An anxiety self-management programme for women with gynaecological malignancies

**Keywords:** Anxiety management, pre-operative care, practice development, experience based design

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**Summary of the project**  
The Northern Gynaecological Oncology Centre (NGOC) is a specialist centre, based in Gateshead, Tyne and Wear, which provides care for women with suspected and/or confirmed gynaecological malignancies diagnosed through tests at their local hospital. Patients are referred from eight different hospitals across the north of England. Geographically patients often travel long distances for review and treatment in the centre and frequently express feelings of anxiety whilst waiting to undergo surgery. Existing methods of managing patient anxiety have not always been successful and this sparked the project team’s initial interest in the development of an anxiety self-management programme. As the project progressed, the overall aim changed as the project team wanted to understand the lived experience of anxiety in women with gynaecological cancers and to use this experience to redesign the service. The experience based design methodology (NHS Institute for Innovation and Improvement, 2009), was used as the framework for the project, with methods such as patient diaries and questionnaires initially used to try and gain an insight into what anxiety meant to the woman experiencing it. However these methods did not yield the in-depth information anticipated and emotional touchpoint interviews (Bate and Robert, 2007a) were then used to gain this level of understanding. Initial attempts at engaging project stakeholders through the use of meetings and presentations were unsuccessful. Stakeholders in the project were ultimately engaged as part of ward away-days and workshop events, using practice development techniques such as fourth generation evaluation (Guba and Lincoln, 1989). Through this process staff were able to identify areas for improvement to the patient experience and the service is currently being redesigned to incorporate these changes. Additional outcomes include a closer working relationship amongst the nursing teams involved in the project and improved facilitation skills of the project team. Recommendations for future practice development initiatives include more thorough exploration of all potential stakeholders at the start of the project with a senior member of staff as part of the project team, use of skilled facilitation techniques earlier in the project to encourage stakeholder engagement, use of digital recording equipment for interviews and the use of a workplace culture analysis tool at the start and end of the project.
**Background**

In 1999, the Department of Health produced good practice guidance on commissioning cancer services for gynaecology, entitled ‘Improving Outcomes in Gynaecological Cancer’. The new guidance called for a reorganisation of services, working in multidisciplinary teams and a concentration of surgical expertise in centres (Department of Health, 1999). The Northern Gynaecological Oncology Centre (NGOC) is one such specialist centre, based in Gateshead, Tyne and Wear, which provides care for women with suspected and/or confirmed gynaecological malignancies diagnosed through tests at their local hospital. Patients are referred from eight different hospitals across the north of England and consequently, patients often travel long distances for review and treatment in the centre.

The gynaecology centre is staffed by a multidisciplinary team which consists of the following:

- four surgeons
- two visiting clinical oncologists
- two visiting medical oncologists
- a team of subspecialty trainees and research fellows
- a dedicated outpatients facility which is staffed by registered nurses, healthcare assistants and administrative and clerical staff
- in-patient care provided in a 22-bedded single sex ward comprising four, four-bedded bays and six single bed cubicles
- specialist nursing services: two Macmillan clinical nurse specialists provide support to the patients throughout their treatment pathway; a nurse practitioner provides a pre-operative surgical pre-assessment service; there are two research nurses in post and a nurse consultant who provides specialist psychosexual assessment and treatment
- allied health professionals including dieticians and physiotherapists

Patient pathways from the point of experiencing symptoms to having surgery are often highly complex. Patients have often undergone numerous investigations via their general practitioner and local hospital prior to their arrival at the centre. Some may have been investigated for benign causes of their symptoms such as inflammatory bowel disease before a gynaecological cancer was suspected. For some patients, attending the gynaecology centre may be the first time they are aware that investigations they have undergone are indicating a diagnosis of cancer. Patients report that travelling to a hospital which is out of their local area is also a highly stressful event. After completion of surgery at the centre, patients may be referred onto other hospital trusts to have treatment with chemotherapy or radiotherapy, another part of the process which patients find difficult to negotiate. All of these factors compound the high anxiety levels experienced by people with this diagnosis.

A visual representation of two potential patient pathways into and out of the centre is shown in Figure A.
Patient has an undiagnosed gynaecological malignancy and experiences clinical symptoms. Patient visits primary care provider or admitted acutely to secondary care.

**Direct, non-complicated pathway**
- Patient is referred to a regional diagnostic service, e.g. rapid access service at patient’s local hospital
  - Clinical suspicion of gynaecological malignancy
    - Regional diagnostic service performs physical examination, ultrasound scans, CT scans, and tumour markers +/- biopsies
    - Patient has confirmed gynaec malignancy or continued high suspicion of gynaec malignancy
      - Patient is referred to the regional centre for gynaec cancers at the Northern Gynaecological Oncology Centre
    - Patient may or may not have surgery and then be referred to nearest treating hospital for possible chemotherapy or radiotherapy treatment

**Complicated, difficult diagnosis pathway**
- Clinical suspicion of non-gynaecological malignancy, e.g. irritable bowel syndrome and menopause
  - Patient managed in primary care or referred to non-gynaec secondary care service
  - New clinical symptoms or further investigation reveals clinical suspicion or actual diagnosis of gynaec malignancy
The National Institute of Clinical Excellence (NICE, 2004) released guidance for those who develop and deliver cancer services for adults to ensure that cancer patients, their families and carers are well informed, cared for and supported. This document ‘Supportive and palliative care services for adults with cancer’ (NICE, 2004), prompted a team of clinical nurse specialists in the department to initiate a project to set up a supportive care clinic (Guest et al., 2010). The initiative was sparked by the realisation that the clinical nurse specialist was most likely to be the individual best able to assist the patient in navigating their pathway. The supportive care clinic provided the patient with a one hour appointment slot with the clinical nurse specialist in which their holistic needs were assessed and a care pathway established to meet those needs. The supportive care clinic is now firmly established in practice within the outpatients setting. The holistic needs of the patients attending the supportive care clinic are assessed using the Holistic Assessment of Concerns Tool (Guest et al., 2010, p 7) which was developed and piloted by the North of England Cancer Network (NECN). Patients are asked to complete an assessment which lists a series of potential concerns, broadly grouped under the physical, emotional, social and spiritual domains. The patient is asked to indicate any areas of concern that they may have and to use the distress thermometer incorporated within the tool to score the degree of distress that this concern has caused them; 0 on the scale suggesting no distress and 10 on the scale being the worst possible distress. Feelings of anxiety are commonly identified utilising this tool. Whilst the nurse specialists have an existing set of strategies to help the patients manage their anxiety, it was felt that something more could be offered.

This sparked the interest of this project team in developing an anxiety self-management programme to help patients to manage their anxiety at home, when support services weren’t necessarily available. A successful application was made to the Foundation of Nursing Studies (FoNS) and the Patients First Programme to support this. The project team was formed with three members; two nurse specialists, one with a focus on clinical trials and the other, responsible for the implementation of an enhanced recovery programme within the department, and a staff nurse from the inpatient ward. The project team considered it important to have an individual on the project team who was ward based to ensure that the ward team felt included within the project.

**Aim and objectives of the project**

As outlined above, the initial project aim was to develop an anxiety self-management programme. The project team were interested in looking at the techniques of guided imagery and relaxation to manage anxiety and they envisaged the development of some kind of resource for patients to take home with them, which would equip them with the tools to manage their anxiety in their own home. The initial aim of the project however was somewhat prescriptive in nature and assumed that the team already understood the experience of anxiety from the patient’s perspective and the interventions required to manage it. The project team first came to realise this after attending the first two practice development workshops which were hosted by the Foundation of Nursing Studies, one month into the project. This approach of ‘doing things for patients’ is not uncommon but the move towards a service which is patient led and where the service works with patients to support them with their health needs is advocated in the document ‘Creating a patient led NHS’ (Department of Health, 2005). Having attended the initial workshop days hosted by FoNS and received support from their practice development facilitator, a new aim was identified and associated objectives then evolved.
Aim
To understand the lived experience of anxiety in women with gynaecological cancers and to use this experience to change practice within the service.

Objectives
1. To identify and engage stakeholders in the project
2. To explore the lived experience of patients by using diaries and questionnaires. This was later extended to include conducting interviews using emotional touchpoints
3. To explore staff perspectives of caring for a patient who is anxious
4. To host a staff feedback event
5. To utilise a practice development framework to implement changes in practice
6. To evaluate the changes in practice and their impact on patient experiences and redesign where necessary

Methods and approaches
The project team decided to utilise the experience based design (EBD) approach (NHS Institute for Innovation and Improvement, 2009) in an attempt to understand experiences of anxiety from the perspective of both users of the service and those delivering it and to collaboratively redesign the service so as to improve the patient experience.

*The EBD approach (experience based design) is a method of designing better experiences for patients, carers and staff. The approach captures the experiences of those involved in healthcare services. Staff then work together with patients and carers to firstly understand these experiences but then to improve them. (NHS Institute for Innovation and Improvement, 2009, p 3)*

Bate and Robert (2007b) identify two core elements of experience based design which they describe as:
1. The experience element - focusing on improving the whole experience of the service
2. The participatory element - directly involving users in the design and development of the service

Table 1 illustrates the time line of the methods used in the project.

<table>
<thead>
<tr>
<th>Method used</th>
<th>Date utilised</th>
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<tbody>
<tr>
<td>Communicating with stakeholders</td>
<td>January 2012</td>
</tr>
<tr>
<td>Stakeholder newsletters</td>
<td>January 2012</td>
</tr>
<tr>
<td>Patient experience diaries and questionnaires</td>
<td>February 2012</td>
</tr>
<tr>
<td>Emotional touchpoint interviews with patients</td>
<td>April-May 2012</td>
</tr>
<tr>
<td>Facilitation of values and belief exercise at ward away-days</td>
<td>May 2012</td>
</tr>
<tr>
<td>Interviews with staff</td>
<td>June 2012</td>
</tr>
<tr>
<td>Staff feedback workshop</td>
<td>September 2012</td>
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</tbody>
</table>
Each of the methods used in the project will be outlined below. In addition, a ‘process evaluation’ of the methods used will be discussed. A ‘process evaluation’ documents and analyses the development and actual implementation of a programme, evaluating whether strategies were implemented as planned and whether expected outcomes were actually produced. The team utilised the following five questions to evaluate each of the methods:
1. Whether it works?
2. Why it works?
3. For whom it works?
4. Under what circumstances it works?
5. What has been learnt to make it work?
These questions are described by Redfern (1998) and McCormack and Manley (2004) as essential to an evaluation framework in practice development.

Communicating with stakeholders
The Northern Gynaecological Oncology Centre has a strong and dynamic research ethos where evidence-based and patient-centred care is given a high priority. However within the workplace there has previously been a sense that change happens with little involvement of those whom it affects or explanation of the benefits of such change. Such actions have resulted in negativity and resistance to change. Also from the start of the project, the project team were already aware of a perceived lack of cohesion and teamwork between the staff practicing within the outpatient setting of the department (clinical nurse specialists) and the ward team. Individuals working within the ward team were often heard to pass comment that non-ward staff “have no idea what goes on in this ward” and equally the witnessed behaviours of ward staff indicated that there was a lack of appreciation of the role of the non-ward team members. To be able to achieve the aim of reducing patient anxiety the project team acknowledged that there would need to be a more cohesive working relationship between the two staff groups.

The project team were keen to promote closer working between the ward and outpatient staff so the first step in the project was to identify all potential stakeholders in the project and to inform them of the project and its aims and objectives.

The following stakeholders were identified: patients, ward nursing staff, medical staff and clinical nurse specialists. However on reflection, the project team realised that not all stakeholders had been identified at the outset and realised that the involvement of the out-patient clinic staff and administrative and clerical staff would have been beneficial from the beginning of the project. A number of methods were used to inform the various stakeholders of the project:
1. An educational meeting is held every Tuesday in the department with the aim of promoting awareness/knowledge of educational issues affecting clinical practice. This meeting is typically attended by the medical staff and clinical nurse specialists, and although the outpatients and ward staff are invited, they rarely attend. At this meeting, the project team used a Powerpoint presentation to provide background information on the project. The first meeting was well attended by the medical team and clinical nurse specialists and generated a lively discussion about the anxiety needs of patients receiving care within the department. The project team were encouraged by their medical colleagues’ level of enthusiasm and ideas for the project and
felt that utilising this meeting was a convenient means of informing a number of stakeholders about the project.

2. The project team also attended the ward staff meeting to provide an overview of the project. A newsletter was developed for this purpose using a template from the experience based design toolkit (NHS Institute for Innovation and Improvement, 2009) and refreshments were provided by the team using the FoNS bursary. However the agenda of the nursing staff meeting was very full and it became evident that very little information given by the project team was absorbed. When the project team visited the ward in the weeks after people were still overheard to comment “What project, I don’t know anything about it”.

3. Midway through the project another slot at the weekly educational meeting was booked and a presentation prepared to update the medical and nursing staff on the progress of the project with the aim of maintaining engagement and momentum. That particular day however, the outpatient clinic overran so no one attended the meeting.

On reflection the project team felt that attending the educational meetings and ward staff meeting did not achieve their intended objective of engaging stakeholders in the project, instead they had only informed stakeholders about what was going to happen. The timing of the educational meetings also made it difficult for ward staff and outpatient clinic staff to attend. The absence of the ward team and outpatient staff at the initial meeting had two consequences. Firstly, it maintained the feelings of fragmentation and marginalisation already felt within the staff teams and secondly, the ward/outpatient nurses were not exposed to the enthusiasm and support that the project team received from their medical colleagues. In future the project team decided that they would consider planning a specific stakeholder meeting to be held at a time mutually convenient for all stakeholders and with an agenda purely based on the project. It is anticipated that this would increase the level of participation and engagement of the stakeholders.

**Questionnaires and patient experience diaries**

An understanding of the patient experience of anxiety was part of the overall aim of the project. Only by understanding the patient experience of anxiety could the project team begin to consider how to change the service to improve that experience. Initially, the project team decided to utilise questionnaires and patient experience diaries as a means of accessing patient experiences of anxiety. These methods were chosen as it was felt that they would allow the patient to inform the team how they experienced anxiety in ‘real time’. The questionnaire incorporated the hospital anxiety and depression scale (Zigmond and Snaith, 1983), a visual analogue scale to determine the effect of anxiety on the patient’s current quality of life and a question asking about the coping techniques currently being used by the patients and their carers. The patient experience diary was developed from a template provided by the NHS Institute for Innovation and Improvement (2009) and within the diary the patient was asked to “tell us about your experience whilst waiting for surgery. This is your space to express yourself. There are no right or wrong answers”.

The clinical nurse specialists were enlisted to hand out the questionnaires and experience diaries to patients being seen within the supportive care clinic. These were provided as two separate documents to the patient and the nurse specialists then gave the patient a verbal explanation of the project, a
step which was considered important in ensuring good return rates. The intention was to collect the completed diaries and questionnaires on admission to hospital for surgery.

Six questionnaires and diaries were distributed to patients and two of each were returned completed. Reasons given for non-return included that the patient had forgotten it/left it at home or they had too much going on to complete it.

Information gained from the two returned questionnaires and two returned diaries helped to provide some insight into how the patient felt at home waiting to have surgery. The technique was non-intrusive for patients and not time consuming for the project team to deploy. However, it was evident from the number of questionnaires and diaries returned that patients were not fully engaged with the technique and with such a small sample, it was difficult to perform any kind of analysis of the information. There was also no opportunity to probe deeper into the patient experience. On reflection, the project team acknowledged that these tools were also chosen for their ease of use and initial feelings of discomfort at using other techniques that would require more skilled facilitation to acquire information.

Figure B contains excerpts from the patient diaries.

**Figure B**

“Went into ward day room waiting to go into the ward. Another lady came in and we got on talking straight away. We were both in the same bay and we both had the same cancer and kept each other’s morale up.”

“I saw my doctor for diazepam to try and calm me as I’m very anxious. I got upset explaining my “cancer” to her. She was very compassionate and helpful explaining about stress and my illness. I took my first diazepam this afternoon.”

“I find the waiting time since knowing I have to have an operation quite hard. Night time is worst as everything starts going around in my head.”

**Emotional touchpoint interviews with patients**

As only two each of the patient questionnaires and diaries were returned, the project team wanted to find an alternative method for capturing the experience of patients. With support from the FoNS practice development facilitator, the use of emotional touchpoint interviews was explored. The concept of touchpoints is central to the experience based design methodology in all its forms (Bate and Robert, 2007a). Touchpoints represent the key moments or events, those that stand out as crucial to the experience of the individuals receiving or delivering the service (Bate and Robert, 2007a). Touchpoints are not only points of contact with the service but also intensely personal points on the journey where one recalls being touched emotionally or cognitively in some kind of way (Bate and Robert, 2007a).

The emotional touchpoint interview technique allows the person being interviewed to select word descriptors of touchpoints which they would like to discuss (for example, arriving on the ward) and then emotion words which portray what they were experiencing at that time (for example, “on edge”, “supported”). Freshwater (2004) discusses how people generally do not have a large vocabulary of
emotional words to describe how they felt at a certain point in time. Offering examples of emotional words can therefore help people to tell their story more accurately and vividly (Freshwater, 2004). After the selection of the touchpoints and the emotion words by the patient, the interviewer encourages the interviewee to tell their story of the experience and what was good and bad about it. The method thus helps the interviewer and interviewee to directly focus on the emotion related to the different touchpoints in the patient’s experience (Dewar et al., 2009).

To ensure that the patients adequately understood the purpose of the interview and how the information that they provided would be used, an information sheet about the interviews and a consent form (see Appendix 1) was developed, based on a template from the experience based design toolkit (NHS Institute for Innovation and Improvement, 2009). Patients who were due for admission the subsequent week were identified by members of the project team and the information sheet was posted out to them with an introductory cover letter. On admission to the ward a member of the project team introduced themselves to the patient and ascertained whether or not the patient had any questions and was willing to take part in the interview. Interviews were held in a private room, away from the ward bays, at a time agreed as convenient with the patient and the ward nursing staff. Four interviews were conducted by the project team and these were audiotaped for transcription at a later date.

The interviews followed the following process:

- discussion with the patient about the methods used in the interview and the taking of written informed consent
- patient selection of touchpoints to discuss (with option to write own touchpoint if they wished)
- patient selection of emotion words related to those touchpoints (with option to write own emotions if they wished)
- use of facilitation techniques such as clarifying, reflecting back and encouraging to allow the patient to describe their experiences
- questioning how the service could be improved when a negative point was raised
- thanking the patient for their participation and ensuring that the interview has not raised any issues for the patient which may have caused distress
- typing of the interview transcript soon after the interview

The power of the stories contained within the interviews was immediately evident during their transcription. A healthcare assistant who had offered to assist with the typing of the transcripts was so moved emotionally by what she was hearing that she needed to take a break away to digest it. The value of getting the patients to tell their own stories also became apparent when the interviewers heard patients describing issues relating to their anxiety which would never have occurred to them had they not heard it directly from the patient.

When asked, the patients who were interviewed all expressed feeling happy they had been able to tell their stories. The project team also all reflected on the fact that the technique was an extremely comfortable one to use with the patient taking the lead on the direction that the interview took. The project team did however recognise that there were some limitations to the way that the technique was used. The process could have been improved by the actions listed below:
• a ‘do not disturb’ sign at the door of the interview room to minimise interruptions
• allowing the touchpoints to have been derived by patients rather than staff, perhaps through prior semi-structured interviews
• reducing the volume of emotion words for the patients to choose from
• allowing the patient access to the touchpoints and emotions words prior to the interview to allow them time to prepare
• allowing the patient to write the touchpoint and emotion words down before the interview
• providing support and training for the ward staff in the use of the technique and involving them in the emotional touchpoint interviews
• returning to the patient with the interview transcript to ensure that it accurately represented their story and allow them to make any changes or additions that they felt necessary

It was planned that the interviews would be analysed thematically by the participants at the staff feedback workshop. Figures C and D are excerpts from transcripts obtained in the emotional touchpoint interviews. The excerpt in Figure C is from a lady who describes the degree of anxiety caused to her by worrying about having to remove her false teeth when going to theatre. The excerpt in Figure D is from a patient who describes the anxiety caused by wanting to use her mobile phone but being unsure whether or not this was allowed on the ward or not.

**Figure C**

<table>
<thead>
<tr>
<th>Patient (P)</th>
<th>“I mean nobody can say that they are perfectly relaxed when they come in for surgery and I don’t suppose that there is much that you can do about that either, but this is one that nobody can do anything, I wear dentures and I’m really, really embarrassed to take them out, my children have never seen us without them, my husband never saw us without them, and that is the worst bit for me.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewer (I)</td>
<td>“that’s a big issue for you?”</td>
</tr>
<tr>
<td>(P)</td>
<td>“I’ve been more worried about that than any of this, really, it’s erm yeah I’m more embarrassed about that because I can’t talk without my teeth, never even tried, but you know the last thing they ask you is your name and your date of birth and without my teeth in that is a big deal for me. (Laughs) Oh God.”</td>
</tr>
<tr>
<td>(I)</td>
<td>“That is a big deal for you.”</td>
</tr>
<tr>
<td>(P)</td>
<td>“Yes I think most women feel exactly the same they would rather have a wooden leg or false boobs (laughs embarrassed). Or whatever than having to take their teeth out but I realise you have to do that.”</td>
</tr>
<tr>
<td>(P)</td>
<td>“I even threatened to get some superglue last week (laughs).”</td>
</tr>
<tr>
<td>(I)</td>
<td>“Did you?”</td>
</tr>
<tr>
<td>(P)</td>
<td>(Laughs) “Aye.”</td>
</tr>
<tr>
<td>(I)</td>
<td>“No I mean I’m glad you said that because there is a few of our ladies where it is a big deal for them as well you know and if we can change that and stop it from being a big issue for people then you know that is a good thing.”</td>
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</tbody>
</table>
Facilitation of a values clarification exercise

Four months into the project, the project team were concerned with the apparent lack of engagement with the gynae-oncology ward staff. The emotional touchpoint interviews with patients had been commenced on the ward and staff were beginning to ask about the interviews and what was happening. However there remained many members of the team who, on discussion, still denied any knowledge of the project. The project team also perceived reluctance from senior staff members to engage with the project. In addition, securing time for a project team member to be released from the ward was difficult. However, opportunely the ward sister had planned two nursing staff away days and the project team (with the support of the FoNS practice development facilitator) was able to work with the ward sister to secure a one hour slot on each of these away days to facilitate a values clarification exercise.

A values clarification exercise (Warfield and Manley, 1990; Manley, 1992) is a tool frequently used within practice development to develop a common shared vision and purpose. It is a useful tool when starting a journey of cultural change or as a way of developing a common vision (Manley, 1997). The intention of using this exercise was to aid the engagement of the ward team with the project as well as to increase the cohesiveness of the nursing team by exploring shared beliefs about the nature of person-centred care.
Person-centred care is a philosophy that centres care on the whole person and not only their healthcare needs (Manley et al., 2011a). Person-centred care is the fourth principle (principle D) of the Principles of Nursing Practice developed by the Royal College of Nursing (RCN) in collaboration with patient and service organisations. Principle D reads ‘nurses and nursing staff provide and promote care that puts people at the centre, involves patients, service users, their families and their carers in decisions, and helps them make informed choices about their treatment and care’ (Royal College of Nursing, 2010).

It was hoped that through the facilitation of the values clarification exercise related to person-centred care, the values and beliefs of the members of the ward team could be discussed and made explicit. From this, the development of shared vision and purpose would help the ward team to recognise the gaps between what they say they believed and what they actually did.

The values clarification exercise was prepared in advance of the two nursing staff away days. The two days were held one month apart. Half of the nursing staff attended the away day, while the other half looked after the patients on the ward, and vice versa. The first away day exercise was facilitated by the FoNS practice development facilitator whilst the project team observed the facilitation styles that were used. This allowed the project team to gain confidence in the techniques to be used when facilitating the exercise themselves on the subsequent away day. The exercise was facilitated in a private venue at a location away from the workplace. A time slot of one hour was allocated to the exercise.

At the start of the session the project team introduced themselves and the project, conducted an icebreaking exercise and established group ground rules with participants (Figure E).

**Figure E: Group ground rules**

1. Acknowledging the individuality and importance of the views of each member of the group
2. Confidentiality
3. No right or wrong answers
4. Consent for the project team to observe facilitation styles of the FoNS facilitator
5. Setting of the time limit for the exercise

The values clarification exercise then consisted of the group participants working alone to answer the following questions:

“I believe that the purpose of caring for a patient as a person is to ...”

“I believe that this purpose can be achieved by ...”

“I believe that the factors that enable this purpose are ...”

“I believe that the factors that hinder this purpose are ...”

“Other values and beliefs that I consider important in relation to caring for a patient as a person are ...”
Once everyone had finished answering the questions, individuals fed back their answers to the wider group and then looked to find common words/themes amongst the answers provided. These themes were scribed on flip chart paper by the project team.

Working in teams of three to four people the participants then completed the exercise by using the common themes identified to develop mission statements for the ward. Examples of the mission statements created are in Figure F.

**Figure F: Example mission statements**

<table>
<thead>
<tr>
<th>Mission Statement</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>“We believe that the purpose of our ward and team is to provide a good standard of care, to be able to communicate well with the patient at a level that they can understand. To support individual patients and their needs. To provide a welcome and friendly atmosphere. To show respect at all times and to listen to patients’ concerns and fears. To adhere to confidentiality and to work well as a team at all times.”</td>
<td>“We believe that the purpose of our ward is to provide a holistic approach, encompassing individual care in a professional manner. To recognise the need to be respectful, open and honest throughout the patient journey. We endeavour to provide a compassionate environment for patients and their significant others.”</td>
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</tbody>
</table>

The project team considered the values clarification technique to be highly effective in engaging the ward team in the project and in providing a sense of united purpose. This was evident through the spontaneous rounds of applause that erupted as teams fed back their statements and the verbal feedback on the exercise from participants was extremely positive. Feedback included statements such as “it’s nice to realise that everyone is singing from the same hymn sheet when it comes to what we want for our patients” and “it feels much less like us and them now” (health care assistants and qualified nurses). Other participants verbalised “it was nice to do something different on the away days”.

At the end of each exercise, the project team spent time debriefing and reflecting on how the exercise had gone. Personal reflections were that all members of staff were equally engaged in the exercise and that there were several ‘light bulb’ moments in which participants realised that the values and beliefs held within the room were very similar. There was a general sense of enthusiasm and energy within the room. On the second away day, the ward manager provided formal feedback on the project team’s facilitation skills based on her observation. This was very positive, stating that the exercise was timely, friendly and well facilitated. The facilitation styles used encouraged each member of the team to participate in a comfortable, supported and non-confrontational manner.

On reflection, the project team acknowledged that using the technique earlier in the process and with a wider range of stakeholder would have been highly beneficial.

**Staff interviews**
From the outset it was considered important to gain an understanding of the staff experience of caring for patients who are anxious and also to highlight any differences between staff perceptions of what makes the patient anxious and the patient stories of their anxieties. Also the project team felt it
important to find out what methods and strategies were employed by nursing staff whilst caring for patients who are anxious. The project team chose semi-structured staff interviews as the method for obtaining this information. Five semi-structured interviews were undertaken by the project team, with staff members; two qualified nurses, two healthcare assistants and a ward housekeeper. A member of the project team conducted the interviews. Verbal consent was given by the staff attending to take part in the interview. The questions asked were intentionally broad to allow the interviewee to tell their own story.

1. Can you please tell us about what things you think make people anxious on our ward?
2. Is there anything that you think we could do to make things better for people on our ward?

The interviews were again audio-taped for ease of transcription. The staff participating in the interviews all expressed some initial reluctance at being interviewed. However, the fact that the interviewer was a close and trusted colleague seemed to reduce this reluctance and put them at ease, allowing them to tell their story during the interview. One of the interviewees chose to write down her responses to the questions and read them out to aid her recall. The staff interview transcripts were thematically analysed at the staff feedback workshop.

The transcripts of the staff interviews produced interesting findings. They were effective in highlighting the strategies used when caring for the anxious patient. The interviewees were at ease discussing these strategies which included in depth information giving, orientating patients to their environment and making time to ‘be with and there for’ patients. There was some congruence between what patients said made them anxious and what staff thought made patients anxious. Perhaps more importantly however, some of the issues highlighted by patients were unique to their own stories. However, there were also some limitations to how useful the interviews were. The interviews failed to achieve any insight into how caring for the anxious patient impacted upon the staff member as an individual. It was also difficult to determine to what degree the staff members’ actions were congruent with the values that they espoused. On reflection, the interview questions employed did not lend themselves to gaining this information and an observation of practice utilising an observation tool such as the workplace culture critical analysis tool (McCormack et al., 1999) or indeed emotional touchpoint interviews may have been a more fruitful approach.

Staff feedback workshop
Following the patient and staff interviews the project team wanted to work with the ward staff to hear and analyse the information gained from these interviews, and a staff feedback workshop was organised. It was considered to be an opportunity for the team to hear about the positive experiences expressed by the patients who were interviewed as well as the chance to hear the issues which caused patients to be distressed. The project team felt that hearing the patients tell their stories in their own words may in itself act as an impetus to promote changes in practice but in addition, themes would be established and a plan of action put in place to address issues raised.

The workshop was held in a location outside of the work environment at a time which allowed staff to attend in their own time without the pressures of work commitments acting as a distraction. The individual staff members were given a gift to thank them for their attendance and were provided with refreshments, which were funded by the FoNS bursary.
The workshop was attended by the following staff members:

- qualified nurses from the ward 5
- healthcare assistants from the ward 4
- specialist nurses 2
- admin and clerical staff 1
- project team 3
- junior doctor 1

The agenda for the workshop and the rationale for the activities are in Figure G below.

**Figure G**

| Welcome and introductions | Introduce project team. Thank participants for attendance  
|                          | Provide overview of schedule for the workshop  
|                          | Provide overview of the aims of the workshop | Provide those new to the project with overview  
|                          | Update staff on progress with project  
|                          | Inform staff of purpose of the workshop - “at the end of the session the group will have a list of issues that affect patient anxiety levels and an action plan for re-designing the service” |
| Setting of ground rules | Explain the following ground rules: Confidentiality  
|                         | Respect for others  
|                         | Equal contribution  
|                         | Listening to each other’s contributions | Ensure that all members of the workshop feel comfortable with the tasks at hand |
| Ice Breaker “Fact and fiction” | Explain the task “reveal 3 things about you to the group - 2 of which are fact, 1 of which is fiction  
|                             | The group will then vote on which of these if fiction”  
|                             | Set time limits | Allow the group to introduce themselves. Break down barriers |
| Ward philosophy statements | Introduction  
|                            | Recap on how the mission statements were created  
|                            | Explain task - “3 mission statements are available please vote for the one which you would like to be the ward mission statement”  
|                            | Once votes are in, ask all participants if they are happy with the winning statement and if they feel anything is missing | To complete the work previously started at the away days |
| Patient stories | Introduce the emotional touchpoint interview technique  
|                  | Instruct the participants what to do whilst listening to the audio feedback “please write down any words or thoughts that come to mind whilst you are listening on an individual post it notes”  
|                  | At the end of the audio playback ask the participants to put the post it notes onto flipchart paper | To allow participants to hear patient stories told in their own words |

Refreshment break
### Staff feedback transcripts
- Split the group into 2-3 teams (try to split skill mix between teams)
- Provide transcripts to each team
- Ask for volunteers to read out the transcripts and for the other group members to write thoughts and words that come to mind on individual post it notes
- Place the post it notes on flipchart paper

- To allow participants to hear excerpts from staff interviews (whilst protecting the identity of the staff involved)

### Theming of the words pulled from the interviews
- Ask one of the teams to consider the post it notes created by listening to the patient interviews and the other team to consider the post it notes created by listening to the staff interviews
- Instruct the teams to arrange the post it notes into themes that they can see emerging and to give each theme a name

- To draw out the common themes portrayed by both the patient and staff interviews

### Claims, concerns and issues exercise
- Provide verbal instructions on how the exercise is performed
- Use facilitation skills to manage the group dynamics

- To get the participants to explore what is good and bad about what they have heard and to turn the concerns into questions related to patient anxiety that need to be answered

### Volunteers, feedback and next steps
- Inform the group of the plans to move the identified issues forward:
  - Identify leaders to work with the project
  - Team to look at potential solutions to the anxiety provoking issues raised

- Ask for volunteers to move the actions forward
- Gain feedback on how the workshop felt to participants

### Close the session, dinner, thank-you gifts
- To demonstrate the project teams gratitude for the participants’ attendance and enthusiasm

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The matron for the division, the director of nursing, members of the clinic nursing staff and senior members of the medical team were also invited to attend but due to prior commitments declined.

During the workshop a claims, concerns and issues exercise (Guba and Lincoln, 1989) based upon fourth generation evaluation was used to encourage the workshop attendees to consider what was good and bad about what they heard during the staff and patient interviews and to turn any negative issues into questions that could be answered. Each question to be answered was then allocated to a ‘leader’ to assess and develop a plan of action. Figure H represents the claims, concerns and issues which were identified at the workshop.
Figure H: Claims, concerns and issues identified

Claims: What good things can we say about what we heard from patients and staff?
- ward is a welcoming environment
- patients felt well informed
- patients felt ‘at home’
- patients received consistent information
- staff were friendly and helpful
- the environment was ‘nice’ and ‘calm’
- patients had a named contact
- patients and their families felt ‘cared for’

Concerns: What are our concerns about what we have heard from patients and staff?
- too much waiting
- not sure about use of mobile phones
- patients fear not waking up
- patients are anxious about their body image
- communication between the supportive care clinic and the ward is lacking
- patients are anxious about missing their family and friends
- patients worry about their discharge home
- patients don’t feel adequately prepared
- patients are anxious about the unknown
- patients have unfounded fears not based on reality, how can we find out about those fears?

Issues: What questions do I have? How can we turn our concerns into questions?
- What can we do about the amount of time that people spend waiting on our ward?
- How can the patient safely and reasonably use their mobile phone on our ward?
- How can we help the patient to manage their fear of the unknown/ their fear of not waking up?
- How can we improve communication between the supportive care clinic and the ward?
- How can we find out how patients will communicate with their family and friends while they are in hospital?
- How can we help to familiarise the patient with the hospital environment?
- How can we improve the discharge process/discharge information?
- How can we elicit patient fears appropriately?

At the end of the workshop the project team spent time reflecting on the workshop and felt that it had been successful in achieving its aims. By the end of the workshop a list of actions had been identified and a nominated lead identified to take these actions forward. Conducting the workshop at a location away from the work environment, free from distractions was integral to the success of the workshop and this was evidenced in feedback received on the evaluation form. The attendees appeared to be well engaged and enthusiastic and the project team encouraged all to participate and express their opinions. The improvement in the team’s facilitation styles and skills was evident when they were required to challenge blocking type behaviours from some of the attendees. The project team all
reflected that at the start of the project they would not have felt comfortable challenging these behaviours.

The staff gave both verbal and written feedback (in the form of an evaluation form). The evaluation form contained questions aimed at collecting both quantitative and qualitative data and each staff member was asked to complete one. Disappointingly only four evaluation forms were returned. Three out of the four respondents rated the evening overall as being excellent. A summary of the content of the evaluation forms is contained in Figure I.

The quality of the audio voice recordings from the emotional touchpoint interviews was poor which impacted negatively on the feedback for this part of the workshop. It would be helpful in the future to use digital voice recording equipment.

Figure I: Evaluation feedback

![Evaluation feedback chart]

Implementation of developments in practice
At the staff feedback workshop many of the staff were keen to suggest strategies that could be employed to improve the areas highlighted and were keen to move forward with these as quickly as possible. However, it was decided collectively that in order for changes to be implemented effectively that a nominated lead person would take responsibility for working with other members of the team in order to develop initiatives. This process has just begun within the project, with the nominated leads from the ward team spending periods of time with the project team away from the ward setting to devise and implement interventions. This time away from clinical practice is being backfilled with the bursary provided by FoNS to pay staff to work on the project.
Ideas for developments in practice so far include the following:

- staggering of admission times to avoid long waits for patients
- writing a ward standard, based on trust policies relating to the use of mobile phones on the ward and the production of a patient information sheet to accompany it
- an individualised assessment process to elicit patient fears and to implement strategies accordingly
- the use of distraction therapies on the ward to reduce the anxiety experienced
- the introduction of pre-admission ward tours to orientate patients to their environment
- having a member of the ward nursing team at the departmental pre-operative meeting to allow the handover of information gained at the supportive care clinic to the ward staff

Discussion

The aim of this project was to understand the lived experience of anxiety in women with gynaecological cancers and to redesign the service in order to improve this experience. At this point it is somewhat difficult to determine to what extent this aim has been achieved. Whilst the emotional touchpoint interviews yielded a rich narrative of how it felt to experience anxiety in the words of the patient, the project is still in progress. Once the changes have been implemented the project team plan to formally evaluate the value of these interventions using a further claims, concerns and issue exercises and other practice development tools.

Manley et al. (2008, p 9) define practice development as:

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\text{a continuous process of developing person centred cultures. It is enabled by facilitators who authentically engage with individuals and teams to blend personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformation of individual and team practices. This is sustained by embedding both processes and outcomes in corporate strategy.}
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Whilst the project team at the start of the project had not planned or acknowledged the fact that they were working within a practice development framework, it became apparent during the evaluation process that this was indeed the case. Some of the outcomes achieved during the project were consistent with the proposed outcomes of practice development.

Manley et al. (2013, pp 48-49) pose questions to help practitioners to reflect on values and beliefs, knowledge and skills in relation to the key components of practice development. The key components are:

- person-centred care
- transforming cultures and contexts
- values and beliefs
- learning in and from practice
- systematic approaches to change
- facilitation skills

These are discussed below in relation to the project.
Person-centred care
In terms of understanding the lived experience of anxiety in women with gynaecological cancers, the emotional touchpoint interviews that were conducted provided a rich source of data, told in the words of the patients themselves, which have greatly enhanced both the project team and the ward staff’s understanding of the issues faced by patients in terms of their anxiety. It was evident from the comparison of the patient and staff narratives that staff correctly identified many of the issues which provoked and worsened the experience of anxiety for their patients. But there were many issues faced by the patients which came as a surprise to members of the healthcare team. This process helped to challenge the assumptions made by healthcare professionals and in addition challenged the attendees at the workshop to question to what degree their care, in relation to the anxious patient, was truly person-centred. The participants at the workshop had all previously completed the values and beliefs exercise related to person-centred care and were able to describe what person-centred care meant to them. However realising that patients experienced anxieties that they were unable to predict helped the participants to realise that in order to be truly person-centred, a means of eliciting each individual’s anxiety, be that anxiety related to leaving their dog at home or anxiety about having cancer, needed to be developed. Hence one of the objectives set at the end of the feedback event was to identify a tool which would help to elicit actual patient fears rather than staff assuming that they already knew.

Hearing narratives from patients expressing their gratitude for excellent care also highlighted the importance of being person-centred. The nurse who was praised for ‘being there’ for the patient whilst she was vomiting, had taken for granted this element of her practice until she heard from her patient how much of an impact it had had on her.

Transforming cultures and contexts
‘The culture of the healthcare workplace is influential in delivering care that is person-centred, clinically effective and continually improving in response to a changing context’ (Manley et al., 2011b, p 1 ). Drennan (1992) refers to culture in its simplest form, ‘how things are done around here’ (Drennan 1992, cited in Manley et al., 2011b p 2).

Whilst it was not one of the initial aims of the project, unintentionally the workplace culture in which this project took place was examined. Prior to commencement of the project, the teams of staff predominantly outpatient based and those predominantly ward based had had a sense of separation. There was little cohesion between the two teams and it was initially difficult to gain access to the ward staff in order to utilise their experience and skills within the project. Progress with the project was initially extremely slow due to the fact that there was a sense of resistance from members of the ward team to working alongside the project team. This resistance had to be handled sensitively and it was only through persistence, ‘being present’ and working at the pace of the ward staff that ultimately a productive relationship was formed with the ward team, which it is anticipated will form the foundation for changes in practice in the future.

In addition it also became apparent that some of the issues that made patients feel anxious were caused by behaviours and attitudes deeply ingrained within the workplace culture. An example of this would be one of the themes identified by participants at the feedback workshop ‘why do patients
It was evident that ward staff were aware of the fact that patients spent large amounts of time waiting around and that it was the system of asking all the patients to arrive at the same time on the day of admission which caused this. However none of the staff had previously questioned this policy let alone considered how to begin to change the practice for the benefit of the patient. Participants at the workshop were easily able to provide solutions to enable the patients to be admitted at times staggered throughout the day but didn’t know how to start the process or feel that they had the authority to do so. By the end of the feedback workshop it was agreed between the project team and the ward staff that this was an area in which change was required and an individual from the ward team agreed to work towards this objective.

Because the project team never gained a benchmark impression of the workplace culture at the start of the project it is difficult to determine overall how many changes in the workplace culture occurred as a consequence of individuals participating in the project. It would have been helpful for the project team to have undertaken observations of practice using a workplace culture critical analysis tool (McCormack et al., 1999) both at the start and completion of the project to determine shifts in the behaviour of individuals and teams. However, in spite of this lack of benchmarking the project team did find some evidence of subtle shifts in workplace culture moving from a culture with rigid routines to one with more of the attributes of an effective workplace culture (Manley et al., 2011b). These shifts will be discussed in relation to the attributes of an effective workplace culture as described by Manley et al., (2011b).

- **Involvement, collaboration and participation by stakeholders**: stakeholders who were initially reluctant to engage in the project fully participating in events by the end of the process
- **Teamwork**: positive feedback from ward staff on the values and beliefs exercises and the staff feedback workshop in which staff reported “it is nice to feel a part of the wider team and to know what other people are working on”
- **Person-centredness**: staff attended events in their own free time because they were enthusiastic about improving care for their patients. Ward staff worked additional hours during their days off to look at processes that can be improved in order to improve the care received by patients
- **Open communication**: staff who had worked in the department for a long time reported that never before had the ward and outpatient teams come together to work on a project in this way
- **High support and high challenge**: staff at the feedback workshop challenged the ‘no mobile phone policy’ in spite of resistance from senior members of the team. The junior members of staff supported each other in this challenge

**Values and beliefs**
The values and beliefs exercises related to person-centred care, which were utilised at the nursing staff away days, were initially intended to engage stakeholders with the project. In addition however the exercise was also particularly useful in reminding staff of the importance of dealing with patients as people. The values and beliefs exercise allowed individuals within the team to reflect upon their own thoughts and feelings on the meaning of being person-centred and indeed what being person-centred meant to others within their teams. Working within the current pressures of the NHS it can be all too
easy for an individual’s behaviours to become incongruent with the values that they actually hold. The opportunity to revisit values about person-centred care outside of the pressurised work environment was welcomed by all the attendees as evidenced by their feedback on the programme, and whilst the project team do not have the evidence to be able to show whether this made a difference to behaviour in practice it is hoped that this would be the case. Again production of this evidence is something which the utilisation of a workplace culture critical analysis tool (McCormack et al., 1999) would have helped the project team to achieve. At the staff feedback workshop contradictions became evident between the mission statements related to person-centred care and practices happening on the ward. These contradictions are subject to action plans to change practice.

Learning in and from practice.
The facilitators in the project maintained reflective diaries through the entirety of the project. The process of reflection helped the facilitators to examine the skills that they had developed and the skills that they needed to continue to develop in order to advance their practice. In addition using the emotional touchpoints with the patients revealed a range of issues that caused the patients anxiety that the facilitators would never had envisaged in advance, for example the project leads were genuinely surprised that being separated from their mobile phones caused such high anxiety levels. This was an example of learning in and from practice.

Systematic approaches to change.
Prior to the start of the project, changes undertaken in the project team’s department had not been done in a systematic manner. This often led to a reluctance by staff to undergo changes, changes in practice not being maintained and low morale amongst team members. Within this project, by using systematic approaches to understand individual beliefs, values and practices and by working alongside them to effect change, the team felt that not only were the patients’ feelings about their experience taken into account but that the feelings and needs of the staff were also considered. The project team feel that as a consequence, the changes in practice resulting from this project will be better accepted and are much more likely to be sustained.

Facilitation skills
Enabling facilitation skills is a vital component of practice development (Shaw et al., 2008). Practice development relies on skilled holistic facilitation and facilitators who utilise multiple strategies to enable individuals and teams to become aware of and empowered to change their environment and culture (McCormack et al., 2009). At the outset of the project, the project team were complete novices to the world of facilitating practice development and its tools and strategies. At the initial FoNS workshop days, the project team rated on a numerical scale their confidence and skills as practice development facilitators. Each member rated themselves as having very little in the way of skills and confidence. This exercise was repeated at the final workshop day some ten months later and each member of the team had grown in confidence and ability as a consequence of being part of the project. The entries in the reflective diaries made by each project team member and feedback from participants in the project activities were also testimony to this fact and demonstrated significant learning, especially when the project did not progress as expected. The facilitators readily acknowledge how useful it would have been to recruit a cohort of patients to work with them throughout the duration of the project, both participating in the information gaining and the redesign elements of the
project and how enlisting a senior member of staff to be part of the project team would have been a useful strategy in encouraging engagement in the project. It can also be seen that more time spent at the start of the project considering who the stakeholders were and preparing an overall strategy and evaluation plan would have been hugely beneficial.

The learning and development that has taken place within the project team will be utilised not only in future practice development initiatives but the project team already find that they use some of the techniques learnt within current clinical practice. Individual members of the team have found that their leadership and facilitation styles have changed and become more flexible to the situation in which they are working and tools such as the values clarification and claims, concerns and issues exercises are frequently used within the workplace to enable more effective and focussed communications amongst team members.

**Conclusion**

In conclusion, this project aimed to improve care for women with gynaecological cancer by understanding their lived experience of anxiety and to use this experience to inform developments in practice. The methods and approaches used in the project have been highly effective in allowing the project team to develop a picture of the patient’s experience of anxiety and the elements of the service that need to be changed in order to support a reduction of this anxiety. However, in the future, the project team would like to involve patients more in the redesign of the service.

One of the main challenges faced by the project team during the twelve months of the project was the development of a cohesive working relationship between the outpatient based staff and ward staff within the unit. Although engagement of the ward staff in the project was initially a challenge, through patience, persistence and the utilisation of exercises that enable the engagement of staff, this working relationship is now much advanced. It is hoped that this changed relationship along with positive shifts in the effectiveness of the workplace culture can be the foundation of the changes in practice needed in order to alleviate and relieve patient anxiety.

**References**


Appendix 1

Consent form for interviews

1 COPY FOR PARTICIPANT, 1 COPY FOR INTERVIEWER

The development of a patient centered anxiety management programme.
TITLE OF PROJECT

Rachel Mignall
INTERVIEWER (NAMED INDIVIDUALS CONDUCTING THE INTERVIEWS)

1. I confirm that I have read and understood the information sheet for the above project and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time.

3. I understand that I can ask for any comments I have made on tape, in writing or on film to be removed.

4. I understand that my comments (or part of them) may be used in different formats such as video, paper and/or electronic to share with others the benefits of designing services that are based on patient experience. This will include staff in health and other related industries both within and outside the UK.

5. I understand that any of my comments used may be edited and will appear anonymously.

6. I agree to take part in the above study.

_________________________________________  ___________  ______________________________
NAME OF PARTICIPANT  DATE  SIGNATURE

_________________________________________  ___________  ______________________________
NAME OF INTERVIEWER  DATE  SIGNATURE

Using patient and staff experience to design better healthcare services
www.institute.nhs.uk/ebd