An Exploration of the Patient’s Experience Following an Acute Myocardial Infarction and Participation in a Clinical Research Study

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Summary of the project
The Royal Brompton and Harefield NHS Foundation Trust is a partnership of two specialist hospitals which are known throughout the world for their expertise, standard of care and research success. This specialist trust only provides treatment for people with heart and lung disease. The Harefield Hospital has pioneered the use of primary angioplasty for the treatment of myocardial infarction (MI) commonly known as ‘heart attacks’ and has one of the fastest arrival-to-treatment times in the UK, a crucial factor in patients’ survival. 1400 patients per year attend the Harefield Hospital through the primary angioplasty programme, with approximately 900 patients receiving immediate angioplasty (stent) treatment.

As Astin et al. (2009) discuss, emergency admission to hospital with a heart attack can be a frightening and life-changing event. It is recognised that delivering a high quality clinical service, which provides a meaningful patient experience, is the responsibility of all NHS care providers. Similarly it is widely acknowledged that research is a core business of the NHS. It seems appropriate, therefore to undertake a project which will allow the Harefield team an opportunity to explore the patient’s experience of having a heart attack in a research focused organisation.

This project was centred on exploring the patient’s experience of suffering a heart attack and taking part in a research study. The project was endorsed by the Director of Nursing and was supported by the Patients First Programme from the Foundation of Nursing Studies (FoNS) in partnership with the Burdett Trust for Nursing.

To gather both patient and staff experience, an emotional touchpoint framework (Dewar et al., 2010) was used to allow patients and staff to share their experiences of chest pain, hospital arrival, angioplasty, research participation and discharge preparation. Eleven patients hospitalised for an acute MI agreed to participate and were interviewed four to six weeks after discharge (May-Oct 2014). Twenty-two members of the nursing staff team were also interviewed. Narratives were audio recorded and listened to by the project team to identify key themes. Nursing staff and patients acknowledged the seriousness of a heart attack situation. Nurses act in an efficient way to ensure that the patient is treated promptly and compassionately within the catheter laboratory and the ward. The treatment is appreciated by patients with many narratives referring to efficiency and kindness. Nurses see the overall benefit of clinical research but feel that the timing of research involvement needs to be carefully managed to avoid the risk of research information diluting discharge information. Patients welcomed the opportunity to take part in research as a vehicle to help future patients.

There were areas of alignment of nursing staff and patient perspectives of the experience of a heart attack related to the emotional impact of lifestyle and medications. While pain is addressed as a priority by nursing staff, there appears to be a lack of understanding of how the memory of the heart attack pain stays with the patient beyond the actual heart attack.

The information gathered from these interviews has been shared widely and the project steering group is continuing to work with this information to develop changes which will allow the service and clinical research programme to grow in harmony with each other.
knowledge and skills gained in undertaking this project have also given the team confidence to do more work exploring patients’ experiences with other heart conditions.

**Project setting**
The Royal Brompton and Harefield NHS Foundation Trust is a partnership of two specialist hospitals which are known throughout the world for their expertise, standard of care and research success. This specialist trust provides treatment for people with heart and lung conditions. The Harefield Hospital has pioneered the use of primary angioplasty for the treatment of myocardial infarction (MI), commonly known as a ‘heart attack’, and has one of the fastest arrival-to-treatment times in the United Kingdom (23 minutes compared to a national average of 56 minutes), a crucial factor in patients' survival. 1400 patients per year attend the Harefield Hospital through the primary angioplasty programme, with approximately 900 patients receiving immediate angioplasty (stent) treatment for their heart attack.

**Background**
The face of cardiac care has recently undergone rapid change. Percutaneous coronary intervention (PCI) has overtaken bypass surgery as the dominant treatment for coronary heart disease (CHD) (Bhargava et al., 2003). Primary PCI, also known as primary angioplasty is now the ‘gold standard’ treatment for patients suffering an acute myocardial infarction. In simple terms, primary PCI involves inserting a catheter peripherally (via the wrist or the groin) and directed into the coronary circulation under X-ray control to restore coronary blood flow. This may involve the insertion of a stent to maintain the lumen of the blood vessel (Davidson and Bonow, 2008). The Myocardial Ischaemic National Audit Report (MINAP, 2012) states that 95% of patients in England with ST Elevation Myocardial Infarction (STEMI) received primary PCI in 2011-2012, compared to 27% in 2007 (Department of Health, 2012).

Despite the increasing number of patients being treated with primary PCI, there is little known about patients’ experiences of this relatively new treatment option. Alongside the primary angioplasty services, many centres undertake clinical research programmes in order to develop the knowledge about and outcomes for this patient population. However, there are important ethical issues to consider when undertaking research with patients who are suffering an acute myocardial infarction. The medical condition and potential lack of comprehension may render them vulnerable to manipulation and bring onto question the informed consent process. Despite the ethical dilemmas facing researchers wishing to undertake research with this patient group, research is on-going.

The hospital stay for a person suffering an acute heart attack averages at three days at the Harefield Hospital, which is a short time for the patients to come to terms with their condition and to understand the lifestyle changes which may be required in terms of medication, diet, exercise, blood pressure and cholesterol control. As well as coming to terms with their heart attack, some patients agree to take part in a research study during the admission.

Emergency admission to hospital for a heart attack is a frightening, life changing event. An individual’s response to their illness is strongly influenced by the way in which they interpret
and understand their experience (Skelton and Croyle, 1991). The focus of this project is to concentrate on the emotional journey of patients who have suffered a heart attack and have also agreed to participate in a clinical research study during their hospital admission following the heart attack.

**Discoveries from evidence review**

The purpose of the review of published evidence was to explore current literature in relation to the patients’ experience of suffering a heart attack and agreeing to take part in a research study. It seemed appropriate to undertake a literature review in the first instance, to discover if there was data to which the project team could compare their own findings.

The literature search question was guided by the question:

- ‘What is the experience of patients who have suffered a heart attack and agree to participate in a clinical research study?’

Patient and carer experiences were included and the search demanded results which originated from formal research, irrespective of the research paradigm.

Search terms used for the literature review were:

- Patient experience
- Myocardial Infarction / heart attack
- Clinical research participation
- Compassionate care

The search was limited to published papers after 2004, which coincides with the primary angioplasty service development. The search was not restricted to UK institutions to provide a global experience of search terms. CINAHL, BNI and Medline databases were searched and revealed only two papers which captured the totality of search terms (Lanfear et al, 2011; Gammelgaard, 2004).

‘Patient experience of suffering a heart attack’ produced many research papers, although many focused on rehabilitation aspects, medication adherence and lifestyle issues. Similarly a search of ‘informed consent in clinical research’ revealed many papers which did not focus on the acute setting or indeed heart attack patients.

The literature search revealed that there is a lack of published evidence to address this question directly. Published evidence related to ‘research consent’ and ‘patient experience of suffering a heart attack’ did exist and the most relevant publications to this project were selected to be reviewed in detail.

The table below provides an overview of the papers which were chosen to be the most appropriate to the project question:
## Consent Papers

<table>
<thead>
<tr>
<th>Author</th>
<th>Date</th>
<th>Participants</th>
<th>Paradigm</th>
<th>Source of Evidence</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burns et al</td>
<td>2011</td>
<td>221 members of the general public</td>
<td>Quantitative</td>
<td>Questionnaire</td>
<td>Most respondents wanted to take part in low risk study</td>
</tr>
<tr>
<td>Gerber et al</td>
<td>2012</td>
<td>922 patients</td>
<td>Quantitative</td>
<td>Questionnaire</td>
<td>Consenter experience and timing of consent are significant factors.</td>
</tr>
<tr>
<td>Gammelgaard</td>
<td>2004</td>
<td>103 patients who were participants and 78 who did not consent</td>
<td>Quantitative</td>
<td>Questionnaire</td>
<td>Informed consent should be sourced following the heart attack</td>
</tr>
<tr>
<td>Lanfear et al</td>
<td>2011</td>
<td>3484 consented patients. 856 patients who refused</td>
<td>Quantitative</td>
<td>Retrospective analysis of major study</td>
<td>Consent variable depending on study site – consenter variability</td>
</tr>
<tr>
<td>Sen Biswas et al</td>
<td>2007</td>
<td>184 patients</td>
<td>Quantitative</td>
<td>Questionnaire</td>
<td>Higher intervention trials had poorer consent rates</td>
</tr>
</tbody>
</table>

## Patient Experience Papers

<table>
<thead>
<tr>
<th>Author</th>
<th>Date</th>
<th>Participants</th>
<th>Paradigm</th>
<th>Source of Evidence</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nakano et al</td>
<td>2008</td>
<td>30 patients</td>
<td>Interpretative</td>
<td>Interviews</td>
<td>Good experience – pain under-estimated</td>
</tr>
<tr>
<td>Eriksson et al</td>
<td>2010</td>
<td>15 couples</td>
<td>Interpretative</td>
<td>Interviews</td>
<td>Importance of including partners in care planning</td>
</tr>
<tr>
<td>Tod</td>
<td>2008</td>
<td>15 patients</td>
<td>Interpretative</td>
<td>Interviews</td>
<td>Individual persons recovery should be used to develop support following heart attack</td>
</tr>
<tr>
<td>Hogg et al</td>
<td>2007</td>
<td>6 patients</td>
<td>Interpretative</td>
<td>Interviews</td>
<td>3 themes: Difficulty reflecting Needing to talk Back to normal</td>
</tr>
<tr>
<td>Astin et al</td>
<td>2009</td>
<td>29 patients</td>
<td>Interpretative and quantitative</td>
<td>Interviews Questionnaire</td>
<td>Emotional shock – mismatch between reality and expectations</td>
</tr>
</tbody>
</table>
Aim of the Patient’s First project
The aim of the project was to explore the experience of people who had suffered a heart attack and also choose to participate in a research study at the Harefield Hospital.

Objectives
- To engage key stakeholders
- To gather the patient experience using the emotional touchpoint approach
- To gather the nursing staff experience of caring for a person who had suffered a heart attack using an emotional touchpoint approach
- To compare and contrast the patients and nursing staff experiences to identify learning and future direction

Table 1. Timeline of the project journey

<table>
<thead>
<tr>
<th>Time Line</th>
<th>Activity</th>
</tr>
</thead>
</table>
| December 2013 – March 2015 | Establish project team  
                           | Create shared vision  
                           | Develop staff questionnaire  
                           | Develop interview schedule for nursing staff and patients |
| April 2014 – June 2014 | Prepare Research Ethics Application for proportionate review  
                           | Conduct individual nursing staff interviews  
                           | Undertake two nursing staff focus groups using an emotional touchpoint framework |
| July 2014 – September 2014 | Undertake patient interviews |
| October 2014 – December 2014 | Transcribe interviews and focus groups data |
| January 2015 – March 2015 | Data analysis and report writing |
| April 2015 – May 2015 | Planning celebration event  
                           | Next steps ... |

Methods and Approaches
The project consisted of the following phases and each phase will be explored in detail:
- Establish project team
- Create shared vision
- Nursing staff experiences
- Patients’ experiences
- Recommendations

Establish the project team
The project lead invited staff to join the project team to represent the main nursing roles that care for patients who have suffered a heart attack and included ward sisters, the nurse consultant, the catheter laboratory lead nurse and the project lead was a member of the research team. The head of nursing research also joined the project team for facilitation support. To assist the project team with practice development experience, senior staff members were also chosen so they could influence change in the project. Initially the
the project lead approached team members individually to assess their level of interest in the
proposed project design. All of the project team were in agreement that the project provided an
opportunity for the ward and the catheter laboratory nurses to work together for the overall
benefit of patients and carers. The project team aimed to meet monthly to maintain momentum
and support for the project. However, monthly meetings were challenging due to clinical
commitments. In the end, the team were able to meet every second month and e-mails were
circulated regularly to inform the project team of the progress being achieved. Meeting notes
were circulated to those team members who were not able to attend.

The project team utilised the same agenda for each meeting to maintain focus and reach
the pre-determined goals. The agenda is outlined below:

<table>
<thead>
<tr>
<th>1. Action Planning:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Objective – what do we need to achieve?</td>
</tr>
</tbody>
</table>
| • Timescale – when do we need to have achieved the
  objective?                                           |
| • What support is available?                           |
| • Where will the challenges lie?                       |
| • Claims, concerns and issues                         |

<table>
<thead>
<tr>
<th>2. Desired outcomes for workplace culture:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What are the desired outcomes for service users?</td>
</tr>
</tbody>
</table>
| • What are the desired outcomes for the wider nursing
  teams?                                               |
| • What are the desired outcomes for the wider
  organisation?                                        |
| • Claims, concerns and issues                         |

| 3. What activities do we need to undertake to achieve
  the objective?                                       |
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<tr>
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<tbody>
<tr>
<td>• Resources – what do we need to achieve our objective?</td>
</tr>
<tr>
<td>• What are the timelines of such activities?</td>
</tr>
<tr>
<td>• How do we evaluate such activities?</td>
</tr>
<tr>
<td>• Claims, concerns and issues</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Creating the action plan:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Description of activities</td>
</tr>
<tr>
<td>• Start date</td>
</tr>
<tr>
<td>• Finish date</td>
</tr>
<tr>
<td>• Lead and co-workers</td>
</tr>
<tr>
<td>• Claims, concerns and issues</td>
</tr>
</tbody>
</table>

Each agenda item ended with a ‘claims, concerns and issues’ exercise (Guba and Lincoln,
1989) which allowed the project team to express potential pitfalls and potential solutions.
This process facilitates a collaborative and democratic approach looking at what works and
how to make it better. The process starts by identifying the positive statements that can be
made about the chosen topic, and then moves to the concerns individuals have about the
topic, and finally looking at the questions they are beginning to ask about the topic
culminating in an action plan. For this to be successfully implemented, everyone must be
involved equally in the activity and this was a step towards creating shared decision making
systems. One of the key concerns highlighted at one of the earliest meetings was that the
project team were anxious about the recruitment of patients and cardiology staff to the project. The project team developed a strategy to encourage engagement with the project which resulted in a very positive response from those approached. There was overlap within the agenda items but the original meeting structure was maintained throughout the project, to enable an open discussion.

Create a shared vision
Engaging team members in the creation of a shared vision is a key component of practice development activities in order to provide direction and clarity of purpose. The guiding principles of practice development include the principles of collaboration, inclusion and participation, which develop ownership for change and self-empowerment (McCormack et al., 2013).

At the first project team meeting, the team discussed individual beliefs about delivering the project. It was a supportive environment and individual beliefs were documented, which helped to identify the common aims, which are outlined below:

- To gather information related to the number of patients who experience a heart attack and receive a coronary stent in a six month period
- To gather information related to the number of those patients who take part in a clinical research study
- To identify patients who are also willing to explore the emotional impact of their heart attack and taking part in the clinical research study by way of an emotional touchpoint interview (12 to 15 patients)
- To identify the perceptions of staff related to the patients’ emotional journey, via a questionnaire or group discussions
- To map the patients’ lived experiences with the staff’s perceptions and plan for delivery of service improvement in areas of mismatch
- To ensure the team feel supported throughout this new learning experience by holding regular team meetings and by using practice development techniques to ensure an inclusive participative team approach
- To develop action plans with the team to ensure the project’s success and dissemination of the findings

Following this discussion, it was felt by the steering group that it would be in the best interests of patients to submit the project proposal to a Research Ethics Committee, via the proportionate review service. The importance of the wider nursing teams in the ward and catheter laboratory areas was acknowledged and the project group wanted to include their perceptions of the patient’s journey.

The emotional touchpoint method
Emotional touchpoints (Dewar et al., 2010) is a method of engaging with people through conversation. Emotional touchpoints refer to the most significant aspects of an event. Within the heart attack scenario, an emotional touchpoint might be the start of the chest pain, calling for help, receiving treatment through to hospital discharge and beyond. According to Dewar et al., exploring emotional touchpoints helps to emotionally engage with patients and to understand their experience at a deep level. The emotional touchpoint framework allows
practitioners to take emotional risks when describing their own feelings and nursing staff need to be supported through the interview process. The project group was very fortunate to have a member who is very familiar with facilitating such interviews. The project group decided to use Evoke Cards© (Jane Stokes, DJ Stotty Images, www.evokecards.com), as a way of helping individuals to define their emotions and to describe how they were feeling. Evoke cards are double sided cards with words on one side and pictures on the other side. The cards provided an ideal ice-breaker at the beginning of interviews and focus groups and allowed participants to use the cards to highlight words which reflected their feelings. As the interviews progressed, the cards were used less often, which may be a sign that patients and nursing staff became more comfortable to use their own words to describe their emotional feelings, rather than focus on the cards which were laid out in front of them.

**Nursing staff experiences**

The project group developed a staff questionnaire (see Appendix 1) to gauge the level of interest of nursing staff from the ward and the catheter laboratory in participating in individual interviews or focus groups. Seventy questionnaires were circulated to staff individually and 40 completed responses were received. The response was very positive with all returned questionnaires expressing an interest in taking part in the project. The staff questionnaire allowed participants to choose if they preferred a one to one interview or to take part in a focus group and the requests were adhered to. The project lead conducted the one to one interviews in a private office away from the ward area to minimise the risk of disturbances. The focus groups took place in the education centre, with lunch provided for the whole group. Both the one to one interviews and the focus groups were audio-recorded with permission from the attendees. The interviews took an average 30 minutes to complete, whereas the focus groups took much longer at 90 minutes, due to the depth of discussion.

In total, 22 members of nursing staff were interviewed either during a one to one interview (10) or in two separate focus groups (12) using an emotional touchpoint framework (Dewar et al., 2010). The following touchpoints were used and the nursing staff were asked to describe their emotions in relation to these (see Appendix 2 for the full schedule):

- Being notified that a new patient is en-route to Harefield Hospital
- Involvement with the emergency ambulance
- The patient’s arrival at the hospital
- The angioplasty (stent) procedure
- Arriving on the ward
- The research experience
- Preparing to go home
- Impact of having a heart attack

The focus groups were facilitated either by the project lead or the Head of Nursing Research and there was an additional project team member taking notes to complement the audio recordings. Feedback from the focus group highlighted that being part of the focus group provided a positive experience and allowed members of the ward team to listen and share experiences with the catheter laboratory nursing team. The ward sisters were instrumental in arranging duty rotas to accommodate the interviews and the focus groups. Each interview and focus group began with an introduction from the project lead regarding the aims of the project and an overview of what is known from the literature. Participants were made aware
that contribution to the interviews or focus groups was completely voluntary and if they changed their mind about their narratives being used, they could do so at any time. The Evoke cards were displayed on the table and the project lead explained that the cards may be helpful for some participants to choose words from the selection of Evoke cards to express their experiences. In order to demonstrate how the cards may be useful, the interviews and focus groups began with an ice-breaker, asking how each participant felt at the beginning of the session.

To analyse the narratives, the project team listened to the audio recordings of the interviews and focus groups and classified the narratives into main headings (for full findings please see Appendix 4).

1. All respondents recognise how scared and powerless the patient may feel and manage this through communication with the patient and their family. This is illustrated through the following comments.

   ‘Patient will be feeling vulnerable and scared’
   ‘Not all patients have family with them’
   ‘Priority is to give the patient a good service and a good experience’

2. Attention is paid to personal dignity throughout the hospital admission.

   ‘When the patient arrives, I want to find out as much as I can about the person – there is a lot to learn’
   ‘It’s important to make the patient feel comfortable in the lab – they are cold and scared’
   ‘Make sure the patient feels cared for and included in care decisions’

3. Pain is addressed as a priority.

   ‘It’s important to address the pain’
   ‘Priority is to receive the patient, assess their condition and treat the heart attack quickly’
   ‘It’s a relief when it’s over for the patient and especially that their pain has gone’

4. Reinforcing information needs and allowing patients to take part in care decisions is evident from most narratives.

   ‘Communication is key – informing patients of events is a priority’
   ‘Divide the information into manageable chunks – it can cause too much stress if everything is discussed at once’
   ‘Make sure the patient feels safe – make sure patient is aware that they can ask for anything and not to feel frightened’

5. Facilitating a safe discharge is key to the long term recovery with emphasis on medications and lifestyle issues. The provision of a discharge nurse on one of the wards was highlighted as being a necessity in the future. Although nurses recognise the need for
research to be undertaken with this patient group, there were concerns that the research information might dilute the important discharge information.

‘Some people are not able to take in the research information. I understand that they are not forced to take part and even if they agree to join in, they can change their mind’

‘Research interventions can have an impact on a smooth discharge process. Patients can become bombarded with information. Research nurses need to work closely with the discharge nurses. We don’t want the important messages about going home being lost by all the research information’

‘Patients understand that without previous research they may not have survived the heart attack’

Patients’ experiences
Eleven patients hospitalised for an acute MI agreed to participate and were interviewed four to six weeks after discharge (May - Oct 2014), using the emotional touchpoint framework (Dewar et al., 2010). The following touchpoints were used (see Appendix 3) and the patients were asked to describe their emotions in relation to these:

• Experiencing chest pain
• Calling the emergency services
• Arriving at the hospital
• The angioplasty (stent) procedure
• Arriving on the ward
• The research experience
• Preparing to go home
• Impact of your heart attack

To analyse the narratives the project team listened to the audio recordings of the interviews and classified the narratives into main headings (for full findings please see Appendix 5).

1. Intensity of chest pain

‘The pain took over everything – it was unbearable’
‘The pain was so bad – I knew there was a serious problem’
‘Pain was very severe – it was the scariest thing I can ever remember’

2. Fear and lack of control

‘I felt completely out of control – very helpless – nothing would kill the pain’
‘I didn’t want to be out of control – I didn’t take the pain killers – I needed to know what was going on and I was scared that strong pain killers would knock me out’
‘I was really scared in case I would have another heart attack – no one could tell me that it definitely wouldn’t happen again’

3. Relief following angioplasty procedure
‘As soon as the stent went in, I felt on top of the world. I felt like I could have gone straight home. They told me off for standing up!’

‘The pain had gone and I was relieved it was all over. I was wondering what would happen next and what the heart attack would mean for my future’

‘It was relaxing being back on the ward. The pain had gone and I knew I had received the best treatment’

4. A desire to help others through research participation

‘I wanted to help other patients. Having the heart attack is an experience I wouldn’t wish on anyone – if I can be part of something to help other people, I was very happy to help’

‘Research is a really good thing – I wanted to help because not everything is known. My wife had a massive operation and was given a 50% chance of surviving – I wanted to help out here because I wasn’t able to help her’

‘I was aware that if my heart attack had happened twenty years ago, I may not have survived and that is all because of research’

Comparison of nursing staff and patient experiences

There are both areas of alignment and divergence in the staff and patient perspectives, though the areas of alignment outweigh the differences. Nursing staff and patients both acknowledge the seriousness of the heart attack situation. Both believe that nurses act in an efficient way to ensure that the patient is treated promptly and compassionately within the catheter laboratory and the ward. The treatment is appreciated by patients with many narratives referring to efficiency and kindness. Both nurses and patients see the overall benefit of clinical research and nurses were aware that the timing of research involvement needs to be carefully managed to avoid the risk of research information diluting discharge information. Patients strongly welcomed the opportunity to take part in the research as a vehicle to help future patients. There are areas of alignment from nursing staff and patients perspectives of experiencing a heart attack related to the emotional impact of lifestyle and medications. However, while pain is addressed as a priority by nursing staff, there appears to be a lack of understanding of how the memory of the heart attack pain stays with the patient beyond the actual heart attack.

Discussion

The project has helped to achieve something for the wider team which is unique as it has stretched between the acute cardiology unit and the catheter laboratory. For the project team, it has been a new way of working and all benefitted and enjoyed the experience. The project lead and team have stated that they have developed new skills from working on the project, which are transferrable to other areas of practice. Breaking issues down into problems and potential solutions has enabled the project team to work effectively and made sure each voice was listened to. The project team had pre-conceived ideas regarding the project outcome. One of the areas it was thought would be important to patients and families was the restricted visiting hours currently in place. Interestingly, visiting times were not mentioned by the majority of patients that took part. Similarly, the impact of the severe chest pain experienced by patients was underestimated by the nursing team. Despite the fact that by the time the patients arrive at the hospital, they have received pain relief from
the paramedic crew, there is evidence from the patients’ narratives to suggest that they do not forget the intensity of the chest pain as many patients referred to the pain repeatedly during the interviews.

The project was designed to include patient interviews and patient focus groups. The project lead was very concerned that the patients were willing to undertake individual interviews but all patients declined the opportunity of being part of a wider focus group. The project team agreed that they would continue to offer patients individual or group interviews in the future and acknowledged that it was important to continue to offer choice. On this occasion the patients chose to explore their experiences on a one-to-one basis.

Conclusion
This project has enabled the team to work collaboratively and discover things about each other and about the patients in a supportive environment. The ward and catheter laboratory areas have increased mutual respect for the work of each other and are more understanding of the challenges facing each area. The next steps are to develop changes which will allow the cardiology service and clinical research programme to grow in harmony with each other.

Recommendations
Based on the staff narratives, the project team are now working on two areas that may result in a service improvement:

1. In order to increase the capacity of discharge nurses, the project team are exploring ways to improve the discharge service on one of the cardiology wards.

2. In order to develop the clinical research programme, the project team are looking to develop a further project to explore if discharge information is being retained by patients who have agreed to take part in a study during the original admission. It is anticipated that this work will use the same format as this project and may involve a questionnaire as well as conducting one to one interviews.

Based on the patient narratives, the project team are working on two areas:

1. In order to address the issues of fear and lack of control, the project team are planning to include these areas as discussion points within nursing study days. This will be addressed by the practice educators from the ward and catheter laboratory areas.

2. Research participation appeared to help some patients to feel that they were able to contribute to the research programme. This view is not always shared by the nursing staff and more effort is needed to help ward and catheter laboratory nurse to feel more involved in the research programme. A potential solution is to have a member of the ward and catheter laboratory teams attend research planning meetings to allow their voice to be heard at an earlier phase of research study development.
References


Appendix 1- Nursing staff questionnaire

Dear

We are writing to invite you to take part in a patient experience project. The aim of the project is to generate information related to the patient’s emotional journey of suffering a heart attack and taking part in a clinical research study. We will collect information from patients and staff to help us understand the patient journey and to help us to understand our practice.

We have been very fortunate to secure support and funding from the Foundation of Nursing Studies (FoNS) Patients First Programme.

We are planning to invite patients to take part in one to one interviews or a focus group. The patients will be approached at their first out patient’s appointment, following their heart attack, to see if they are willing to take part and what their preference would be.

Patients will be invited to Harefield to undertake the interview or to participate in the focus group. We are looking for staff volunteers to take part with either the interviews or the focus group. In addition we are also looking for volunteers to take part in a staff focus group.

It is really important that staff who care for this group of patients are involved, as you have so much to offer and a wealth of experience between you. We realise that this is a new concept for many people and there will be opportunities for training in interviewing techniques before you will be expected to interview the patients.

Please be assured that all discussions will be treated with full confidentiality. We hope you are excited about this project and would like to be involved as we plan to use this project to implement changes in practice that will improve the patients experience at this traumatic time in their lives.

In the event of us receiving an overwhelming response, then names will be drawn randomly.

Thank you for taking the time to read this letter.

Kind regards
Patent experience project team
Reply Page:

Name:

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<th>I would like to take part in</th>
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Please tick your response and place in box in coffee room.

Patient Experience Project Group:

Mandy Brown

Jo Goodyer

Alison Pottle

Sumesh Thiruthalil

Sajed Ali

Sharon Fleming

Paula Rogers

Please contact any of the group members if you would like additional information.
Appendix 2 - Schedule for Staff Interviews and Staff Focus Groups

Emotional Touchpoint One – Being notified that a new patient is en-route to Harefield:
Please describe how you feel when you are aware that a new patient is en-route? Can you describe the actions you take?

Emotional Touchpoint Two – Involvement with the emergency ambulance:
Please tell me if you have any involvement with the emergency services? How do you feel during your conversations with them?
(Cath lab staff only)

Emotional Touchpoint Three – Arriving at the hospital:
Can you describe how you feel when the patient has arrived into the hospital? What are your main priorities? From your experience of caring for patients who have suffered a heart attack, do you think they remember any of the information shared with them when they arrive to our hospital? Please describe your emotions towards the relatives when they arrive in the hospital?

Emotional Touchpoint Four – The angioplasty (stent) procedure:
How do you feel about the angioplasty procedure? Can you describe your feelings when you are working during a PPCI?
(Cath lab staff only)

Emotional Touchpoint Five – Arriving on the ward:
Please describe to me how you feel when you transfer the patient from the cath lab? (Cath lab staff).
Do you ever have the opportunity to visit the patient on the ward?
Please describe to me how you feel when you collect the patient from the cath lab? (Ward staff)
When you get back to the ward, what is your priority? What are the challenges during the first few hours of receiving the patient? How do you feel about caring for a high volume of patients who have suffered a heart attack?

Emotional Touchpoint Six – The research experience:
What are your views on approaching patients to take part in research so soon after the heart attack?
Do any of the patients ask for your opinion on the studies? Do you feel equipped to answer the patients’ research questions? What do you think motivates some patients to take part in our studies?

Emotional Touchpoint Seven – Preparing to go home:
Tell me about the discharge process – do patients share any concerns with you? How do you feel when the patients are discharged?

Emotional Touchpoint Eight – Impact of having a heart attack:
The PPCI programme has an impact on the whole team. What are your personal feelings of working within the service? Do you find caring for such patients a pleasure or a burden?
Appendix 3 - Schedule for Patient Interviews and Patient and Carers Focus

Groups

**Emotional Touchpoint One – Experiencing chest pain:**
Please describe where you were and the circumstances of the chest pain.
Do you remember how you felt?

**Emotional Touchpoint Two – Calling the emergency services:**
What made you call the ambulance?
Can you describe your feelings at the time you called the ambulance?
How did you feel during your transfer to Harefield hospital?

**Emotional Touchpoint Three – Arriving at the hospital:**
Do you remember arriving at the hospital? Was there a team of people waiting for you to arrive? Do you remember any of the information you were given? What were your feelings at this time?

**Emotional Touchpoint Four – The angioplasty (stent) procedure:**
Tell me about the actual procedure – what do you remember? Did you understand what was happening? How did you feel during the procedure?

**Emotional Touchpoint Five – Arriving on the ward:**
Tell me a little bit about how you felt when you arrived on the ward? How did you feel at that point? Were you able to see your family?

**Emotional Touchpoint Six – The research experience:**
It was very kind of you to agree to take part in a research study. How did you feel when you were asked to consider the study? What did you understand about the nature of the study? What motivated you to agree to take part?

**Emotional Touchpoint Seven – Preparing to go home:**
How did you feel about going home? Tell me about the information you received? Did you have any concerns about going home? How were your family coping with the news that you had suffered a heart attack?

**Emotional Touchpoint Eight – Impact of your heart attack:**
Tell me a little bit about how you feel your heart attack has affected your life and the lives of your loved ones? What has been the most difficult aspect to come to terms with?
Appendix 4 - Data Analysis for Staff Interviews and Focus Groups

Pre – Interview Feeling:

- Appreciated, capable, happy but distracted by heavy workload on ward today.
- Safe, curious about the outcomes, appreciative of the chance to be involved.
- Interested, feel fortunate to be invited to the interview.
- Happy, safe and valued.
- Fine and happy.
- Comfortable and relaxed
- Comfortable and enthusiastic.
- Excited to be part of the project – very happy to help.
- Not very comfortable about conversation being recorded.
- Calm, curious, included as part of wider team.
- Scared about being recorded.

Emotional Touchpoint One – Being notified that a new patient is en-route to Harefield:

- Depends on the age of the patient
- Heart sinks if it is a very elderly patient
- Is it an appropriate call?
- Priority to prepare the bed space and gather paperwork
- Adrenaline kicks in – not knowing what is coming through the door
- Patient will be feeling vulnerable, scared
- Not all patients have family with them
- Mortality may be an issue for some patients
- I hope the patient will be okay
- How old is the person – age makes a difference
- Preparation – paperwork and bed space
- Assess existing patients and attend to their needs
- Arrange staff breaks – unstable patients may need extra attention.
- General preparation
- Make sure the bay is covered in case I am with the new patient for a long period of time
- Need to be organised.
- Go into auto-pilot – start preparing to receive the patient
- Sometimes feel pressurised depending on the workload of the bay
- Priority is to prepare the bed space
- I always think about the patient and their family and wonder what they are going through.
- If I’m in charge, need to organise the ward – inform staff
- Age of patient is really important information – person may need special mattress – need to consider the best bay to place the patient
- Sometimes feel pressurised depending on the bed state and workload
- Difficulty to put into words
- It’s like starting a race – the preparation is important
- I look forwards to seeing the patient
- Different feelings depending on the time of day
- When we have a call in the middle of the night, you realise that the person having the heart attack is relying on our team
- You have to move quickly, prepare the room and the trolley
- Make sure the wider team is aware of the patient’s arrival
- Priority is to receive patient, assess their condition and treat the heart attack quickly
- I feel the same as I do before any other case
- Time of arrival is important to know as this helps your planning
- Age, sex and condition of patient – is the patient intubated – do I need anaesthetic staff?
- It depends on the arrival time of the patient – if it is 5 minutes
- I tend to feel very pressured – there is a lot to prepare
- If we have 30 minutes
- there is plenty of time to let everyone and be prepared in a calm fashion
- Check equipment and prepare the room
- Feel very different depending on the time of day. 3am feels completely different to 3pm
- Priority is always to give the patient a good service and a good experience
- Pressured – depending on the ward situation
- Finding a bed can be a problem
- Try to evaluate the patient’s condition
- If the patient is intubated – we would like more information. Patient may not need ward bed.
- The patient may not go straight to the lab
- I try to stay calm until I have all of the information
- I like the team work – everyone pulls together
- I feel confident in the ability of everyone to do their job
- Communication is good between the ward and the cath lab – although there are times when the communication is not so good
- Sometimes feel worried
- Each patient is different
- Sense of anticipation and stress
- Sometimes feel unprepared
- Age of patient is significant
- State of my bay plays a part in the waiting
- Depends on the work load and who else is working
- Awful if we have to do a bed move
- Makes a difference if the patient is a direct admission or a transfer
- Priority is to get organised with equipment.
- Stressful if there is not a free cath lab – pressure to finish existing case

Emotional Touchpoint Two – Involvement with the emergency ambulance: Cath Lab Nurses Only

- Enjoy working alongside the paramedics
- Ambulance crews are part of the team
- Important to reassure them that they have done the right thing bringing the patient to HF
- We welcome them to stay and watch the procedure – it’s good to share the experience with them
- A nurse usually takes the handover from the crew
- Communication is the key – listening to the handover while observing the patient and assessing the ECG
- We take in a lot of information for the benefit of the patient
- The priority is to open the blocked artery quickly – there is no time for small talk – it a good professional relationship
- Paramedics achieve so much – they are amazing
- Communication is important related to past medical history, what drugs they have received
and chest pain start time

- Handover of patient observations is really important as well as looking at the ambulance paperwork
- The paramedics contact switchboard and the PCI call goes out – ETA is really important – sometimes accurate and sometimes not!!
- It’s good to be able to receive the patient as soon as they arrive although it is not always possible to be outside the main reception for every patient

Emotional Touchpoint Three – Arriving at the hospital:

- The patients know that they are having a heart attack
- The paramedics are good at informing patients of what is happening and what will happen when they get to Harefield
- Patients who are transferred from other hospitals often don’t know why they have been transferred here
- Consent needs to be done quickly – very occasionally patients refuse treatment
- Patients need to be reassured that they will feel much better when the stent is placed.
- On arrival to the hospital, patients feel powerless and scared
- Some patients go straight to the ward – we have to be calm as this gives the patients confidence
- Most patients tell us that they thought they had indigestion and are really shocked that it was heart attack
- It’s important to address the pain
- Patients often worry about their families outside or at home – they need to be reassured that the relatives have been seen
- Patients can be really traumatised by the event
- When the patient arrives I want to find out as much as I can about the person – there is a lot to learn
- I always feel thankful that they have arrived to us safely and they have a good chance of recovery within our excellent service
- It’s great to be part of the team looking after the patient
- Some patients are really scared that they are going to die

Emotional Touchpoint Four – The angioplasty (stent) procedure:

- Very enjoyable, fast paced environment
- Feel that we are doing something worthwhile and valuable
- Helping people when they are at their most vulnerable
- It’s very exciting – specialist area
- Need to have knowledge regarding individual consultants like s and dislikes
- It is very satisfying to see the heart attack pain subside
- Very satisfying to see blood flow restored to the blocked artery
- Can be a worrying time, depending on the condition of the patient
- Never under estimate the importance of having wires in the heart
- Feel confident in the lab and well supported
- It is more difficult if you are the only qualified nurse during the night. Managing the situation and giving all the drugs can be really stressful
- It feels more controlled with 2 staff nurses
- You worry about the level of responsibility for the HCA
- It’s a relief when it’s over for the patient and especially that their pain has gone
• You have to be prepared for worst case scenario at all times. Sometimes you feel vulnerable
• You feel like a valuable member of the team – there is a missing link without the nursing support
• It’s important to make the patient feel comfortable in the lab – they are cold and scared
• Talking the patient through the procedure is really important and explaining the equipment and what is happening
• Some patients think they will go home straight after the procedure – they feel so much better

Emotional Touchpoint Five – Arriving on the ward:

• Communication is key – informing patients of events is a priority
• Due to the hustle and bustle of the cath lab, patients may not have understood everything or been able to take in the information at that point
• Divide the information into manageable chunks – it can cause too much stress if everything is discussed at once
• It’s important to show compassion and be confident around the patients
• Make sure the patient feels cared for and included in care decisions
• Make sure patient feels safe – make sure patient is aware that they can ask for anything and not to feel frightened
• Lots of patients do not realise that they have had a heart attack and are very keen to share their story with you
• Few patients realise how potentially serious the situation is
• When I collect patient from lab, assess patient, receive handover, and make a judgement about clinical condition to make sure patient is safe to transfer
• On arrival to the ward, monitoring is a priority and should be done first – it’s easy sometimes to get sidetracked
• Make baseline observations – assess the need for the medical team
• Assess emotional condition of the patient – this can vary enormously from very shocked to very calm
• Try not to bombard the patient with too much information
• Keeping the patient calm is important
• Any deterioration usually happens in the first few hours so it’s important to be vigilant with constant observation
• Some patients are very jokey as a way of coping – often these patients are the most anxious and upset
• Important to assess the social situation early on – do they live alone or will they have someone to care for them on discharge
• If I need more information, I call the cath lab. Handovers can be difficult if there have been loads of PPCIs
• I think we have fewer complications with radial access
• Each person is different with different needs and anxieties
• If you collect the patient from the cath lab, you tend to form a bond with them quite quickly.
• Priority is to check that they have no pain
• Patients who do not go straight to the lab can be more stressful as they arrive on the ward earlier than you expect and they have received no treatment for their chest pain so can be poorly
• If I am working with a HCA, PPCIs can be stressful as you have the pressure of caring for the other patients in the bay. It only takes one of them to need more attention and care and you feel guilty that you are neglecting the other patients
Emotional Touchpoint Six – The research experience:

- Personal opinion – it’s good to be involved in research although not all patients have come to terms with their heart attack before they are asked to take part
- It seems the timing is not always appropriate, although I understand that patients are not forced to take part in the study
- Patients take part because they want to give something back
- I feel confident to ask the research nurses not to approach the patient if I am unhappy with their condition. How the patients are approached for research is very important
- If I am asked a research based question, I call the research nurses for help
- Patients seem very willing to take part in the study. They want to give something back as they are very grateful for the treatment and care they have received
- The PCI programme would not exist if it wasn’t for previous research in the field. We have a duty to continue the heart attack research that has gone before
- Patients see the need for research from the media and newspapers – they seem glad to be asked to help
- I know that all the studies are fully approved – if I can’t answer a question, I call the research nurse
- The social situations of some patients do not make them eligible to be approached for the study
- I hear the patients telling their relatives that they are taking part in a study – they seem really proud to be able to help us with something
- Patients like to be chosen for the study – it makes them feel useful and able to give something back
- I understand the need for research but taking consent in the cath lab can be a real burden for the patients and the staff. The research team create an instant rapport with the patients which is helpful
- I understand that most of the research information is explained on the ward which is better than the cath lab
- Some people are not able to take in the research information. I understand that they are not forced to take part and even if they agree to join in, they can change their mind.
- Patients always say that the research has been well explained
- Patients are really affected by their heart attack. They think research provides the opportunity for fewer people to go through what they have been through
- I am really looking forwards to the outcome of this study. We all think we do a great job but maybe we are missing something
- Research is necessary if we want to improve the patient experience and affect patient outcomes
- Research interventions can have an impact on a smooth discharge process. Patients become bombarded with information. Research nurses need to work closely with the discharge nurses. We don’t want the important messages about going home being lost by all the research information
- Gratitude motivates patients to take part
- I think we are asking too much of some patients by expecting them to take part in studies. The timing of the consent is really important
- We have to ask if it is always necessary to take part in such studies
- Patients don’t want to say no – they seem to want to please us
- Patients understand that without previous research, they may not have survived the heart attack
- I hope the patients don’t feel obliged to help us, just because we have given them the best heart attack treatment
Emotional Touchpoint Seven – Preparing to go home / Impact of having a heart attack

- Reinforcing the do’s and don’ts information – making sure patients know that they can call the ward if they are unsure of anything
- Relatives are often more nervous about the discharge than the patients
- There is no physical scar and some patients really believe they can get back to work and back to m=normal too quickly
- The majority of patients are ready for home. Occasionally patients seem to go home too quickly – especially elderly patients
- Patients seem more nervous about work than previously – they are scared that they will lose their job if they take time off work
- Driving is always an issue – patients want to get back to normal routines quickly
- Patients are sometimes nervous that they will have another heart attack. It’s important to share the angio details and the echo results as well as the blood tests
- Patients and family should be advised what to do if the heart attack pain happens again
- The more poorly the person has been whilst in hospital, the more nervous they are about going home and these patients need more reassurance. By this I mean patients who may have had an ITU admission or a balloon pump or maybe they suffered a cardiac arrest
- Oak ward is a smoother discharge process due to the efficient discharge nurses
- The discharge information is excellent. I always make sure they have a point of contact and instructions about how to use the GTN spray. I always share the information with the family when they arrive to collect the patient
- I like seeing the patients going home – it means we have done a good job and they are happy to go home. They feel much better than they did when they arrived!
- Patients have concerns about medications, their social life and their sex life and all of these have to be addressed
- Concerns about discharge vary depending on the age of the patient
- The discharge process n Acorn ward can be difficult – the doctors don’t prioritise the letters and we have to wait longer for everything to be ready. Some nurses need extra support to discharge a patient safely
- It would be great if Acorn ward had their own discharge nurse. It would also be good if the discharge nurses were here a bit later as a lot of patients are now being discharged in the evenings
- It’s really important to stress the importance of medications. Some patients come into hospital and they have never had to take tablets regularly. They feel so well by the time they go home, it’s important to stress the need to take the tablets as prescribed
- The rehab team are fantastic and spend so much time with the patients – it’s our job to reinforce those messages and answer any questions
- Patients do not realise that the emotional impact of having the heart attack may kick in when they get home – I try to prepare them for that so it doesn’t come as a massive shock
- I worry about the patients who go home with no support. It would be useful for some patients to have their relative with them during the chat from rehab – it would help to reassure the person and the family

Emotional Touchpoint Eight – Working in the PPCI service:

- A very positive experience – I couldn’t do the job if I didn’t enjoy it.
- Patient feedback is really positive which makes me more positive.
- Real sense of achievement that I have contributed to making someone better.
- Feel proud to look after such patients – proud to be part of the service.
- Patients are really thankful. We provide a great service and patients receive very smooth
treatment.
• I have had to learn lots of new skills and I’m grateful for the opportunity
• Always feel that we have done a good job when patients go home
• Patients feel that we have saved their life and it’s great to be a small part of that
• I really enjoy looking after the patients. I feel respected and appreciated
• Working here gives you great job satisfaction
• 10 years ago before the PPCI service, lots of people died from their heart attack. It’s great to think that we have reduced the number of heart attack deaths
• Study days and conferences allow us to see what other units are doing
• I have huge enthusiasm for the service – its motivating to know that we work in such a great centre
• We have all embraced the service and helped to take it forward. It works like clockwork
• It’s a supportive environment for learning
• The only bad thing is when the patients don’t survive – especially when you have formed a bond with them
• We help to provide improved long term health to patients and we are in a good place to educate patients and their families about lifestyle issues
• There is a real sense of belonging here – I’m proud to say I work at Harefield
• Sometimes the patients send a card to the cath lab – it’s always good to be remembered by the patients
• We are always building our experience and expertise
Appendix 5- Data Analysis for Patient Interviews:

Pre-Interview Feeling:

- Happy, calm, thankful for Harefield
- Relieved, up-beat and thankful, appreciative
- Good and calm
- Interested to find out what will happen next
- Very good – 9 out of 10
- Very grateful for the care and treatment I have received
- Frustrated that I can’t do everything I want to do
- Hopeful, thankful and fortunate
- I feel okay – we really very lucky to have Harefield

Emotional Touchpoint One – Experiencing chest pain:

- On my knees with the pain
- Really sweating
- The pain took over everything – it was unbearable
- All of my energy went away – I couldn’t walk
- I was sweating and vomiting
- The pain was so bad – I knew there was a serious problem
- The pain took over everything
- Pain was so bad, I couldn’t breathe, I was gasping for air
- I was shocked by the pain – I was relaxing, not even exercising
- Pain was very severe – it was the scariest thing I can ever remember
- The pain was so bad I thought I was going to faint so I had to lie on the floor – I was nervous I was going to fall
- The pain was excruciating – I was really short of breath. I knew it was a heart attack when the pain moved to my left arm
- It was like being stabbed – the pain was intense – right between my shoulder blades
- I knew I was unwell. I caught sight of myself in the mirror and knew how awful I looked
- I knew it was a heart attack because the pain was so bad. I remembered my Mum having a heart attack and it was the same as that
- The pain started in my arms and it became unbearable very quickly

Emotional Touchpoint Two – Calling the emergency services:

- Neighbour called the paramedics – I knew it was serious
- Paramedics arrived quickly – they took ECGs and told me I was having a heart attack
- The ambulance people gave me pain killers – it took the edge of the pain but I could still feel it
- Ambulance came very quickly and told me I was having a heart attack – I was so shocked
- Ambulance crew told me Harefield was the best hospital around if you are having a heart attack
- That was scary but reassuring. They gave me pain killers and were very kind to me
- The ambulance crew knew what they were doing – they brought me straight to Harefield – everything happened so quickly
- I’ve seen heart attacks on the television – I always assumed it was like being shot. When the
paramedic said I was having a heart attack – I didn’t believe him – I was convinced they were wrong

- Paramedic was fantastic – the stickers wouldn’t stick as I was sweating so much – he was so patient and did his best to help me to relax
- I felt calmer when they told me they would bring me to Harefield – I have heard so much about the hospital and how good it is
- The paramedics gave me morphine but even that didn’t lift the pain – when they said they would bring me to Harefield, I knew it must be really serious – they wouldn’t use Harefield unless it was serious condition
- I felt completely out of control – very helpless – nothing would kill the pain
- I was lucky that we got to Harefield very quickly – I knew it was serious when they said they would bring me to Harefield – it’s only for emergency patients and very sick people
- The ambulance crew were magnificent – they acted so quickly to get me here in one piece
- I don’t think I would be here today if it wasn’t for the ambulance crew and the people in this hospital. The paramedics didn’t leave my side – I think they thought I would need CPR
- I didn’t want to be out of control – I didn’t take the pain killers – I needed to know what was going on and I was scared that strong pain killers would knock me out
- The ambulance said Harefield was the best hospital – I didn’t like having all the stickers on my chest
- I felt really frightened in the ambulance – I knew I was in some sort of process and the system was working but it didn’t feel very good to be part of that process
- You are grateful that people are taking such good care of you – you feel safer once the proper medical staff are involved

Emotional Touchpoint Three – Arriving at the hospital:

- The team were all waiting for me and they explained what would happen – I don’t remember what they said
- I had to sign a consent form – I would have signed anything as long as they took the pain away
- There were about 10 people waiting when they opened the ambulance door
- I went straight to the theatre – I didn’t realise they would fix the problem straight away
- Everything happened so quickly when I got to the hospital – they stripped me off and shaved me – they left my socks on!!
- That has really stuck in my mind – I wondered if they were meant to leave my socks on
- It was 9pm – I didn’t expect anyone to be around but there were loads of people all expecting me
- They took me straight to the operating theatre – the surgeon was a lady and she put the needle in my leg
- I couldn’t lie flat – I really couldn’t breathe. They had to get a special doctor to put me to sleep – they said I needed to have the operation immediately
- I was worried because it was a bank holiday and I expected to wait for treatment. They took me straight to the theatre and did the operation straight away
- It was surreal to be in the middle of such frantic activity – it was very scary but it was clear they all knew what they were doing
- I went straight to the cath lab- it was like Holby City or at least the Star ship Enterprise
- Everyone was brilliant – I felt really cared for
Emotional Touchpoint Four – The angioplasty (stent) procedure:

- I can remember them cutting my wrist and I could feel the wire moving up my arm
- I was expecting a major operation. They were watching screens and told me they had found the problem after a few minutes
- There was no cutting or anything. I couldn’t believe they were fitting the stent without a real operation
- They showed me the before and after pictures. I was amazed by what I was seeing
- I though the procedure was to find out what was wrong with me – I couldn’t believe they fixed the problem at the same time
- I was feeling so nervous – they told me not to worry and they would help me
- I had to lie very still and tried my hardest to keep calm – I just wanted them to get on with the job
- They had to put me to sleep – I didn’t know anything about the operation
- I’m sure they were talking to me all through the procedure but I can’t remember now what was being said to me
- I have taught myself a lot about the heart and I understand now what they had to do to take the pain away
- It must be hard for the team to explain everything to everyone. Everyone was working really hard but I felt as if they were talking more to each other than they were talking to me
- I remember them cleaning my groin and my wrist. I was so relieved that they could use my wrist
- The x-ray machine was noisy and a bit scary – it came so close to my body. Comforting words were being said to me – I can’t remember what was being said but I can remember how comforting the people were
- They showed me the blocked artery and how they had fixed it. It was such a relief to see that the other arteries were clear. It was such good news to hear
- Everyone was being controlled by the consultant – he seemed to be getting anxious
- It took a while for them to find a vein – eventually they had to go through the groin
- I was bursting for the toilet – they kept telling me to hold on. I was in there for over 2 hours
- It was professional and first class. They saved my life
- I don’t think I realised the severity of the situation until afterwards – I just didn’t think that it would happen to me
- I can remember the procedure – I didn’t have an anaesthetic. I couldn’t feel anything apart from them fiddling about with my arm. The pain went away as soon as they fitted the stent
- I think they thought I was asleep because I kept my eyes closed. I didn’t like the x-ray machine – it came so close to me
- The pain went away as soon as the stent went in
- Everything was explained so well to me. I was so impressed at how efficient everyone was
- I was so pleased that they spent so much time explaining everything to me while they were operating on me

Emotional Touchpoint Five – Arriving on the ward:

- As soon as the stent went in, I felt on top of the world. I felt like I could have gone straight home. They told me off for standing up!
- My daughter came with me in the ambulance and stayed with me all the time.
- The pain had gone and I was relieved it was all over. I was wondering what would happen next and what the heart attack would mean for my future.
- My family were all really upset and shocked that I had suffered a heart attack.
- My friends still can’t believe I had a heart attack – they have made lifestyle changes to stop it
happening to them.

- I felt so lucky – the ambulance arrived quickly and everyone got rid of the pain quickly.
- I was able to see my wife straight after the operation – I was so pleased to see her so she knew I was okay.
- It was very traumatic – I had a drip and a monitor – I thought what the hell has happened to me?
- I was concerned by my physical heath but emotionally I felt I had been hit by a bus.
- I was happy that I could see a nurse all of the time – she really helped me to calm down – she looked after me really well.
- I was able to see my wife as soon as the operation was over. I sent her home to collect my phone and books to read.
- By the time I got to the ward it was the middle of the night. I slept really well but I can remember the lights were on all night.
- My wife drove herself to the hospital and got lost! She had to wait ages to see me because I was on the table for more than 2 hours. It must have been dreadful for her.
- My 2 boys came to see me and I haven’t seen them cry since they were small boys – it was so emotional for all of us.
- The consultant said that not all people would have survived my heart attack – the realisation that my life had been saved was overwhelming.
- I didn’t mind being on the ward – it was very busy with lots of noise and lots of people coming and going.
- Everyone was so kind – I wasn’t afraid of anything.
- It was relaxing being back on the ward. The pain had gone and I knew I had received the best treatment.
- I felt sorry for the nurses – the doctors seem to give out all of the instructions but they don’t do any of the work themselves.
- The older nurses seemed much better with coping with things – some patients were abusing the visiting rules – it was not nice when one patient constantly had a group of relatives with her. The older nurse came on the night shift and asked them to leave – I was so relieved it had been so noisy all afternoon and evening. I had to sit in the main reception to get some peace and quiet.
- I was worrying about things back on the ward – I had only just started a new job.

Emotional Touchpoint Six – The research experience:

- I spend all of my time working – I had never thought about research before. I was very happy to be part of the research. I wouldn’t have said yes if I thought it was anything sinister.
- I wanted to help other patients. Having the heart attack is an experience I wouldn’t wish on anyone – if I can be part of something to help other people, I was very happy to help.
- I was more than willing to help out. My father had a bypass here and now Harefield have saved me too. My sister has done charity work to raise money for Harefield so I wanted to help as well.
- I just wanted to give something back to Harefield in a small way by helping out where I could.
- I haven’t got a problem with research – it’s the only way we can get a bigger picture of things. I always take part in surveys if anyone asks for help. I enjoy taking part in research things.
- Research is a really good thing – I wanted to help because not everything is known. My wife had a massive operation and was given a 50% chance of surviving – I wanted to help out here because I wasn’t able to help her
• I was happy with the research paperwork – everything was explained well – it was important for me to help the hospital develop their research work.
• I was aware that research is always going on but it wasn’t anything I had considered before.
• I was aware that if my heart attack had happened 20 years ago – I may not have survived and that is all because of research.
• I have been so well looked after here – I wanted to give something back. I would have done anything to help the hospital.
• As a family, we are all involved in research – my son-in-law is a research professor for cancer and my daughter is involved in research too. I really want to help with the study.
• Research is a big part of my working life. I just felt that I owed Harefield an enormous debt – I would do anything to help the hospital.
• For me it was about giving something back – we all have a responsibility to put something back in the NHS to help other people who may benefit from the research.
• If the research will help someone else, I was happy to take part. I just wanted to help the hospital.
• I know about research and have done a few charity events to raise money for cancer research. I really wanted to do something that would help Harefield.
• I knew that research went on at Harefield. If my involvement in the study will help other patients, I was very happy to take part.

Emotional Touchpoint Seven – Preparing to go home:

• The rehab team gave me lots of information – I asked loads of questions. I couldn’t wait to get home
• I felt ready to go home. I was worried about the total lifestyle changes especially stopping smoking. I feel much better since I stopped smoking.
• I was ready to be back at home with my own things around me. There wasn’t anything I didn’t already know about diet and exercise but doing the right thing all of the time is sometimes hard.
• I couldn’t wait to get home – I find that I do get very tired but I feel very well.
• I was a bit sad to be going home – I liked being looked after. I was worried that when I got home, I wouldn’t feel as well as I had in the hospital.
• I was nervous about all of the tablets – I hadn’t ever taken tablets before and I was upset to learn that I would have to take tablets for the rest of my life.
• I can see the benefits – but it’s a real game changer.
• I was really scared in case I would have another heart attack – no one could tell me that it definitely wouldn’t happen again.
• The side effects of the tablets scared me – I didn’t have to take any tablets before.
• I knew that one of the other arteries had a narrowing – I was nervous about going home in case the artery blocked. I can’t wait to have the scan so I know everything is okay.
• The staff were so good in all departments – the rehab team were excellent.
• I wasn’t anxious about going home – I have a really supportive family and I knew I would be well looked after at home.
• I was happy to be going home. The advice was all very easy to follow. I still need to learn more about the tablets.
• All of the information was great – the only thing I would say is that the information about having a sick note for work should be at the front of the booklet. It’s right at the back and I didn’t read it until I got home. I was nervous that I should have asked the ward sister for a sick note.
• It’s helpful that you have to take the tablets in the morning and evening – it makes it simple
Emotional Touchpoint Eight – Impact of your heart attack:

- The biggest effect of the heart attack has been on my job. It has been really strange taking time off work. I am really bored at home and can’t wait to get back to work.
- Taking the tablets is okay and I think I have finally got my head around taking tablets every day. I am really bored at home and can’t wait to get back to work.
- I realise that I can’t take anything for granted any more. The heart attack has taught me a lot about life and the need to look after myself. I have realised that I wasn’t looking after myself at all and that is why the heart attack happened.
- It was hard getting into a routine with all of the tablets but I think I am settled into a routine now.
- The heart attack has had a big effect on my life. I have stopped smoking – not through choice but because I was told I must stop or this could happen again. Stopping smoking has been as hard as having the heart attack – I miss it every day. I need to get into a proper exercise routine – I’m hoping the rehab sessions will help me with that.
- It never occurred to me that I wouldn’t survive the heart attack but I have really started to question my own mortality. I am happy to talk to you now to get some of these thoughts out of my system.
- It was really stressful in 2012 when I lost my job – I was drinking far too much. I’m now back to exercising like before 2012. I’ve cut down my alcohol, I’ve lost weight – I actually feel much better about myself.
- The heart attack has affected the whole family – we are all thinking about diet and exercise a lot more.
- On the whole, my heart attack has had a positive effect on myself and the rest of the family because we are all living a healthier life. I wouldn’t want to ever have to live through that day again.
- The worst thing for me is not being completely independent. I still need help to do the gardening. I just want to get back to where I was before the heart attack.
- I’ve done everything that has been asked of me. Sometimes I feel vulnerable because I can’t do exactly what I would like to do.
- I’m still having bad days – I keep thinking about what might have been. Both my parents died in their early 60’s – will that happen to me?
- I don’t like taking things easy - my daughters are insisting on doing the cleaning and the gardening. I don’t like watching them do all the work.
- I’m getting back to normal now and doing everything myself. I’ve gone back to my voluntary work with adults with disabilities.
- I just thank my lucky stars that I’m still here and able to enjoy life. I’m in my 80’s and I’ve never been sick before – I am so lucky and grateful for everything.
- I’ve had loads of visitors and loads of flowers – I’ve been really spoilt.
- I have followed the instructions – I’m much more aware of what I am eating now.
- I know I have had a lucky escape so I need to be more careful – I’m making the changes slowly.
- It’s frustrating not being able to get back to work – the rules say I can’t go back to work until after this appointment. I’m really looking forwards to the cardiac rehab course.