



NHS Improvement



Learning from patient and carer experience

A guide to using Discovery Interviews to improve care

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www.improvement.nhs.uk/discoveryinterviews



section one

Introduction and overview

Introduction to the Guide

This document provides information and guidance about 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 they can test out in their services.

Staff have given positive feedback 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. They have found stories very useful to keep in mind even though it may not lead directly to specific improvements in services.

The information in this guide reflects the pioneering work of the Coronary Heart Disease Collaborative and Critical Care programmes from 2000 to 2003. Following successful testing the Discovery Interview approach is now used across a number of specialties in the UK health system. An evaluation in 2005 identified recommendations included in section 5.

The contents of the guide are divided into sections representing major elements of the Discovery Interview process, from thinking about carrying them out to planning and monitoring improvements that arise from their use. The diagram on page 5 outlines these elements and shows tasks that must be carried out to make the process go well. Advice for carrying out these tasks is included in the appropriate section of the guide. We have also included links to detailed guidance already available from other sources.

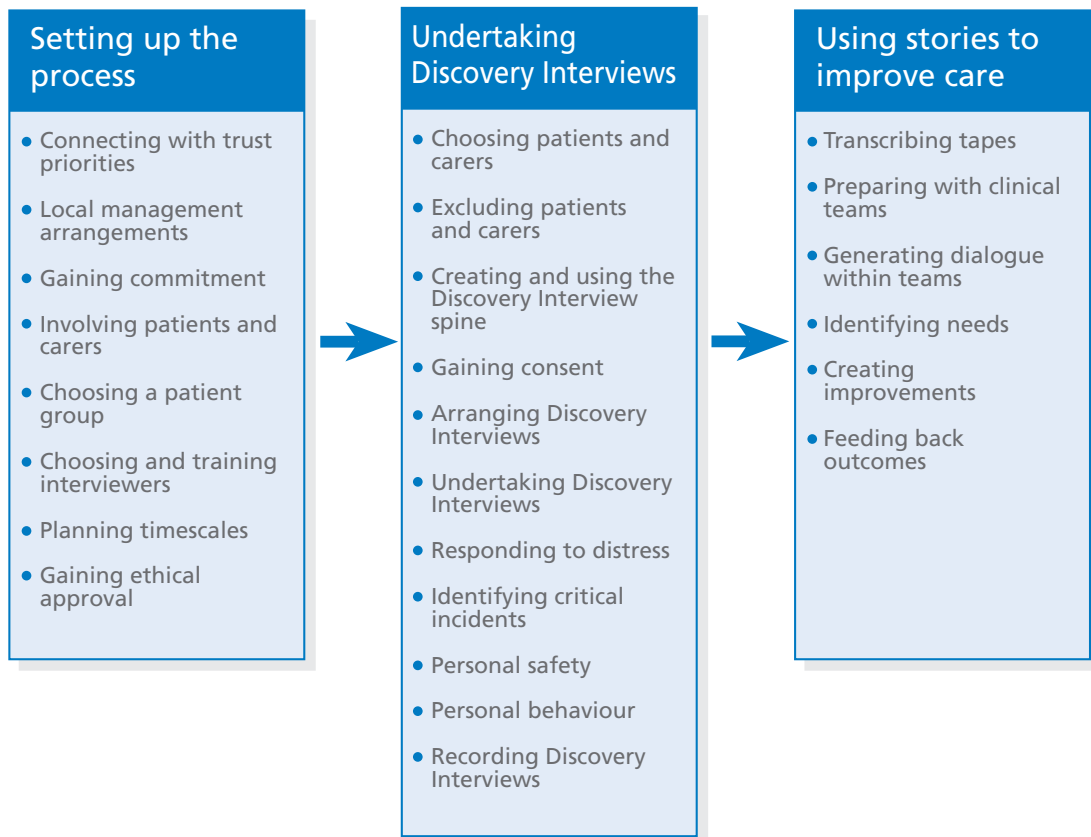


Fig 1: **Outline of the Discovery Interview process for improving care**



The importance of learning from patient and carer experience

Broadly speaking the collaborative goals were:

“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 Collaborative and Critical Care Programme provided a unique opportunity to explore one of the most important challenges in healthcare today. That is: how can we learn directly from our patients and their carers about ways to improve the services we provide to better meet their needs? This is one of the underpinning principles of continuous quality improvement: 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.

The early work of the 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 “Toolkit for learning from patient and carer experiences”. The Toolkit was subsequently used by the Critical Care Programme which has provided further rich experience. Other national improvement programmes also adopted the Discovery Interview approach. These included Action on ENT and Orthopaedics; Access Booking and Choice Programme; Ideal Design of Emergency Access (IDEA); Cancer Services Collaborative: Wheelchair Collaborative and Older Persons Collaborative. There is now a substantial amount of experience of their use in practice.

The experience outlined above has been brought together to produce this document. We foresee that the learning from experience of using Discovery Interviews will be a continuous process and arrangements to support this are suggested on pages 31, 33 and 34, of this guide. We also hope in the future to use continuing experience to keep the guide up to date.

Using the Discovery Interview process to improve care

The CHD Collaborative and Critical Care Programme have built upon innovative work to explore ways to learn what it is like to be a person or a carer of a person, rather than a patient, with a particular illness or condition. The aim is to explore and learn from, the impact of 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 well-being.

One underlying principle is that the area where patients and carers understand best is the impact of their illness or condition upon their own lives. It is more 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. Using their own clinical and professional knowledge and experience to interpret what they hear from patients and carers, service teams are able to create better or new ways of meeting patients’ and carers’ needs.

Opportunities were therefore created for patients and carers to provide information unconstrained 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, which triggers significant memories and thoughts. This provides 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 which is why they are referred to as “Discovery Interview”.

The essence of the 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.

Using Discovery Interviews with staff

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

A small amount of pilot work has been carried out using Discovery Interviews with staff by the Retention and Recruitment Initiative. 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 they may be met.

Not quantity but quality

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.

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. It is the core business of the NHS Improvement.

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 has shown that inter-professional clinical improvement teams 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 Figure 2 on page 8). It draws on an action learning approach which is fundamental both to CQI and to the use of Discovery Interviews. The Nolan framework allows for small changes to be quickly implemented and tested. Feedback measures are built into each small change and used to plan next steps

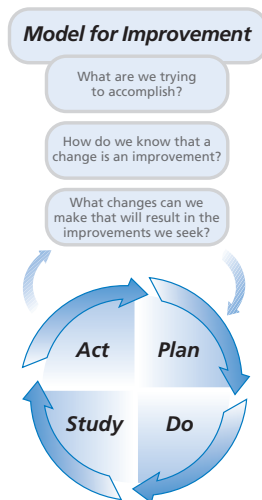


Fig 2: Building Knowledge for Improvement framework Reference: Langley G, Nolan K, Nolan T, Norman C, Provost L, (1996), *The improvement guide: a practical approach to enhancing organisational performance*, Jossey Bass Publishers, San Francisco

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 improvement ideas on a small scale before introducing the change on a wider scale. By building on the learning from these 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 different people are involved in trying something out on a small scale before implementation.

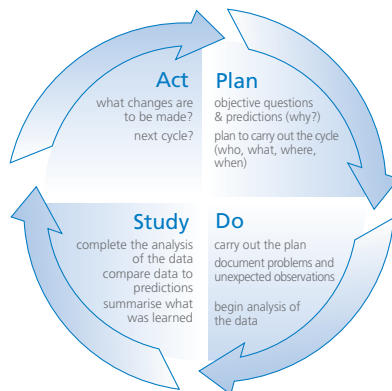


Fig 3: The PDSA cycle to test a change idea (©IHI)

This model of learning for improvement underpins the work of programmes across the NHS. This model of learning for improvement underpins the work of improvement programmes across the NHS.

Within the context of Discovery Interviews, the aim is to generate improvement activities (such as PDSA cycles), that are inspired by hearing patients' and carers' stories. When making 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 NHS Institute for Innovation and Improvement, Improvement Leaders' Guides published in 2005. See www.institute.nhs.uk for more information.

An illustration of using the model for improvement can be seen in Figure 4 on page 9.



Case study of issues identified from Discovery Interview: identifying and providing support

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 while patients often felt abandoned during these early weeks.

Outcome:

A cardiac 'drop-in' clinic is now a regular weekly event, hosted by a British Heart Foundation Cardiac liaison nurse. Patients together with their informal carers, lead sessions either independently or in groups. They are supported by the nurse who offers advice, information and support on living with their cardiac problem or issues related to readjustment and 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 also available at the clinic.

5 PDSA cycles to:

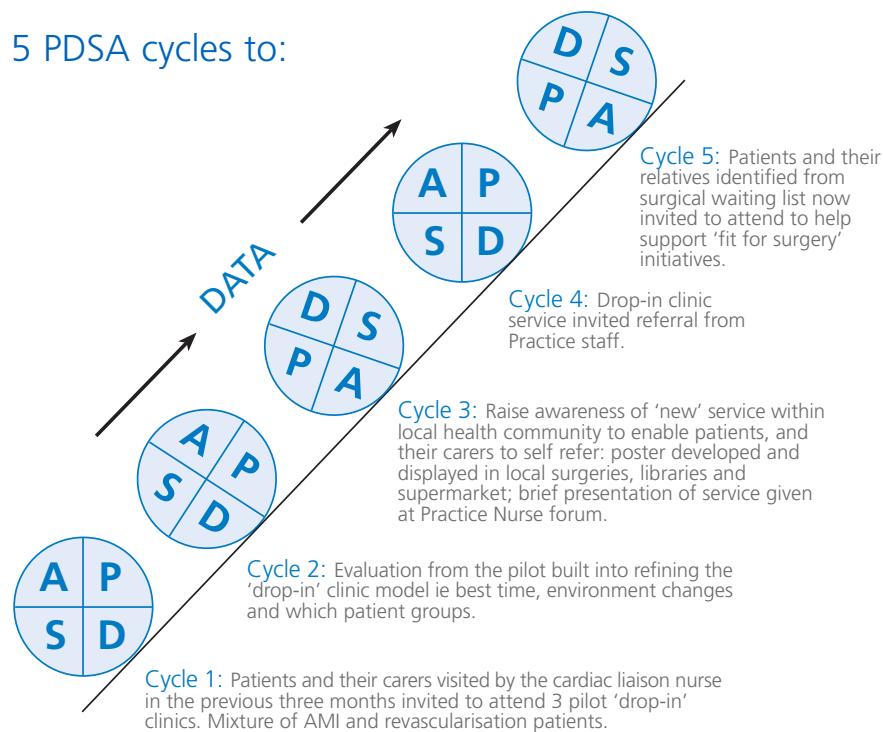


Fig 4: **Testing process:** To pilot a health centre based 'drop in' clinic for patients and their carers during the early period post discharge from hospital providing a forum in which individuals may access information, advice and support.



Further reading

If you would like to read more about aspects of using patient narratives there is a list of useful references at www.improvement.nhs.uk/discoveryinterviews

Touchstones for Discovery Interviews

When people use Discovery Interviews well to improve care they:

- Ensure that executive level members, senior managers and clinicians in health care organisations are aware and supportive. Necessary connections across services and departments are made so that the stories are used to improve care across the whole patient's journey.
- 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 at www.institute.nhs.uk
- Make sure that members of the teams involved have expressed a desire to use them to improve care. They have been well prepared and protected time is planned.
- 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.
- Appropriately identify and inform patients and carers about their purpose and implications and obtain written consent to involve them.
- Arrange the interview at a time and in a venue chosen by the patient and carer, usually in their own home.
- Actively use the stories to generate demonstrable improvements in the way patients' and carers' needs are met.
- 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

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 therefore needs 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. Figure 5 illustrates three broad modes of participation: informing, consulting and partnership.

The Discovery Interview focus fits into the shaded elements in the model in Figure 5, 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			

Figure 5

Discovery Interviews should not be established as stand alone activities. They should be part of local service improvement plans and quality improvement activities, fitting into wider organisational strategy and priorities. Learning 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. It is available at www.institute.nhs.uk

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'. This means 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.



Local management arrangements

As the use of Discovery Interviews develops, it is crucial to involve senior staff in healthcare organisations who have appropriate responsibilities. Where appropriate, the commitment of trust chief executives, medical directors and clinical and nursing directors must be gained.

Part of this depends on building them into an organisations strategy to ensure that support is made available as part of key business priorities and that the Discovery Interview process fits into the organisation's patient participation strategy. Within a health community a range of health and social care organisations are likely to be involved.

On page 11 we read that 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.
Building into the clinical governance framework.
Gaining senior management and clinical commitment.
- 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.

Gaining commitment within the service

Discovery Interviews should always be carried out 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. A small number of stories are held centrally and available for this purpose.

It is important to gain the commitment of all clinicians if teams approach their patients and they should have the implications for them and their patients explained. Clinicians have an important role in helping to choose the group of people from who interviewees will be randomly selected. They 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 this guide on page 26.



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.

You can find more detailed guidance about how to involve patients and carers in service improvement in the “Improvement Leader’s Guide to Involving Patients and Carers” at: www.institute.nhs.uk

Choosing a patient group

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 men and women, who are typical rather than an exact representative sample.

Finding out what other patient involvement activity is underway is

important in order to avoid patient involvement fatigue. In other words, the team needs to know if more activity is happening 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.

Groups requiring special consideration: the whole health community approach

Non-English speaking communities

Teams may need to make special arrangements for people from ethnic minorities. Non-English speakers who use services 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 these people and the best ways to make contact. Additional resources are also likely to be needed and it will require separate ethical approval.

For more information on applying the Discovery Interview approach with non English speaking communities visit www.improvement.nhs.uk/discoveryinterviews where you can access the report on piloting using Discovery Interviews with Punjabi speaking patients.

People with specific difficulties

People with particular difficulties such as mental health, illiteracy, blindness, deafness and learning disabilities also need special arrangements. Work is currently being planned to test ways to use Discovery Interviews with people who are experiencing difficulties with their mental health.

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 carry out, and by who. As a rule of thumb three or four interviews a quarter per interviewer seems an appropriate number to maintain skills. The availability of peer review and support meetings will also play an important part in maintaining skills as explained on page 33. It is important to the success of the Discovery Interview process that the people carrying them out them are committed.



Local managers need to be involved in identifying prospective interviewers and the criteria for selecting interviewers can be found in the blue box below.

Criteria for selecting interviewers

For a person to be considered as an interviewer, prior to undergoing training and assessment, they must have had experience in at least one of the following:

- A role involving front line contact with patients.
- Qualitative research.
- Working with patients/relatives in connection with the NHS Complaints Processes.
- Other relevant roles such as Citizens Advice Bureau, advocacy.
- Demonstrable experience of dealing with patients and their carers in a one-to-one environment.

Ideally the interviewer will be employed in the local health community to build capability embedding the process within the organisation. Suitable interviewers may come from the following backgrounds:

- PALS
- Audit departments
- Health promotion
- Project management
- Clinical background
- Advocacy services
- Local authority
- Voluntary sector

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 process which involves questioning. 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 informs 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: They are:

- 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 they are interviewing.

Key issues in undertaking Discovery Interviews

- Training in listening to patient and carer stories.
- Careful preparation by the interviewer.
- Ensuring interviewers are familiar with the relevant patient pathways.
- Awareness of important aspects of the particular service whose patients are being listened to.

One of the conditions for meeting ethical approval is that anybody wishing to conduct a Discovery Interview must have attended a training workshop and demonstrated in practice that they have the necessary skills.



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 satisfy themselves that all those involved match the skills criteria outlined above.

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.

Every new prospective Discovery Interviewer will be required to:

- Meet the requirements of the person specification.
- Attend a training session.

All trained interviewers will:

- 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 peer review and support meetings.

As this work develops, 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

Experience of interview work has shown the importance of supporting interviewers. This is 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. For more details, turn to page 33.

Peer review and support meetings

Local interviewer peer review and support meetings are held in different parts of the country. All those involved in conducting interviews can meet on a regular basis to provide peer support and challenge in the process. For more details, turn to page 33. Anonymous transcripts may be used at these meetings to help interviewers reflect on practice.

Planning the timescale for interviews

a. Lead-in times

The time it takes 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.

Gaining ethical approval

It is essential to gain ethical approval for carrying out 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 CHD Collaborative and Critical Care Programme 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. The organisation research and development leads and NHS managers must be consulted before Discovery Interviews take place in order to comply with the conditions set out by the LREC.

In November 2005 the North West Multi Research Ethics Committee gave approval for the Discovery Interview approach to be considered a mainstream service improvement methodology in the NHS (MREC 02/8/57).

Equipment

Interviewers have used a variety of different audiocassette 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 a patient group has been identified and relevant service teams have agreed to participate, arrangements must be made to carry out the interviews and ensure that they are used to improve care. Figure 6 on page 18 shows a process map describing the key steps in achieving this. Sections three and four provide further guidance about implementation.

Choosing patients and carers to be interviewed

Identifying individuals

As teams must respect patient confidentiality, then it is not possible to approach healthcare organisations directly to 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 such as 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.
- Asking local GP surgeries, rehabilitation classes, follow-up and outpatient 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. Service teams initially identify appropriate patients and from this group, a process of randomisation must be agreed with the service teams to reduce the possibility of bias being introduced. It is important that teams maintain patient confidentiality.

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.

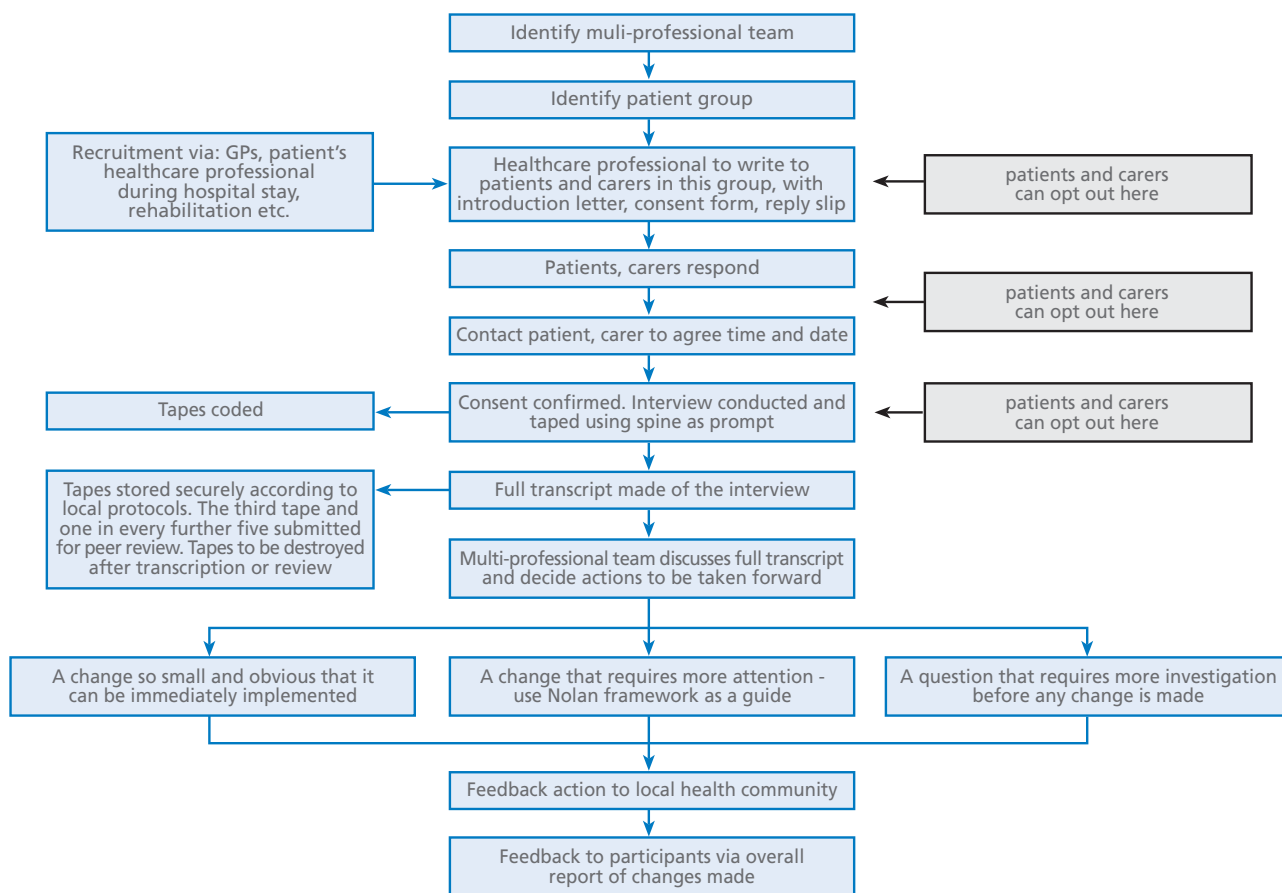


Fig 6: **The Discovery Interview process** (see sections three and four)



Using Discovery Interviews across patient pathways

Conducting interviews across the breadth of the patient's journey allows service 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 Heart Improvement teams 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 an 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 Heart Improvement Programme made efforts to obtain a reasonable spread of patients and carers from across stages of the illness journey. They also considered the recruitment of patients at different stages, across the care pathway, to emphasise different aspects of services.

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

- Cover the whole spectrum of the condition being considered. For example in CHD, this included different types of CHD, heart failure, angina, rehabilitation and surgery. For critical care it includes both elective and emergency patients.
- Interview both patients and carers and also include some patients who do not have carers. Teams may also consider interviewing close family members who are not direct carers.
- 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 are relevant to a particular service priority or to learn about a specific aspect of interest. Examples include, patients with long-term conditions, those receiving long-term care and those with progressive illnesses.

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 be excluded and reassured 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 until the complaint has been completed. 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, 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.

Creating and using the Discovery Interview spine

Creating a Discovery Interview spine

A standardised 'spine' is used to offer guidance to patients and carers while telling their story. It describes the key chronological stages of the patients' and carers' 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 service team about the whole journey of care within which they play different parts.

Generating a spine involves meeting with the team at an early stage before any interviews are carried out. It is also useful to work with teams to clarify the patient's journey as they understand it, for example, by using process mapping. This enables a spine to be developed to provide the structure for the interviews and also provide background knowledge for the

interviewers. More detailed information about process mapping is available at www.insitute.nhs.uk

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 spines used by the CHD Collaborative and Critical Care Programme and from a Whole Health Community pilot site are shown below.

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.

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.

Intermediate Care Spine

- What happened that meant you need extra help and support.
- Talking to someone about getting extra help and support.
- Deciding on the right help and support.
- Receiving help and support.
- Learning about other support.
- Learning to cope with the future.

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

Using the Discovery Interview spine

Patients and carers vary considerably in the way they talk during interviews. Some are quite focused and present their views in a structured way. Others are 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 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.



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. The cards can be turned over when an interviewee has finished with a particular step or if they have nothing to say.

Benefits of using the spine for the Discovery Interview process

- Helps to cover the whole journey of the illness or condition under consideration.
- Triggers significant memories and allows the patient/carers to tell their story in their own way and in their own words.
- Allows the patient/carers 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.

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

Interviewers should bear in mind that the more they ask questions the more the patient or carer may feel they have their own interests or agenda and may try to respond to what they assume these to be.

Gaining consent

A letter is sent by a clinician involved in the care of the patient or carer explaining what the interview intends to achieve and asking if they are prepared to take part. The letter explains there is no obligation to take part and their decision will not have any impact on current or future treatment. A patient information sheet must be sent with the letter, consent form and reply slip which gives more detailed information about the process. All correspondence needs approval of the organisation's research and development department and the Local Research Ethics Committee.

The letter should make it clear that the interview will be tape-recorded and later transcribed 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 also 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 and reply slip should provide space for a contact address and telephone number so that the interviewer can telephone the patient or carer to arrange a convenient time and venue. The patient letter 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. It is good practice to include a pre-paid envelope 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.

You can see examples of consent forms and letters for patients providing information about the nature and purpose of Discovery Interviews on pages 36-41.

Arranging Discovery Interviews

It is easy to underestimate the time you need to carry out interviews and find unfamiliar locations. Therefore, protected time for the interviews must be allocated. 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

Patients and carer should be interviewed separately if possible as this helps each to speak freely. Experience from phase one has shown that carers in particular may have things to say 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 patients' and carers' needs that are unlikely to have emerged during a joint interview about for example information and support. The carer may be husband or wife or partner, daughter or son, other relative, friend or companion or perhaps a neighbour.

Guidelines for setting up a contacts list

Southern Derbyshire whole health community pilot focused on intermediate care. They agreed with the relevant health professional to supply a shortened contact list. This helped to avoid confusing patient or carers about who to contact and provided more structured signposting. It was achieved by using a Patient Advice and Liaison Service (PALS) telephone number, email address and website address. PALS are able to find the most appropriate person to talk to and offer appropriate advice.

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, for example, significantly changed relationships with their partner. Therefore, 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.

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 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 opposite.



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 use of 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 to the interviewee with an explanation that although there will not be any feedback about their particular story, they will be told about benefits from the overall process. Feedback to patients has involved sending newsletters, publications in local media and through patient and carer groups.

Interviewers need to use words the interviewee will understand and be sensitive to their current health status. For example, 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

Explain to the interviewee they can withdraw, either before, or during the interview, if they wish. They also need to know there is no compunction to answer any questions they feel uncomfortable with. Make sure that you have obtained a signed consent form before the interview begins.

Preparation before a Discovery Interview

To prepare for the interview, it is helpful to give interviewers a short briefing about the patient, though not a detailed history. This is to ensure 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 which the interviewer may think are inappropriate to discuss during the interview or that they may not be able to answer at the time. It is good practice for each service involved 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. It is good practice to consult with contacts before including them within the directory. That way, they are prepared for calls from patients and carers who have participated in Discovery Interviews.

Responding to feelings and distress that may arise

The wellbeing of the person being interviewed should always take precedence over the interview itself. Telling their story may 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 becomes 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.



Follow-up phone call

Responding to colleagues' comments, the Critical Care Programme amended the Discovery Interview protocol to improve safeguards for the well-being of interviewees. A follow-up phone call is made, one week after the interview, to ask whether the interviewee is still concerned about any issues mentioned during the interview. The phone call is an opportunity to give advice, which will address any continuing concerns. This is now considered good practice and should be adopted by all teams using Discovery Interviews.

You can read guidelines to help interviewers respond constructively to distress in appendix 4 on page 42. Local interviewer peer review and support meetings, outlined on page 33, also offer opportunities for interviewers to explore coping with such situations during an interview and strengthen their ability to manage them.

Identifying critical incidents

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 is 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. This also emphasises the need for linkage with local organisation management structures as referred to in section 2 on page 12.

On occasion it may be the service 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 carers 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 appendix 5 on page 43.

Personal safety

Most interviews will be conducted in patients' or carers' homes, often without the interviewer having met them beforehand. This can pose a potential risk to the interviewer's personal safety. Interviewers must comply with their employing organisation's staff security policy or lone worker policy if one exists. Interviewers are trained in personal safety and they are encouraged to follow their lone worker policies from their employing organisations and complete a risk assessment form. 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.

Interviews should be scheduled during daytime and generally in office hours and the interviewer must leave details of the address where the interview is taking place and the anticipated time of return. The interviews must be pre-arranged by letter and telephone. A local manager or team leader who is supervising the process must record visits. This individual must also ensure that details of staff whereabouts are known.



Interviewers should be responsible for ensuring they have good directions and make appropriate travel arrangements. 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.

They should take a mobile phone with them and if possible, call a colleague to check-in before starting the interview. This allows the interviewers 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 of return.

Telling the patient or 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.

Personal behaviour

Visitors to other people's homes are representatives of their organisation. It is good practice to carry a form of identification which they can show on request if asked to do so. Name badge and hospital security passes are useful forms of identification. Name badges should omit the title of the interviewer's paid employment role. Interviewers should dress appropriately and professionally

and uniform should not be worn. As interviewers are invited guests, normal rules of courtesy apply and they should respect the wishes of their hosts.

There is also the possibility that accusations could be made against an 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 are minimised.

As the process is recorded on tape or mini-disc, this will help confirm facts and well maintained learning journals will also be helpful should questions arise later. No such incidents occurred during the piloting stages.

Recording the interviews

Confirming the use of recorders

Interviews should be audio recorded and the consent letter to the patient/carer should make this clear. If a patient or carer objects, the interview should not take place. The audio recording 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 recordings in this way.

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

Coding tapes

A separate code should be allocated to each interview, as the patient or carer's name is not recorded. If using minidisk or cassette tape this information should be written onto the disc or tape 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 or 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

Transcribing tapes

Transcribing tapes is time consuming and needs to be properly resourced. The time it takes depends on the typing expertise of the transcriber depending on their experience. Also important are their familiarity with the patient's journey and the terminology used. Some transcripts are typed by interviewers and some by local secretaries or other administrative staff.

Because of the nature of the task it helps if the transcriber is a skilled typist. If possible, it is better to use the same person regularly so that their growing experience will make the work easier. It can be helpful if the interviewer listens to the tape before it is typed so 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 the service 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. For example, non-critical pauses, expressions and passing references to things such as the weather.

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. For example, 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.

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 carried out.

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 teams 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.



Generating dialogue within teams

A key part of the Discovery Interview process is that practice teams hear a patient's or carer's story in their own words. The evidence is they learn things they would otherwise miss and the strong patient or carer focus generates feelings in listeners which are a powerful motivator for making changes that are an improvement.

Attempting to extract themes from stories 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

Teams must plan adequate time to hear and discuss 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 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.

Using governance meetings

At South Manchester University Hospitals Trust the Discovery Interview method has been anchored within clinical governance. Governance meetings have been used to share Discovery Interview stories with the multidisciplinary healthcare team. These protected time bimonthly meetings feature Discovery Interviews as a core agenda item. Having a regular place on the agenda has meant that there has been no shortage of areas ready with ideas for using Discovery Interviews, willing to act on the information they receive. Integrated care pathway and improving patient experience groups, as well as specific groups set up to view the Discovery Interview transcripts are just some of the issues raised by the process.

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 care. They may also offer insights into how to establish 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 carrying out 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. A diagram showing examples of teams who may need to listen to the same stories is on page 28.



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

Coronary Heart Disease

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

Critical Care

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

The box below lists ways that have been tried by other teams.

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. The British Heart Foundation are delivering 'Hearty Voices' training that helps to prepare the public for working with healthcare providers. More information can be found on their web site at www.bhf.org.uk

Learning from the story

The more involved the full team is, the more likely they are to learn from a story with feedback being seen as an opportunity to improve interprofessional knowledge. Remember, the team involves more than just the clinical staff and that people such as administrators, secretaries, receptionists and managers are key members who should also be included.

If team members are able to identify a patient from an anonymous story they are expected to behave in a professional manner. They must pay respect to the promised anonymity without entering into personal discussion about the patient. It is useful to remind the team at the start of any session where a story is being shared of their responsibility in respecting the interviewee's right to anonymity.

Facilitation of meetings

Meetings are likely to need facilitation by someone not directly involved in the team. As well as possessing general facilitation skills to help teams create constructive and purposeful dialogue, facilitators need to be familiar with the underlying principles of Discovery Interviews and their relationship with improvement methodology.

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 to find an opportunity to reflect on what has been learned and decide how and where to make improvements 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 comment.

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 which is based on 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. For example, 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. One method is to use "The Five Whys" to go deeper into the issues. You can, for example, keep asking "why does it happen?", "why did this person feel like this?" and so on until there is no further sensible answer. Of course, this may not take as many as five "whys".

Take this example: "Because the rattle had the wrong hospital name on it and this made him anxious about where he was and whether his family knew".

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

Like this: "His underlying need to know where he was, what day it was and whether his family knew about his condition." A change idea 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 the team to offer a change idea that might lead to sustainable improvement.

For example, using a different rattle might improve patients' experience, but it would not on its own meet underlying needs. Those can be achieved by placing an easily visible information board next to the patient's bed with a few key details to orientate and reassure them.

6. At this stage the improvement methodology described in the Improvement Leaders' Guides published by the NHS Institute for Innovation and Improvement can be used to turn the improvement idea into action and monitor its effectiveness. You can find them at: www.institute.nhs.uk

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

Stories have also been used more informally to generate discussion that influences 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.

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 "The Five Whys" illustrated previously allows teams to create a list of changes to their practice that helps them to meet their patients' and carers' needs better. It is also helpful if teams have some simple criteria in mind when deciding where best to devote their time and energy.



The box below illustrates some criteria others have found useful.

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 such as other surveys, audit results and complaints. 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. Using the 'Building Knowledge for Improvement' Nolan framework will enhance the chances of learning and success.
- Further investigation of a specific question or of 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 have a wider relevance. If remembered when treating individual patients or relating to their carers, they may make a significant improvement to their care. These may be attitudinal 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 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. Sometimes an issue may be mentioned by a single patient or carer which is of sufficient importance or concern to be taken forward, though only highlighted once.

Feeding back outcomes

Feeding back outcomes to patients and carers

It is critically important that patients and carers receive feedback to confirm that good use has been made of the time they spent giving their story. However, the person giving feedback must explain that it is not usually possible to talk about specific incidents they may have described. Feedback is usually 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 publication in local media. Sometimes interviewees are invited to join patients' group meetings where improvements 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, of being prepared to participate in the future.

Feeding back to the wider organisation

In our experience, lessons learnt from stories are of benefit for the wider organisation as well as for the service teams directly involved in the story tellers' care. Hearing about the impact, for example, of car parking problems on people's lives in their own words is likely to have a greater impact than yet another survey confirming 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 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 and quality groups.
- Local modernisation projects.



section five

Maintaining local learning

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 a learning journal. Entries should be made after each interview and used to inform reflection at a later date. This will help to focus discussion at peer review and support meetings. Interviewers should use formats for reflective practice with which they are already familiar and feel comfortable.

Maintaining a record of benefits ascribed to Discovery Interviews

Teams must maintain records of the benefits resulting from Discovery Interviews must be maintained for checks of value and to provide learning for others. A record of things that did not happen as expected also provides useful learning opportunities. This 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 which 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.

Local interviewer peer review and support meetings

Local peer review and support meetings should be held on a regular basis for all those involved in conducting interviews. These meetings should provide a forum for peer support, constructive challenge and gathering learning about the process. Anonymous transcripts may be used to help interviewers reflect on practice.

Further training can also be provided at these meetings to ensure that interviewers' skills are updated. 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.



National Learning

In December 2004 an evaluation of the Discovery Interview technique was carried out, looking at the way in which it has been implemented across the country in the 30 Coronary Heart Disease Collaborative sites and five Strategic Health Authority 'whole health community' pilots.

A set of recommendations were developed to support successful implementation of Discovery Interview learning across the country which included the following:

Implementing Discovery Interviews

- To achieve successful implementation, protected time for the Discovery Interview lead is required, along with an understanding that Discovery Interview roles are a significant part of other jobs, that sufficient effort is expended 'selling' the approach to people who are given a Discovery Interview role, that administrative support is acquired and that support is gained from senior clinicians and managers.
- Significant effort "selling" the approach to clinical teams can be beneficial: sharing 'out of date' stories or stories from other areas can have a stronger impact than simply describing the technique.

Gaining ethical approval

- Discovery Interview teams submitting an ethics application should seek to ensure that the application is led by a member of staff with experience in submitting such applications. Establishing good links with the local R&D committee may help to facilitate this process.
- In order to keep momentum and enable training in Discovery Interviewing to be put into practice while fresh, ethical and research approval should ideally be acquired before training takes place.

Recruiting and training discovery interviewers

- The number of trained Discovery Interviewers should be small within each Discovery Interview team, as this is likely to be more cost effective, make better use of the training, and help to ensure consistency in the team's approach. If desired, a small team can still be drawn from a diverse range of disciplines and departments.
- While training and support can ensure that the background of Discovery Interviewers does not adversely affect their ability to undertake successful Discovery Interviews, it is generally a good idea to aim for a team of Discovery Interviewers drawn from a diverse range of backgrounds and disciplines.

Recruiting patients and carers

- In order to maximise the response to invitations for patients and carers to participate, it is a good idea to have a named healthcare professional on the recruitment pack, so that the patient or carer is able to respond to a person with whom they are familiar.

Undertaking interviews

- Interviewees need to be clearly informed about the length of the interview before it begins, and the interviewers then need to actively manage the interviews to prevent them lasting too long. While direct questioning on a particular area of care runs contrary to the Discovery Interview methodology, information on particular service areas can be obtained by targeting recruitment on patients in a particular department or with a particular diagnosis as these patient and carer stories will be likely to include their experiences of the targeted subject.



Managing the process

- Discovery Interview teams should employ project planning techniques to help ensure that stories do not get 'out of date' before they are shared.
- It does not seem an effective use of time for interviewers to undertake transcription; ideally this should be done by the CHD administrator or contracted out to a professional transcriber or trust department with spare capacity.
- Setting up a database for monitoring the interviews that take place, the stories that are shared and the service improvements that are put in place as a result enables the effectiveness of Discovery Interview to be demonstrated.
- With the increasing prevalence and competitiveness of digital technology, new sites may wish to buy digital recorders to allow easier sharing of files across teams (ensuring that confidentiality is maintained). This also reduces tape costs and the need for physically secure storage.

Sharing stories

- Developing a "sharing stories pack" to support those sharing the stories at meetings can be beneficial: contents could include guidance on how best to run the session, answers to frequently asked questions, information on service improvements that have already been achieved and sheets for the reactions, decisions and changes made to be recorded.
- Stories can be shared with a range of aims in mind; to improve understanding of the care pathway the whole story should be shared, while sharing sections of stories would be appropriate to promote the Discovery Interview technique to forums not familiar with Discovery Interviews. It would also be acceptable to report key themes to the wider organisation as part of a reporting process.
- Producing a newsletter for patients and carers (or acquiring space in an existing newsletter) to report on service improvements made as a result of Discovery Interviews can help to ensure that patients and carers are aware of the effect that the work is having.
- It is important to be prepared to work with clinical teams in supporting them to implement service improvements. Leaving them to make the changes without support once the story has been shared may not be effective.

The role of NHS Improvement

NHS Improvement has continued to test, pilot and evaluate this methodology supporting dissemination of the learning across the wider NHS.

This includes:

- Training interviewers
- Review of interviewers
- Supporting quality assurance of the process locally
- Support teams to obtain LREC approval
- Local training
- Consultancy for specific projects.

Discovery Interviews are now being used in the following specialties:

- Mental Health
- Emergency Care
- Intermediate Care
- Stroke
- Critical Care
- Non English Speaking.

The role of the NHS Improvement is to:

- Act as a central resource.
- Review and update resources based on learning and where significant changes occur
- Lead and support the use of the Discovery Interview process with other Public and Patient Engagement activities
- Publish and present work.



Organisation's 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

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:



Organisation's Address

NHS Heart Improvement Programme Patient and carer 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 carers (i.e. a spouse or partner, close family member or companion) who are being investigated or receiving treatment for heart disease. 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 shared with people interested in improving ***** services. This has been found to be a very useful way to 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 Rehabilitation Nurse has selected you as you have recently received care or treatment for your heart condition. It is likely that we will be interviewing up to fifty patients and carers in your local area.

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 given this information sheet to keep and be asked to sign a consent form. 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 heart services. We will be interviewing patients or carers who have made a complaint, but only after the complaint process has been completed.

continued >>>

appendix two

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, a trained interviewer will ask you to discuss your experiences of living with a ***** condition or caring for someone with a ***** condition. It is important that you tell this in your own words, as if you were telling the interviewer your story. We have found from previous surveys that it is better to hold the patient and carer 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. Trainers will listen to some of the tapes to maintain high standards during the survey. The tapes will then be destroyed. The written story is then shared with people interested in improving health services. We have found that listening to these stories helps people to understand patients and carers needs and to make improvements to health services. The written story may also be used for educational and training purposes.

What happens if something goes wrong?

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. All NHS staff are required to report anything they hear that might suggest poor practice. If you are unhappy about anything that has happened during the interview you can contact the person whose details are given at the bottom of this sheet. They will discuss the matter with you and will take any appropriate action.

continued >>>

appendix two

continued

What will happen to the results of the survey?

People will use the stories to help improve healthcare at a local and national level. The improvements will be published in a number of ways for example newsletters, open meetings and guidance on improving health services.

Who is organising and funding the survey?

The NHS Heart Improvement Programme provides funding and training to help your local health care services organise the survey.

Who has approved the survey?

This survey study has undergone a rigorous process and has been approved by a national Multi- Centre Research Ethics Committee and your local Research and Ethics Committee.

Contact for further information

Name and contact details of local contact

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

Organisation's Address



Using the discovery interview technique to learn from patient and carer experiences and thereby inform future change of NHS services.

Consent Form

Improving Local ***** Services

Acknowledgements:

- 1 I confirm that I have read and understand the information sheet dated 2nd January 2004 for the above study and have had an opportunity to ask questions. ☐
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
- 3 I understand that sections of my medical notes may be looked at by responsible individuals from (organisation name) or from regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records. ☐
- 4 I agree to take part in the above study. ☐

Name of Patient/Carer	Date	Signature
<input type="text"/>	<input type="text"/>	<input type="text"/>

Name of person taking consent (If different from researcher)	Date	Signature
<input type="text"/>	<input type="text"/>	<input type="text"/>

Researcher	Date	Signature
<input type="text"/>	<input type="text"/>	<input type="text"/>

Day time telephone number	<input type="text"/>
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Managing distress during Discovery Interviews

There may be occasion when interviewees become upset and distressed during the course of an interview. It is important that the interviewer is prepared to manage such a situation appropriately.

The points listed below may help the interviewer to manage such a situation.

- Turn off the tape.
- Respond appropriately according to the circumstances or level of distress.
- Offer to restart when and if the interviewee is ready.
- Offer to finish or stop the interview.
- If the interviewee lives alone, ask the interviewee if they would like the interviewer to contact a relative or friend to be with them.
- The interviewer should offer appropriate contacts taken from the locally agreed contacts list. The contacts list will be prepared prior to starting any interviews and will be taken by the interviewer to each interview. This will contain local contact details of groups, organisations and key personnel who can offer different types of support.
- Leave the interviewee only when it is felt that the situation appears calmer.
- If there is on-going concern about the interviewee's distress, it would be appropriate to contact the interviewee's general practitioner following obtaining their permission.
- Make follow-up call within 24 hours to check if interviewee's concerns remain. Reiterate the suggested contact source if necessary.
- Document situation which should be attached to the consent form and held centrally.

Critical incident reporting

It is assumed that all interviewers will have followed the standard guidelines for explaining the purpose of the interview and confirming consent.

At the beginning of the interview the interviewer should also explain that s/he is required to report any concerns s/he may have about clinical negligence or misconduct that may arise from information obtained during the interview. This is likely to be a very rare occurrence.

A critical incident may be identified in one of two ways: a) during the course of the discovery interview itself, b) when the story is listened to by the clinical team.

If this occurs during the interview:

1. Turn off the tape.
2. Discuss with the patient or carer whether they want the incident reported or explain that it must be reported due to its potentially serious nature and it may not be possible to maintain anonymity.
3. Outline the process for doing this (use local trust reporting system).
4. If the incident is to be reported terminate the interview and follow the guidelines below.

If this occurs when the clinical team are hearing the story;

1. A member of the clinical team will contact the interviewer to make them aware of the issue.
2. Follow steps 2 and 3 above.
3. Follow the guidelines below.

Guidelines for taking further action:

- The patient or carer is given the required time and support and empathic approach to the issue.
- The patient or carer is given a thorough explanation of the course of action required to ensure the event is fully investigated and acted upon.
- The patient or carer is treated with respect and dignity at all times.
- The interviewer maintains responsibility for keeping the patient or carer informed and involved where appropriate.
- The patient or carer is offered support and guidance in line with research governance.
- The interviewer collates the necessary information from the patient or carer to report to the most appropriate senior personnel in order to take further action.

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 and we are grateful to them.

We thank Professor Peter Wilcock for his great inspiration, wisdom and in sharing his passion for quality improvement. Without his help in our pioneering years, Discovery Interviews would not be what they are today.

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