SUMMARY REPORT OF PATIENT EXPERIENCE
PILOT PROJECT IN LOTHIAN CANCER SERVICES

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on behalf of the Project Steering Group

July 2012
Patient Experience pilot project in Lothian Cancer Services

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Acknowledgments:
This pilot project was funded by the Scottish Government with ‘Better Together’ and was made possible by the efforts of all the patients, carers and staff who participated.

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EXECUTIVE SUMMARY

This report is to summarise the achievements and learning from the pilot patient experience project in Lothian NHS Cancer services which began in 2008.

The project focused on clinical areas where there were potential issues of inequalities of access and care for the patient group. For example, patients with head and neck cancer where there are higher patient numbers from socially/economically deprived circumstances, young people and patients with learning disabilities. Additionally patients undergoing chemotherapy were chosen as a broad group representative of diverse social circumstances.

Experience based design (ebd) was chosen as the methodology with the aim of testing its value within cancer services and then consider its applicability to other specialities. Experience based design focuses on understanding the experiences of both those using and providing the services and using this understanding to jointly plan service improvements.

Developments arising from the work with the different groups were:

• New transition clinic for young adults with cancer set up in the HEBA centre WGH.
• New assessment clinic for patients presenting with neck lumps suspicious of cancer set up, waiting times reduced and efficiency improved.
• DVD made for patients with head and neck cancer to inform them about the radiotherapy planning and treatment process.
• Patient experiences contributed to the information booklet developed for chemotherapy patients.
• Visual information developed to use with patients with learning disabilities and others who might have difficulties accessing the written information.
• Other initiatives developed as part of the project have been varied.

Key to progress has been the involvement of patients and the commitment of particularly dedicated staff.

Developing practices that will be sustainable at the end of the project has been considered throughout the project. Staff training, finding easy and flexible ways of getting patient experience, seeing how to use a cycle of improvement actions to use the experiences gathered have all been important in this.

Learning has been that ebd as a methodology is valuable in informing change but given limited resources it has to be adapted to suit local circumstances.

Most improvements have been made in the services which were selected in order to consider possible areas of inequality. There is evidence from the head and neck service
of faster patient access to diagnostic tests and treatment with the new clinic. Whilst it is difficult to demonstrate that overall inequalities have diminished, changes have been made to provide better support and information in different formats in response to the experience of these patients.

Maintaining the use of patient feedback and the cycles of improvement in the clinical areas will be vital to continuation of this work if patients are to continue influencing and being involved in service change.

Project management was vital to initiating, supporting and achieving planned actions. A post aligned to quality improvement that worked with this methodology would have the potential to lead similar developments within the service.
INTRODUCTION

This report summarises achievements from NHS Lothian’s Patient Experience pilot projects.

The overall aim of the project was to explore patient and staff’s experiences of selected services, using an experience based design (ebd) model, with the purpose of improving patient services based on the outcomes. The four clinical specialties were identified as pilot project groups within NHS Lothian for specific reasons, Table 1.

Table 1: Identified specialties

<table>
<thead>
<tr>
<th>Setting</th>
<th>Reason for selection</th>
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<tbody>
<tr>
<td>Head and neck cancer services</td>
<td>High representation of patients from economically/socially deprived circumstances</td>
</tr>
<tr>
<td>Young people with neuro-oncology cancer making transition to adult services</td>
<td>Recognised as vulnerable groups whose needs are not always adequately met by health services</td>
</tr>
<tr>
<td>Chemotherapy services</td>
<td>Represents patients from all social groups and many different types of cancer</td>
</tr>
<tr>
<td>Patients with learning disabilities within cancer services</td>
<td>Recognised as vulnerable groups whose needs are not always adequately met by health services</td>
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In addition to the project background and methodology the following report will also provide a summary from each setting on how experience was captured, understood and used to improve patient and staff experience. Learning outcomes will be discussed at the end of this section.
BACKGROUND

The Scottish government wanted to create a wholesale systems approach to patient experience based service improvement. In order to develop this approach it decided to fund a three year pilot patient experience project within three regional cancer services; NHS Glasgow, NHS Grampian and NHS Lothian.

The project scope was left open to individual settings interpretation, with encouragement to design and deliver service improvements based on patient’s experiences from diagnosis to treatment. There was to be a focus on including groups where potentially there were service inequalities. It was envisaged that learning would then be shared with other specialties (Appendix 1).

A project manager in each region managed the pilot projects on a day to day basis, reporting to a local project steering group (Appendix 2).
METHODOLOGY

Experience based design

Experience based design developed by Bate and Robert (2007) was chosen as the projects approach because it involves capturing the experiences of patients, carers and staff at points along the patient pathway, working together to understand these experiences and then patients and staff together developing priorities for action and improvement. Following implementation of the actions it is important to measure effectiveness by capturing further patient experiences and looking at other measures of quality such as reduced waiting times, fewer complaints and critical incidents.

A variety of staff (Appendix 3) were trained in the ebd methodology and in conducting the patient experience interviews with staff, patients and carers. It was envisaged that this select group would be released from their primary roles intermittently to work with the project manager on a variety of project tasks; interviewing patient and staff; analysing outcomes; planning future project approaches.

Capturing experience

Experiences of staff, patients and carers were captured using a variety of methods: Initially with interviews using open ended questions and prompts about particular points of the patient journey, observation of clinical areas, focus groups, questionnaires, telephone interviews and at the improvement events where staff and patients participated. The ebd agency ‘Thinkpublic’ who were commissioned to work with the head and neck project, suggested filming the interviews and this was attempted however the quality was not sufficiently good to show at the group events and the experience was that neither patients nor staff felt particularly comfortable being filmed.

Later in the project simpler feedback methods proved more realistic, such as shorter more focused interviews using emotional touchpoints (Dewar et al 2009), questionnaires and simple feedback forms. These were useful for very busy clinical areas and getting day to day feedback.
**Understanding experience**

Once the feedback was gathered it was themed, by the project manager and staff undertaking the interviews.

Patient and staff groups were encouraged to listen to and understand the interviews before theming the findings at the organised project specific events.

**Improving experience**

The next stage after theming was to identify what were the most important things to address from the findings, then for staff and patients to develop and plan the actions for service improvement.

Quotes from patients and staff were often very powerful and influenced a variety of changes, from designing a new clinic to simpler responses such as making a new patient information leaflet.

**Measuring experience**

Evaluation has been carried out throughout the three years of the project by an independent researcher who was able to be involved over the time frame of the projects and who had the opportunity to see how the different aspects of the projects worked. The evaluation reports for each project give more detail as to the processes which worked best in each area. These together with this report will be available on the SCAN website.

Evaluation of other projects will be taken forward by the clinical areas concerned as the remaining changes are implemented.

Staff working in clinical areas within cancer services have been encouraged to continue getting feedback from patients, carers and staff in order to understand how the developments are working and to ensure a process by which further change and improvement cycles can take place.
SUMMARY OF EACH MAIN PROJECT

Young adults with cancer

Initial scoping work for the Patient Experience Programme revealed that staff in both paediatric and adult neuro-oncology services identified the need to design a better transition between services for the increasing number of teenage patients who were being seen in age inappropriate environments, as this staff quote demonstrates:

“Involvement in adult clinic setting must be hugely negative experience given the range of what people see and hear out there.

Truly believes answer is dedicated clinic for teenagers.

In addition to providing a more comfortable environment and less traumatic experience provides opportunity to: pull in support services staff to be present during clinic (i.e. that lack of space prevents in current adult set up); and look at working to support patients to take more independent ownership over health and wellbeing by introducing joint and separate consultation model.”

(i.e. with parents and then young adult alone)

The enthusiasm of key clinical staff to be involved in the design of a transition process created an ideal situation for a small scale project to begin the project work. The focus on teenagers/young adults also demonstrated the commitment to working with hard to reach patient population groups.

Capturing experience

Clinical staff agreed that they needed to understand teenagers and young people’s experiences of moving from children’s services to adult services if they were to improve the experience.

A variety of approaches captured the teenagers/young persons and their parents/carers experiences:

- Observations of the existing children’s and adults clinics were made by the project manager.
- Questionnaires were completed with patients, their parents and staff.
- Interviews with patients, their parents and staff.
Understanding experience

A service improvement event was held with key staff from Royal Hospital for Sick Children (RHSC) and adult services. Patients and parents were invited too but due to their university and work commitments they were unable to attend.

Key themes from all the interviews and observations were displayed for all to share, together with relevant literature and policy.

The observation revealed that neither hospital environment were found to be ideal for teenagers. The one in RHSC was dominated by much younger children with toys and in the WGH a clinic environment with a much older patient group and no facilities aimed at younger people.

The following quotes highlight teenage patient’s feelings about their experience:

“I was mainly treated at the WGH. There were no other teenagers there. I felt it would have helped me if I had the chance to meet other teenagers. Therefore a better link between the two hospitals would be beneficial. Perhaps a dedicated ward/room specifically for teenagers would be great.” (patient)

“I just really think that separate unit, separate place, if there could be for young people to go and have their appointments would be so much easier. You don’t feel as uncomfortable. You would just feel a bit more normal. Is that the word? Is that the right word to use? You just feel like it’s just a normal routine. When you go at the moment and you’re the only younger person in the room it’s actually like it’s their appointment. It makes you feel a bit uncomfortable and you just want to get out of there, really. You’d be much more relaxed, definitely, having a separate day and separate unit. I think that would be good.” (patient)

Feedback also suggested that the move from children’s services should occur when the individual patient is ready and the decision should be agreed by staff in partnership with patient and parents.
Parents and teenagers felt very safe and supported by their consultant and teams at Sick Children’s and expressed anxiety about transition to adult services.

“It’s the fear of the unknown, I would say. Yeah, definitely. Points of contact as well. If xxxx did become ill I would know that I could phone up either Mr Wallis, his office, or ward and say, ‘Something’s happened,’ or, ‘I feel unsure. Can I bring him in?’ Whereas I wouldn’t know what to do if something did happen when he was at the big hospital. Keep on saying the big hospital; the Royal. If he was going to the Royal, who would be the point of contact or would it be through our GP? Would it be a long-winded waiting list and... that’s not clear, how the transition would be.” (parent)

**Improving experience**

An outcome from the teenagers and young people’s experiences project was to create a transition clinic for current young patients and for newly diagnosed patients in this age group.

The first dedicated clinic was held in May 2011 within the HEBA space at the Edinburgh Cancer Centre. The HEBA space was considered ideal as it was a pleasant environment where young people have an opportunity to meet other young people in a similar situation. In addition it offers privacy to see the relevant clinicians and nurse specialist together. Alongside the change in physical surroundings have been changes in practice as the young people are also encouraged to see the clinicians alone as well as with their parents so that they take ownership of managing their health as they mature.

**Measuring experience**

Initial evaluation of the young adults with cancer clinic was done using questionnaires and a very positive experience of the new clinic was reported by patients and their families.
Head & Neck patient project

Thinkpublic, a social innovation and design agency, won a tender to support the Head & Neck project, working on a co-design basis with the project manager. Thinkpublic input included training the experience based design team (ebd) team to capture patient and staff experience and joint delivery of three improvement events.

Eight staff volunteered and were trained in interviewing and experienced based design methodology.

Capturing experience

Patients with Head & Neck cancers attending clinics either at St Johns hospital or WGH were invited to share their experiences of diagnosis, treatment and care.

Interviews with patients and the staff who cared for them were also undertaken.

Patients had concerns about varying aspects of their treatment journey, including delays in diagnosis, getting information, being prepared for clinics, privacy, support and what happened during treatment planning.

“Scariest bit was getting the mould made, the girls talking to me and explaining and then the guy comes in and puts it over your face. It’s like someone coming in and putting a very heavy pillow over your face and trying to smother you, I just wasn’t ready for it. I didn’t get the chance to get a deep breath in, there wasn’t any real warning. Then it was peeled off.” (patient)

Staff concerns were about communication, meeting patient expectations, patient and staff support, having time and space to meet patient needs.

Understanding experience

Initial workshops were held separately for staff and patients in which they decided what were the most important issues to look at.

Another joint event was held inviting patients and staff to look at the themes from the interviews and to work in groups to share ideas as to how to make improvements.

An Action plan was developed from the ideas put forward and leaders were decided for each of the 12 improvement actions to take forward.
Improving experience

The following are some of the developments and some of the quotes that influenced them.

“One of the things that I have had feedback from the patient is the initial diagnosis. Sometimes there’s a delay in that diagnosis and obviously then the patient finds that very frustrating.” (staff)

Following the initial development stages of the project the modernisation (LEAN) team were asked to support the ongoing development of a new clinic. Together with the clinical and support teams they have developed the neck lump clinic to see all patients with neck lumps suspicious of a cancer diagnosis. The clinics started in March 2012. The patient referral pathways from GP’s to the clinic have been improved so that patients do not experience delays in being sent for tests. Waiting times have already been reduced. Clearer routes for managing all related biopsy specimens have been put in place.

Following a clearer pathway to diagnosis, patients are then referred to the appropriate clinical specialty i.e. Haematology or Head & Neck teams. Some patients can be told following investigations done at that first clinic visit that they do not have cancer.

“I feel a bit rushed in that I’ve had questions to ask and I’ve forgotten them by the time I get to the end of the consultancy, I’ve either forgotten them or I’ve felt there hasn’t been enough time or the flip side of that is that the questions have been answered during the process, so I haven’t had to...But there have been times when I’ve come out afterwards thinking well that was a bit of a sort of whirlwind kind of thing.” (patient)

Following successful testing of the ‘Distress Thermometer’ with a small group of patients staff intend to use it regularly in clinics. It is a tool to help identify and prioritise patient concerns (Appendix 4).

“I think my big beef, and if anything comes out of this, would be that we really have to have some sort of room on the ward for breaking bad news. Behind a curtain in a busy ward is not acceptable.” (staff)
It was decided to improve the use of quiet areas for breaking bad news to patients and a room for this purpose was established in Ward 19A in St John’s hospital.

“What puzzled me when I came here, I was asked by a team of consultants, having explained the various kinds of treatment, which treatment I would opt for. I thought this was very odd. Here we have a team that specialise, and they're asking a patient who has just heard that he has cancer which of these options he would opt for.” (patient)

A patient information leaflet to help prepare patients better for the Combined Oncology clinic after their surgical experience has been developed and is about to be tested.

“I am extremely claustrophobic, and the one thing that nearly stopped everything else I've coped with was the mould room for the facemask. I'd read up a bit about it in the Macmillan book but it was the morning I came in and they didn't give me very much warning, I lay down on the table and I suddenly found this big hot towel smothering my face. They said it was hot and it had to stay over me for a quarter of an hour until it moulded and went cool. It covers my eyes, my nose, my mouth and the top half of my shoulders...

It’s funny, the woman in the flat across from me works with cancer, children’s cancer and I was telling her about my experience. She said when the children with cancer go, they are given dolls and they're shown exactly what is going to happen. I think it almost could be done, to visualise it, certainly the facemask.” (patient)

A DVD of the Radiotherapy planning and treatment process including the mask making has been made to help patients with head and neck cancers be better prepared for what this will involve. It will be offered to patients in clinic prior to them starting radiotherapy. It will also be used for staff education when linked to the new learnpro module on head and neck cancer. This has been developed by the nurse specialists to help staff understand the care and treatment these patients need.

**Measuring experience**

Some projects such as the management of neck lumps clinic have just being completed and evaluation will be taken forward following discussions at the final project meeting. Other aspects will have to be evaluated as their use is rolled out i.e. the DVD and information leaflet.
Chemotherapy services

Capturing experience

Patients attending for chemotherapy in the outpatient chemotherapy areas in WGH and St John’s hospital and inpatient Wards 3 and 8 in WGH were interviewed to gain an understanding of their experience of the service.

Hospital and community staff involved in caring for chemotherapy patients also shared their experiences.

At this time the project manager was involved with rolling out across Lothian a patient experience questionnaire, the Rapid feedback questionnaire (Appendix 5). Initially this was tested in the inpatient and day case areas of Cancer services.

Results from the Rapid feedback questionnaires were added to the interview data and the observation data of the clinical areas.

Understanding experience

Data was shared with local staff and actions agreed with them that arose from the themed data.

Patients were generally very positive about their experiences, appreciating good teamwork, care and support and continuity of staff.

“If I need to speak to anyone when I am at home I can phone straight here and ask for area 2 and get a nurse on the phone who is confident, knows what’s going on and gives me excellent advice.” (patient)

“I feel the staff here in Ward 3 always explain things to me and if I don’t understand they will give me time to try and explain in more detail. I was really scared when I first came terrified of needles they had to give me tablets to calm me down. Now I am not over my needle phobia but I am better and that’s down to these lassies being calm and having time for me.” (patient)

There were varying needs for clearer information about specific things, advice out of hours,

“I have contacted the on call register at the WGH, told it was the wrong number, but they would get the registrar to contact me. They did 20 mins later and again on the following day and the next which I appreciated.” (patient)
adequate preparation before coming for chemotherapy,

“I was really well prepared before coming in here, well I thought I was until you are actually here, but I don’t know how you can get better prepared other than coming along and having a look around, but that’s not easy when you stay far away.” (patient)

waiting for treatment.

“If I get my treatment started at the right time then I will get away a the right time. Don’t like being held, being late when you have nothing to do cracks you up” (patient)

**Improving experience**

During the time of the project a new patient chemotherapy information book was being developed. Although already in development staff were able to respond to the patient feedback by incorporating elements into the book which answered some of the questions and issues raised.

Patients had asked for clearer information regarding out of hours advice. Some of this is incorporated in the new Chemotherapy information booklet. Additionally work initiated in the cancer centre is currently being taken forward at a national level to develop a national triage system for responding to all calls from patients on chemotherapy.

Pre admission visits have been tested in Ward 1 and there is a plan to develop their use.

New computerised systems for chemotherapy services are being put in place which should ultimately increase efficiency and reduce the time patients wait to get their chemotherapy.

**Measuring experience**

Staff in all chemotherapy areas are using a quick open feedback form (originally developed by the Leadership in Compassionate Care Programme), (Appendix 6) with patients and relatives to continue the listening to feedback, action, improvement cycle. In Ward 8 Haematology two members of staff had also been on the Leadership programme of the Compassionate Care Programme so were already using the feedback and emotional touchpoints interviews to look at both the experience of patients and staff and make improvements.

Rapid feedback surveys are also used approximately 6 monthly which provide more quantifiable feedback on the service.
Patients with Learning Disabilities receiving Cancer Treatment

Some preliminary planning work involved a public health worker speaking to a range of key individuals who worked with patients with learning disabilities across Lothian. There was also a focus group held with District nurses who had experience of working with patients with learning disabilities. The feedback from both these was used to help plan the interviews and project.

Capturing experience

Initially 13 staff were interviewed to explore their experience of giving care to patients with learning disabilities within the cancer unit. Following this the results were themed and then available for discussion at the improvement event. Patients were invited to this event through groups that worked with people with learning disabilities, although none in fact attended. However improvement actions were agreed by staff and individuals accepted responsibility for taking them forward.

Six patients and eight carers were subsequently interviewed and after each interview they were asked if there were any things they would improve in relation to experiencing the cancer service. Some of these related specifically to the individual’s care and were responded to there and then, others fed into the action plan.

It had been decided to train a small group of staff to use Talking Mats (a method for using visual communication aids to help patients with limited language skills communicate their likes and dislikes) in order to use this to gather further patient experiences. In the end although the training was achieved, it proved difficult to get further patient involvement within the time frame of the project due to changes of project manager and the small numbers of patients who had learning disabilities.

Understanding experience

Most patients interviewed felt their needs were well met, with information being given in a step by step way that they could understand and that staff were supportive.

“The staff have been good and let me know what’s going on a bit at a time, that way is better for me, can’t manage when they tell you everything at one time.” (patient)

“On the ward I had a room to myself. That was good.” (patient)

“I liked the nurses. They made sure I was alright. And they told me what was happening.” (patient)
Staff interviewed felt anxious about getting care right for patients, having enough knowledge and preparation for each individual and more generally about Learning Disabilities and sources of support for patients.

“I feel that without that kind of formal training we’re just kind of muddling along, and hoping we’re doing it right.” (staff)

“because you don’t have a lot of dealing with people with learning disabilities, I think you’re scared that you make matters worse or you say something that will upset them.” (staff)

Some staff wanted more symbolic and visual information that they could use with patients to explain proposed tests and treatments.

“I think as well you need to know what sort of level they can understand. If they’re getting treatment and you’re trying to explain what the treatments are that they’re getting, it’s really difficult to put it into words that they understand so that they’re not frightened.” (staff)

“I think quite often, written resources are fairly simplified but some maybe not.”
Improving experience

In response to the quotes from staff and patients the project managers have worked with FAIR (an Edinburgh based organisation that provides ‘easy read’ and illustrated information for people with learning disabilities) and the project lead from the Learning Disability service to develop resources relevant to cancer patients. Using key information from the newly developed cancer information booklet, simplifying the language and adding illustrative drawings cards have been developed with the intention of using these with any patients who might have problems reading the standard booklet (Appendix 7 & 8).

Simple laminated communication sheets have been made for the Wards to aid communication about basic needs, clinical tests and feelings. They use the ‘Boardmaker’ symbols (see references). These have been used to aid communication with patients who have poor or no spoken English in addition to those with a learning disability.

The project manager has worked with staff to highlight resources and the risk assessments available on the Lothian intranet to support their care of patients with learning disabilities.

In response to staff anxiety about caring for patients with a learning disability sessions were led by the local Learning Disability Liaison nurse on the two staff study days organised around the Patient experience. In the sessions case studies were used to highlight the assessment tools and appropriate care planning support available to improve the experience of people with learning disabilities in hospital.

Measuring experience

Feedback from patients on the simple communication aids has been positive in the Ward areas that have used them.

Future patient and carers feedback can be gathered by the clinical areas with staff using the simple feedback form with these patients and their carers by asking about their experience directly.
OTHER PROJECT INITIATIVES

Pagers

Sometimes ideas which came up within the main projects were used within different areas of the cancer centre and became mini projects which required support and follow up to test their general usefulness.

An example of this is the use of pagers in busy clinics to allow patients who are going to be kept waiting, to get a drink or to visit the information or Maggie’s centre (this arose from informal discussion rather than an interview or questionnaire and was originally proposed within the LD project). These have been used in some of the Breast clinics. However they are not the only solution to late running clinics and they have an ongoing cost attached which would have to be justified once the project has ended. In the main outpatient area there is a WRVS café within the waiting area and staff can easily call the patients from there.

Rapid feedback questionnaires

The Patient Experience manager became involved in developing and rolling out this survey across Lothian inpatient and day case areas. This allied with the aims of the project in that it was a means of embedding feedback across most areas. It was led by the Associate Nurse Director who was also on the project steering group.

The surveys mirror the national Scottish patient experience surveys in the areas that it asks questions about and there are two open questions to allow free comment at the end. The surveys are distributed at approximately 6 monthly intervals and are given to patients as they leave an area. They are then posted back to the company who process them. The results are accessible at www.patientperspective.org once a minimum of 25 are returned for the area in question. Staff can access the survey results via the internet, printing them out for discussion. The ongoing challenge is to take time to understand the survey results and for staff as a whole team to decide on possible actions. Involving others in the multidisciplinary team in responding may be difficult as there are not always very local multidisciplinary meetings.
**Simple paper feedback form**

Related to this is the simple paper feedback form (Appendix 6) which is more open ended in that it asks patients, carers, staff or students “What have we got right for you?” and “What could we have done differently?”

The advantage is its simplicity and that it can involve an interaction between the patient and staff member to gain further detail on their comments. It also means staff can immediately share and discuss the feedback.

The challenge as before is for staff to find the time to discuss and make an action plan based on both these sources of feedback.

Staff in clinical areas within cancer services have been encouraged to continue getting feedback from patients, carers and staff in order to understand how the developments are working and to ensure a process by which further change and improvement cycles are in place. Discussions have been held with managers to ensure this feedback is reviewed and that it feeds into the Quality Improvement Team and other relevant management meetings so that where staff need help in taking things forward, these can be prioritised and supported. Opportunities have been taken at study days and team meetings to ensure that staff are aware of these pathways, which have been mapped out to help staff visualise them (Appendix 9).

**Staff education and study days**

Staff in parts of the cancer service not covered by the projects have approached the project managers for help getting patient feedback to support different aspects of their service. They have been trained to use the Emotional Touchpoints technique for getting stories reflecting experience of particular clinical areas i.e. Within Haematology the information was gathered initially to contribute to a review of services for patients having stem cell transplants. They have also been used when teaching staff groups from Haematology to help their understanding of their patient’s experience.

A radiographer from the radiotherapy treatment area sought help getting patient feedback so she was trained in the emotional touchpoints method and some initial patient interviews were carried out. This information was used to help design a new feedback for use within that department.

During the project different staff have received training in interviewing, exploring patient experience and experience based design. Opportunities have been taken by the project managers to work with staff in sessions on different study days to raise awareness of the value of listening to feedback for services.
At the end of the project study days were run for a wider variety of staff to share some of the learning and explore the tools for getting patient experience. The aim was to support the embedding of patient experience work within parts of the service not involved in the project. Feedback from the study days was very positive and has raised the awareness of staff as to the value of listening to the voices of those who use and provide care.

**CRT**

This computer based system can be used to deliver surveys on either stand alone touchscreens or using hand held computer tablets. There is a bank of machines available for use within Lothian. Their use was suggested by one of the steering group as a useful supplement to paper based feedback, particularly for use within busy clinic areas where having an accessible machine for patients to give feedback without requiring direct involvement of staff. One staff member from the Breast clinic received training in using CRT however access to the machines held within Lothian has proved more challenging to achieve.
OVERALL LEARNING POINTS

Project ownership

The values of a pilot are that it brings extra resources in terms of the project manager, finance and flexibility to try out different ways of working.

Various changes at the early stages of the project as it came under the ‘Better Together’ framework instead of more directly under the Scottish Government, meant a change of emphasis. It subsequently took a longer time to make decisions about the direction the project would take. Although this also meant that there was valuable time spent analysing the methodology and on background research. Clear direction and ownership for projects from the beginning would be more time efficient.

Where the governance lay was also initially unclear, whether regionally, with all the areas covered by SCAN or within Lothian.

Key to success has also been that local management has been positive and supportive to the whole project. Working with a service that is open to feedback and willing to support the work makes it easier to bring about change.

Project management issues

Location

The project manager was initially based at Deaconess House and then Waverley Gate, both remote from the service. This made it harder to foster relationships with staff in the Cancer centre and work flexibly when opportunities arose in busy areas. When the project manager was based at the WGH it was much easier to react flexibly to circumstances in the clinical areas and enabled chance meetings which are often helpful in sharing information.

Changes in project manager

In this case there were three appointed over the three years of the project which led to loss of momentum and support for staff taking forward the individual projects. Although each project manager brought different skills and focus to the project there would have been less significant delays without these changes. Perhaps it is an inevitable consequence of short term fixed contracts that individuals move to something more secure or at least ongoing before the project is completed.

Time frames for the individual projects changed with delays due to changes in project manager. As the focus also changed over time with the desire for an early successful outcome (the young peoples clinic) meaning an initial early focus on that and then
the head and neck project. As a consequence time for the learning disabilities and chemotherapy projects was more restricted.

As the third project manager in post employed for the last 7 months of the project it was helpful that having worked in the service previously, building staff relationships from scratch was not generally necessary. When staff knew what my current role was I was then approached for support and advice regarding getting feedback from patients. This was valuable in terms of spreading awareness and further embedding the use of patient feedback in the unit.

**Steering group membership**

A broad group was established to oversee the project. Attendance varied over time with the attendance of the group changing as the focus changed from planning to more clinical involvement. Achieving regular attendance of clinical staff was difficult. It was valuable to have a group that both supported and challenged the project manager.

**Being one of three pilot studies**

The project managers from each pilot site met periodically together to discuss how the work was progressing in each study area. The projects were developed very differently in each region and the project managers valued the opportunity to share experiences. Each manager approached the project from quite different starting points and were all influenced by the teams they were hosted in. They gained peer support, ideas for recruitment of patients, suggested approaches to governance of the project locally and reassurance that it was reasonable to adapt the experience based co-design quite flexibly.

**Addressing inequalities**

Improving inequalities is somewhat challenging to demonstrate within the scale of the project. This would have required a very much more clearly defined focus early on, a clearly defined patient group and a clear idea of what aspect of inequality was being studied. This is rather the antithesis of the methodology chosen which was flexible and open ended to the responses of patients.

This is not to say that improvements have not been made in the management and care of vulnerable groups, with their active participation, but how this has affected inequalities is hard to measure.
Experienced based design

Experienced based design as a methodology for change has a very clear focus on patients, carers and staff jointly working and planning together. This brought great benefits in getting people to work together and enabling patients to prioritise their concerns. It is also a very resource intensive method with the joint events and requirement for groups of staff to be released together to attend them.

Use of a private agency, Thinkpublic, the group who worked with the initial stages of the Head and neck project, (an organisation who work largely with the public sector and charities to support change based on experience based design principles) although valuable is also an additional cost which outside a separately funded project would not usually be possible.

For some of the later project work getting groups of patients or staff together was difficult and costly in terms of time and resources so the methods were adapted and staff made decisions about priorities checking progress and ideas out with subsequent patients.

Although productive the larger events were challenging to organise, get the right people to come those who had the experience but also those who would take forward the actions.

Where patient numbers are small, such as those with cancer who additionally have a learning disability, getting groups of patients and staff together is even more challenging and may be stressful for the participants.

Using ebd methodology Thinkpublic originally intended the interviews to be filmed for the Head and neck project. This was initially attempted but the recordings were found not to be of sufficient quality to use at the joint events. Both patients and staff were reluctant to be filmed. In the end the interviews were audio taped and transcribed. In selecting methods to record feedback consideration needs to be given to the possible sensitivities of the groups involved before committing resources.

Some of the original interviews were very long and required professional transcribing, another cost resource, possible in a funded project but less sustainable in the long term. The emotional touchpoints interviews and other feedback methods being quicker, more focused and thus more sustainable options especially for busy clinical areas.
Measurement

A key component in experience based design and in all projects, measuring the change is very important so that ongoing evaluation of effectiveness is achieved.

This has been achieved in some parts of the project, but not yet in others as time frames have slipped and some actions are still in progress. Nevertheless efforts been made to ensure ongoing feedback processes are in place so that overall there will be a continuing process of feedback and action within the service.

Staff commitment

Energy and enthusiasm and commitment from staff was vital when it came to carrying forward actions. It also helped if staff had some control over their working day or support from their manager to take actions forward.

Those staff enthusiastic to make improvements were often already committing their own time to other aspects of service development and although with the support of the project manager some of the activities progressed the workload seemed to be unbalanced as other staff were less committed.

At the same time as this project, Releasing Time to care was also being rolled out throughout the unit. This was challenging for staff to be involved in two big projects at once although both aim to improve the delivery of services in a way that takes account of the voices of service providers and users.

Where there was already a commitment from clinical staff to improving a service the patient experience work helped provide the evidence and the impetus for change. The support of the patient experience project manager helped bring people together to make decisions and changes. This was the case in both the clinic developments (in young peoples service and in head and neck) where staff had for a long time wanted to make some changes to the way things were organised and the project very much supported and influenced the changes.

Achieving change where that change involves cooperation and reshaping of workloads (particularly the administrative staff support) across specialities and hospitals was challenging and led to some delays in achieving a successful outcome.

One of the projects advantages lay in the ability to look across departments following the patient journey, made possible by having the project manager being able to work with the different areas.
Consideration needs to be given as to how this aspect of understanding the experience of patients as they move between specialties can be sustained and acted upon. Clearly the QIT teams have a role in this, however too work within specialties rather than across them. The patient’s experience is not always one of seamless transition or of consistent care as they move between departments.

**Staff training**

A variety of staff have been trained in new techniques, Experienced Based Design, using Emotional Touchpoints to elicit patient’s experiences. The amount of autonomy staff have in their work should be considered when deciding which training is suitable as it may be challenging for some to continue to use their new skills if they have little control over how their time is spent. Some staff who completed training were unable to carry out interviews for a variety of reasons, including little flexibility in their working time and pressing needs of their service not allowing them to be released from their clinical area. Balancing staff interest in training and what realistically they can contribute needs careful consideration.

Staff may not be aware of which other staff have particular skills, somehow sharing this information across a unit could be beneficial in terms of spreading expertise and enabling people to look for support for service improvement work.

With gaps in the project management it was difficult for staff to take forward some of the projects without the support of the project manager to coordinate and push things along. Within their daily workload most staff have little time for researching options and coordinating activities with other staff, i.e. for making the DVD.

**Talking mats**

Although valuable learning for the individuals trained, using the technique required a level of skill that the new learners did not feel confident in. With hindsight both the time frame and the challenges of using the Talking mats to elicit complex information from patients meant that ultimately this was not very practical. Although two staff working within the cancer centre received the training, patient numbers were very low and using the technique successfully requires multiple encounters with an individual in order to get to know them well and a skilled user to get beyond organizing simple likes and dislikes. The individual patient also needs to have an ability to reflect on a past experience if more than a like/dislike response is to be evoked.
Textools

Textools was proposed for use by administrative staff to remind patients of clinic appointments and clinical staff to give results to patients. After some research and deliberation by administrative staff it was thought not to be cost effective because of the additional administrative resource required and the low patient default rate for cancer centre clinics. This was eventually dropped from the mini projects.
RECOMMENDATIONS

- That clinical areas continue to use the paper based simple feedback forms to gain an understanding of how their service is experienced by patients and carers and that this information is discussed by the local team and ways are found of sharing the good practice highlighted and of making local changes where feasible.

- That actions taken are shared visibly with patients, staff and visitors by displaying them on the notice boards, for instance using the ‘You told us, We responded by’ form (Appendix 10).

- That feedback is also fed into the local quality structure and continues to be a standing item on the agenda of departmental meetings.

- That the principles of experienced based design are followed whenever service changes and developments are considered.

- That a list of people trained in the project with their specific skills are put on OOQS so that they can be used as a resource within the unit and so that they can continue to develop and share these skills.

- That funding a more permanent type of quality project worker who could work with the QI team to further developments of this kind or more clinically based projects is considered. This would provide a stable worker with developed project management skills who might be less likely to leave than individuals on short term contracts. The service would keep the skills and the project workers would gain better security.
CONCLUSION

Overall the project had some very successful outcomes, particularly in those areas where the focus was on inequalities, i.e. the young adults with cancer and the patients with head and neck cancer.

The experienced based design methodology as fully utilised is very productive in terms of the process of involving all service users and producing jointly agreed actions. This initial process does require a significant input of time both staff and patients and for the organization of the joint events. It is possible to use the principles of ebd in a less resource intensive way which may be appropriate for smaller scale ongoing developments.
REFERENCES


• Boardmaker software information available at: http://www.mayer-johnson.com/boardmaker-software/ Accessed 24/05/12.


• For access to this report electronically go to: http://www.scan.scot.nhs.uk/Pages/default.aspx
APPENDIX 1 – PROJECT OVERVIEW

Cancer Services Patient Experience Programme Overview – January 2009

Overarching national vision

- To create a wholesale systems approach, starting within cancer services, to patient experience based service improvement.
- Programme can be seen as a test bed which will support move to mainstreaming patient experience within service delivery/improvement work both nationally and locally through large collaborative agendas and smaller scale local agendas.
- Test approaches to capturing patient experience, undertake improvement work, measure and evaluate.
- Propose a general population focus with explicit recognition of diversity of needs with resulting service improvement activities taking this into account minimising discrimination and inequalities. (Where a particular population group is under represented supplement through work with bodies and advocacy groups that represent this particular population group.)
- Although there is recognition much of improvement work will relate to softer areas of patient experience there must still be measurable improvement impacts and outcomes relating to patient experience, equity and diversity, and inequalities.
- Ultimately the programme should facilitate the development of an approach/toolkit and infrastructure for patient experience based redesign/improvement work to be maintained in specific service areas and rolled out to others.

Funding

- £100k 2008/9, £100k 2009/10 and £100k 2010/11.
- Deferral and carry-forward currently being arranged.

Focus areas

Scottish Government has indicated the choice of speciality focus areas lies with funded Health Boards. It has, however, indicated that:

- The developed work plan should ensure activities cut across the full breath of cancer services – screening, diagnostic and treatment pathways and chemo therapy.
- It would also support, in addition to identifying specific speciality focus areas, integration of the programme within a specific locally planned/required service development or redesign programme/initiative.

Given the vision for the programme, and the overall objective of being a test bed for standardised approach to patient experience based redesign within mainstream service delivery, focus on a smaller number of higher volume specialities/service areas rather
than a plethora of smaller speciality areas or component of a speciality area may be appropriate.

**Agenda linkages**

This programme will, to an extent due to objective overlaps, need to link closely with a range of agendas/work streams including:

- Better Together
- PFPI
- Equality and Diversity
- Improvement Collaboratives
- Lean in Lothian
- Leading Better Care
- Patient Safety Programme
- Roadmap to Recovery

**Important priorities and areas for local consideration**

The following items are an initial list of the priorities and questions which need to be explored to support the initial start up the programme and while the programme progresses:

- **Developing the work programme:**
  - How many focus areas do we wish to include during the first two years of the programme?
  - Are there any specific service development or redesign projects pending were we could look to integrate patient experience based redesign approach from the beginning?
  - Which specialities will be focus areas for the programme?

- **Collection of supporting data:**
  - Which data sources should be utilised?
  - Should equity audits be a core component of work programme?

- **Capturing patient experience:**
  - What approaches to capturing patient experience should be utilised?
  - Learning from others who have undertaken patient experience initiatives.
  - Required resources to capture and analyse patient experience.

- **Selecting improvement approaches/methodologies:**
  - How can we best facilitate rapid improvements?
• Illustrating outputs and outcomes:
  - How do we get a balance between qualitative and quantitative approaches?
  - How do we measure and quantify improvements in patient experience following improvement/redesign work?

• Working in partnership with staff:
  - Facilitate the delivery of programme with staff not to staff.
  - Facilitate skill development within local teams.
  - Focus from day one to ensure ongoing local maintenance after spotlight shifts to another speciality.

Katie C. Edwards
Patient Experience Improvement Manager
# Appendix 2 – Steering Group & Project Manager List

<table>
<thead>
<tr>
<th>Patient Experience Project Steering Group Members</th>
<th>Patient Experience Group Project Managers</th>
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<tbody>
<tr>
<td>Elaine Anderson</td>
<td>Katie Edwards</td>
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<tr>
<td>Sandra Bagnall</td>
<td>Scott Taylor</td>
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<tr>
<td>Jo Bennett</td>
<td>Jenny Kalorkoti</td>
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<tr>
<td>Elizabeth Bream</td>
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<td>Kathryn Brechin</td>
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<td>Pat Dawson</td>
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<tr>
<td>Gail Dean</td>
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<td>Margaret Douglas</td>
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<tr>
<td>Annette Gallimore</td>
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<tr>
<td>James Glover</td>
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<td>Grahame Howard</td>
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<td>Kathleen Imrie</td>
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<td>Melanie Inness</td>
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<td>Nora Kearney</td>
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<td>Mary Kenyon</td>
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<td>Gillian Knowles</td>
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<tr>
<td>Kate MacDonald</td>
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<tr>
<td>Caroline McKinnel</td>
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<tr>
<td>Kirsteen MacLean</td>
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<td>Peter McLoughlin</td>
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<tr>
<td>Elizabeth Preston</td>
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<tr>
<td>Kate Price</td>
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<td>Shona Simon</td>
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<tr>
<td>Sarah Sinclair</td>
<td></td>
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<tr>
<td>Claire Smith</td>
<td></td>
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<tr>
<td>Libby Tait</td>
<td></td>
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</tbody>
</table>
## Appendix 3 – Staff Trained List

### Staff Trained in ebd

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane Coskun</td>
<td>Discharge Planning Coordinator</td>
<td>Edinburgh Cancer Centre</td>
<td>Western General Hospital</td>
</tr>
<tr>
<td>Lindsey Main</td>
<td>Clinical Support Worker (Oncology)</td>
<td>St John’s Hospital</td>
<td>Howden, Livingston</td>
</tr>
<tr>
<td>June McIntosh</td>
<td>Staff Nurse</td>
<td>Oncology Treatment Floor</td>
<td>Western General Hospital</td>
</tr>
<tr>
<td>Pamela Swanson</td>
<td>Patient Liaison Advisor</td>
<td>Royal Hospital for Sick Children</td>
<td>Edinburgh</td>
</tr>
<tr>
<td>Jackie Whigham</td>
<td>Macmillan Project Manager</td>
<td>Edinburgh Cancer Centre</td>
<td>Western General Hospital</td>
</tr>
<tr>
<td>Mary Tait</td>
<td>Specialist Radiographer/Health Promotion Facilitator</td>
<td>SE Scotland Breast Screening Programme</td>
<td>Ardmillan House, Edinburgh</td>
</tr>
<tr>
<td>Annette Gallimore</td>
<td>Senior Public Health Researcher</td>
<td>Deaconess House, Edinburgh</td>
<td></td>
</tr>
</tbody>
</table>

### Staff Trained in Talking mats

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tricia Thorburn</td>
<td>Clinical Support Worker (Breast Clinic)</td>
<td>Edinburgh Cancer Centre</td>
<td>Western General Hospital</td>
</tr>
<tr>
<td>Jenny Kalorkoti</td>
<td>Senior Nurse, Leadership in Compassionate Care Programme</td>
<td>Edinburgh Cancer Centre</td>
<td>Western General Hospital</td>
</tr>
<tr>
<td>Mariola Lzydorczyk</td>
<td>Head Occupational Therapist</td>
<td>Royal Hospital for Sick Children</td>
<td>Edinburgh</td>
</tr>
</tbody>
</table>
APPENDIX 4 – DISTRESS THERMOMETER

Distress Thermometer (DT)

Adapted from NCCN Practice Guidelines in Oncology (2007).

Distress Thermometer (DT)

First, please circle the number (0-10) that best describes how much distress you have been experiencing over the past week, including today.

Second, if any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then rank your top 4 difficulties (1 would be the biggest problem, 4 = your fourth biggest problem).

Physical problems
- Body image
- Breathing / dressing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue / tiredness
- Feeling swollen
- Fears
- Getting around
- Indigestion
- Mouth sores
- Nose dry / congested
- Pain
- Sexual
- Skin dry / itchy
- Sleep
- Tingling in hands / feet
- Metallic taste in mouth

Practical problems
- Childcare
- Housing
- Finances
- Transportation
- Work / school
- Dealing with children
- Dealing with partner

Family problems
- Depression
- Nervousness

Emotional problems
- Sadness
- Worry
- Anger

Spiritual / religious concerns
- Loss of faith
- Loss of meaning or purpose of life

Other problems:

RANKING

THERMOMETER
APPENDIX 5 – RAPID FEEDBACK QUESTIONNAIRE

Rapid Feedback Survey
Core Inpatient

Ward ##
## Hospital

What is the questionnaire about?
This questionnaire is about your current stay as an inpatient on Ward ## at ## Hospital.
Your responses will help us continue improving our care and services for patients across NHS Lothian.
The survey is voluntary. You do not have to take part. If you don’t want to take part you don’t have to give us a reason. But by telling us what you really think, you’ll be helping improve the care patients receive in the future.

What do I have to do?
If you would like to take part, please answer as many of the questions as you can. If you can’t answer a question, or don’t want to answer a question, just leave it blank and move on to the next question.

Completing the questionnaire
For each question please tick clearly inside one box using a black or blue pen.
Don’t worry if you make a mistake, simply cross out the mistake and put a tick in the correct box. Please do not write your name or address anywhere on the questionnaire.

Once you have filled in the questionnaire, you can put it in the freepost envelope and either hand it back to a member of staff or post it back to us (at no cost) once you have left the hospital.

If you don’t want to fill in the questionnaire, you can just hand it back to a member of staff or throw it away.

THANK YOU VERY MUCH FOR YOUR HELP

About the Ward

Q1. In your opinion, how clean is the hospital ward or room you’re in?
1. □ Very clean
2. □ Fairly clean
3. □ Not very clean
4. □ Not at all clean

Q2. How clean are the toilets and bathrooms that you’re using in hospital?
1. □ Very clean
2. □ Fairly clean
3. □ Not very clean
4. □ Not at all clean
5. □ I have not used a toilet or bathroom

Q3. How would you rate the hospital food?
1. □ Very good
2. □ Good
3. □ Fair
4. □ Poor
5. □ I didn’t have any hospital food

Q4. Did you get help with eating your meals if you needed it?
1. □ Yes always
2. □ Yes sometimes
3. □ No
4. □ I didn’t need any help
Doctors

Q5. When you have important questions to ask a doctor, do you get answers that you can understand?
1. Yes, always
2. Yes, sometimes
3. No
4. I have no need to ask

Q6. Do you have confidence and trust in the doctors treating you?
1. Yes, completely
2. Yes, to some extent
3. No

Q7. As far as you know do doctors wash or clean their hands before touching patients?
1. Yes, always
2. Yes, sometimes
3. No
4. Don’t know / Can’t remember

Nurses

Q8. When you have important questions to ask a nurse, do you get answers that you can understand?
1. Yes, always
2. Yes, sometimes
3. No
4. I have no need to ask

Q9. Do you have confidence and trust in the nurses treating you?
1. Yes, completely
2. Yes, to some extent
3. No

Q10. As far as you know do nurses wash or clean their hands before touching patients?
1. Yes, always
2. Yes, sometimes
3. No
4. Don’t know / Can’t remember

Your care and treatment

Q11. Sometimes in a hospital, one member of staff will say one thing and another will say something different. Has this happened to you?
1. Yes, often
2. Yes, sometimes
3. No

Q12. Are you involved as much as you wanted to be in decisions about your care and treatment?
1. Yes, definitely
2. Yes, to some extent
3. No

Q13. How much verbal information about your condition or treatment has been given to you?
1. Not enough
2. The right amount
3. Too much

Q14. How much written information about your condition or treatment has been given to you?
1. Not enough
2. The right amount
3. Too much

Q15. Have you been given enough privacy when discussing your conditions?
1. Yes always
2. Yes, sometimes
3. No

Q16. Have you found someone on the hospital staff to talk to about your worries and fears?
1. Yes, definitely
2. Yes, to some extent
3. No
4. I had no worries or fears
Q17. During your time in hospital, how much of the time have you been in pain?

1 □ All or most of the time
2 □ Some of the time
3 □ Occasionally
4 □ I have not had any pain

Q18. How would you describe the level of pain you experienced?

1 □ Severe
2 □ Moderate
3 □ Mild
4 □ I have not had any pain

Q19. Do you think the hospital staff did everything they could to help control your pain?

1 □ Yes, definitely
2 □ Yes, to some extent
3 □ No
4 □ I have not had any pain

Leaving Hospital

Q20. Do you feel that you were involved in decisions about your discharge from hospital?

1 □ Yes, completely
2 □ Yes, to some extent
3 □ No
4 □ My discharge has not been planned yet

Overall

Q21. Overall, do you feel you are treated with respect and dignity while in the hospital?

1 □ Yes, always
2 □ Yes, sometimes
3 □ No

Q22. Overall, how would you rate how well the doctors and nurses work together?

1 □ Excellent
2 □ Very good
3 □ Good
4 □ Fair
5 □ Poor

Q23. Overall, how would you rate the care you have received?

1 □ Excellent
2 □ Very good
3 □ Good
4 □ Fair
5 □ Poor

About You

Q24. Are you male or female?

1 □ Male
2 □ Female
3 □ Transgender

Q25. How old are you? □□□ years
Q26. To which of these ethnic groups would you say you belong?

A. WHITE
1. [ ] Scottish
2. [ ] English
3. [ ] Welsh
4. [ ] Northern Irish
5. [ ] British
6. [ ] Irish
7. [ ] Gypsy Traveller
8. [ ] Polish

B. ASIAN, ASIAN SCOTTISH OR ASIAN BRITISH
9. [ ] Pakistani, Pakistani Scottish or Pakistani British
10. [ ] Indian, Indian Scottish or Indian British
11. [ ] Bangladeshi, Bangladeshi Scottish or Bangladeshi British
12. [ ] Chinese, Chinese Scottish or Chinese British

C. BLACK, BLACK SCOTTISH OR BLACK BRITISH
13. [ ] African, African Scottish or African British
14. [ ] Caribbean, Caribbean Scottish or Caribbean British
15. [ ] Black, Black Scottish or Black British

D. OTHER ETHNIC GROUP
16. [ ] Arab
17. [ ] Other

E. MIXED
18. [ ] Any mixed or multiple ethnic group:

Any other comments

Is there anything particularly good about your hospital care?

Is there anything that could have been improved? Please tell us what could be improved and how to improve it.

Any other comments or suggestions?

THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE
APPENDIX 6 – QUICK FEEDBACK FORM
(DOG ROSE)

What could we have done differently?
Help us to understand how we could improve your experience

What have we got right for you?
Share with us what helped you to have a good experience

Thank you very much
Leadership in Compassionate Programme (NHS Lothian/Edinburgh Napier University) 2011
APPENDIX 7 – BOARDMAKER SYMBOL SHEET FOR ONCOLOGY WARD

- happy
- sad
- sleepy
- worried
- question
- agree
- no
- do not understand
- I need help
- do not know
- please repeat
- thank you
- blood pressure
- ear thermometer
- examination
- pulse
- urine
- faeces
- injection
- xray
- breath
- scan
- diagnose
- care plan
APPENDIX 8 – CHEMOTHERAPY INFORMATION SHEET*

Be careful after Chemotherapy

For the first week of chemotherapy you should protect others from splashes of your urine by sitting down to use the toilet.

Wear plastic gloves to clean up any urine, bowel movements or vomit.

If you have a stoma or catheter, after changing the bag, put it in a plastic bag. Tie the bag up then put it in another plastic bag. Then put it in a dustbin.

Close the lid and flush the toilet twice when you are finished.

Wash any clothes that have been soiled by urine, bowel movements or vomit by themselves in the washing machine. Wear plastic gloves to pick them up and put them in.

Always wash your hands after you have been to the toilet or cleaned up anything dirty.

* Produced in collaboration with FAIR (www.fairadvice.org.uk)
<table>
<thead>
<tr>
<th>You told us..</th>
<th>We responded by...</th>
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<tr>
<td><img src="image1.jpg" alt="Image" /></td>
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Leadership in Compassionate Care Programme (Edinburgh Napier University/NHS Lothian) Dec 2011