“HOW TO” KIT

UNDERTAKING DISCOVERY INTERVIEWS /
PATIENT STORY COLLECTING PROJECTS

2008
This “How To Kit” is a comprehensive introduction to how to undertake Discovery Interviews or Patient Stories. It was developed by Jane Price, Patient Support Specialist and Gwent Healthcare NHS Trust, while she was on secondment to the South East Wales Cardiac Network as the Discovery Interview and Patient and Public Involvement Facilitator. We are very pleased that her substantial work is being shared by the 1000 Lives Campaign as part of their Patient Stories. Jane has a passionate belief that the best way to improve services for patients is by learning directly from the patients and carers who use the NHS.

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1. **INTRODUCTION**

“A common criticism of the NHS is that it sometimes fails to reflect or respond to the views and experience of patients and public when planning and delivering NHS services. The importance of the patient’s voice is recognised as being centrally important in the drive for service improvement”.

*Improving health in Wales: Chapter 3: Listening to patients. 2002*

As part of the Department of Health Cardiac Heart Disease (CHD) National Service Framework, a major Discovery Interview project was developed in England to incorporate the patient perspective into CHD service development and improvements. Discovery Interviews are patients and carers experiences, their own stories which are recorded by NHS staff who have undertaken skills building to enable them carry out one-to-one semi structured interviews. They are a qualitative and data rich source of evidence of good practice and areas for reflection and change.

In Wales, in 2006 the South East Wales Cardiac Network initiated, supported and facilitated a two year project working with the four Network Partner Trusts. This “How to Kit” is a result of the learning, often steeply inclined, of the project facilitator.

This “How to Kit” is specifically designed for health professionals who may be venturing into this field for the first time. It’s important to recognise that not everyone will be in a position to undertake this project approach, nor is it essential in order to collect patient and carers experiences for PPI or service improvements. This kit should be regarded as the gold standard and there are certainly some corners which cannot be cut (in Appendix IX you will find an opportunistic story checklist).

Discovery Interviews/Patient Story Collecting are one of many methods which can be employed in PPI activity. They can be used as a standalone, to complement other methods or as a way of digging deeper following on from focus groups, patient and public feedback or a chance remark. They differ from satisfaction tools in that they seek out the patient/carer experience and this method represents the only opportunity for most patients and carers to recount their experiences in detail in their own words and in their own way. Hearing what patients and carers have to say in audio or audio visual form is a powerful tool which accounts for its growing popularity in education and organisational learning arenas in the NHS.
2. SYMBOL KEY

Throughout the kit you will notice symbols alongside of checklist boxes. These symbols are designed to help prompt you to ensure that you approach your project methodically and in a detailed manner.

Symbol key:

- **Championship support.**
- **Important information to remember.**
- **Practical resources needed to ensure project success.**
- **Task and Finish Group etc.**
- **Specific information for people undertaking degree or research project work.**
- **Actions that need to be taken to ensure the project is conducted professionally and properly.**
- **Actions needed to ensure that the interviews/stories are subjected to appropriate scrutiny.**
3. SELLING THE CONCEPT

You may have chosen or been asked to undertake a project either as part of a professional development programme or possibly as an audit process or a component of your areas Patient Public Involvement commitment. You may already know about Discovery Interviews/Patient Story Collecting and the important role they can play in eliciting patients and carers experiences, reflecting on these and how they may correlate or differ from the provider’s understanding of what is on offer or what they may perceive service users to need.

There is no doubt that this sort of qualitative project has resource implications and can be time consuming so it is important to have some understanding of why it is a good thing to do. You are going to need to be able to convince line managers and the senior level of the organisation that your proposals are worthwhile.

“The insights patients can provide from an external perspective often identify issues which may not be apparent to those working within the system”

Healthcare Foundation (2007)

[Light bulb]

DECIDE WHY AND HOW YOU WANT TO DO THE PROJECT

The difference between using quantative or questionnaire surveys and Discovery Interviews and Patient Stories is that it helps us to get a detailed patient provided view of their experiences of healthcare. It is especially useful when you want to find out how treatment and care is for the people on the receiving end.

You may want to evaluate an existing service or be planning to develop a new one. Whatever the reason this method will help you get a real insight from the service user or implement service improvements to existing services.

It is always useful to look at the bigger picture. There is an increasing political expectation that patients and carers will participate in shaping NHS services. In the wider NHS the power and value of listening to patient stories and experiences is gathering momentum. Managers and healthcare staff are recognising that hearing what patients have to say in their own words can influence and improve the way in which they work, deliver and evaluate services: patient stories to be used by the Welsh Assembly to evaluate progress in implementing the Chronic Conditions Framework and are at the core of the 1000 Lives Campaign.
**THE POTENTIAL BENEFITS TO ORGANISATIONS USING DISCOVERY INTERVIEWS AND PATIENT’S STORIES**

- They are a genuine demonstration of listening directly to the patient experience.
- At Board level they enable the Trust to comply with the patient experience domain of the Healthcare Standards and Clinical Governance requirements.
- If analysed intelligently, they provide innumerable opportunities for patient-focused improvements to the way patients are communicated with and services are delivered.
- As well as providing opportunities for service improvements, Discovery Interviews provide a wealth of examples of good practice where staff are getting things right. It is just as important to recognise and share with staff the evidence of compassion, caring and professionalism as it is to learn from the more negative experiences.
- They provide development opportunities for staff at all levels in terms of patient involvement, interviewing techniques, service provision assessment and service improvement.
- There is a potential to work across the multidisciplinary arena when undertaking this type of project: this brings a broader perspective of values, focus and beliefs as well as a greater understanding of colleagues’ roles in the NHS arena. It promotes bridge building and professional understanding and mutual respect.
- Discovery Interviewers/Story Collectors within Trusts offer a trained resource for other PPI initiatives.
- For you it is a chance to develop and enhance communication, analysis, service reflection and improvement skills.
- For patients, carers and the public it provides a real opportunity to talk to the organisation about what it does for them and how well it does it.
- For the organisation it offers a real opportunity to gain a detailed insight into how it performs as well as offering valuable opportunities to really engage the public as it plans for the future.
4. WHAT YOU NEED FROM YOUR ORGANISATION AND WHAT IT CAN DO TO HELP - STRATEGIC STUFF

TRUST SUPPORT AND LOCAL LEADERSHIP

Discovery Interviews/Story Collecting is good for everyone. It’s important even if colleagues are not directly involved that they know what you are doing and why. It is essential to get support, not just in principle but in practice. Service improvements resulting from learning opportunities which the project presents need high level buy in, so you need to be clear about why the project is worthwhile and deserves their support.

FIND A CHAMPION

To get the best from this type of work it needs people at all levels to engage in it with enthusiasm and commitment. You will need to find someone at Executive or Non Executive Board level to act as a project champion to:

- Help you sell the concept and the benefits to your organisation.
- Help you ensure that you have all the resources and support which you need to get the job done properly.
- Give practical support to set up a Sub Group/Steering/Task and Finish Group.
- Chair/Lead or Sit on the project Task and Finish Group.
- Where necessary have the difficult conversations which may be needed to encourage others to act on the project findings and recommendations and make service improvements.
- Help you make sure that the organisation and the public know what work is happening and why it is important.
Once you have strategic support, you will need to negotiate with your champion and line managers to get what you will need in order to carry the work out.

IDENTIFY PROJECT LEADS

Unless you are doing only one or two interviews/stories it is important to have a project lead whose overall responsibility will be to co-ordinate all phases of the project. If you intend to carry out more than five interviews or stories it is strongly recommended that a second person is recruited to jointly lead the project to cover for sickness, annual leave etc. Do remember that the Task and Finish Group should be able and willing to help with some of the lead responsibilities and don’t be afraid to delegate!

LEAD AND SECOND RESPONSIBILITIES

- Produce a project proposal/protocol
- Follow ethical approach guidelines (see page 21)
- Identify potential interviewers/collectors and clerical support person (see page 19)
- Meet and negotiate agreement with potential interviewers/collectors and clerical support line managers
- Identify and assemble the Task & Finish group members (see page 11)
- Arrange skills building sessions (see page 19)
- Identify target group patient/carers (see page 24)
- Organise paperwork and equipment to carry out interviews/stories (see page 12)
- Oversee/co-ordinate invitation and response phase (see page 27)
- Identify and allocate interviewers/collectors with participating patients/carers

Continued...
✓ Set up and oversee a buddy system for interviewers/collectors (see Appendix IV page 70)
✓ Quality check recordings/transcripts (see page 33)
✓ Oversee/co-ordinate transcription and safe storage/destruction of transcribed recordings (see page 34)
✓ Carry out transcript analysis (see page 35)
✓ Reconvene Task & Finish Group (see page 44)
✓ Write oversee project report and oversee report dissemination (see page 44)
✓ Link and collaborate with colleagues who action identified service improvements
✓ Feedback service improvements to Task & Finish group

End.
FORMING A TASK & FINISH GROUP OR SIMILAR TO WORK OUT WHAT TO DO WITH WHAT YOU HAVE

ADVANCED PLANNING - IDENTIFY AND ASSEMBLE THE TASK & FINISH GROUP

Once you have an agreement to your proposed project and have found your Champion it is a good idea to pull together the Task & Finish Group (or whatever you are calling it). At this stage you won’t be in a position to start making recommendations and service improvements, you will however be able prepare and this will help ensure you keep within your set timescales.

✓ Agree on TASK AND FINISH Group composition: Should it be multidisciplinary? Do you want to invite a lay person such as a patient or carer to join?

✓ Make sure that you have at least one influential person who works at your organisation’s board level

✓ Set out terms of reference for the Group

✓ Discuss the project proposal, hypothesis, target patient/carer group and ethics

✓ Plan target dates for the interview, analysis and reporting stages to be completed

✓ Find out who in the Group is willing to commit to helping you with any practical aspects that arise during the project

✓ Agree a method by which the Task & Finish Group can be kept informed of the projects progress

We’ll return to the Task & Finish group’s role later on page 44
5. MAKING DISCOVERY INTERVIEWS HAPPEN: PROCESSES AND RESOURCES

PLAN THE PROJECT TIMESCALE CAREFULLY

Remember timescales will vary depending on the size of your project and the agreement which you reach with your organisation.

- A one-off, two-day period for the leads each identified Discovery Interviewer/Story Collector to learn about the project, process, enhance skills and practice
- Set aside time for the Discovery Interview/Patient Story leads to administrate the project. Apart from skills building days, time commitments are likely to be split over the weeks or months of the project and will be blocks of time rather than whole days. As a rough guide allow for 8 to 12 days in total for the leads
- Depending on the level of involvement for interviewers/collectors allow 2 days for skills building and then up to a half day for each of the patients/carers who they meet with for the project. If they are more involved for example, transcribing, participating in the Task & Finish Group etc you will need to factor in more time for them. N.B. Not more than 3-6 interviews per person in a 12-month period
- Set aside time for a Trust staff secretary to transcribe the interviews
- One off purchase of recording equipment
- Loan of a Trust mobile phone (where applicable)
- Accommodation for Task and Finish/Steering Group/Service Improvement Cohort, time for meetings, actions, Board presentations etc.

You will find Executive Briefing to Board in Appendix I (page 54), Sample Recommendations in Appendix II (page 57), and the Discovery Interview Flow Charts in Appendix III (pages 59)
WHAT YOU ARE TRYING TO FIND OUT: SOME EXAMPLES

Depending on the aims of your project you may just want to find out in very general terms what patient/carer experiences are in your clinical area with a view to making service changes or improvements. On the other hand you may want to probe further because you have a specific theory in mind. The following examples may help you to develop a focused and structured approach when you plan to explore the patient/carer experience or journey in more detail.

You may think that patients with a long term illness may prefer to stay at home when they have a health crisis. You may know that at present they are almost certain to be sent into hospital. Your theory is that they want to remain at home so you will be working with them to find out. These points could form the foundation for the interview or story.
EXPLORING PATIENT FEEDBACK IN MORE DETAIL - EXAMPLE ONE

Patient feedback has suggested that some people do not want to attend Cardiac Rehabilitation sessions. Patients are selected for the project who have:

(a) Not attended Cardiac Rehab services at all

(b) Who have attended only one session and then dropped out. The hypothesis is that this patient group may not understand the purpose of Cardiac Rehabilitation.

Questions you may want to include to explore your theory

- When were they referred to Cardiac Rehabilitation (this is important as they may not have been)
- Who spoke to them and explained what Cardiac Rehabilitation was about
- If they attended one session what was it like
- If they only attended one session why was that
- If they didn’t attend a session what made them decide not to
- What do they think Cardiac Rehabilitation is about
EXPLORING PATIENT FEEDBACK IN MORE DETAIL - EXAMPLE TWO

Following your Discovery Interview/Story Collecting project regarding why patients don’t attend Cardiac Rehabilitation, it is clear that there are a few themes emerging:

- Not all patients have been referred to Cardiac Rehabilitation
  
  This is a straightforward service improvement issue which will require an overview of the current referral system and developing a safety net strategy by working collaboratively with clinical colleagues

- Not all patients know what Cardiac Rehabilitation is about whilst others in the first project had misunderstood the purpose of it and the activities and support which is available

  Again this is a straightforward service improvement issue requiring the Cardiac Rehabilitation team to review and improve the verbal and written information which colleagues and Cardiac Rehabilitation nurses give to potential patients

- The Cardiac Rehabilitation team may decide to revise their programme and how it is being offered to reluctant patients, they may develop a more personalised and tailored service for this patient group as a pilot project
The theory or theme for this project then is that, by making service improvements reluctant patients are more likely to attend and complete the Cardiac Rehabilitation course.

Following the pilot project the original patient group is asked the following questions.

- What difference did the new programme make to them?
- How easy was it for them to get to it and why?
- What did they most like?
- What did they least like?
- If a friend or relative asked them about Cardiac Rehabilitation what would they say?
You need to be realistic about the number of interviews/stories you plan to do: remember that a single hour’s interview could potentially give you a lot of information.

Your project is likely to be an additional role to your day job. Both you and the people who are participating in it will need to invest time in it and you will have to negotiate and gain line manager agreement for set aside time. If the patient/carer numbers are too large you may over run your agreed time and put pressure on yourself, your colleagues and clinical resources.

You need to be confident that you will be able to achieve what you set out to do.

Keeping things manageable will keep EVERYBODY’S stress levels down.

Getting enough of the right type of support will help your project to be a success.

Remember small can be beautiful! The emphasis in Discovery Interviews/Patient Stories projects should be to focus on quality and content, not quantity you don’t need huge numbers of people to make it worthwhile.

As a general rule the frailer or older your patient group the more invitations you should consider sending. For example, during the South East Wales Cardiac Network project response figures from people with Heart Failure were extremely low: On the first occasion 20 were invited and none responded. On the subsequent attempt a further 20 were sent, 4 responded, however only 2 were carried out as 2 sadly died in the interim. So you may want to send out four times as many invitations as you hope you will have people to participate.

If you do get more patient/carers than expected, all of them need to be responded to. You will need to negotiate and decide with them whether you go ahead and work with them now or, if they are willing to be contacted at a future point.
SETTING UP YOUR DISCOVERY INTERVIEW/STORY COLLECTING TEAM

If you intend doing a small number of interviews/stories (1-6)

You may already have experience in this field. If you do, you may decide to do the project on your own or with a similarly experienced colleague. If you don’t, then it is worth seeking out help and support from someone who has undertaken the RCN Professional Development course as they will have done at least one interview or you may want to consider approaching colleagues in your organisation who have been involved in the South East Wales Cardiac Network Discovery Interview Project. (See Appendix XIII page 133 for a list of SEWCN DI contacts)

If you intend a larger number of interview/stories (7 plus)

It is advisable to assemble a team of interviewers/collectors and appoint a project lead and second. It is surprising how much work even a small number of interviews/stories will generate.
SKILLS/QUALIFICATIONS TO CARRY THE PROJECT OUT

You don’t need formal qualifications to carry out this type of project. You do however need some skills and attributes. Currently there are no accredited training programmes for Discovery Interview/Story Collecting in Wales. Networking with colleagues with previous experience is really important.

SKILLS BUILDING

It is not possible to train most people to undertake Discovery Interviews/Patient story collecting in a day or two. As part of the South East Wales Cardiac Network Discovery Interview project the How to Kit author developed a skills building package which you can access on the 1000 Lives Campaign Website (http://www.1000livescampaign.wales.nhs.uk)

The Skills Building Days Programmes can be seen in Appendix V (pages 74-76)

* If you want assistance to deliver the skills building package please contact Jane Price: email - Jane.Price@gwent.wales.nhs.uk

IDENTIFYING POTENTIAL INTERVIEWS/STORY COLLECTORS

Nurses tend to spend the longer periods of time with patients, therefore they have more opportunity to communicate with patients and carers than other healthcare colleagues and may be regarded by some as skilled communicators and therefore the most appropriate people to become interviewers and collectors. In order to get the best results however it is important to recognise that colleagues from other disciplines are also likely to have an interest and the necessary attributes to engage in this type of project. The right attributes and competencies are more important than the background or rank of interviewers and collectors.
CORE ESSENTIAL ATTRIBUTES TO LOOK FOR IN POTENTIAL INTERVIEWERS/COLLECTORS

Effective Communicator
✓ Attentive Listener
✓ Skilled Questioner
✓ Astute Observer
✓ Self awareness

Professional Attitude
✓ Awareness of professional scope
✓ Practices within boundaries
✓ Ability to recognise when issues are raised that need to be addressed outside of the interview arena.

Enthusiasm for the project
✓ Empathy towards patient and carer experiences
✓ Commitment to service improvement

Emotional Maturity
✓ Reflective practitioner
✓ Objectivity
✓ Impartiality
✓ Personal reflection and insight

Commonsense
✓ Awareness of and adherence to Trust Lone Worker Policy
✓ Sensitivity to environment and atmosphere

A complete Discovery Interviewer Protocol in Appendix IV (page 63)
ADOPTING AN ETHICAL APPROACH: PATIENTS/CARERS

If you are undertaking your Discovery Interview/Story Collecting as part of a degree course or a research project you will need to ensure that you are practising within the expectations and principles of your proposed work.

✓ You should be discussing your proposal with your degree course tutor or senior manager

✓ If you are lucky enough to have a Clinical Ethics Committee in your organisation you may want to contact a CEC member informally in the early stages of planning

✓ All NHS Trusts will have a Research and Development team who may keep a central register of research and audit projects. It is really worth linking up with them to find out if there are similar pieces of work being undertaken or already done

✓ Generally, Ethics Committees deal with research proposals and can issue guidance and will need to grant approval for studies involving patients and carers

✓ You should also seek advice from the above resources to establish whether or not you will need to apply for Regional or Central Ethical Approval. (Because the South East Wales Cardiac Network Discovery Interview project was a region wide piece of work regional ethical approval was necessary in addition to in-house Trust approval)
ADOPTING AN ETHICAL APPROACH: STAFF/COLLEAGUES

It is important to adopt an ethical practice approach to those partner Trust staff that are directly involved in any project. This work will be carried out by busy staff in addition to their day to day responsibilities. Their contribution to Patient Public Involvement and organisational learning through service improvements needs to be both acknowledged and supported at local, Directorate and Executive Level.

The well-being of staff, their ability to carry out the role, appropriate support and safety nets, personal well being and satisfaction, induction and skills training to carry out the interviews professionally and confidently, protected time and travel expenses plus the knowledge that the work they are engaged in is making a difference, are all essential contributors to a successful outcome. By ensuring that these elements are addressed it is hoped that Discovery Interviewers/story collectors will be motivated and enthusiastic, prepared to continue in the work and possibly encourage others to engage in it beyond the boundaries of their own clinical area.

If you are undertaking it for local purposes (such as personal professional development, audit, service improvement or local PPI initiatives) then whilst you may not want or need to apply for formal ethical approval, you will still need to ensure that you are acting ethically. It is useful to measure your proposed plans against ethical principles (Chadwick & Tadd (1992)).
HOW WILL IT AFFECT THE PATIENT/CARERS AUTONOMY?

- How will you ensure that they have time to think about whether they want to participate in the project?
- How will you demonstrate that you are protecting their anonymity?
- Do they understand that they don’t have to participate and that if they decide not to it won’t affect their future?
- What processes are in place to support the patient/carer if they become distressed during or after the interview?

IN WHAT WAY IS YOUR PROPOSAL AND THE WAY IT WILL BE ENACTED BENEFICENT/ NON MALEFICENT?

- What potential is there for it to harm the individual patient/carer?
- How will you ensure that colleagues and departments are protected from identification?
- In what way will your project benefit individuals and the wider community of service users?
CHOOSING YOUR PATIENT GROUP AND INVITING THEM TO TAKE PART

“Asking patients what they think about the care and treatment they have received is an important step towards improving care for patients in hospitals and other health services.”

*Quote: Professor Sir Ian Kennedy, Chair, Healthcare Commission, 2004*

The Project Lead and usually a colleague will identify the target patient group and will have discussed this at the preliminary Task and Finish Group meeting. The aim should be to capture as broad a range of experiences and diversity as possible.

![CAUTION]

Whether you are carrying out an audit or small project, a degree course or research project you will need to ensure that you follow a random selection process and don’t cherry pick patient/carers.

If you are undertaking your Discovery Interview/Story Collecting as part of a degree course or a research project you will need to ensure that you are practising within the expectations and principles of your proposed work using a protocol and local criteria.
HINTS AND TIPS FOR CHOOSING PATIENT/CARER GROUP

Consider the likely fitness level of the patients you hope to invite e.g:

? Will you travel to them or if not will they be able to travel/need help etc

? Are they likely to tire easily/will they be able to hear and understand easily

Consider what experiences they may have had e.g:

? How long ago did they last use your service (recall for traumatic events will be longer than routine experiences, however in most cases aim to include people who have had recent contact (within the last 3-6 months)

? Will they have more dealings with Primary or Acute Healthcare providers

Consider the diversity of the patient group e.g:

? Is the condition you are exploring likely to affect a wide or narrow range of the population? More men than women etc.

How will you best obtain a balanced view of patients and carers experiences e.g.:

? Should certain patients be excluded

You need to consider how balanced a view you would obtain from patients/carers who have made formal complaints or those who have written compliments to the organisation or the local press, people who are involved in Healthcare Pressure Groups or who represent Patient Bodies. A blanket exclusion may deprive your project of valuable contributions or conversely may distort it

This aspect will need thoughtful discussion before reaching a decision.
HINTS AND TIPS ON HOW TO SEND OUT INVITATIONS

You have a number of choices about which method you choose here are a few examples. Remember, you will need to think about which one suits your project best and ensure you are fully prepared before you start your patient/carer recruitment.

<table>
<thead>
<tr>
<th>METHOD</th>
<th>POINTS TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post</td>
<td>This gives people time to consider the invitation and discuss it with others</td>
</tr>
<tr>
<td></td>
<td>It puts no pressure on the recipient as they can choose whether to respond or not</td>
</tr>
<tr>
<td></td>
<td>You will need to set a time frame for them to reply as well as when they can expect a follow-up phone call</td>
</tr>
<tr>
<td></td>
<td>Avoid busy times of the year, Bank Holidays etc. as this may affect the response rate</td>
</tr>
<tr>
<td>Phone</td>
<td>This method is sometimes used by audit teams to carry out satisfaction questionnaires. It is probably best avoided for Discovery Interview/Story Collecting projects as a method of recruiting participants</td>
</tr>
<tr>
<td></td>
<td>“Cold calling” can be difficult, it may make some people feel pressurised (remember your own experiences with unwanted telemarketing calls)</td>
</tr>
<tr>
<td>Accessing Existing Patients</td>
<td>This may be done by attending an outpatient clinic, visiting a ward, setting up a “recruitment” stand in a public area of your organisation or attending a patient interest or support group</td>
</tr>
</tbody>
</table>

**CAUTION**

Whichever method you settle on, do make sure that you don’t leave too long a gap between them agreeing and when the interview/story collection is carried out. Ideally it should be done within two weeks of agreement.
ADMIN HELP

Don’t forget that you will need administrative help to send out invitations, co-ordinate replies and keep clear logical records of every step otherwise you will get in a muddle!

Sample patient/carers invitation letters and information in Appendix VI (page 78)

CARRYING OUT THE INTERVIEW

CONSENT

It is essential on the day that the interviewer/collector checks that the patient or carer understands what they have agreed to do and that they still want to do it.

Sample consent form and list of what you need to take with you, how to stay safe etc can be found in Appendix VII (A) (page 94)

Remember that this is the patient’s/carer’s story and they must be allowed to tell you what they want to and not necessarily what you expect or want to hear. Remember that the skill of the Discovery Interviewer is in extracting as much information as possible about each significant patient-professional contact throughout the patient’s journey. This requires the interviewer to think beyond the limitations of their own professional sphere; as well as how the patient was affected clinically, physically, emotionally and the impact on their lifestyle and family.
PRACTICAL AND COURTESY ISSUES: HINTS AND TIPS

✓ Be familiar with your organisation’s Lone Worker Policy or equivalent and ensure that you adhere to it
✓ Check the route to the place where you are meeting the patient/carer in advance of the session
✓ Allow enough time to get the venue and if you know or think you may be late ring the patient/carer to let them know
✓ Don’t forget to introduce yourself, remind the patient/carer why you are there and how long the interview will take
✓ Make sure before starting that the patient/carer still wants to participate and complete the consent documents
✓ Remind them that you are not there to comment on their story or tell them what to talk about
✓ Explain that you will warn them when you need to turn the tape over/when there are five minutes of time left
✓ Do remember to thank them at the end of the interview and remind them about their decision in relation to their recording i.e. it will be safely stored and destroyed after the transcription process or it may be used for learning purposes and if so they will be contacted to make sure they are still comfortable with this arrangement
✓ If any points of concern were highlighted in the session in relation to the patients ongoing health ask the patient if they will give permission for you to pass this information on to the appropriate clinician
✓ If a “complaint” crops up during the interview give them your organisation’s complaint information so that they can pursue it if they wish
✓ If the session prompts you to be concerned about their current health discuss it after the interview and agree an action plan
✓ Make a prompt exit
**GENERAL THEMES TO EXPLORE WITH THE PATIENT/CARER**

- ✓ What happened to them
- ✓ What they understood those experiences to be
- ✓ How it has affected them both at the time and after the events (including how they felt about things)
- ✓ How they measured their experiences (in terms of positive or negatives)
GETTING THE BEST OUT OF THE SESSION: HINTS AND TIPS

✓ If you can, try not to be too linear in your thoughts. If the patient/carer wants to start in the middle of their journey or deviates from the anticipated path this is how their mind works. You will need to ensure that you get as much of their story as they want to tell you which is where a “question spine” may come in useful

✓ Don’t worry either about getting from A to Z. If something which obviously has importance to the patient/carer crops up then you may need to use your tape time in helping them to explore that aspect

✓ The more open questions (what, why, how, who, when, feel) you use the more information you will get from the patient/carer

✓ Listen out for:
  • “cues”, does the patient/carer mention the same thing a couple of times for example being afraid, not understanding why they became ill etc.
  • Tone of voice, do the words match the tone? Are they saying they were fine but the voice makes you think that they weren’t.
  • “Hanging statements” for example “the doctors were really wonderful they sorted out my problem for me …..” this sounds fine however if you hear the unspoken “but”, then ask them about it, for example “but?” or “were they all wonderful?”

✓ Be sensitive to silence, if they are quiet it is an indication that they are thinking, reflecting or collecting their thoughts: try not to fill the silence they will speak again when they are ready

✓ Watch for indications of feelings while they are talking, an obvious one is crying, however there may be more subtle indicators such as tensing their body, rubbing their face etc.

Continued...
✓ If you do notice that they are upset, tone doesn’t match voice etc. ask them how they are feeling about what they have just said, for example “you are sounding quite cross at the moment”

✓ Clarify as you go through the session. If you are not sure what someone is saying it is perfectly acceptable to ask for clarification

✓ Don’t steer away from asking how they felt about something. Health professionals sometimes assume that patients/carers will automatically share their feelings with them because of the unusual and privileged relationship they have; this isn’t always the case. While someone may have very positive things to say about their treatment and care they may equally have felt confused, isolated and afraid but unless you give them an opportunity to talk about that you will never know

End.

Sample question spine and stuff happens handout in Appendix VIII (page 97)
TRANSFERRING THE INTERVIEW INTO TYPED FORMAT AND SAFE STORAGE

If you are lucky enough to secure the services of a good audio typist then do so! Transcription is a skilled process and very time consuming especially if you are not used to it.

During the transcription process you will need to make sure that:

- The person typing is familiar and compliant with your organisation’s confidentiality and Data Protection requirements (you should be able to find out your local policies via the Intranet or the Human Resources team)
- The whole of the interview/story is transcribed including any questions which the interviewer/collector asked
- Anything which can identify either the patient/carer, their family or health professionals is changed/anonymised for example: Mr Williams may become the patient/carer or Mr A; Doctor Foster will become Doctor 1
INTERVIEW/STORY QUALITY CHECKS

Getting the best out of interviews/stories is a challenging and exciting task. Some interviewers/collectors will have previous experience or may have highly developed skills acquired through experience, others will still be learning or may worry about getting it right. Ensuring that they are supported to do their best is an important role for the project lead and second. The only way to help interviewers/collectors develop and enhance their skills is through objective listening of their work. The project lead and second will need to listen to a proportion of the recorded interviews/stories and should aim to listen to at least one recording per interviewer/collector. The interviewer/collector will need to be given constructive and positive feedback and when indicated additional help and support to refine their technique.

Interviewers/collectors should be encouraged to listen to their recording and give them self a fair and honest appraisal of how the session went prior to handing the recording over for transcription. The chances are they may be pleasantly surprised even if they pick things that they could have done differently or spot things which they missed.

The project lead should arrange to meet with the interviewer/collector whose recording has been quality checked. Before giving the interviewer/collector feedback they should listen to the recording together.

The important thing is that the project lead and the interviewer/collector both recognise what was done well and what needs work for the next time.

A quality check matrix is available on the 1000 Lives Campaign website story telling learning zone. (www.1000livescampaign.wales.nhs.uk)

Quality checking will only be effective if the transcript had been typed verbatim, this means including:

- All questions and responses.
- Sounds like sighs, laughter etc.
- Indications where speech may is inaudible
ONCE THE TRANSCRIPTION IS COMPLETED

What happens to the recording will depend largely on what has been agreed for your project. If you have told the patient/carer that the recording will be destroyed then it must be. If you have the permission to keep the recording or to use it for teaching purposes then you must have this clearly documented (along with a copy of your arrangement left with the patient/carer) and the recording must be safely stored. If you change or leave your job you must make sure that someone takes over this responsibility.

Respect the interviewer/collectors rights. If you have permission from the patient/carer to use their story as an audio record in teaching it is equally important to ensure that the interviewer/collector also gives consent. This is essential if you are considering using the recording as a “critique” tool i.e. asking others to consider what the interviewer/collector could have done differently to improve the quality of the interview/story. If they feel uncomfortable about the use of their work then you could consider the following options which would render the interviewer/collector unidentifiable:

- Re recording using actors/actor volunteer voices
- Using the story in typed transcript format

If neither of these alternatives is acceptable to the interviewer/collector then the recording should be destroyed.
6. MAKING SENSE OF WHAT YOU HAVE: FROM TRANSCRIPTION TO SERVICE IMPROVEMENTS

HOW TO ANALYSE WHAT YOU ARE HEARING

Once you have transcribed your interviews they will need to be analysed. It is advisable to ensure that this analysis is done by either the project leads (who should not be carrying out interviews or collecting the stories) or an independent analyst (such as a member of the audit department). Buried treasure sits in each recording.

If you have undertaken Discovery Interviews or Patient Story Collecting as part of a degree or research project you should have received guidance on which tool or model will most suit your needs.

If you don’t have access to a specific tool or model then it is really important that you approach the transcripts systematically to help you to theme and analyse the patient’s journey. It is important to appreciate that the teller may not start at the beginning or finish at the end! Therefore it is helpful to have a map of the “average patient’s” journey before you begin the analysis. Use your question spine to help you map the journey.

This model can be adapted to your own clinical area, but do remember the bigger picture. Whilst you may be focussed on discovering what it was like for the patient when they were using your service, they will have a much broader experience that they have shared with you. For example: elements of their story are likely to reflect on how health professionals responded and behaved towards them and the effect this had, the cleanliness of the hospital etc. This is the sort of information which can help you to reflect about your own area, practice and standards and may well be important to share with other clinical areas and colleagues when the final report is disseminated.
WORKING ON THE TRANSCRIPT - PRACTICAL MATTERS:

BEFORE YOU BEGIN

☑️ Think about **the best way for you** to draw out the information from the transcript. You may want a separate copy you can mark for each of the elements of the patient's journey (in which case make sure you have plenty of copies)

☑️ Don't be over ambitious! If you are doing this for the first time you will need to make sure that you don’t take on too much at once. Reading through the transcript needs a lot of concentration and mental effort. If you get tired you may miss something important

☑️ Make sure that you have enough protected time to work

☑️ You may find it helps to have a printed sheet with the patient's journey beside you to refer to as you work

☑️ Make sure that you are comfortable and that you can work without being disturbed

☑️ Make sure you have all the equipment you think will be essential for the job. For example you may choose to use different coloured highlighters for each theme or, if you are used to using a database you may want to use this as you work
BEGINNING

Now you are ready to start: Remember how you do this will be personal to you but there will be a common purpose and outcomes.

- At this stage don’t concentrate on what you are specifically looking for, get a more general feel for the patient’s experience
- Read through their story without making any notes, really try to hear what they are saying and if you can, what they are not
- Once you have finished reading have a brief break from the story and then prepare to start analysing it

To help you here is an extract from a story which has been analysed from the patient’s perspective. This extract was received without the original questions by the interviewer/listener included in the transcript. It is tempting when reading any extract to want to know what the patient was asked and whether attempts were made to explore statements which you may think as you read could have been expanded upon.

It is really important to put those thoughts aside and get on with the task in hand, however you may keep them in mind for the next interview/story collecting you undertake and adapt your technique as a result of them.
IDENTIFYING THE PATIENT’S JOURNEY

To help you focus on analysing your transcripts the following section is an example of what you may want to look for from the patient’s perspective or journey.

This patient had already been to A & E earlier in the day with “indigestion” and been discharged home.

Thinking something was wrong

“So my friends came across and took me back (to the hospital) and unfortunately I had to wait, in my memory, 2-3 hours before anyone saw me in the way of a doctor? The nurse wouldn’t give me anything to ease the pain in case it was the wrong thing to give. So that went on and on and on. Then they did more blood tests and all the rest of it and nothing was showing up and then he came back around 6 o’clock in the morning and he said there’s a slight hint that you may have had a slight heart attack”.

How might this patient have felt while having to wait?
What might it have been like for this patient being in pain all this time?
It appears that until the doctor returned at 6am that the patient may have felt that they were ok

“I said what’s the procedure now? So he said “we’ll we need to give you clot buster”

This patient appears to want to know what happens next: Communication

“So I said what does that entail? So he said “we need you to sign the indemnity form”

This patient does not appear to have an understanding at this point about why they needed to sign the form

“I said I’ve come here to be cured not killed and he didn’t have a sense of humour at all.

“He said I’m calling the coronary gentleman down and he came down and he was a lovely guy, I think it was Dr A. He together with the charge nurse, a tall chap, B. They were absolutely outstanding”

Apart from the patient’s opinion about the doctor’s sense of humour what might this statement suggest to us?
How might you describe this patient’s feelings about the arrival of the Coronary doctor and the Charge Nurse?

“So I said why do I need to sign an indemnity?” the said 3 people in 1000 will get a severe stroke after this stuff”.
WHAT YOU ARE LOOKING FOR

The essence of the story which you are working through is that it is entirely the teller’s experience; what they have chosen to tell you. What you need to gain from the transcripts are the themes. To help you to analyse these themes the table on the next page lists themes identified from the South East Wales Cardiac Discovery Interview Project transcripts.

You should already have a clear plan in your mind about the purpose of your Discovery Interview/Story Collecting project. In the same way that you have a patient’s journey mapped out you should have already have a set of objectives, a rationale, an hypothesis, as well the themes and learning outcomes you expect to get from the project.

Unless Discovery Interviews or Patient Stories are going to be used to honestly reflect on your area, how it functions and how that impacts on patients there is no point in doing them. Equally, if you find evidence that there is room for improving patients services and thereby their experiences then you need to commit to making those changes a reality.
IDENTIFYING LEARNING THEMES FROM THE TRANSCRIPT

Clinical And Emotional Impact
- Becoming unwell/ seeking help
- Interventions/outcomes
- Emotional Impact

Procedural Impact
- Waiting and the system
- Frustrations
- Tests and investigations
- Medication times
- Sleep disturbance

Communication
- Breaking bad news
- Poor communication skills
- Information giving

Environmental
- Ward cleanliness
- Hospital design
- Staff hygiene (hand washing)

Life After Discharge
- Going home
- Primary and social care support
- Outpatient appointments
- Cardiac Rehabilitation: accessibility and perceptions
- Ongoing impacts (emotional, relationships, work etc.)
IDENTIFYING THEMES FROM A HEALTHCARE PERSPECTIVE

However you choose to label your themes you will of course need to analyse the transcript in a way which identifies those themes. You will be able to see an example of how this was done for the Network project by visiting the link for Skills Building Zone on the 1000 Lives Campaign website. (http://www.1000livescampaign.wales.nhs.uk)

IDENTIFYING POTENTIAL LEARNING OPPORTUNITIES FOR SERVICE IMPROVEMENT

The Task & Finish Group will be working together to recommend action points on potential learning opportunities, you will need to identify them first. You may find it helpful to go through each transcript and ask yourself some questions about the themes you have identified. You will be able to see an example of how this was done for the Network project by visiting the link for Skills Building Zone on the 1000 Lives Campaign website. (http://www.1000livescampaign.wales.nhs.uk)

Once you have repeated the analysis phase of the process for each of the transcripts you will be ready to move on to the next phase of the project.
WRITING UP WHAT YOU HAVE FOUND OUT

Once you are ready to start compiling your report you should give notice to the Task & Finish group and set a date for a meeting.

Depending on the size of your project you may choose to put together a briefing paper or a consultation document. Using a systematic approach will make it easier for others to read and understand it. Your organisation may have a template which you are expected to use. If you are free to format your report as you wish then it is worth considering the following suggestions.

- Follow the processes and project progression to write your report (in others words begin at the beginning and end at the end!)
- Use simple explanatory headings
- Don’t feel compelled to recount every small detail of the project but do:
  - Concentrate on the main themes
  - Include powerful quotes from patients/carers to punctuate the themes of the report
  - Recommendations
  - Potential service improvements
  - Action plans
- Do consider asking someone who is used to producing professional-looking documents to review the report before finally sending it out
- Include a covering letter and a feedback form and keep a list of everyone who you send the report to
- Be sure to set a deadline date for comments (be realistic about this at busy times or holiday seasons you will need to allow a little more time.)
M. Edgar (2007) cites a quality assessment tool which may be a helpful model to consider in constructing your project final report. It is eminently useable as it provides the report author with a set of headings which can be used to neatly fit those themes.

- **Tangibles**: physical facilities, equipment, personnel and communication materials
- **Reliability**: the ability to perform a promised service dependably and accurately
- **Responsiveness**: the willingness to help customers and provide prompt service
- **Assurance**: the knowledge and courtesy of employees and their ability to convey trust and confidence
- **Empathy**: the caring attitude which provides individualised attention to customers

(Parasuraman et al 1985)
RECONVENING THE TASK AND FINISH GROUP

Now you are in a position to look at what you have found during the project. You should have clear themes or strands. You may have decided to group your findings into Good Practice/Learning Opportunities and Mixed.

It is really important to acknowledge (and make sure others do as well) the good practice which exists and promote and encourage its continuation. The really exciting nuggets of information are the Learning Opportunities for service improvements.

TASK & FINISH GROUP RESPONSIBILITIES AT THE REPORT PHASE

✓ Identifying the top themes or trends which need to be addressed

✓ Identifying who needs to know about them: disseminate your final report as widely as possible. **Do remember that a copy needs to go your organisation’s Executive Board**

✓ In addition you should consider sending copies to:
  • Clinical Governance/Quality Board
  • PPI Board and lead
  • Research and Development Group (if appropriate)
  • Ethics committee (if appropriate)
  • Directorate/clinical lead
  • Directorate Clinicians (Consultants)
  • Senior Nurses and Ward Managers in the relevant clinical area.
  • Training and Development Department

✓ You may also decide to send out a summary of the **final report** including service improvements resulting from the project to:
  • Organisation’s patient panel or forum

Continued...
✓ You may also decide to send out a summary of the final report including service improvements resulting from the project to:
  • Organisation’s patient panel or forum
  • Community Health Council
  • Trust Communications team (media officer)

✓ Providing recommendations on what to do in order to encourage the relevant clinical areas to reflect on the findings and develop their own strategies for service improvement and sharing good practice

✓ Agree a mechanism by which they can revisit the service improvements at a later stage to measure and record the project’s impact

✓ Champion and support the continuation of Discovery Interviews/Patient Story Collecting as an essential aspect of Organisational Learning

✓ Share what you have learnt and changed to help to embed best practice throughout your organisation (for example training sessions, audit and service review days, organisation award schemes) and potentially beyond it. Consider contacting national or region projects and campaigns who have a declared interest in Patient Public Involvement feedback

End.
HOW TO MAKE SERVICE IMPROVEMENTS AND CHANGES AND BEYOND…

This is where your Executive or Non Executive project champion will be a real asset to you. Depending on your clinical area or your organisation you may find it a challenge to get support to make recommended improvements and changes - but don’t despair!

Here are some really important things to remember about service improvements and changes:

- They don’t have to cost a fortune
- They may be easy to implement
- They may make a huge difference to patients and the public who use your service
- They will clearly demonstrate your organisation’s commitment to listen to its service users and respond to their needs
SOME HINTS AND TIPS

✓ Don’t try to change the world overnight

✓ Make the most of anybody in your organisation who has a genuine interest and enthusiasm in helping to affect change. Identify colleagues with a can be done outlook and involve them along with managers and staff who work in the areas where service improvements are indicated.

✓ Remember that the most effective change agents are the people who will have to make it happen and commit to ensuring that once changes have been made they stay changed.

✓ Make discussions about potential service improvements and how to develop them as broad as possible and do be sure to listen to peers and colleagues as well as patients/carers who may just have good suggestions that you haven’t even thought of.

✓ Choose the easy to do work first and leave the harder to do stuff until you have clear plans and commitments to support it.

✓ Someone else may already have done the hard work and be willing to share it so it can be adapted.

✓ Whatever you learn or change as a result of all your hard work: don’t forget to shout about it!
  • Put information on your organisations intranet
  • Do presentations for your clinical area and directorate
  • Ask to presentation to organisation boards such as Quality, PPI and Clinical Governance (if you aren’t sure which ones you should go to talk to a senior colleague about it,)
  • Consider writing up your work in your professional journal and finally

If there are any local or national award schemes which your effort would qualify for do submit a paper.

Patient inspired service improvements from the SEWCN project can be found in Appendix XI (page 124)
REYON SERVICE IMPROVEMENTS

As this kit is being written (Summer 2008) the emphasis on a patient centred and qualitative approach to health care is becoming increasingly important as a core message of the Welsh Assembly Government’s expectations of health delivery in Wales. The 1000 Lives Campaign and the Safer Patient Initiative are firmly rooted in this philosophy and approach and the South East Wales Cardiac Network share the vision that in the future Board meetings, Task and Finish Groups and learning sets will use patient and carer experiences and feedback as the stepping stone on which their efforts are focused. There is a real opportunity to utilise the contributions of the public and the hard work of interviewers/collectors in this process. Here are some suggestions about these contributions might be put to work:

Organisational Level.

✓ Central collation point for all patient/carer interviews/stories to be stored and publicised
✓ Organisation wide access to this resource for use in Board Meetings, Task and Finish Groups etc.
✓ Use by PPI team of feedback and service improvements using these resources
✓ Use by Training and Development teams in study days and courses to embed patient/carer experiences as a strong central theme

Local Level.

✓ Use by managers and staff at operational level to include interviews/stories in governance and quality settings
✓ Using interview/story projects as a learning tool in response to service user complaints and feedback
✓ Presenting these activities as evidence of PPI work in Healthcare Standards etc.
✓ Using interview/story projects as a staff development tool
7. CONCLUSION

As I have been constructing this How to Kit it has dawned on me just how much work is involved in the Discovery Interview/Story Collecting process. I really hope that you will not be daunted by it or throw in the towel when I point out that this is not a definitive Kit and that there are likely to be new things for you to consider as you go along.

I also hope that you will be inspired by the prospect of having an opportunity rarely found in today’s health service of time to sit down with patients and carers and listen to what they have to say, that you will be stimulated by the prospect of being able to reflect on what the service you deliver can offer at the moment and in the future and that you will reignite the spark that made you want to be a Health Professional in the first place.

“The most erroneous stories are those we think we know best - and therefore never scrutinize or question”.

8. REFERENCES


APPENDIX I

EXECUTIVE BRIEFING TO BOARD

(GENERIC VERSION)

Sent out to each of the Network Partner Trust Executive Board as part of the project development process
INTRODUCTION

As part of the Department of Health Cardiac Heart Disease (CHD) National Service Framework, a major Discovery Interview project was developed in England to incorporate the Patient perspective into CHD service development. Discovery Interviews were undertaken as a qualitative and data rich source of evidence of good practice and areas for reflection and change. The South East Wales Cardiac Network created a part-time role within their structure for a Discovery Interview Facilitator/PPI-E Lead who would empower Network members (initially Acute Sector Trusts) to develop a cohort of Discovery Interviewers with the specific purpose of listening to the Patients experience during their journey through the NHS. Pontypridd & Rhondda undertook the Pilot work for the Network in February 2006.

WHAT WE ARE DOING

Working with Networks to build a cohort of staff who can undertake Discovery Interviews to explore their own Cardiac Services. Work in Cardiff & Vale is well underway, North Glamorgan are about to start their first tranche of interviews and Gwent are in discussion. On completion of the interview and transcription phase of the project, the Discovery Interview Facilitator scrutinises the transcripts and extracts the pertinent information which is then embedded in the report prepared for the Trust Steering Group. It is the Network member Trust’s responsibility to identify what Learning Opportunities can be reviewed and reflected upon, make recommendations and implement and evaluate change.

HOW WE DO IT

The Network has already received SEWREC approval for the Discovery Interview Protocol. In house ethical approval to undertake the project is essential, without it the project cannot begin. Joint ethical approval of the Discovery Interview Facilitator and the person identified within the Directorate as the Principal Investigator, as well as the project itself is required. All patients are identified by a unique marker to protect their anonymity. On completion of the transcription the tape is destroyed.

The Principal Investigator (usually with a Cardiology Clinician) then identifies what area of Cardiac Services they wish to explore and selects the target patient group, using the Protocol and local criteria.

Patients are invited to participate in the interview. Enhanced skilled staff (who have attended special sessions provided by SEWCN) then make contact with the patient and visit them to record the interview. A semi-structured form of questioning is used, the objective being to follow the patient’s journey from the outset of their diagnosis through to their present situation. The skill of the Discovery Interviewer is in extracting as much information as possible about each significant patient-professional throughout the patients journey. Interviewers are encouraged to give equal weight to each clinical group as well as eliciting the patient’s story in a holistic manner which incorporates physical, emotional, lifestyle perspectives. The experiences, learning opportunities and outcomes will be shared across the whole of the Network in order to provide the maximum benefit to patients and health organisations.
HOW IT CAN BENEFIT YOUR TRUST

Well conducted Discovery Interviews offer a 360 degree snapshot of Cardiac Heart Disease services. They enable Trust staff at all levels to see what they do well and how they can further enhance the patient experience and their own practice. The level of engagement with patients represents real PPI reaching far beyond a paper exercise and enables the patients voice to be heard and responded to in a demonstrable way, enhancing partnership with the community who use health care services.

For the Trust staff who become Discovery Interviewers it enables them to follow the patient on their journey and acquire a better understanding of how the NHS fits together for patients.

It also offers opportunities to develop enhanced communication and listening skills which can be used in daily practice and promoting these skills amongst their peers by example. It is a valuable way for staff to develop their personal and professional profile. Whilst staff engaged in the project will undertake interviews for the Cardiac Directorate, the skills they acquire are eminently transferable and can be utilised in their own clinical area for future work.

WHAT WE NEED FROM YOU

Agreement was reached at Network level to ensure:

✓ Experienced and committed staff member to undertake the role of Principal Interviewer.
✓ Protected time and travel expenses for staff undertaking Discovery Interviews.
✓ Recording equipment.
✓ A Trust admin support person skilled to undertake the transcription work.
✓ A commitment from the Trust to ensure that all issues identified in the DI report are reflected on seriously, that all outcomes from this reflective process are fed back to the SEWCN with a rationale for their action or rejection.

RESOURCE IMPLICATIONS

One off three day periods to learn about the project, process, enhance skills and practice.

Two to two and a half hours to undertake the interview (plus travelling time), one to two interviews per person per year (for the Network).

WHAT YOU WILL GET FROM US

SEWCN will provide support from the Discovery Interview Facilitator, skills enhancing (training) sessions, a completed report for the Trust for each tranche of interviews, shared Discovery Interview data, learning opportunities and outcomes from across the Network.
APPENDIX II

REALISING THE BENEFITS OF DISCOVERY INTERVIEWS
WHAT TRUSTS AND BOARDS NEED TO DO

Executive Briefing Paper Prepared by Jane Price Discovery Interview & Patient Public Involvement Facilitator
Whilst some improvements have been made to services, experience is showing that Discovery Interviews Steering Groups on their own are having difficulty in making the changes needed to realise the benefits of their findings. Discovery Interviews are not an end in themselves - they are only ultimately of value if Trusts actively implement some of the changes that they suggest. The four Trusts in South East Wales have all shown demonstrable commitment to enabling staff to train and undertake interviews, but the level of follow through to implementing change is proving far more challenging. The processes involved in training, interviewing, transcribing, and reporting involve time and resources and it is frustrating and disappointing for those committed and enthusiastic staff who undertaken the work not to have the support they need to realise the benefits. Many of the service improvements that can be made are cost neutral, but require leadership and imagination to put into effect. This is not something that is in the gift of the Network Discovery Interview project. Implementing change needs to be committed to and undertaken by each organisation and the improvements periodically reported back to both the Trust and the Cardiac Network Boards.

The following recommendations are made to enable Trusts to realise the benefits of their investment in Discovery Interviews:

i. Demonstrable commitment at Trust Executive level to continue undertaking Discovery Interviews as a means of gathering patient views on cardiac services

ii. Support for Discovery Interview leads and staff at Directorate level in managing and undertaking Discovery Interviews

iii. Commitment to evaluating findings and identifying areas for service improvement

iv. Commitment to provide mechanisms and resources to learn from and make changes where appropriate

v. Periodical reporting back to Trust and Cardiac Network boards of project findings and any service improvements which result

vi. Continuing opportunities for staff involved in the Discovery Interviews/Story Collecting projects to network with colleagues across the whole of the South East Wales Cardiac Network

vii. Encouraging and supporting the growth of Discovery Interviews throughout the organization, wherever there is active interest
APPENDIX III

DISCOVERY INTERVIEW PROCESS
FLOW CHARTS
**DISCOVERY INTERVIEW FLOWCHART**

**PHASE ONE**

**DISCOVERY INTERVIEW PATHWAY**

- Approach the Trust (PPI/E Lead)
- (Cardiac Directorate Manager)

- Identify Project Leads

- Identify Potential Interviewers (corpus 8-10 total)

- Identify Task and Finish Group

- Hold inaugural T & F Group Meeting to identify patient cohort

- Secure Protected Time:
  - Travel Costs, Secretarial Support
  - Recording Equipment

- Potential interviewer introduction:
  - (SEWCN DIF job)

- Skills Building Sessions:
  - x 2 full days
DISCOVERY INTERVIEW FLOWCHART

PHASE TWO

1. Project Leads select patient cohort and write
   - Collate cohort responses and pair with interviewers
     - Carry out quality checks and feedback to interviewer
       - Interviewers contact patient and arrange appointment
         - Carry out interviews
           - Review recording
             - Hand to secretary for transcription
               - Secretary transcribes
                 - Secure tape
                   - Destroy / Store tape as agreed
                     - Analyse theme and report on transcripts
                       - Reconvene Task and Finish Group

DISCOVERY INTERVIEW FLOWCHART

PHASE THREE

- Project Leads collate responses
- Secretarial support duplicates and disseminates reports
- Project Leads contact Directorate staff to confirm planned service improvements
- Directorate staff make service improvements
- Report progress to Task and Finish Group
- Task and Finish Group:
  - Review Report
  - Make recommendations
  - Identify recipients
APPENDIX IV

DISCOVERY INTERVIEWER PROTOCOL
Protocol for Potential Discovery Interviewers

Author: Jane Price
Discovery Interviewer Facilitator and Patient Public Involvement Lead
South East Wales Cardiac Network

Revised 2008
CONTENTS

1.0 Introduction

1.0.1 Project Leads: responsibilities

1.0.2 “Recruiting” Discovery Interviewers

1.0.3 Core Essential Attributes for Discovery Interviewers

1.0.4 The Next Step

1.0.5 Discovery Interviewers: Responsibilities

1.0.6 Supporting and Retaining Interest
1.0 INTRODUCTION

In order to build on previous work for the project, this document was devised to be used by Network Partnership members carrying out Discovery Interviews/Patient Stories in collaboration with SEWCN.

The context of this document relates to the SEWCN project 2006-2008, however the principles can be applied to any similar projects.

Use of the document is intended as an aide and if it is suitable can be used freely and adapted to fit local needs and issues.

It is important to adopt an ethical practice approach to those partner Trust staff that are directly involved in any project. This work will be carried out by busy staff in addition to their day to day responsibilities. Their contribution to Patient Public Involvement and organisational learning through service improvements needs to be both acknowledged and supported at local, Directorate and Executive Level.

The well-being of staff, their ability to carry out the role, appropriate support and safety nets, personal well being and satisfaction, induction and skills training to carry out the interviews professionally and confidently, protected time and the knowledge that the work they are engaged in is making a difference, are all essential contributors to a successful outcome. By ensuring that these elements are addressed it is hoped that Discovery Interviewers/story collectors will be motivated and enthusiastic, prepared to continue in the work and possibly encourage others to engage in it beyond the boundaries of their own clinical area.

Refer to the SEWCN How to do it Kit for further information on setting up Discovery Interview/Patient Story projects.
1.0.1 Project Leads: Responsibilities

In each Trust the Cardiac Directorate Manager has identified the Principle Investigator as Trust project lead. They have ethical approval from both C.O.R.E.C and their local ethics board. In addition to leading or serving on the Steering Group it is to be hoped and encouraged that they will take responsibility for the following elements:

- Identifying or assisting in, the identification of suitable potential patients for the project.
- Liaising with the Lead Facilitator at SEWCN to initiate contact with potential patients.
- “Recruiting” potential Discovery Interviewers (see 1.0.2).
- Ensuring, with the support of training sessions and the Lead Facilitator that potential Discovery Interviewers have a broad understanding of the purpose of the study and what would be expected of them.
- Collaborate with the Lead Facilitator at SEWCN to ensure that Discovery Interviewers are appropriately trained, supported and receive feedback relating to the outcome of the interviews, which have taken place in their Trust.
- Ensuring that Discovery Interviewers have made an informed and valid decision to commit to the study and that they know they can withdraw at any time without explanation and with confidence that it will not prejudice their professional reputation or potential.
- Support the Discovery Interviewers through the process of explaining the study; its implications and the securing of protected time to carry out the interviews, in harmony with locally agreed conditions.
- Act as an informal or formal (according to need and choice) point of contact for Discovery Interviewers to feedback to following interviews.
- Discuss with Discovery Interviewers the need for and details of a mutual support network or “buddying” system to be agreed and arranged at a local level.
- Ensure that Discovery Interviewers who express an interest are kept informed of any actions that result from the Steering Groups analysis of the content of the interviews.
FOOTNOTE

Whatever the size of your project (unless you are doing only one or two interviews/stories) it is important to have a project lead whose overall responsibility will be to co-ordinate all phases of the project. The project leads should not be involved in the interviews/collection process. The more patients/carers who are involved then you will need to have a second to help the lead, cover for sickness etc. Do remember that the Task and Finish Group should be able and willing to help with some of the lead responsibilities and don’t be afraid to delegate.
1.0.2 “Recruiting” Discovery Interviewers

It is a reasonable conclusion that trained nurses are most likely to be the natural choice for this role. It is important however to recognise that colleagues from other disciplines are likely to have an interest and the necessary attributes to engage in the study.

Whilst it is undoubtedly useful to draw from a pool of nurses who have undertaken the R.C.N Clinical Leadership Course those who have not done so should not be discounted.

A potential “bonus” of the scheme is that it provides the Discovery Interviewers with a valuable opportunity to gain a greater insight into the experiences of patients and carers. This insight could inform their day-to-day clinical practice and influence the way in which they interact and care for patients. With this in mind it may be worth considering “widening the net” to include others ECG technicians, physiotherapists, specialist dieticians, occupational therapists etc.

The Principle Interviewer in the Trust may find it helpful in considering who to approach initially to select individuals who they know professionally or whom trusted colleagues think may be interested and appropriate: an informal “reference” as it were.

Securing interest and local management support should be reasonably straightforward; the study is pertinent and has value in terms of Clinical Governance, Quality, Statutory expectations in relation to Patient Public Involvement & Experience and professional and personal development.

The “qualifications” which the Principle Investigator may find helpful to look for when considering potential Discovery Interviewers are outlined on the next page.
1.0.3 Core Essential Attributes for Discovery Interviewers

Effective Communicator

✓ Attentive Listener
✓ Skilled Questioner
✓ Astute Observer

Professional Attitude

✓ Awareness of professional scope
✓ Practices within boundaries
✓ Ability to recognise when issues are raised that need to be addressed outside of the interview arena.

Enthusiasm for the project

✓ Empathy towards patient and carer experiences
✓ Commitment to service improvement

Emotional Maturity

✓ Reflective practitioner
✓ Objectivity
✓ Impartiality
✓ Personal reflection and insight

Commonsense

✓ Awareness of and adherence to Trust Lone Worker Policy
✓ Sensitivity to environment and atmosphere
1.0.4 The Next Step

Having identified and approached a potential Discovery Interviewer an information pack should be provided. The pack should contain:

- A welcome letter from the Network
- A copy of the SEWCN Discovery Interview Protocol and Patient Information
- A copy of this document
- Contact details for the Lead Interview Facilitator at SEWCN

If the potential Discovery Interviewer makes the decision to proceed then they should be encouraged to make contact with a Discovery Interviewer who has already undertaken training and carried out an interview - it is envisaged that in some circumstances this may involve contacting someone in a neighbouring Network Trust.

(Over time a “buddying” directory should evolve which the Principle Investigators will have access to, with consenting Discovery Interviewers contact details. The buddy would then initiate contact with the potential Discovery Interviewer).
1.0.5 Discovery Interviewers: Responsibilities

✓ A clear understanding of what participating in the project means

✓ Written agreement from line & Directorate manager to participate in the project, including protected time for study days, interviews and reimbursement of travel costs

✓ Mandatory attendance of initial skills training provided free of charge by S.E.W.C.N.

✓ Regular contact with the Principle Investigator (to be mutually agreed)

✓ Initiate phone contact with identified patient to make arrangements for the interview

✓ Collection and familiarity of the recording equipment

✓ Provision to the participating patient of documentation

✓ Establishment of participating patient’s informed and valid consent to carry out the interview

✓ Safe keeping of the tape and the equipment following the interview

✓ Delivery of the tape for transcription (in accordance with locally agreed arrangement)

✓ Identification at the time of interview of any significant **non cardiac specific** issues that are not covered in the scope of the study

✓ Explaining to the patient at the time of interview that:

✓ Some concerns they have talked about may be discussed with the Principle Investigator & the project lead (SEWCN Facilitator.)

✓ Permission to contact the patient later if clarification is needed during the writing up or collation stage

✓ Referral back to the Principle Investigator of any issues that arise during interview which relate directly to their Cardiac Health
1.0.6 Supporting and Retaining Interest

The Principle and Discovery Interviewers in each Trust are undertaking the study on a voluntary basis. It is important that the S.E.W.C.N need to acknowledge and value this. The following measures should help to support and promote continuing commitment:

- Information and clarification of the study
- Training opportunities
- Promotion of prompt interview assignment following training
- Strong links to the Principle Interviewer and Discovery Interview Team
- Feedback from the Discovery Interview teams to the S.E.W.C.N Discovery Interview Facilitator
- Encouragement via Directorate Lead Manager for Discovery Interviewers to attend Steering Group meeting as observer/contributor
- “Get together” day - to meet up with colleagues from Network Trusts and share experiences and developments (annually)
- A formal thank you to each participant from the SEWCN core group - copied to Trust Board and participant line managers
APPENDIX V

SKILLS BUILDING DAYS PROGRAMMES.

USED DURING THE SOUTH EAST WALES CARDIAC NETWORK DISCOVERY INTERVIEW PROJECT.

Note: Materials used on these days can be found on the learning zone on the 1000 Lives Campaign Website (http://www.1000livescampaign.wales.nhs.uk)
Day 1

9.00 am  Arrive and coffee etc...

9.30  Icebreaker What’s in my suitcase?

10.15  Bigger picture & our back yard

10.45  Ian’s story

11.00  BREAK

11.15-11.30  Group work & Feedback

11.45  DI Process

12.45 pm  LUNCH

1.30  Post lunch energizer & Quiz

1.55  DI Story - listen to a recording & Group work

3.00  BREAK

3.15  Stuff happens

4.00  Reflection and evaluation

4.30  Finish and home
SEWCN DISCOVERY INTERVIEW SKILLS BUILDING WORKSHOP

Day 2

8.30 am  Coffee
9.00  Icebreaker
9.15  Establishing and building rapport + communication
10.30  BREAK
10.45  Re-introductions & Ice Breaker (2 truths and a lie) - How not to do and how to do an interview
   Open / Closed question exercises
12.30 pm  LUNCH
1.15  The Big Interview Experiment
2.30  BREAK
2.45  Dealing with “Stuff”
   Reflection and evaluation
3.30  Finish and home
SEWCN DISCOVERY INTERVIEW REFRESHER DAY

MONDAY 28TH JULY 2008 - LLANFRECHFA GRANGE CONFERENCE CENTRE

9.30 am  Introduction and about the day. Review of “homework”!!

9.35  What they want to get from the day (your two things each)?

9.45  Exercise 1: Question techniques

10.00  Exercise 2: Question techniques

10.15  Exercise 3: Listening, analyzing & feedback

10.35  Reminder session: Brainstorm or Idea Shower!! - Getting the best from interviews

11.00  BREAK

11.20  Exercise 4: More listening and analyzing.

12.00  Actors arriving, introductions reviewing the morning session.

12.30 pm  Lunch

1.00 - 3.00  Practice Practice Practice! Interviewing & observing & feedback: Two groups.

(Take small natural breaks as they occur)

3.00  Question opportunity. Evaluation

3.30  Finish and home
APPENDIX VI

SAMPLE PROFORMAE:

PARTICIPANT’S INVITATION/REPLY LETTERS AND INFORMATION SHEET
Improving Heart Services

We would like to invite you to help us find out what it’s like to use our cardiac services. It’s important to us that we use your experiences to assist us in thinking about and developing our services in the future.

If you choose to take part it would involve:

♥ A Discovery Interviewer listening to you & making a tape recording of your experience.

♥ A paper version of the recording, which makes it impossible to identify you, will be made & your recording will be destroyed.

♥ Local health care staff getting together talk about the views of carers such as yourself to look at what changes & developments would provide people like yourself with the support & information you need.

♥ Helping health care staff throughout the South East Wales area understand how to develop cardiac services based on what you and others who take part in the project have said.

We are enclosing an information leaflet that should answer any questions you may have.

Your partner or your main carer may like to have their say as well and they are very welcome. Just include their name on the reply form if they want to take part. If they decide that they want to tell us their story we will generally arrange for them to be interviewed separately by another interviewer.

If you feel able to help by taking part please complete the reply slip and post it back to us in the pre paid envelope.
You will then be contacted by one of the Discovery Interviewers. Please don’t worry if you decide not to take part, you don’t have to explain why and it will not affect your care in any way.

The attached Patient Information Leaflet gives you more details about what to expect. Whether you decide to take part or not, you do not have to give a reason and it will not affect your treatment or care now or in the future.

If you would like more information before deciding please contact me on Tel No:

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

We would also be interested in learning from the experiences of your main carer if you have one. A carer may be a husband or wife, daughter or son, a relative, friend or companion who may or may not live with you. If your carer wishes to take part please let us know on the reply slip and we will write to them separately.

Thank you for taking the time to read this letter and considering taking part.

Yours sincerely

Project Lead Name & Job Title
Contact details here
REPLY FORM
DISCOVERY INTERVIEWS

Using the Discovery Interview technique to learn from patient and carer experiences to inform developments in delivery of cardiac care.

Please tick the appropriate box

♥ I am interested in talking to someone about my experience ☐
♥ I do not wish to take part ☐
♥ My carer would be interested in taking part (husband or wife, daughter or son, relative, friend or companion) ☐

Name: ........................................................................................................................................

Day time Tel No: ............................................................................................................................

Mobile No: ....................................................................................................................................

Email address: ............................................................................................................................... 

Address: ....................................................................................................................................... 
...................................................................................................................................................
....................................................................................................................................................
Carers details

Name: ...........................................................................................................................

Day time Tel No: ...........................................................................................................

Mobile No: ...................................................................................................................

Email address: .............................................................................................................

Address: .....................................................................................................................
........................................................................................................................................
........................................................................................................................................

Please use stamped, addressed envelope to return to:

Insert Project Lead’s contact details here

Code: ............................................................................................................................
I still have some Questions, Who Can I talk to?

A. Please contact your local Principle Investigator:

**FREQUENTLY ASKED QUESTIONS**

**Ever Wanted to Have Your Say?**
About your Healthcare.

**Would You Like to Help the NHS in your area?**
And have a little spare time.
♥ IMPROVING LOCAL HEART SERVICES

We’d like to invite you to take part in a project, which we are doing along with the South East Wales Cardiac Network to improve heart services. Before deciding if you would like to help, we want to explain why the project 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 about anything that is not clear or if you would like to know more. Take time to decide whether or not you think you may want to help.

♥ WHAT IS THE PURPOSE OF THE PROJECT?

We want to hear from adult patients who have been or are receiving treatment for a heart condition. We are also interested to hear about carers’ (i.e. a spouse or partner, close family member or companion) experiences. The important thing is that we hear your story in your own words. These stories are known as ‘discovery interviews’.

♥ WHAT HAPPENS TO THE INFORMATION WHICH PEOPLE TELL US?

Local health care staff will be given a report, which includes quotes from the Discovery Interviews to help them learn how their services affect patients and carers. This is really useful as it helps staff discover what they are doing well and explore areas where they may be able to make changes that can improve services. Work already done in other parts of the UK has proved that this type of project is very productive and can make a real difference.

♥ WHY HAVE I BEEN CHOSEN?

You have been selected as you have recently received care or treatment for your heart condition. It is likely that we will be interviewing at least twenty patients and carers in your local area.

♥ DO I HAVE TO TAKE PART?

NO. If you do not wish to just return the letter and the information in the prepaid envelope without filling anything in and we will not contact you. You don’t have to give us a reason and saying no will not affect the care you receive.
I WOULD LIKE TO TAKE PART WHAT SHOULD I DO NEXT?

Keep this information sheet and the consent form, on the day of your interview you will need to sign it to show that you have agreed to do the interview. Remember: If you decide to take part you are still free to change your mind at any time, even during the interview, without saying why. If you decide not to go ahead with the interview it will not affect the care you receive.

I WAS VERY UNHAPPY WITH MY TREATMENT AND HAVE MADE A FORMAL COMPLAINT ABOUT IT, CAN I STILL DO THE INTERVIEW?

YOU MAY BE ABLE TO. If your complaint has been completed and you are satisfied with the response and not intending to do anything further about your complaint. Please contact the Principle Investigator who contacted you to discuss your situation.

WHAT DO I HAVE TO DO?

If you are interested in taking part, please return the reply slip attached to the letter and keep the rest of the paperwork. You will then be contacted by the person who is going to interview you to arrange a date and place convenient to you. Any questions you have can be discussed with the caller.

CAN MY CARER HAVE THEIR SAY AS WELL?

Yes of course. We would be happy to hear from them. To make sure that you both get to say what you want we can arrange to do separate interviews. If you both think you would like to be interviewed together talk to the Discovery Interviewer about this when they telephone you.

WHAT HAPPENS AT THE INTERVIEW?

The Discovery Interviewer will ask you to talk about your recent experiences of cardiac care. They have been directed to ask you some questions to help you tell your story, it is important that you tell this in your own words.

WILL I KNOW THE INTERVIEWER?

NO. To make sure you feel completely comfortable to tell your story - whatever you have to say, the interviewer will not be someone you know or who has been directly involved in your treatment or care.
WHERE WILL THE INTERVIEW HAPPEN?

It’s up to you. You can choose where you wish the interview to take place, this may be in your home 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. Any travelling expenses incurred will be refunded.

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 story and they will not be disclosed at any time.

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. Experiences from the written story may be shared with others for the purpose of education and training.

CAN I KEEP A COPY OF THE TAPE?

YES. If you would like to, you will need to tell the interviewer when they visit you to make the recording, otherwise the tape will be destroyed after it has been typed up.

WHO WILL HEAR THE TAPE?

The person who is typing up your story will be someone working in the Trust who is bound by a Confidentiality agreement. The Discovery Interview Lead from the Cardiac Network may listen to your tape to ensure that the interviewer is getting the best from the people who they interview.

Occasionally patient stories may be really useful for teaching purposes, if your story is suitable you will always be contacted to fully explain what that would involve and NOTHING will happen without your permission. The interviewer will ask you when you meet to do the recording whether you would be prepared to consider this or not. They will make a note of it and give you a copy for your records.
WHAT HAPPENS IF SOMETHING GOES WRONG?

If you mention something during the interview about your health which concerns the interviewer they will discuss it with you after the recording finishes.

If you tell the interviewer something that occurred during your treatment and care that may suggest unacceptable or unsafe practice, the interviewer will be required to report this matter. This is because all NHS Staff are bound by Professional & Employment conditions to make sure that patients are kept safe & report anything that may suggest poor practice.

In the unlikely event of this happening, the interviewer will discuss this with you and explain what will happen. If you have any concerns about this please tell the Discovery Interviewer who will give you contact information.

WHAT WILL HAPPEN TO THE RESULTS OF THE INTERVIEWS?

The stories may be used to help improve cardiac health care at a local or national level. The stories and any resulting service developments may be shared with other cardiac teams in Wales.

HOW WILL I KNOW THAT WHAT I HAVE SAID HAS MADE A DIFFERENCE?

It will take some time to make some of the changes that are indicated by the things that you and others who take part in the project tell us. It is not possible to let you know on an individual basis about your story specifically, but we would like to offer you the chance to read about the progress of the project & the differences it has made. If you would like to be informed please tell the Discovery Interviewer when they come to see you that you agree to your name & address being added to the Project Mailing List.

WHO IS ORGANISING THE PROJECT?

The South East Wales Cardiac Network is organising the project collaboration with your hospital.

WHO HAS APPROVED IT?

This study has undergone a rigorous development process and been approved by the NHS South Wales Research Ethics Committee and the Research Department of your local Trust.
APPENDIX VII

SAMPLE CONSENT FORM
DISCOVERY INTERVIEW CHECKLIST & CONSENT FORM

Discovery interviewers copy

Please complete this form & the interviewee’s copy with the patient/carer **before** you start the interview. Use prompt questions to ensure that both you and the interviewee are clear that you understand each other.
The interviewee:

♥ Still wants to do the interview

(If they don’t, reassure them it will not affect their care)

Understands:

♥ The purpose of the interview & how the information is used
♥ That they can withdraw from the project at any time
♥ Knows how they can withdraw after the interview

Does or Does Not (delete as applicable)

♥ Does/ Does Not want to be sent information about the outcome of the project
♥ Does/Does Not want to consider their recording being considered for training purposes
♥ Does/Does Not want a copy of their tape & typed transcript
♥ Has given permission for you to notify
INTERVIEW IDENTIFICATION CODE: [Redacted]

Complete following section only if the interviewee wants further contact following the interview.

I ………………………...

Give my permission for the Discovery Interviewer to contact the Discovery Interview Facilitator at South East Wales Cardiac Network regarding their choices.

Name

Address & Day time Phone Number

Mobile No. /Email address

Insert Trust Logo here
Thank you for agreeing to help us with our project. The Discovery Interviewer has been asked to go through this form with you before you start the interview. If you have any questions or concerns about the interview or what happens after, please talk to the Discovery Interviewer now.

Interviewer before you start the interview.
DISCOVERY INTERVIEW CHECKLIST & CONSENT FORM

Interviewee Copy

Please tick the boxes

♥ I am still prepared to do the interview

I Understand:

♥ The purpose of the interview & how the information is used

♥ That I can withdraw from the project at any time, even after the interviewer leaves

If you changed your mind don’t worry just tell the interviewer now - changing your mind is not going to affect the treatment or care you are getting. If you decide later on that you DON’T want your interview used you contact the South East Wales Cardiac Network Office.

I Do /Do Not (delete as applicable)

♥ I Do /Do Not want to be sent information about the outcome of the project

♥ I Do /Do Not want to consider their recording being considered for training purposes

♥ I Do /Do Not want a copy of the tape & typed transcript

♥ I have given permission for you to notify the Discovery Interview Facilitator at South East Wales Cardiac Network regarding my choice to have further information/contact

If you change your mind later about anything on this form please contact:

📞 email

South East Wales Cardiac Network

Discovery Interview How to Kit
Final Version - 1/12/08
APPENDIX VII (A)

DISCOVERY INTERVIEW BE PREPARED AND PERSONAL SAFETY LIST
BE PREPARED - BEFORE YOU GO!

INTERVIEW KIT

Consent Forms
Spare FAQS Booklet
Trust Complaints Leaflets
Directions to home address
Contact number of participant

Recording Equipment & spare batteries CHECK IT WORKS BEFORE YOU LEAVE AND CHECK AGAIN BEFORE YOU START THE INTERVIEW!

Note Pad & pen
Packet of tissues

FULLY CHARGED Mobile Phone

Watch or timer device
PERSONAL SAFETY CHECKLIST

In addition to this list you should make sure that you know your local lone worker policy and follow it for the purposes of carrying out a home interview. If you feel at all uncertain about visiting someone’s home alone then make an alternative arrangement.

ALWAYS

! Tell a colleague where you are going, when and what time you will be finished. Leave the details of the person you are visiting with a colleague.

! Arrange to phone in after you have finished and make sure they know what to do if you don’t contact them.

! When you arrive, make a mental note of the front door mechanism

! The interview must take place in a downstairs room. If the participant is not able to do this then abandon the interview.

! If there are pets in the room which may be a potential threat ask the owner to move them somewhere else. If you feel uncomfortable about asking explain that you are nervous or have an allergy: it’s up to you to decide what you want to say.

! Try to position yourself so that you a clear exit from the room

IF AT ANY TIME THE PHYSICAL OR VERBAL BEHAVIOUR OF THE PERSON YOU ARE VISITING LEADS YOU TO BELIEVE THAT YOU MAY BE AT RISK MAKE AN EXCUSE AND LEAVE IMMEDIATELY.

TELL YOUR LINE MANAGER OR PROJECT LEAD AND FILL IN AN INCIDENT FORM.
APPENDIX VIII

SAMPLE QUESTION SPINE

Note: This “tool” was packaged as a landscape format A5, “back to back” laminated set.
DISCOVERY INTERVIEW PROMPTS

Developed by Lynne Williams.
Modified by Jane Price November 2006
Discovery Interviewers Checklist

- Name, address & contact details of interviewee.
- Directions.
- Mobile Phone.
- Prompt cards.
- Recording equipment & accessories.
- Copy of interviewee consent document.
- Notebook & Pen.
- Watch or timer device.

These prompt cards are designed to assist in the course of your interview work with the patient/carer. Some interviewers prefer to have a structure in their head; however, an aide memoir may be useful to you especially in the early days of interviewing.

💡 It is important not to be too directive or proscriptive during the interview. The prompt cards can help if either you or the interviewee appear to be getting stuck or repeating yourselves.

💡 If something is said which is clearly important to the interviewee or may be valuable to pursue, please do so - the content of the story is what matters, not starting at Point A & finishing at Point Z! Don’t be afraid to stop the interviewee to clarify information and do remember that you will need to warn them when you are approaching the need to turn the tape over or the end of the tape is close.
Looking back to the beginning of your illness, what has it been like for you and your family?

What particular events stick in your mind?

(As a person, fears & anxieties, uncertainties, good & bad things, what you needed etc)

Thinking that something was wrong

What first made you think that something may be the matter with your heart? Initial symptoms/attack

What happened to you next?

Seeing someone in the NHS (Being assessed)

What did you think about the time you had to wait for this to happen?

What can you remember about the assessment?

What was good/ not so good about the assessment?

Having tests to find out what was wrong

What can you remember about this?

(How you were prepared for them, why the tests were done, how you felt when you were having them done)

Being told the results of the tests

What do you remember about being told your diagnosis?

(Who was with you, how did the doctor seem, what were you told, what did you understand about what you were told, how did it make you feel immediately after you heard it etc)
To keep the story moving don’t forget to ask questions such as - What happened then, how did that make you feel, why do you think that happened/didn’t happen etc.

Having treatment

*What were you told about the treatment for your condition?*

(Who told you about the treatment plan, how were you told, what options were you given, what agreement did you come to, how did you feel about the process etc)

As they are talking about a particular aspect of their story and before they move on to another, it may help to ask:

What particular thing about this situation stick out in your mind?

(Good & not so good experiences, frustrations etc.)

Thinking about your experiences with the Healthcare people you came into contact with, what was it like for you?

*What sticks in your mind?*

*How did it make you feel?*
Being followed up

What happened after you were.....?

This question can be used throughout the interview.

Getting Better

Now that you have had your treatment how would you describe your health?

(What difference has it made to you - if interviewer can recall the symptoms the interviewee described in the early phase of the story it may help to use comparison e.g. You talked about how breathless you were before you realised you had a heart condition - how is it now you are on treatment?)

If they say they don't feel any better try and explore that with why questions, what have they done about it, who have they discussed it with etc...

Final Stage of the interview

I am interested to hear what life is like for you now...

(What impact it has had on them, lifestyle, self esteem, relationships, work, play, spirituality, sexuality etc)

Don't forget to warn them when there are five minutes left. Remember to thank them at the end of the interview.
APPENDIX VIII(A)

THE “STUFF HAPPENS” GUIDE

Note: This FAQS sheet was developed as the result of Discovery Interviewers raising questions and concerns which directly related to the project.
“Stuff Happens” Common queries & concerns for Discovery Interviewers

These are responses to the concerns raised by attendants of the first of two skills raising study days.

This FAQS sheet isn’t definitive and if you think of anything else later then please contact the author.

Q. Will I know the person I am interviewing

A. Unless it is entirely unavoidable you shouldn’t know them. This will help because it will let you get on with the interview more easily & keep a professional distance.

Q. What happens if I recognise the patient’s details when I get them

A. As soon as you suspect or realise that you do contact your Discovery Interview Lead Person to discuss it.

Q. What happens if I don’t realise until I get there

A. You will have to use your personal discretion & judgement. Talk to the patient about it & see if you both feel comfortable to go ahead.

Q. What happens if we aren’t comfortable to do that

A. Ask them if they are prepared to go ahead with the interview with someone else at a later date.

If they decide they want to withdraw, thank them for their interest & reassure them that withdrawing will not affect their future treatment and care.

Please remember to let your Discovery Interview Lead person know what has happened.
Q. Will they know what job I do

A. No. They will of course know that you work in the NHS and that you are taking part in the project for your Trust and the Cardiac Network.

Please remember to cover your ID badge job title before you meet them. They may well ask you what you do, just explain that it could affect the interview and that if they are really interested to know you will tell them when the interview has finished.

Q. Where will the interview take place

A. The person you will be interviewing has been given a choice. If they decide that they want you to come to their home you will need to be extra vigilant about keeping yourself & the patient safe. Please see the section Keeping myself & the patient safe for further information.

Q. How do I keep myself and the person I am interviewing safe

Keeping safe advice from the DOH

“Familiarise yourself with your organisation’s procedures, including those for when you are working away from your base or with colleagues from other organizations. Recognise what triggers violence and abuse, so that you are prepared to cope ......: your employer should have told you about this (as well as) the procedures for raising any concerns you have with colleagues and managers.”

If you are not used to working in people’s homes on your own and don’t feel confident you prefer to find out if the patient is fit enough to travel to a nearby hospital or health centre to be interviewed. If they are then you should negotiate arrangements first before asking the patient if they would be willing to do so.

If they are unable to travel or prefer to be interviewed at home and you are uncomfortable about this you may be able to suggest that they have a family member or friend present when you visit.

Please refer to the “Be Prepared” Card you have in your pack for quick tips on safety.
Q. What do I do if they get upset

A. On a positive note, most of the people interviewed for the project so far haven’t become inconsolably upset. Remember that you are a health professional & a human being & may be more skilled at dealing with distress than you realised!

Be very careful about offering any physical comforting, you can be empathic without needing to touch.

If it does happen while you are recording ask them if they want you to stop. Give them a few moments; silence often helps in these situations. Acknowledge that they are upset & ask if you can do anything for them like fetch them a cup of tea. If they continue to be upset and there is no-one who they know available ask them if you can contact someone for them.

If they are really distressed you may have to seek medical support, but do discuss this with them first.

Q. How long will the interview last

A. The recording of the interview should last no more than one hour.

Remember that this is a chance for them to talk about their journey and experiences. The subjectivity of Discovery Interviews enables the story teller to say how they felt about what happened to them.

If there is a particular thing that is important to them the interviewer needs to ensure there is adequate opportunity to talk about that. Remember: Quality is more important than quantity.

Q. How do I close the interview down

A. Before you start, remind them that you will be recording for about an hour, less if they want. Tell them what time you have to be away by.

If you have a tape that needs to be turned over explain this and time the interview so that you can remind them a few minutes beforehand that you need to stop turn the tape over.

Also explain before you start that you will drawing things to a close ten minutes before the hour is up/the tape runs out.

You may want to say something like “well Mr Evans, we have about ten minutes, what do you want to talk about in the time we have left?”
Q. What do I do if they want to keep me chatting after the interview finishes

A. Be pleasant & polite, thank them for making you feel so welcome and remind them that you have to leave as you have another appointment to keep.

Q. How many interviews will I be doing

A. This is hard to judge. For the Network project we would expect that you would do one or two per “run” of patients. It’s your organisations decision as to how many “runs” are carried out for the project.

Don’t forget though that if you are enthusiastic about Discovery Interviews there is huge potential for more work to be done outside of the confines of the Network project. You will need to work with your colleagues and line managers to identify areas which would be valuable to explore & follow your organisations protocols with any future projects that may be set up.

Q. Professional Issues (POVA, complaints etc)

A. It is extremely unlikely that you will be told anything that will cause you major concern. Remember that the “learning opportunities” i.e. the not so good things are part of what you are there to hear so that it can be picked up in your organisation and addressed through the project process.

If you do hear anything that alarms you that may be a professional, POVA or potential complaint you will need to make an on the spot judgement.

If you can justifiably continue the interview then do so, but make sure that you discuss it with the patient before you leave them. Take some complaint leaflets for your organisation with you & details about Patient Support Teams (if you have one) and be sure to leave one for them.

If they have disclosed something extremely serious; for example physical abuse by an NHS employee, you will have to tell them that you need to finish the interview. Ask them what they have done about the matter, explain that you have a legal and professional responsibility to discuss this with a senior NHS manager, write down as much information as you can, and tell them that someone from the Trust will be in contact with them within the next two working days.

Contact your Line Manager as soon as possible and explain the situation & that the patient will be expected to be contacted by an appropriate person as soon as possible.
Speak to your Discovery Interview Lead Person & explain that the interview had to be abandoned. You DO NOT have to give them details of the reason.

Q. Will the patients who take part get feedback about the project

A. At present the project protocol does not have ethical approval to keep individual patients details. Jane Price is in the process of trying to get this amended, meantime though think about creative ways in which you may be able to provide general public feedback through avenues available in your own area. A poster in the public restaurant or on a ward notice board, or perhaps on your organisations PPI web page. Link up with your Discovery Interview Lead person if you are interested in making this happen.

Q. Will the project make a difference

A. We really hope so. The biggest challenge to any organisation undertaking a Discovery Interview project is ensuring that what is learnt from the process is disseminated, discussed and where indicated changed to make a real difference.

Arguably these hidden treasures should be shared across the whole of individual organisations so that all patients and staff can benefit from them. Realistically, this is probably more easily said than done!

What you as Discovery Interviewers can do though is:

✓ Let colleagues know before the work begins that it is going to happen.
✓ Tell them what it is about.
✓ Be positive about the benefits of Discovery Interviews for colleagues as well as patients.
✓ Share in general terms what you found out from the interviews you undertook yourself, good and not so good.
✓ Remember that different people will see the same events in different ways and take account of that when reflecting on processes and practice.
✓ Encourage front-line colleagues to read the report that result from the project.
✓ Encourage front-line staff to come up with suggestions and make changes in their own area.
✓ Ask the working group looking at the report what is happening as a result of it.
Q. Will I get paid

A. Sadly no, sorry.

However your organisation has already committed to giving you protected time to attend study days, make initial contact with the patient and carry out the interviews. You will also be able to claim travel allowance if you have to carry out the interview in the community.

There are other rewards as well!

☑ On a personal level undertaking Discovery Interviews will help you to:

☑ Gain a clearer understanding of how what Health Professionals actions impact on the people they are treating & caring for.

☑ Build on your existing communication skills which will help you in your everyday professional and we hope, personal life.

☑ Increase your confidence when dealing with members of the public in your professional capacity.

☑ You’ll gain a unique insight into what it is like to be a patient or carer & be able to appreciate the good things that happen as well reflecting on the not so good, understanding why these things may happen & discuss & development changes in practice to improve services in the future.

☑ You will be able to help put the patient more fully back in the picture.

☑ And finally we hope, it will help you to remember why you joined the NHS in the first place.
APPENDIX IX

AN OPPORTUNISTIC STORY COLLECTING CHECKLIST

Note: This may be helpful for staff intending to undertake story collection for audit, quality and service improvement purposes. This approach will work best for small numbers of patients/carers when you only want an overview or snapshot of their journey or experiences.
Things to do in order to ensure that you follow best practice when collecting snapshot stories for audit or quality purposes. Do make use of the How to do Discovery Interviews/Patient Stories Kit so that you have an informed understanding which will aid you in your opportunistic endeavours.

✓ Be clear about what you want to do and why
✓ Think carefully about the resources you will need to carry out your objectives and be realistic about how long things may take
✓ Make sure you discuss your plan with your line manager and that you have their support and resource needs have been agreed
✓ Remember that you will still need to adopt an ethical approach with patients/carers including;
   ▪ Enabling them to make an informed decision to participate
   ▪ Ensuring that their anonymity and privacy is respected
   ▪ That they have given their permission for you to include what they tell you in your project summary
   ▪ That they understand that their care won't be affected whatever they tell you
   ▪ That they have the right to change their mind
✓ Be honest with yourself. Are you an effective communicator? If you are not sure ask someone you trust to tell you. If you decide story collecting isn’t for you, find someone with the skills to need your project a success.
✓ Or if you decide to go ahead yourself but think you aren’t so effective you will need to carefully evaluate the outcome of your interaction with the patient/carer.
✓ Avoid using a recorder, use your ears and your brain instead. By adopting a “feedback approach” you will avoid the complications associated with formal ethical approval, data protection and safe storage of recordings.
✓ If you need to make notes as you talk keep them brief and write up the collection as soon as you have finished it.
✓ Keep it brief! Five or ten minutes should be all you need
✓ Keep it focused! Make sure that you cover the objectives you need to and don’t go off track
✓ Do use open questions (what, how, why, when, where, feeling) which will give you more information
✓ Make sure that you can speak to the patient/carer in private (being mindful of your personal safety)
✓ If you are collecting in real time (for example while a patient waits for an outpatient appointment) do make sure that the patient doesn't lose their slot!

✓ When you have finished the collection phase identify the learning themes you have discovered and then write a short structured briefing paper

✓ Share your findings with your line manager/clinical lead for the area where you carried out the collection

✓ Agree an action plan based on what you have learnt
APPENDIX X

AN ABRIDGED EXAMPLE OF A NETWORK PARTNER TRUST PROJECT CONSULTATION PAPER

Note: A full version can be found on the South East Wales Cardiac Network website (http://nww.sewcn.wales.nhs.uk)
STAFF CONSULTATION PAPER FOR CARDIAC DIRECTORATE STAFF
ABRIDGED VERSION FOR HOW TO KIT

DISCOVERY INTERVIEWS

2006

Disseminated after cohort transcript scrutiny and steering group discussion
**Introduction**

As a result of the collaborative project between Cardiff and Vale NHS Trust and the South East Wales Cardiac Network the first of a series of Discovery Interviews with cardiac patients has resulted in this document. It is based on the Trust’s Steering Groups’ discussions compiled into a short report by the Trust consultant nurse for heart failure which resulted from the comprehensive report compiled by the South East Wales Cardiac Network Lead for Discovery Interviews and Patient and Public Involvement.

“There is evidence that, where they take place, Discovery Interviews are having a positive impact on developing a patient - and carer centered culture in the NHS.”

*Matrix Research & Consultancy, 2005.*

This consultation paper has been prepared for all grades and disciplines working in the cardiac directorate at Cardiff & Vale NHS Trust for your contribution to the discussions outlined here. It is essential that everyone reads and thinks about this document and your thoughts and ideas, along with the comments of the patients who participated in the project will lead any developments and improvements that result from the work.

In the document there are quotations from patients who participated in the project to support the trends identified by the Steering Group. The intention is to will lend a sense of realism and encourage reflection on how the process or pathways relate to the reality of the patients journey and experiences.

The top themes and suggested action plan outlined in this document are those agreed by the Steering Group to explore at this stage.

Excerpts from patients’ transcripts are shown in italic font throughout the document.
WHAT TO DO WITH THIS DOCUMENT

- Please read the discussion and suggested action plan points carefully. Use the box at the end of each section to add your thoughts and suggestions.

- Please do not limit yourself to areas which you think apply to your area or discipline, the best suggestions often come from the least expected sources...

- If you are interested in participating in development work write your name, role and work contact details on the end of the consultation paper.

- If you would like an electronic version of this document please email Claire.Lewis@sewcn.wales.nhs.uk

- All comments need to be returned by ..... 

- May we take this opportunity to thank the patients and carers for their contribution and thank you in anticipation for your help in this endeavour. A document outlining any changes arising from the work will be available on the SEWCN website in due course.
ABRIDGED REPORT OVERVIEW

Good Practice

The discovery interviews identified 94 examples of good practice, which were later defined into the following sub groups:

Staff
Staff of all disciplines and grades demonstrated a hard working, caring and dedicated approach to their work with patients.

“All the staff were excellent from the Consultant to the kitchen staff”.

Carer: “She was (at UHW) for two months, she came on in leaps and bounds”.

Outcomes
Patients generally felt so much better after treatment.

“I have felt a huge benefit - I had the operation type pains in the scar but I felt so much better”.

“I’ve Lost 1.5 stone since discharge from hospital, I am running my allotment and fishing with no real handicap”.

Cardiac Rehabilitation
This service was described as being excellent, providing a flexible program in both hospital and community. Patients would recommend it to anyone and considered it to play a major role in building their confidence and opening everything up to them.

The Cardiac Rehabilitation nurses had been round before discharge and explained what to do.

Carer: “The Cardiac Rehabilitation team were reassuring, checking BP and everything. It gave me confidence”.

“I felt very confident (with the Cardiac Rehabilitation nurses). I feel confident with the trained instructor”.
SERVICE IMPROVEMENT OPPORTUNITIES

The Discovery Interviews have highlighted several areas where care could be improved upon - learning opportunities. These have been amalgamated into key themes. A total of 157 learning opportunities were identified.

There were examples of good communication skills:

“When the Cardiologist and Charge Nurse arrived they fully explained about the clot buster medication and why patients were asked to sign an indemnity form”.

“After I was on ITU I had a lot of information” (both verbal and written.)

There were however several comments relating to poor communications. For example:

Several interviewees expressed distress about the manner in which they were told diagnosis. Their descriptions indicated that when it was badly done it was poor and abrupt and had a profound emotional impact on them. Patients expressed feeling shocked after a diagnosis and having no one to talk to about it the following example illustrates a theme that recurred in the transcripts:

“The doctor came in and told me quite bluntly (not in a nice way) that if I didn’t have the operation I would die. There were no visitors allowed on the ward at the time (although partner and offspring had been in the hospital since 11.00hr) it was about 13.00hr but they weren’t allowed into see me. I didn’t have any lunch then. Always at the back of mind that bypass was designed to last 10-15 years. About 17.30hr having evening meal, Doctor and firm arrived as trying to eat. Then they came around me and they just looked at me. It is very difficult to remember the sequences and how he put it to me, but I said to him”. What you are saying to me is that my heart is knackered” and he said “yes”. My wife and son looked at each other and he (doctor) just looked at me and that was it. He said he’d be back in the morning. Doctor came about 10.00hr I phoned my wife to be there with me, but he had been and gone by the time she arrived. They said I could go home. To me what they were saying about the condition sounded terrible.
• Patients found repeating the same information frustrating.

“When I got to ICU they asked all the same questions they had asked downstairs - I thought why didn’t someone write this down the first time they asked me?”

• The video was considered out dated and some written information confusing e.g. warfarin.
• One day case patient was unprepared for the possibility of an overnight stay it resulted in a very distressing and stressful time for them.

The patient describes their issues:

• Kept in following day case angiogram this presented real practical problems. The patient lives alone, unable to get any personal effects. Couldn’t wash or change clothing, couldn’t phone anyone to bring anything in. They made a second request to be allowed to go home (lives just opposite hospital) asked 10.00hr, no-one prepared to say yes. Told that the Consultant would be asked - verdict of no didn’t come until 17.00hr. The letter for the angiogram appointment did not suggest coming prepared for the possibility of remaining in hospital.

• There appeared to be long delays waiting for a doctor to report on results.

Talking Points

1. How do we prepare ourselves, the patient and their family to receive news about diagnosis and treatment? How do we plan for the communication of difficult or distressing news?
2. Who should be present at the time of diagnosis? What happens at the moment?
3. How can patients/relatives be supported at the time the diagnosis is given and immediately afterwards?
4. What can be done about outdated information and who should be involved in updating it?

What preparations are patients currently asked to make for day case procedures? How patient centred are current practices? What changes might improve the patient experience?
SUGGESTED ACTION PLAN

1. Integrating the patients’ needs into care planning and ensuring that they are sufficiently supported at the time of diagnosis.
2. Review and if necessary re-write the day case admission letters and share with patient group to ensure that the cover any normal potential eventualities.
3. Carry out a general review and update of written information currently given to patients.

Please use this box to comment on the section you have just read
BEING IN THE HOSPITAL ENVIRONMENT

- Strange environments can be difficult especially when someone is ill and frightened about what is happening to them and what the future may hold.

“The actual angiogram was like a factory and everybody was lining up to go in on stretchers and it frightened me...” There was blood everywhere and the screens - I think there was five of them. I watched them. It was so cold down there I had the shivers - I couldn’t stop shivering. Terribly cold”.

These are some of the comments relating to the system and environment. Starting with the positive:

- Accommodating the patient’s needs and time in relation to organisation for attending clinics.

“One time I had an appointment with three different people at the hospital all on different days and they managed to get them all on the same day. Absolutely brilliant”.

Another patient remarked on improvement in the Consultant’s clinic, explaining that having the USS carried out first and then going to see the Consultant is much better and more efficient.

- Regular attendance as an outpatient or a visitor to the site has financial implications particularly for those on reduced income due to illness

“Parking costs a lot of money- they are bandits, they rob you!!”

- It was noted that some staff did not always wash their hands before procedures.
TALKING POINTS

1. How can you balance the practical safety & procedure requirements of the clinical environment whilst reducing the “clinical and impersonal” impression it may have on your patients? How could the environment be “softened?”

2. What degree of consistency is there currently in ensuring that the needs of patients are considered and wherever possible accommodated in relation to attending outpatient appointments? What do you think could be done to improve these aspects overall?

3. What financial provisions are in place to help patients and visitors who may need to attend hospital on a regular basis? How do they find out about these provisions (if they exist)? What could be done to reduce the financial impact on patients and visitors?

4. Other than existing mechanisms in place for promoting and monitoring high standards in hand hygiene what more could be done?

SUGGESTED ACTION PLAN

1. Ward/department led objective review of environment and layout. Possible involvement of hospital or external artists and sponsored funding for extra items to “soften” the environment.

2. Offer in patients the opportunity to “visit” the catheter lab the evening before they are due to go down, nurse led visit could help to explain the environment, what will happen and introduce them to some of the staff & ask any questions they may have. This could be trialed and evaluated.

3. Trail a similar “open day” scheme for outpatients to attend.

4. COPD - organisation of tests prior to patients’ appointment with the clinician.

5. Inclusion of written information about parking concessions in printed information given to patients/visitors. Promote discussion and signpost for additional information when needed such as Age Concern, Social Services, and carers associations.

6. Infection control to update steering group in relation to reviewing Hand washing education and internal audit frequency.
Please use this box to comment on the section you have just read

Footnote: Full version of this document can be found the South East Wales Cardiac Network Discovery Interview Pages
APPENDIX XI

PATIENT INSPIRED SERVICE IMPROVEMENTS AND CHANGES
PATIENT INSPIRED SERVICE IMPROVEMENTS AND CHANGES

“A common criticism of the NHS is that it sometimes fails to reflect or respond to the views and experience of patients and public when planning and delivering NHS services. The importance of the patient’s voice is recognised as being centrally important in the drive for service improvement”

*Improving Health in Wales: A Plan for the NHS with its organisations, 2000*

INTRODUCTION

The key purpose of the South East Wales Cardiac Network in supporting the Discovery Interview project was to promote cardiac service improvement through listening to and acting on patients’ and carers’ experiences. It is important to stress that there is a high level of commitment particularly amongst staff who have actively participated in the project; either through carrying out interviews or by hearing about the findings. This section sets out in its entirety the work that has already begun to make a difference using the voices of patients involved in the project. It is a good beginning on which to start the process of embedding Patient and Public Involvement into the South East Wales Network.

i. **Patient experience - emotional impact, environmental and clinical.**

“The actual angiogram was like a factory and everybody was lining up to go in on stretchers and it frightened me. There was blood everywhere and on the screens. It was cold down there, I had the shivers, I couldn’t stop shivering. Terribly cold”

*Improvement made / action taken*

Busy Cardiac Catheter Lab staff recognised that many patients would possibly be frightened by the environment and that it is important to make sure that as well as looking after the physical needs of the patients they now make sure that the patients feel reassured and safe.

This patient also talked about seeing blood and that troubled them. The Catheter Lab staff are now more alert to making sure that the environment is kept as clean as possible.
ii. Patient experience - communication and emotional impact.
“I don’t want to experience people dying before having major surgery this needs looking at”. “I would have preferred that the curtains around the bed had been left drawn. Carers agreed, “something should be done” re others exposure to ill/dying patients.

“(At the time the news was given).” At that point I did get frightened because I thought I could die here and I just wanted to cry. I thought I don’t want to die here. In my head was saying don’t panic, don’t panic you are in the right place, you are in trouble and you are in the right place”.

“In the early hours of the morning (now recovering) I went to the toilet on my own. Well when I was washing my hands I looked in the mirror and saw my face- it wasn’t me. It was like looking at my two dead brothers. To be honest I had a cry. I was talking to other patients and one said I thought you were going to die - you looked terrible.”

Following the evening ward round: “I must confess (the way the doctor broke the news) did upset me. That night I couldn’t sleep, “I had this awful feeling I wasn’t going to wake up”.

Improvement made / action taken
Intensive Care Staff recognised the fear and anxiety expressed by some patients and carers faced with their own or other patients’ mortality. The challenge for the ICU staff is how to embed practice changes in order to help patients deal with this sad possibility.

iii. Patient experience - emotional impact, sleep disturbance
“There was a lot of tension on CCU. I was there 2 weeks and the sister didn’t speak to me once. The nurses were very good but there was a lot of tension between the nursing staff - when people are angry it shows. One night nurse used to come and sit with me and she was distressed because the other nurses would all talk to each other in their own language”.

‘In the night the nurses were chatting at the station and I had to tell them about patients needing attention and about a television blaring at night. I think they should bring the night sisters back”.

Improvement made / action taken
The directorate lead nurse met with directorate ward managers who held discussions with the ward day and night team staff regarding the impact which these experiences had.
iv. Patient experience - communication and procedural
“The only thing that springs to mind, is that when I first went into the Royal no one told me not to leave the area of that particular ward. I had to remain within the area of that ward but I didn’t. I went down to the shop and the nurse had to come looking for me and I got a ticking off from the Sister. But no one had told me otherwise - it was a minor thing really”.

Improvement made / action taken
The Directorate Lead Nurse raised this experience with Ward Managers asking that they improve communication with patients reminding them that patients don’t know the “rules” unless they are explained! NB There is room to include this type of information in ward based printed patient information.

v. Patient experience - environmental.
‘The biggest thing of the lot was the waste bins - they put things in and let go and the lid goes bang. It really is horrendous at night - they should do something about it.’

Improvement made / action taken
This problem took a long time to resolve, partially due to discussions about who would fund replacement. Due to the persistence of two senior staff involved in the project quiet closing bins were eventually purchased for the area where the comments originated from. This information has since been shared with another Trust which is in the process of contracting replacement waste bins for the whole organisation.

vi. Patient experience - communication and procedural.
It was clear that some project participants didn’t clearly understand what Cardiac Rehabilitation was about and were under some misapprehensions.

“I didn’t go to Cardiac Rehabilitation - they asked me but to sit in a room and talk for 2 hours - well I don’t do a lot of talking.”

“I was asked to go to Cardiac Rehabilitation but I didn’t want to go. I'm not very good in company - I don’t like going into crowds. Anyway they had dancing and this and that there but I thought I am not that type of person”.

Improvement made / action taken
The Lead Nurse and Cardiac Rehabilitation team in the Trust where these comments were received discussed how they explain Cardiac Rehabilitation services to their new patients and what information they should be giving.
vii. **General changes and improvements resulting from patient experience.**

Discovery Interview Staff Consultation Paper (Appendix ii) disseminated to all Cardiac Directorate staff (response from Catheter Lab and ITU staff only)

Trust staff involved in the Discovery Interview project are now using patients experiences in a number of ways including:

- Ward team discussions based on patient transcripts.
- Ongoing education of MDT groups including junior doctors and nurses.
- Patient information leaflets changed in Cardiac Day Case Unit
- Adoption of Discovery Interview method by Welsh Ambulance Service Trust, pilot project to look at reasons why diabetic patients request emergency calls which do not result in hospital admission.
APPENDIX XII

KEY RECOMMENDATIONS FOR TRUSTS FOR THE SUCCESSFUL SETTING UP, IMPLEMENTING AND SUSTAINING OF DISCOVERY INTERVIEWS/PATIENT STORY COLLECTING PROJECTS
## INITIAL PHASE: PROCESSES REQUIRED TO BE IN PLACE FOR PROJECT SUCCESS

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<tr>
<th>Recommendation</th>
<th>Rationale</th>
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| **Recruit an Executive Champion**  
(Executive or Non Executive Board Member) | ✓ Support the project and the required resource investment  
✓ Ensure that project findings and recommendations for Service Improvement are supported and recognised at Board Level  
✓ Empower the project steering action group to implement agreed service improvement |
| **Active involvement of Trust PPI/E Lead** | ✓ Participate in the project steering action group  
✓ Feedback DI activity, recommendation and outcomes to appropriate boards  
✓ Feed service improvement evidence into annual Healthcare Standards reporting |
| **Decide whether or not the project will be carried out as:**  
• Audit  
• Patient Feedback  
• Research | ✓ The purpose of the project will determine whether or not formal Ethical approval will be necessary or adopting an ethical approach will be sufficient.  
**NB** In either case it will be necessary to obtain a written formal consent agreement from participating patients/carers. |
| **Identify two Discovery Interview Leads to oversee and co-ordinate the project** | ✓ Share the workload  
✓ Support Discovery Interviewers  
✓ Cover each other in absences |
| **Recruit Discovery Interviewers from multi-disciplinary and speciality backgrounds** | ✓ Provide the broadest group of Trust staff with the opportunity to engage in PPI/E activities, enhance and develop communication skills and professional development.  
✓ Enable all clinical specialties with an interest in Discovery Interviewers to access existing Discovery Interviewers |
## ONGOING PROCESSES: TO ENSURE SUCCESS ONCE INITIAL PHASE IS COMPLETED

<table>
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<th>Recommendations</th>
<th>Rationale</th>
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| Clarify project objectives | ✓ Is the project intended to provide an overview of a specific issue (evaluate current service or practice)  
✓ Is it intended to support a proposed service development e.g. by establishing potential patient service improvement benefits  
✓ Is it necessary to undertake a large volume of interviews or, could a small volume form the basis of an alternative PPI method for example: focus group, structured questionnaire etc |
| Raise organisational awareness of the project work from proposal phase to completion | ✓ Encourage interest understanding & department level buy in, in preparation for consultation and service improvement phases |
| Establish a multidisciplinary Task & Finish Group with influential and enthusiastic membership which can make the project work | Note Task & Finish group members ideally should be a skill mix of:  
✓ Executive or Non executive Board member or representative (see box 1 page 1 of table)  
✓ Directorate lead who can support service improvement developments  
✓ Ward managers (possibly in pilot areas where service improvements can be implemented initially)  
✓ Enthusiastic and committed staff who have participated in the interviews  
✓ A lay patient or carer with an interest in this area (could be recruited from Trust Patient Forum or Panel or equivalent) |
| Agree how the collected transcripts are to be scrutinised and report format | ✓ How will you identify/classify trends  
✓ What will be done with additional information that does not necessarily relate to the project objectives |
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<tr>
<th>Agree who will make action recommendations based on the report and who will endorse these</th>
<th>✓ Will your organisation involve the staff who need to make service improvements a reality or will it impose change</th>
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| Develop and maintain a local public feedback mechanism | ✓ To raise public awareness of PPI/E activities in general  
✓ To demonstrate Trust commitment to PPI/E activities  
✓ To provide evidence of service improvement change directly originating from this type of activity  
✓ To ensure that this type of activity is embedded into the Trust at front line level  
✓ To promote good role modelling and engagement in service improvement change throughout the Trust |
| Continue to provide existing Trust Discovery Interviewers with support and encouragement to undertake further work and participate with developing service improvements by: | ✓ Building DI project work into interviewers IPR & KSF  
✓ Attending relevant study sessions  
✓ Membership of Discovery Interview Forum |
APPENDIX XIII

A LIST OF LOCAL CONTACTS WHO MAY BE ABLE TO HELP YOU.
<table>
<thead>
<tr>
<th>Name</th>
<th>Trust</th>
<th>Tel No</th>
<th>E-Mail Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joanne Davies</td>
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<tr>
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<td><a href="mailto:Ken.Smith@ambulance.wales.nhs.uk">Ken.Smith@ambulance.wales.nhs.uk</a></td>
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