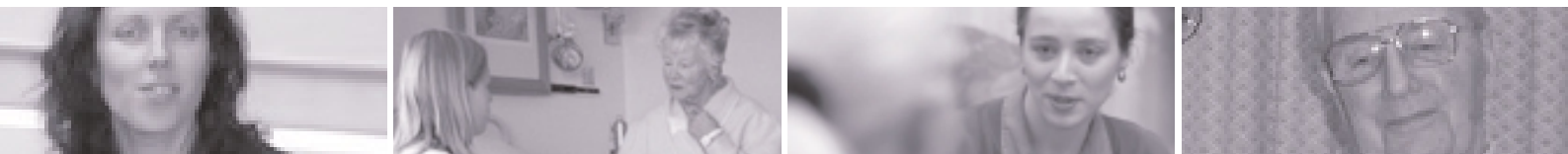
The experience during the first phase of the Discovery Interviews showed that the spine is a more accommodating tool than using a structured set of pre-determined questions. It allows the patient or carer to talk freely about their experiences, but still ensures that the interviewer is able to gather all the information needed by the end of the interview.

#### Using the Discovery Interview spine

Patients and carers vary considerably in the way they talk during interviews. Some will be quite focused, and present their views in a structured way. Others will be much more random in the way they tell their story. Initially, it is best to allow the interviewee to talk, particularly if they have strong feelings about an issue. Avoid, as far as possible, asking questions that will lead the interviewee in particular directions.

People differ in their desire to follow the sequence of steps as laid out in the spine. Some find it very helpful but it does not matter if they want to concentrate on the events in a different order to the spine.

Prompt cards with the key statements from the spine laid out in front of the interviewee can help remind them of the subjects and any topics they have missed. Some interviewers have used laminated cards with each step on so that interviewees can pick them up and use them as prompts if helpful. They can be turned over when an interviewee has finished with a particular step, or if they have nothing to say about it.



## Benefits of using the spine for the Discovery Interview process

- helps to cover the whole journey of the illness/condition under consideration;
- triggers significant memories and allows the patient/carer to tell their story in their own way and in their own words;
- allows the patient/carer to remain in control of the 'interview', rather than being asked a lot of questions;
- provides rich information that can lead to a better understanding of patient and carer needs by offering context and perspective;
- creates an immediacy that cannot be ignored, and a powerful desire to change;
- provides consistency across different interviews by serving as a guide to interviewers.

An emphatic approach should be adopted, and the patient/carer encouraged to cover as much of their journey as possible, even if they have one particular experience about which they have very strong feelings. Prompts or probing questions can be used to encourage the continued telling of a story although these must be kept open and reflecting the interest of the interviewee.

Interviewers should bear in mind that the more they ask questions the more the

patient or carer may feel that they have their own interests or agenda and may try to respond to what they assume these to be.

### iv. Gaining consent

A letter is sent by a clinician involved in the care of the patient or carer, to him/her, explaining what the interview intends to achieve, and asking if they are prepared to take part. The letter will explain that there is no obligation to take part and that their decision will not have any impact on current or future treatment, whatever it is. A patient information sheet must be sent to accompany the letter with more detailed information about the process. All correspondence needs to be approved by LREC following MREC approval.

The letter should make it clear that the interview will be tape-recorded and that the patient or carer can withdraw at any time before or during the interview. If the patient or carer does not wish to be recorded the interview will not take place. It should be made clear that the interviewer wishes to interview the patient and carer separately although they can be interviewed together if they express a strong wish.

The consent form/reply slip should provide space for a contact number so that the interviewer can telephone the patient or carer to arrange a convenient time and venue. It should also contain a question asking whether the patient's carer wishes to be interviewed.

When appropriate the patient/carer should be asked to sign and return the consent form in advance. A reply paid envelope must be included to avoid costs to the patient or carer. It should also be made clear that if they incur any expenses these will be reimbursed at the time of the interview or as soon as possible afterwards.

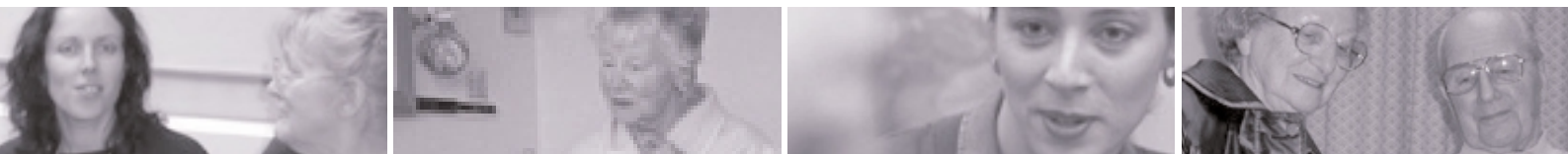
Examples of consent forms and letters for patients providing information about the nature and purpose of Discovery Interviews are included in the Resource File.

### v. Arranging Discovery Interviews

It is easy to underestimate the time needed to undertake interviews including finding unfamiliar locations. Protected time must be allocated for the interviews. Ideally it is best to avoid more than one interview each morning or afternoon (unless a patient and carer are to be interviewed in the same place). This avoids arriving late because a previous interview has overrun, and also helps to reduce potential stress for the interviewer and interviewee.

#### Interviewing Carers

As mentioned above the patient and carer should be interviewed separately if possible. This will help each to speak freely and experience indicates that carers in particular may have things to tell that they may not want their partner to hear. In this context it is important to encourage them to tell their own story rather than give their version of their partner's story.



Separate interviews have provided important insights into differences between patient's and carer's needs that are unlikely to have emerged during a joint interview eg for information and support. The carer may be husband/wife or partner, daughter or son, other relative, friend or companion or perhaps a neighbour.

Interviewers regularly report that carers are very positive at being given an opportunity to tell their story which is often the first time they have been involved. On occasion they have expressed very strong feelings about things that may need following up eg about significantly changed relationships with their partner. It is important to offer contact names and numbers so that they can seek further help if they choose.

The final decision about whether they are interviewed separately or together must rest with them.

#### Making brief notes

It may also be useful to allow time for the interviewer to make some brief notes following the interview, as a back up to the audio recording, whilst it is fresh in the memory. This will be useful if parts of the tape are unclear or if the meaning of what has been transcribed is unclear from the typed manuscript.

## vi. Undertaking the Discovery Interview

### Introductions

Interviewers should introduce themselves, avoid mentioning their own clinical background if possible, and make it clear that they are not part of the clinical team that provided the patient's care. The introduction should focus on their role as an interviewer rather than being a representative of the services. It is clear that the way the interviewer introduces themselves sets the context for the interview and will influence what the patient or carer feels comfortable saying.

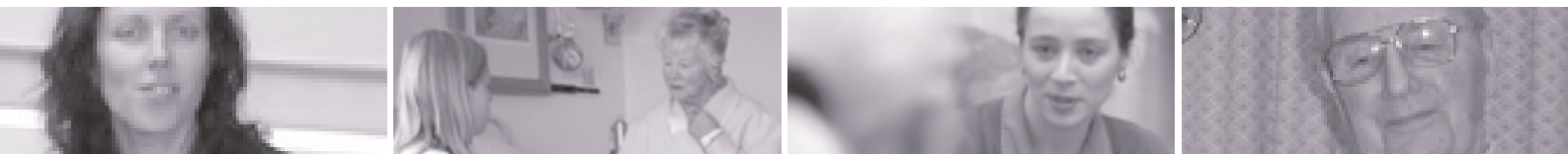
Broadly speaking the success of a Discovery Interview is influenced by the sensitive use of the spine and demonstration of active listening skills by the interviewer. It is important to remember that the essence of a Discovery Interview is to hear the patient's or carer's own story in their own words. This means asking as few questions as possible and making sure those that are asked are open ended and designed to encourage the patient or carer to keep telling their story. Asking too many questions puts the interviewer in control and reduces the opportunity to hear about what is really important to the person telling the story.

Some key aspects of a successful Discovery Interview are listed in the box below.

### Key aspects of a successful Discovery Interview

- describe the purpose of Discovery Interviews and confirm consent;
- show the interview spine to the patient/carer and explain its purpose;
- keep questions to a minimum but do use open questions to encourage the patient/carer to expand their story when appropriate;
- use active listening skills to encourage the patient/carer to continue their story, using the spine to help;
- remain neutral and avoid implying value judgements about what you are hearing;
- consider your body language and that of the interviewee;
- allow silences;
- keep a check on the time and move the interview on as required;
- close the interview positively leaving behind any contact details that the patient/carer may need in order to follow anything up.

The purpose of Discovery Interviews should be described, and it should be explained that although they will not receive feedback about their particular story they will be told about benefits that have been achieved from the overall process.



Interviewers need to make sure that they use words the interviewee will understand and that they are sensitive to their current health status. (eg the CHD Collaborative found it necessary to be sensitive when interviewing patients with heart failure and with a limited life expectancy, especially at the point of exploring aspects of them 'living with their condition').

#### Confirming consent

Confirm to the interviewee that they can withdraw, either before, or during the interview, if they wish. They do not have to answer any questions they do not wish to. Make sure that a signed consent form has been obtained from the patient/carer before the interview begins.

#### Preparation before a Discovery Interview

As part of preparing for the interview it may be helpful to give interviewers a short briefing about the patient, but not a detailed history. This is to ensure that they are aware of significant details that may be important during the interview to avoid appearing insensitive or causing unnecessary distress.

In addition some interviews may generate other queries that the interviewer may think are inappropriate to discuss during the interview or that they may not be able to answer at the time. Good practice will be for each involved service to make available a list of resources to which interviewers can refer, and a list of useful contacts.

The interviewer must be able to provide the interviewee with the appropriate contact names and telephone numbers in relation to their identified query.

#### vii. Responding to feelings and distress that may arise during a Discovery Interview.

The wellbeing of the person being interviewed should always take precedence over the interview itself. It is possible that telling their story will arouse feelings that need to be acknowledged and responded to sensitively. When this has happened in the past interviewees have been happy to carry on with the interview after a short break and have declined the offer of additional help.

If the patient or carer should become too distressed it may be necessary to finish the interview. The interviewer must be able to provide appropriate contact names and telephone numbers so that the patient or carer can seek further support if they wish.

Guidelines to help interviewers respond constructively to distress are included in the Resource File. Local interviewer support meetings (see section 5 iii), also offer opportunities for interviewers to explore coping with such situations during an interview, and strengthen their ability to manage them.

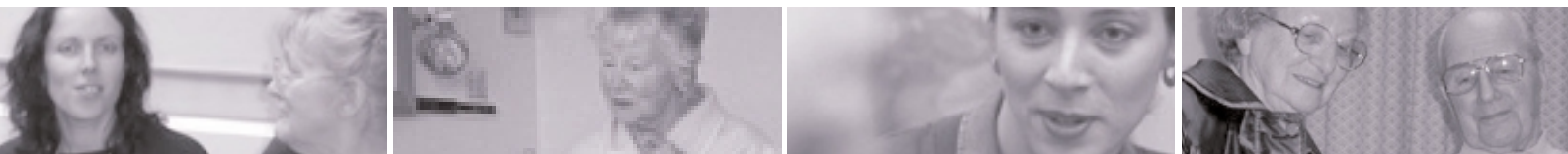
#### viii. Identifying Critical Incidents during a Discovery Interview

It is not the purpose of Discovery Interviews to elucidate comments on specific practice from patients or carers. However in the course of telling their story they may make comments on practice and where these reveal a standard that appears to be unacceptable the interviewer has a duty to report their concerns.

This will need to be discussed and agreed with the interviewee since there will be a need to report the issue and break confidentiality. Under these circumstances it is considered that potential benefit to others should outweigh the need to maintain anonymity. Connections with local Clinical Governance arrangements are essential in these circumstances which also emphasise the need for connections with local Trust management structures as referred to in section 2 ii.

On occasion it may be the clinical team hearing a story, rather than the interviewer, who recognise the need to take further action. In such circumstances the original interviewer should be contacted and asked to revisit the patient or carer concerned and explain the situation.

It is crucial that the patient or carer is provided with as much positive support as necessary throughout any following action. Detailed guidance for handling such situations is included in the Resource File.



## ix. Personal Safety

Most interviews will be conducted in patients' or carers' homes, often without having met them beforehand. This can pose a potential risk to the interviewer's personal safety. Interviewers must comply with their employing Trust's staff security policy if one exists. Particular attention must be paid to such issues if the interview may be taking a member of staff into an area with a reputation for being 'unsafe', or where it may be thought best for staff to visit in pairs. In such circumstances it may be best to consider alternative strategies for gaining a patient's story. It may be helpful to contact staff from local community teams for advice.

Staff are advised that their visits should be during the day-time (generally office hours). All interviews will be pre-arranged by letter and telephone. All visits should be recorded by the local manager or team leader who is supervising the process and who must ensure that details of staff whereabouts are known.

A local manager should be identified to undertake the responsibility for ensuring that staff have good directions and that travel arrangements are made. If they are visiting on their way home from their place of work, they should telephone the manager to inform them that they have completed their interview and have returned home.

The interviewer should take a mobile phone with them, and if possible, call a colleague prior to commencement of the interview. This will allow the interviewer to put the phone onto 'silent' mode throughout the interview. A pre-set time, for later in the day, for a colleague to make contact should be arranged or the interviewer should 'phone in' after completing the visit. The interviewer must leave details of the address where the interview is taking place and the anticipated time for their return.

Telling the patient/carer what time the interview is expected to end can be helpful not only from the security aspect, but also to help ensure the interview finishes on time.

## x. Personal behaviour

Visitors to other people's homes are representatives of their organisation, should carry identification (name badge and hospital security pass) which they should show on request if legitimately asked to do so. Staff should dress appropriately and professionally. Uniform should not be worn. Normal rules of courtesy apply. Staff are invited guests and should respect the wishes of those they are visiting.

Attention must also be paid to the possibility of accusations being made against the interviewer. It is difficult to

plan for this specifically but if the patient's or carer's wishes are always kept at the forefront and the above guidelines followed the chances of such an occurrence should be kept to a minimum.

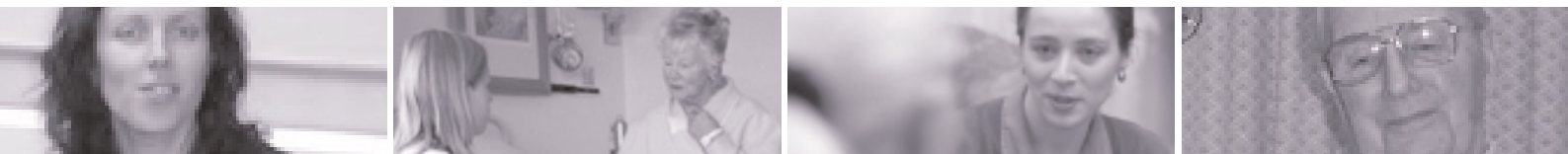
The fact that the process is recorded on tape or mini-disc will help confirm facts and well maintained learning journals will also be helpful should questions arise at a later date. No such incidents occurred during the piloting stages.

## xi. Recording the interviews

### Confirming the use of recorders

Interviews should be recorded on audio-cassette tape or mini disc. The consent letter to the patient/carer should make it clear that interviews will be recorded. If the patient objects the interview should not take place. The tape may also be used for training purposes and for monitoring the performance of the interviewer. If the patient or carer objects this should be noted and care taken not to use the tapes in this way.

Generally speaking the tape recording should be erased immediately after transcription except when it will be used for staff feedback and quality monitoring purposes.



### Coding tapes

A separate code should be allocated to each interview, as the patient's or carer's name is not recorded. This should be written on the mini disc or cassette tape and can be done in front of the patient or carer to avoid confusing tapes. The code must not identify the patient in any way, but should contain:

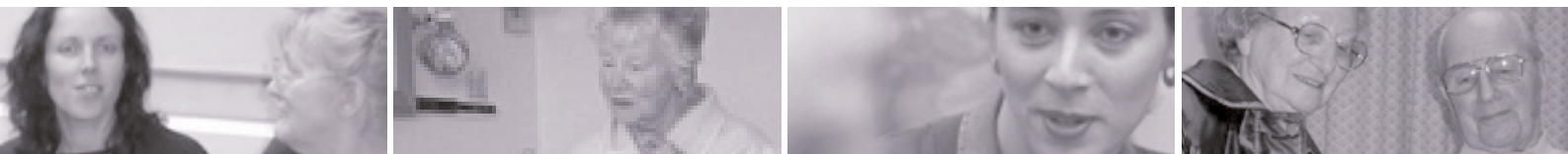
- type of interviewee, patient **P** carer **C**;
- number of the interview;
- initials of interviewer;
- date of interview;
- diagnostic category if appropriate.

This data and anonymous transcripts must be stored safely and confidentially in line with the requirements of the Data Protection Act of 1988.

### Equipment

Make sure the recorder is positioned in the best place to record the interviewee's voice even if it appears to be prominent. Its presence is quite quickly forgotten as the patient or carer tells their story.

Check again that the recorder is working before beginning to record the actual interview. Wise interviewers always carry spare batteries and tapes!



# section four

## Using Discovery Interview stories to improve care

### i. Transcribing tapes

Transcribing tapes is time consuming and needs to be properly resourced. The time taken will depend on the typing expertise of the transcriber, their previous experience of transcribing and their familiarity with the patient's journey and the terminology being used. Some transcripts have been typed by the interviewers and some by local secretaries or other administrative staff.

Due to the nature of the task it is better if the transcriber is a skilled typist and if possible it is also better to use the same person regularly so that their growing experience will make it easier. It can be helpful if the interviewer listens to the tape before it is typed so that they can help the typist where necessary.

The act of transcribing the tapes may itself arouse strong feelings and care should be taken to offer support to the person typing the story when needed.

During transcription, any references to people or places should be removed to maintain confidentiality. However, references to services, such as CCU or A&E will be necessary to enable clinical teams to identify where improvements should be

made. Decisions also need to be made about what can be removed from the transcript that will make it easier to read but will not alter its sense or feel in anyway. eg non-critical pauses, expressions and passing references to things such as the weather etc.

It may also be necessary to add notes to explain the sense of a comment when it is not possible to detect this from the written words. (eg a comment that something was 'awful' when it was clear from the interviewee's inflection that it had actually been very pleasant).

Following transcription, it is essential that the document is kept secure to comply with the Data Protection Act 1998, as it may include references to people and places.

### ii. Preparing with clinical teams

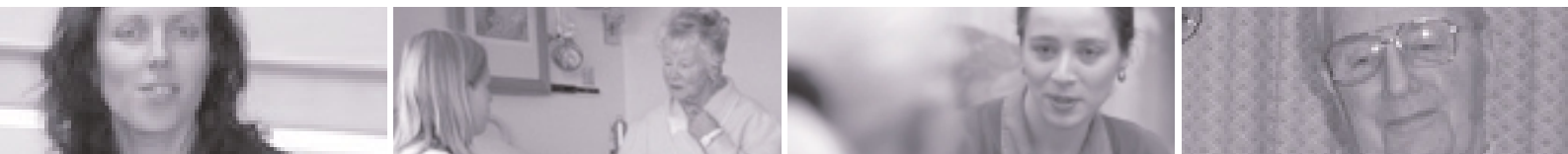
Any improvement activity will only be successful if it builds on the desire that staff and teams already have to provide the best care for their patients. Discovery Interviews are no different and have been most successful where teams have been involved from the outset. It is often useful for teams to test the methodology on themselves to increase their understanding

of the experience. It is also important for teams to plan arrangements for listening to stories and to agree improvements before the Discovery Interviews are undertaken.

Before beginning the process with a team it may be helpful to read a story from another site to help them understand the nature of the process in a non-threatening way and give them insight into how they can use Discovery Interviews to improve care.

Despite best planning and preparation teams just beginning to undertake Discovery Interviews can initially feel criticised and behave defensively when they listen to the stories. It takes time to become comfortable with the process.

Teams should be actively encouraged to consider the benefits of involving patients throughout the whole process and offered support to begin doing so.



### iii. Generating dialogue within teams

It is a key part of the Discovery Interview process that practice teams should hear the patient's or carer's story in their own words. The evidence is that by doing so they learn things that they would not do otherwise and this strong patient or carer focus generates feelings in listeners that are a powerful motivator for making changes that are an improvement. Attempting to extract themes and present these to teams out of the context of the story weakens their impact and may lead to a defensive reaction if they appear to be a list of criticisms. Even if a list of positive points is presented these tend to be glossed over and teams focus on the negatives. There is also a danger that the lists produced will be influenced by the prejudices of the analyst, or at least perceived to be so by team members.

#### Creating time for dialogue

Time must be planned for teams to hear the stories. The best way to create protected time for teams to listen to and discuss the stories must be agreed with them. Where this has been possible the time spent has usually been considered to be an investment of time rather than merely a burden.

Where this is not possible consideration should be given creating space within meetings that are already part of everyday practice. If stories are being integrated into another meeting it is crucial that time is allocated to allow serious discussion of the

story and to make decisions about next steps. For example it is not appropriate simply to tack them on at the end when participants are tired and already thinking about moving on to their next meeting.

#### Listening to stories across teams and Departments

Patients cross team boundaries and the same story will almost certainly be worth sharing across different teams. Holding joint meetings may well be the most effective way to achieve improvements that are related to connections between teams. It has become clear that the most powerful way to use stories is to arrange for staff from the different services to listen to them at the same time and act together upon what they learn about patients' and carers' needs by discussing them.

It may be helpful to discuss this part of the Discovery Interview process with other local teams who have already used them to improve the care they provide and who can offer insights into how they established effective ways to build them into their everyday practice.

Teams need time and experience to become comfortable with the process and when they first begin they are unlikely to be as comfortable as those undertaking the interviews. This is an important point to bear in mind. Learning from the first phase Discovery Interviews showed that a creative approach to sharing feedback was helpful. The box below lists ways that have been tried by other teams.

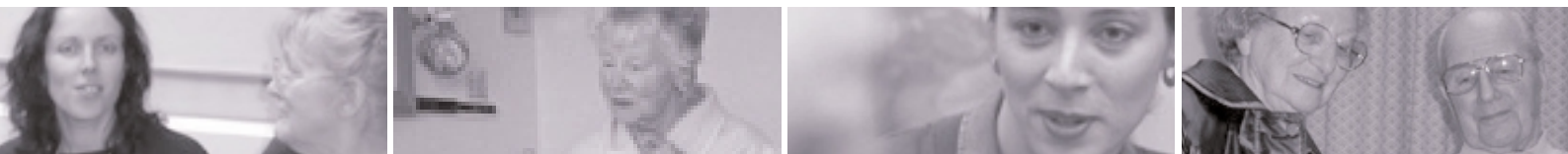
### Examples of teams who may need to listen to the same stories

#### Coronary Heart Disease

Accident & Emergency → CCU → Critical Care → Ward →  
Primary Care → Rehabilitation

#### Critical Care

Ambulance → Critical Care Unit → Ward → Primary Care →  
Rehabilitation



## Possible ways to share stories

- patient and carer transcripts read by a peer at group meetings;
- excerpts of transcripts recorded on audiotape and video by someone other than the patient or carer played back to groups sent a powerful message;
- reading stories at the end of ward reports helped access a broad variety of staff and mix of grades.

### Involving patients and carers in generating dialogue

It is increasingly accepted that involving service users in this process is good practice and will strengthen the relevance of the discussion. However this should not be the people whose transcripts are being heard. The best way to involve patients and carers will need to be determined locally and should itself involve them.

### Learning from the story

This will be more useful if the full team is involved and feedback is seen as an opportunity for inter-professional learning. It should be remembered that the team involves more than just the clinical staff and that people such as administrators, secretaries, receptionists and managers are key members who should be included. If team members believe that they can identify a patient from the story, even though it is anonymous, they are expected to behave in a professional manner and

pay respect to the promised anonymity without entering into personal discussion about the patient.

### Facilitation of meetings

Meetings are likely to need facilitation by someone not directly involved in the team. As well as possessing general facilitation skills of helping teams create constructive and purposeful dialogue, facilitators need to be familiar with the underlying principles of Discovery Interviews and their relationship with improvement methodology. It may well be possible to involve people who are Associates of the Modernisation Agency who will have gained insight and skills through their work with the Agency.

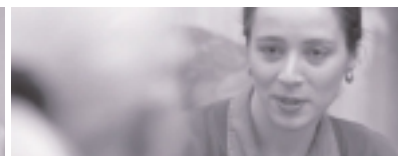
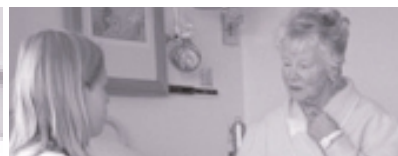
Initial plans must include steps to ensure that stories are used to generate improvements in practice. It does not require many stories to identify improvement opportunities although not all are as rich as each other.

Once the story has been heard by the team it is important that there is an opportunity to reflect on what has been learned and decide how and where improvements may be made to the way they meet their patients' and carers' needs. As many team members as possible should be involved throughout the improvement process. Those not directly involved should be kept informed and have the opportunity to make comment.

## iv. Identifying needs

One inherent danger is that the powerful effect of stories may create a desire in staff to improve by looking for quick fixes. Early process improvements are encouraging but it is also important to look deeper and see if patient and carer needs can be identified that can be better met by the team.

Teams should be encouraged to discuss what they learn about patients' and carers' needs from hearing the stories in order to establish priorities for testing out changes that may lead to improvements. This is not an easy task. An outline process is described in the box on page 30 that is based upon the Critical Care patient's story on page 29. It begins with the identification of key issues and processes that the team feels need improving and then moves to trying to understand the underlying needs. It is easier to begin with real issues and then move to the more abstract concept of 'needs' than to begin with needs identification itself.

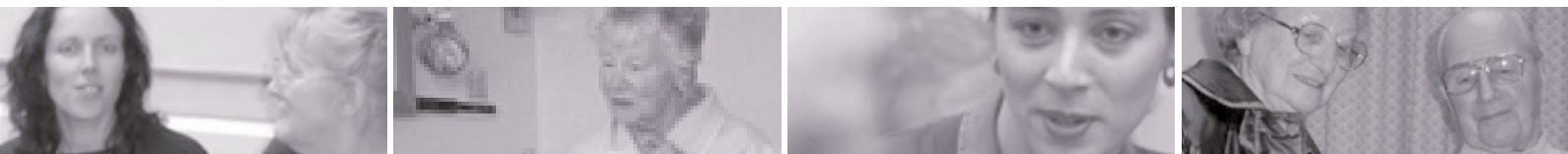


When I woke up in the Intensive Care Unit I believed it to be the following day, in fact it was ten days later. When waking I initially didn't know where I was, but guessed I was in hospital. As I had a tube in my throat and was unable to speak the nurse gave me a rattle, she asked if I was alright and explained that I was doing well, she told me that I was in hospital but didn't say which one.

This rattle was given to me to help get the nursing staff attention, when I looked at the rattle it said supplied by Eastbourne NHS Hospitals. I then suddenly thought why the hell am I in Eastbourne as this is no where near to where I live? I then started to panic thinking how did I get to Eastbourne and do my family know I am here.

I did manage to get the nurse's attention and was able after a while to ask the nurse which hospital was I in. The nurse informed me that the hospital was one in my local town, I felt relieved, panic over.

### **Critical care patient**



## A simple approach to identifying needs and improvement ideas by listening to stories

1. Encourage the team to have a short discussion about the importance of identifying needs to underpin improvement before they listen to the story in order to help them create an appropriate mindset. It is important that they bear in mind that professionals tend to see 'needs' in a very different way to patients and carers.
2. Once they have heard the story ask them to individually identify what they think are major issues or processes that arise and that need attention.
3. Ask them as a team to create a list of these issues, being careful not to write them as solutions.

(eg not as 'the problem is that we need more staff'; but rather along the lines of "this person experienced high anxiety when given the rattle after he recovered consciousness in the ITU").

4. Ask them to choose one issue and consider it further. They could use the "five whys?" to dig deeper; eg keep asking "why does it happen?", "why did this person feel like this?", etc, until there is no further sensible answer. This may not take as many as "five whys?"

(eg "because the rattle had the wrong hospital name on it and this made him anxious about where he was and whether his family knew").

Their answer at this stage should reflect a closer relation to needs than the initially identified issue/process did and will identify areas where changes may well help them meet needs better.

(eg "his underlying need to know where he was, what day it was and whether his family knew about his condition. A change idea that is relevant to these needs would be to design a way to make this information clearly apparent to patients as soon as they recover consciousness").

5. Once they have reached this point ask them to suggest actual changes that might lead to sustainable improvement.

(eg one change would be to use a different rattle but although this might improve patients' experience it would not on its own meet the underlying needs. This would be better done by placing an easily visible information board next to the patient's bed with a few key details that will help to orientate and reassure them).

6. At this stage the improvement methodology described in the Improvement Leaders' Guides published by the NHS Modernisation Agency can be used to turn the improvement idea into action and monitor its effectiveness.

[www.modern.nhs.uk/improvementguides](http://www.modern.nhs.uk/improvementguides)

A leader with sufficient seniority within the service needs to be identified to undertake day to day responsibility for establishing these opportunities and for making sure that appropriate action follows them.

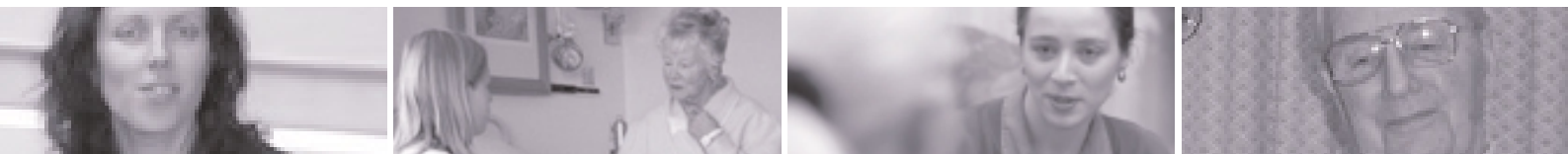
Stories have also been used more informally to generate discussion that will influence practice. The way that this is done can have powerful effects. For example a Consultant Clinician read stories to medical staff in training and encouraged them to reflect on what they learned and what they needed to change as a result.

## v. Creating Improvements

### Choosing improvements

Much is learned from stories that confirms and values current practice. It is important that these aspects are celebrated and messages passed on to the appropriate people so that the 'good news' is spread.

Identifying needs by using an approach such as the Five Why's illustrated previously will allow teams to create a list of changes to their practice that will help them meet their patients' and carers' needs better. It is also helpful if they have some simple criteria in mind when deciding where best to devote their time and energy. See the following box for some criteria that others have found useful previously.



## A guide to choosing changes

- important to patients' and carers needs and to staff;
- linked to key service goals if possible;
- high volume/high leverage/high cost areas;
- manageable and organisationally realistic;
- simple to measure;
- as early in the patient's journey as possible.

It may also be helpful to balance what has been learned from the interview with data from other sources. eg other surveys, audit results, complaints etc. This is sometimes known as 'triangulation' and can help the team to feel more confident about ways forward when it is not immediately clear from the Discovery Interview story.

There are a number of different types of response a team, or its members, may make after hearing a story. These are described in the box below.

### Different types of response a team may make after hearing a story:

- a change that is so small and obvious that it can be immediately implemented;
- a change that requires more attention by the team providing care and for which using the 'Building Knowledge for Improvement' Nolan framework as a guide will enhance the chances of learning and success;
- further investigation of a specific question or an idea that might impact on other services before any change is made.

Additionally individual members of the team may become aware of aspects of care that, although not appropriate for a specific improvement project will, if remembered when treating individual patients or relating to their carers, make a significant improvement to their care. These may be additional or cultural factors and once identified should be explicitly discussed at team meetings and monitored by regular discussions to check their impact on practice.

When making their decisions about what action to take teams must be sure that changes will add benefit to patients and carers and that there is no obvious risk. Using the PDSA method of implementation referred to in Section Two will itself contribute to achieving both these aims. On occasion, an issue may be mentioned by a single patient or carer which, although only highlighted once, is of sufficient importance or concern to be taken forward.

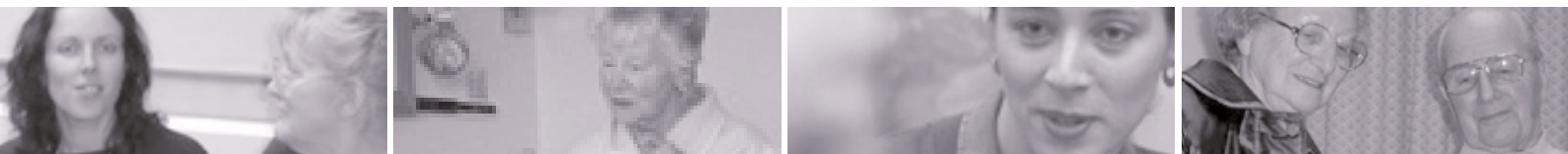
## vi. Feeding back outcomes

### Feeding back outcomes to patients and carers

It is critically important that patients and carers receive feedback that will confirm that good use has been made of the time they spent giving their story. However it should be explained to them that it will not usually be possible to provide feedback about specific incidents that they may have described. Feedback will be in the form of an account of how the clinical team involved has used a number of stories to make a range of improvements.

So far feedback has been offered in the form of newsletters or by inviting people who have been interviewed to join patients' group meetings where improvements that have been derived from listening to stories are discussed.

Making a firm commitment to do this will enhance the importance of the process as well as serve as a reminder that if they do not produce benefits Discovery Interviews



are a waste of everybody's time. Discovery Interviews without follow up have been described as merely voyeurism.

Providing feedback will also increase the chances of the people involved, and others, being prepared to participate in the future.

#### Feeding back to the wider organisation

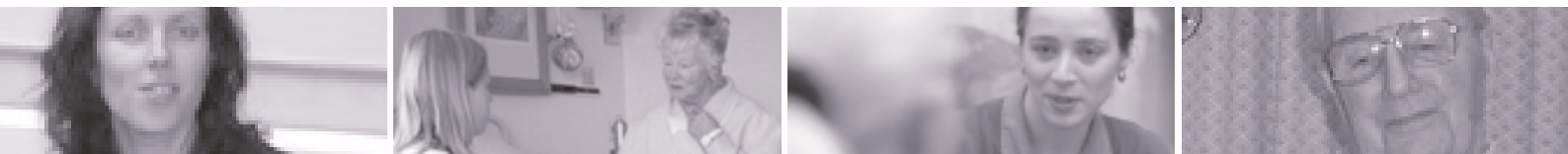
Learning from the early stories demonstrated that they have lessons for the wider organisation as well as for the clinical teams directly involved in the story tellers' care. For example hearing directly about the impact of car parking problems on particular patients' or carers' lives, in their own words, is likely to have a greater impact than yet another survey confirming that it remains a problem.

Previous work with Discovery Interviews resulted in stories being listened to by Clinical Audit Committees as well as clinical teams. These Committees were then able to identify who else in the Trust needed to be involved. For example specific stories identified the need for further audits or for staff from support or portering services to listen to them as well. They may also be useful to generate dialogue at regular clinical audit meetings at Directorate level if this is the mechanism used by the Trust.

One very important aspect to take into account is the need, described earlier, for stories to be listened to by all the departments and services that the patient's journey crossed.

### Some possible routes for feeding back in local areas

- Local Health Improvement Programmes;
- Specialist lead in Primary Care Organisation;
- GP Continuing Professional Education Forum;
- Practice Nurse Forum;
- Patient and public involvement feedback into clinical governance frameworks;
- Patient Advice & Liaison Service (PALS);
- Clinical Effectiveness & Quality Groups;
- Local Modernisation Projects.



# section five

## Maintaining local and national learning

### i. Keeping a reflective Learning Journal

Discovery interviews are relatively new and it is crucial that their use continues to be informed by experience. People who undertake them are therefore encouraged to maintain an ongoing Learning Journal. Entries should be made after each interview visit and used to inform reflection at a later date. They will also help to focus discussion at peer support meetings. Proforma's of two different Journals are included in the Resource File as a guide although it is accepted that interviewers may use formats with which they are already familiar and with which they feel comfortable.

### ii. Maintaining a record of benefits ascribed to Discovery Interviews

Records of the benefits resulting from Discovery Interviews must be maintained to allow checks of value to be made and to provide learning for others. With regard to the latter keeping a record of things that did not happen as expected will also provide useful learning. These may include changes that did not work or situations where teams found it difficult to cope with the process.

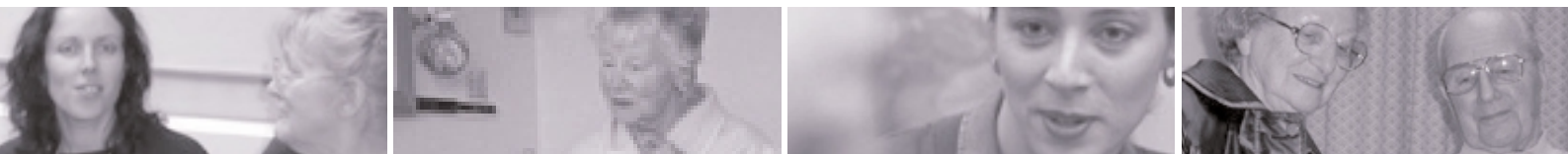
Services need to maintain records of progress to include:

- how many Discovery Interviews have been undertaken;
- how many changes have been tested as a direct result of the Discovery Interviews;
- what improvements have been achieved.

It is planned to establish a national database to record lessons learnt.

### iii. Local and national interviewer support meetings

Local and national support meetings, organised by the Modernisation Agency, are held on a regular basis for all those involved in conducting interviews. They provide a forum for peer support, constructive challenge and to gather learning about the process. Anonymised transcripts may be used to help interviewers reflect on practice. Interviewers will be expected to attend such meetings in order to share their experiences and learn from each other and which will also serve the purpose of updating their skills and knowledge. The learning from these meetings will be distilled and used to update this Guide on an annual basis.



#### iv. The role of the NHS Modernisation Agency in reviewing and supporting

The Modernisation Agency will continue to provide a national lead until systems are in place to take this over locally. It is planned for this to take place over the next eighteen months.

Current responsibilities to be devolved include:

- Training interviewers;
- Arranging support meetings;
- Review of interviewers;
- Quality assurance of the process locally;
- Support teams to obtain LREC approval;
- Providing local training.

Most of the experience in using Discovery Interviews to date is in CHD, Critical Care and to a lesser extent other areas of acute care. Pilots are being planned in new areas especially with vulnerable patient groups' eg mental health and non English speaking patients'.

The future role of the Modernisation Agency will change to:

- Central resource;
- Maintain a database of improvements;
- Maintain a database of learning;
- Annual review of the Guide;
- Lead and support the use of the DI process with other PPI activities;
- Publish and present work.



Organisations Address

*Sample letter of explanation to patients/carers*

Dear insert patients name - this should be done by the health care professional giving out this letter

Improving \*\*\*\*\* services

Would you like to help us and other patients in the future by talking to someone about what it is like to be a person with a \*\*\*\*\* condition or as their carer? I am writing to you to ask if you would be prepared to help in a small survey we are undertaking to improve local \*\*\*\*\* services.

Your local health services wish to improve the way in which people with a \*\*\* condition, and their families, are cared for. We would like to hear your story and experience of living with your \*\*\*\* condition. We would also like to learn from the experiences of your main carer if you have one. A carer may be a husband or wife, daughter or son, a relative or a friend or companion who may or may not live with you. We have found that hearing the person's story, face to face has helped local health staff to improve services for people with a \*\*\*\*\* condition and their families.

Taking part would mean:

- a trained interviewer listening to your experience;
- your story being audio taped;
- local health care staff listening to your story (your name and any details that may identify you will be removed before the tape is shared);
- helping local health care staff understand how to make improvements based on what they hear.

The attached Patient Information Leaflet gives you more details about what to expect. Whether you decide to take part or not will not affect your individual treatment or care now or in the future.

If you would like to help us by taking part please complete the attached reply slip using the pre paid envelope, and we will then contact you.

Thank you for considering taking part

Yours sincerely

# appendix one

continued

Enter code:

## Reply Form

Name .....

Telephone Number .....  
or  
Address .....

.....

***Please tick the correct box***

I am interested in talking to someone about my experience

I am a patient

I am the patient's carer (husband or wife, daughter or son,  
a relative or a friend or companion)

***Please return to:***

Insert appropriate contact details

Tel:

## Patient information sheet

### IMPROVING LOCAL \*\*\*\*\* SERVICES

You are being invited to take part in a survey, which we are doing as part of a national initiative to improve \*\*\*\*\* services. Before you decide, it is important for you to understand why the survey is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### What is the purpose of the survey?

We wish to interview adult patients and their carers (i.e. a spouse or partner, close family member or companion) who are being investigated or receiving treatment for \*\*\*\*\*. The purpose of the work is to hear patients and carers accounts of their experience, in their own words, by telling their story. We refer to these stories as 'discovery interviews'. This is then read out to local health care professionals involved in caring for patients with \*\*\*\*\*. This has been found to be a very useful way in helping health care professionals understand patients and carers needs and identify areas to improve the service.

### Why have I been chosen?

A health care professional involved in your care, such as a GP or Specialist Nurse has selected you as you have recently received care or treatment for your condition. We will be interviewing approximately twenty patients and carers in the next few months as a part of this survey. .

### Do I have to take part?

You do not have to take part if you do not wish to do so. If you do decide to take part you will be asked to sign a form giving your agreement to take part in the survey. If you decide to take part you are still free to withdraw at any time and without giving a reason. This includes your right to stop part way through the interview. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Please do not reply to us if you have made, or are planning to make, a complaint about local \*\*\*\*\* services. We will be interviewing patients or carers who have made a complaint, but only after the complaint process has been completed.

continued >>>

## What do I have to do?

If you are interested in taking part, return the reply slip attached to the letter. You will then be contacted a few days later to arrange a date and place convenient to you for an interview. Any questions you may have can be discussed with the caller. At the interview, you will be asked to discuss your experiences of living with a \*\*\*\*\* condition. A trained interviewer will ask you what has happened to you, right from the time when you first thought that you might have a \*\*\*\*\* problem. It is important that you tell this in your own words, as if you were telling the interviewer your story. We would also like to hear your carer's experiences. We have found from previous surveys that it is better to hold the two discussions separately. The interviewer will not be someone you know or who has been involved in your treatment or care. You can choose where you wish the interview to take place; this may be in your home, your GP surgery or at the hospital. Each interview should take no more than one hour and we will tailor it to the amount of time you are able to give.

## What happens to the information I give at the interview?

The interview will be tape recorded so that the interviewer can listen to you without the need to take notes. Following the interview the story is typed up from the tape. Your personal details, any names of people or places mentioned will remain confidential, as they will not be included in the written story. The story is then read out to local health care professionals caring for patients with \*\*\*\*\*disease. We have found that listening to these stories helps health care professionals to understand patients and carers needs and to make improvements to \*\*\*\*\* services. The written information will be stored securely and only authorised staff will have access to the information.

If something is heard that suggests unacceptable or unsafe practice, the interviewer will be required to report this matter locally. In the unlikely situation of this happening, the interviewer will discuss this with you and will explain what will happen. This is designed to safeguard patients and all NHS staff are required to report anything they hear that might suggest poor practice.

## What happens to the tape recording of the interview?

Some of the tapes will be used to help us to train interviewers and maintain high standards during the survey. The people listening to the tapes for training or quality control purposes are subject to NHS confidentiality policies.

continued >>>

## What will happen to the results of the survey?

Local health care professionals will use the stories to help them improve their care and services. The improvements will be published in a newsletter, which will be made available to you.

## Who is organising and funding the survey?

The NHS Modernisation Agency, which forms a part of the Department of Health, provides funding and training to help your local health care services organise the survey. This may change with future applications.

## Who has approved the survey?

This survey study has undergone a rigorous process and has been approved by an NHS Multi- Centre Research Ethics Committee, who are authorised to give approval to patient surveys.

## Contact for further information

Name and contact details of local contact

**Thank you for reading this information leaflet and considering taking part.**

### Consent Form

#### Improving Local \*\*\*\*\* Services

Your local health services are working to improve services for patients with \*\*\*\*\* disease. As part of this programme, we wish to hear from patients and their carers about their experiences as a person with \*\*\*\*\*disease - about how you felt, the things that happened to you and your family and the things that are most important to you. This will involve you telling your story to a trained interviewer, at a place of your choosing. This will be tape recorded and is what we refer to as a discovery interview.

**Full details are contained in the Patient Information Sheet - 'Improving Local \*\*\*\*\* Services'**

Anything you tell us will be treated anonymously - your name will not be passed on to anyone else and any records we keep of our discussions will not have your name recorded on them.

The experiences that you describe will be used for two purposes: -

1. To help us learn about what is important to patients and carers.
2. To help us improve the service to patients and support for carers.

There is no pressure on you to take part in this process - if at any time (including whilst having the discussion) you wish to stop then you simply need to say so.

For our records - to show that you understand the work we are doing and to show if you are happy to take part - please delete the statement as appropriate below: -

**Patient:** I do / do not wish to take part in a discovery interview

**Carer:** I do / do not wish to take part in a discovery interview

Signed: .....

Name: .....

Date: .....

Daytime telephone number: .....

## Acknowledgements:

The preparation of this guide has been a truly collaborative process. Many people have given freely of their time to contribute their experience of using Discovery Interviews or their knowledge of patient involvement. We are really grateful to them. The danger in producing a list of such people is that some may be overlooked. If we have omitted your name from the list below please accept our apologies. Your help was appreciated and influential, it is merely our administrative systems that are at fault.

John Bateson, Linda Binder, Nilam Bola, Ben Bridgewater, Ceri Brown, Katie Burrall, Jonathan Carver, Cathy Cook, Jane Druce, Gillian Fletcher, Wendy Gray, Julie Harris, Kath Harris, Carolyn Heyes, Patrick Hill, Clair Jones, Dawn Leese, Vanessa Lodge, Trish Lynn, Sheelagh Machin, Fiona Mackie, Sandie Manser, Kate Mudge, Jeff Phillips, Daphne Roach, Jason Salter, Sarah Squire, Helen Tuck, Karen Walsh, Jennifer Walker, John Wells, Peter Wilcock, Joanna Williams, Mel Wright.

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[www.modern.nhs.uk/chd](http://www.modern.nhs.uk/chd)

For further information contact Sheelagh Machin

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