

The Patient-Centred Care Project

Evaluation report

August 2011

Executive summary

The Patient-Centred Care Project aimed to improve the experience and quality of care for patients receiving treatment for breast cancer and lung cancer at Guy's and St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust. The project was supported by King's College London and The King's Fund. It was funded by Guy's & St Thomas' Charity.

The independent evaluation report, commissioned by The King's Fund, described the process and impact of the project within breast cancer services (the first phase of the project). Here, we present a summary of the findings.

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Integrated Cancer Centre

What happened in the project?

A process called Experience-Based Co-Design (EBCD) was used (see box below) to provide an opportunity for staff and patients to work together to identify and prioritise problems, and develop service improvements. As a result, significant changes were made in a number of areas.

The EBCD process

The project process was as follows:

- Staff and patients were interviewed by a researcher from King's College London (KCL), who explored their experiences of working in and using breast cancer services.
- The researcher also spent time understanding the treatment pathway and observing different areas of breast cancer services.
- Patient interviews were filmed, and an edited DVD was produced.
- Staff issues were fed back at a staff event, and patients had a chance to see and review the DVD that was produced. Both staff and patients discussed the findings and identified priorities for improvement.
- These separate discussions then fed into a collaborative staff and patient co-design event, where staff and patients discussed and voted on their priorities.
- Staff and patient co-design groups were formed to work together on the key problems identified and to implement solutions to service improvements.
- Those involved in the process met again after a year to celebrate the improvements made.
- KCL also conducted a survey of breast cancer patients, the results of which were fed into the EBCD process.

The King's Fund carried out additional baseline work to understand the experiences of staff and patients more generally through all cancer services within the two trusts. The Fund worked with senior trust managers to explore how they could best facilitate patient-centred services.

What were the outcomes and impact of the project?

Patients and staff discussed problem areas and suggested ways to make improvements to services. Solutions were implemented in the following areas:

- surgery
- day surgery
- outpatient clinic systems
- communications about appointments
- information for patients
- management of chemotherapy symptoms.

In terms of the project's impact on the patient experience, there was some very positive feedback. Patients could see changes being made almost immediately:

The whole design of the day surgery unit changed and the whole passage through the day became much more patient-focused as opposed to how easy it would be for the nurses. It just looked like it would be a much more comfortable, comforting day than the one I had.

(Patient)

Every time we suggested something, the next time we came, it seems to have been implemented... [the improvement lead] and [the clinic supervisor] seemed to have got it sussed and were getting it done. So it was a very good experience.

(Patient)

As well as making specific changes, the project also supported wider improvements.

- A new patient group was set up to inform the development of the Cancer Treatment Centre, and the project helped to establish a wider culture of patient involvement.
- It facilitated greater and more open team working and better communication across departments, clinicians and staff of different grades.
- It gave health care assistants and administrative and clerical staff more training opportunities and supported their skills development.
- Participants often commented that it was the simple things that made a difference to people's experiences of services; many small changes were made to the way services were provided as a result of the project.

However, not all co-design improvement groups were able to be maintained. Where staff were committed to making changes to services, the project was a great success. But where staff did not engage with the improvement process, patients were disappointed and co-design groups folded at an early stage. It does seem that there has been less systemic change and less cross-departmental collaboration where teams were not already working together. It was also difficult to engage senior management in the process, so broader strategic issues received less attention throughout the project.

More generally, participants in successful co-design groups felt that their involvement in the project had been very beneficial, and that it had had significant impact at both a personal and organisational level:

I think the process has been brilliant... I think that what we have gained from it is enormous, and I don't think we would have got anywhere near as far in solving some of these issues if we hadn't done this.

(Staff)

Breast cancer was a big thing to happen to me and made some major changes in my life... I can see that being part of this project has actually helped me deal with it, deal with the whole process of having breast cancer. It has been part of my recovery.

(Patient)

Appendix 1 sets out the problems that the co-design groups identified and the solutions that were implemented as a result of the project.

What were the key success factors for service improvements?

- **Staff and patients working together** Where staff and patients worked together successfully in improvement groups, there was a collective and collaborative approach.

The staff were really lovely, they were very welcoming and it didn't feel in the slightest bit intimidating. [The Patient-Centred Care Programme Manager] was brilliant, everyone was very welcoming and pleased to hear our views.

(Patient)

It felt really positive and it was just really encouraging to find a group of staff that were so willing to look reflectively at their practice and to change where needed. And I was really impressed about the multidisciplinary input to the group. The consultants came, as did everyone else, they seemed really committed to it.

(Patient)

Staff were able to have conversations with patients outside the normal clinical environment, which meant that they could 'co-design' the most effective, patient-centred solutions to problems. The involvement and interest of a variety of clinical leads, managers and key members of multidisciplinary teams was essential to ensure that service improvements were made. Staff dedication was an important aspect of the project's success.

- **The patient experience DVD** Watching this was a very powerful emotionally, and a lot of staff felt that this way of putting across patients' experiences was a significant catalyst for action.
- **An enabling environment** Changes have been most successful where there was already some other activity that the project was able to link with, and where the focus of the project was aligned with key professionals' roles and responsibilities. It is vital that sufficient resources, space and staff time are devoted to making these improvements. Potential constraints to the process include financial and resource pressures, changes in personnel, organisational politics, and internal organisational structures.

ENABLERS to the process	CONSTRAINTS to the process
Improvements aligned with key professionals' roles and organisational priorities	Improvements are not part of professionals' main roles or organisational priorities
Staff engagement and enthusiasm	Lack of staff commitment
Dedicated resources, space and time	Lack of resource, space and time
Patient involvement for the duration of the project	Inaccessibility of co-design groups to patients
Facilitation and co-ordination resources	No additional co-ordination support
All staff and managers engage with the process	Key staff not engaged, changes in personnel
Patient experience DVD	Organisational politics

What lessons were learned during the EBCD project?

Several lessons from this project may be valuable to those involved in similar projects:

- **Recruiting and involving patients** A wider recruitment system that is not reliant on a few organisational gatekeepers (in this case, clinical nurse specialists) may support greater patient involvement. Introducing the project to groups of patients (for example, hospital support groups) worked well. Getting patients who have already been involved in the project to talk with other patients could be an alternative recruitment route. Offering patients a variety of ways to get involved may strengthen

participation. Where patients are unable to participate in co-design groups, it may be useful to consider how ongoing feedback from a wider selection of people can be used to inform the work of these improvement groups.

- **Co-ordinating and facilitating co-design groups** Clinical ownership was essential to these groups, yet they also benefited from additional co-ordination and facilitation. The issues chosen for the co-design groups could, and did, overlap, and it may be better to have fewer co-design groups to ensure that there is sufficient time and resource to co-ordinate them. It is good to aim for equal numbers of staff and patients in a group to encourage a wider range of views.
- **Promoting more equal relationships between staff and patients** The EBCD process can provide a space for discussions between staff and patients on a more equal basis:

It was an opportunity for everybody to be talking around a table as equals, and in the hugely hierarchical NHS, that doesn't happen very often. So I certainly found it helpful.'

(Staff)

However, patients are rarely in an 'equal' position to clinicians, as they do not have access to the organisational resources and processes that staff do, and they may be dependent upon clinical relationships. Ongoing staff engagement is crucial to patients' experiences within the project, as it is often they who will need to establish changes in organisational systems.

- **Engaging and empowering staff** The EBCD approach attempts to involve all staff from different disciplines and grades in the process, but membership of the co-design groups tended to consist of managers and clinicians. (It was often their responsibility to ensure that changes were implemented and they felt a sense of empowerment belonging to the group). Some frontline staff such as health care assistants and clinic clerks did not participate in the co-design groups, but their managers did ensure that staff were given the opportunity to contribute their ideas even though they were not officially taking part in the co-design groups.
- **Focusing on staff and patient experiences** While the project was designed to focus on the experiences of staff and patients, some people felt that, overall, it focused more on the patient experience. However, the improvements to services implemented as a result of the project often benefited staff too.
- **Adopting and adapting the EBCD process** The original focus of the project was on breast and lung cancer services. The process has already been adopted in other treatment pathways within gynaecological and colorectal cancer services where staff were interested in the approach. Trust improvement leads have adapted the process so it is less resource-intensive. They have not interviewed staff at the beginning of the project (which had not seemed essential to long-term staff engagement in the project) and they filmed patients using in-house resources. They then used a co-design improvement process that was similar to the original patient-centred care project.

Appendix 1: Problems identified and solutions implemented through co-design groups

Day surgery

(Developed during events held by the Day Surgery Co-design Group at Guy's and St Thomas')

Chaotic entry point: patients are received in reception and directed to the area where the day surgery nurses are. On arrival, patients are allocated and introduced to a named nurse, who is their contact point while they wait.

Patients separated from relative/friend early on: a 30-minute notice period has been introduced so the patient can stay with their friend or relative for as long as possible. Patients can now wear their own clothes while they wait.

Public cubicles separated by curtains being used as changing rooms and consultation areas: a pre-assessment room with examination couch has been made available for consultations. Consultants have been informed about it, signs have been put up, and a timetable posted for the room. A curtain has been added to the consulting room door to ensure privacy.

Continuity of care: named nurses are now allocated to each patient as their contact point up until surgery. There's a bell to alert nurses if patients or relatives need anything while they wait. After surgery, the named nurse contacts the relative/carer, and efforts are made to ensure that the same nurse discharges the patient. A board has been put up in the day surgery unit with nurses' photos and names.

Ideally, the patient's designated nurse would also be available in their post-op care bay. But this could create unequal workloads for staff.

Patients and relatives not informed of reasons for delays: communication between day surgery staff and surgeons has improved, so staff can keep patients informed about changes to theatre lists and the time that they will be taken in for surgery.

People in waiting area can see patients coming out after surgery: separate male and female pre-op and post-op recovery areas have been created to protect patients' privacy and dignity.

The need for greater emotional support: nurses have been trained to deal with the sensitivities of breast cancer. A link nurse was identified who attended a breast cancer study day, and then passed on this learning to other staff. The day surgery audit day also included some teaching around breast cancer. Staff were taken into theatre so that they could understand the complexity of the surgery. Closer liaison between the breast care nurses and daycare staff has improved the latter's understanding of the emotional support that patients may need.

Post-op information and discharge procedures vary: day surgery staff liaised with breast clinic staff to review discharge information and protocols. All patients now receive the same information upon discharge.

Surgery

(Developed during co-design events at Guy's and St Thomas')

Individual patients may need different information about surgery and treatment options. A gap between diagnosis and decisions about treatment could be beneficial: patient information was reviewed across the whole of the patient pathway.

A distinction was made between essential and optional information, enabling people to choose the appropriate amount of information they want.

Various ideas were discussed at the patient event, including a support group, more time in pre-assessment, an extra appointment before surgery, or a 'buddy' system.

Patients are not always able to absorb all the information given to them: the consent process is now less rushed. Patients are given the consent form and relevant information before their surgery is scheduled, and can take it home to read, bringing the form in on the day of surgery.

Pre-assessment procedures can be chaotic, and there are sometimes problems with notes: there was a full review of information flows from pre-assessments to operating surgeons. Arrangements for dates of post-operative appointments were changed so that they are booked with patients prior to their surgery. Patients who have had plastic surgery now all come back to the breast oncology clinic. Patients' insights were used to plan the pathway in the simplest, most efficient way.

Procedure for injecting 'blue dye' pre-op for sentinel lymph node identification needs to be improved: an information sheet has been developed for patients explaining this procedure, and is given to them beforehand.

Post-op information and appointments: there was a review of physiotherapy information, the point in the pathway at which it is given to patients, and the system for arranging appointments. It was agreed that it is good practice to see patients pre-operatively, which is being done. Appointments are made with all patients post-operatively to ensure that they are aware of physiotherapy services.

It was suggested that a DVD be produced showing people how to do arm exercises, which are important after surgery.

Inpatient experiences of care: the Head of Nursing and ward Matrons watched the DVD on patient experiences. Ward staff have been invited to attend breast cancer study modules, but take-up has been uneven.

Staff are aware of patients' experiences of these wards. Work to improve the patient experience is continuing through various means, including the 'Showing we care' programme.

Communications

(Developed during co-design events at Guy's and St Thomas')

Breast clinic

Reception can feel impersonal and unwelcoming: all administrative and clerical staff have completed a customer care course, and new staff will receive this training too. The breast clinic reception area has been improved to be more welcoming. Patients are offered drinks while they wait, and are kept informed of waiting times.

Long waiting times in clinic, and patients are not always given reasons for delays: clinic procedures have been reviewed and re-profiled to try and reduce waiting times. Patients are regularly informed of delays through an updated handwritten noticeboard, and in person, by the health care assistants and the clinic supervisor. Notices have been put up explaining that multiple clinics operate at one time, so although it may seem that someone who arrived later is being seen earlier, this is not actually the case.

Health care assistants' interpersonal skills need to be improved: all health care assistants are now more rigorously assessed during the recruitment process.

Patients do not know clinic staff names due to staff badges not being fully visible: all staff names are now displayed on a noticeboard in all breast and oncology clinics.

Appointments

Patients do not know who or what number to call with questions about their appointments: all referral letters and appointment cards now include the name and telephone number of the clinic clerk. Clinic clerks now call patients to arrange an appointment, which has led to a significant reduction in the number of DNAs ('did not attend').

Uncertainty about when voicemail messages will be picked up and returned: the answerphone message now clearly states the clinic clerks' names and provides assurance that all calls will be returned within a stated time.

Conflicting appointment times between central booking and clinic clerks:

This issue is being addressed through the Outpatient Improvement Group (not part of the Experience-Based Co-Design project).

Patients sometimes miss appointments because they have to wait at other clinics first:

This issue is being addressed by the Outpatient Improvement Group.

Missed appointments and missing referral letters: the Medical Oncology Office now logs all new referrals they receive as an extra check and tracking tool. Each referral/patient is now assigned to a named clinic clerk. These two new practices have seen a dramatic decline in complaints about missed appointments.

Not all patients were given a date for surgery when they were given their diagnosis, causing much anxiety: all newly diagnosed patients are now given a date for surgery on the day that they are diagnosed.

Patient information

The amount of written information given to newly diagnosed patients varies: there were discussions about the different information available to newly diagnosed patients, and the implementation of an information prescription.

Finding your way around the hospital site: a map has been developed, with clear signs showing the different areas of the hospital that breast cancer patients may need to visit. All appointment letters now include the hospital map.

Patients need better information prior to starting chemotherapy, better appointment card with correct contact numbers, helpline number or support group details so they can find out what to expect beforehand, and out-of-hours support:

These chemotherapy issues were not voted as a priority at the co-design event to form the focus of a separate sub-group. The design / appearance of the appointment card was discussed, but because it is a generic trust appointment card, it cannot be tailored to address the needs of patients attending the breast clinic.

Appointments

(Developed during co-design events at Guy's and St Thomas')

Patients feel they often get lost in the system: this sub-group only met once. Several issues discussed were similar to the problems and solutions that were being implemented through the Communications Co-design Group.

Some priorities fed into the communications group and solutions were implemented through that group. Other problems were directed to the Outpatient Improvement Group.

End-of-treatment support

(Developed during co-design events at Guy's and St Thomas')

This is often the most difficult time for patients: patients became involved in ongoing work around end-of-treatment support, and helped to develop a four-week, end-of-treatment course for other patients and staff, run in conjunction with Breast Cancer Care. Patients were also consulted on the set-up of a new clinic especially for people at the end of their treatment, discussing communications, the assessment process, and the way in which the clinic would be run.

This work was already under way and was further developed through patients' involvement in the co-design group. Emotional support through treatment was not focused on.

Information about symptoms

(Developed during co-design events at King's College Hospital)

Information about chemotherapy symptoms: the chemotherapy symptom checklist was reviewed, and patients felt that the information provided by external organisations such as Breast Cancer Care and Macmillan Cancer Support was sufficient.

Access to information: the introduction of the information prescription was discussed with patients, who thought this was a very good idea. The new Macmillan Information Centre was also in the process of being opened, and patients from the group went over to visit the centre.

The Macmillan Information Centre at King's College Hospital is in Phase 1 of the national roll-out of the information prescription.

Patient-held records: patients reviewed the patient-held record of care that was developed by the local cancer network. People thought it was a good idea but the layout was poor, and there were examples of inappropriate, overly medicalised language being used, as well as out-of-date phone numbers. These comments were fed back to the network.

Physiotherapy information and services: these were reviewed, and practices were shared with the physiotherapy team at Guy's and St Thomas'. A new exercise leaflet was reviewed and received positive feedback.

Group information sessions on chemotherapy: at the initial co-design event, participants discussed the possibility of holding group information sessions for chemotherapy patients. However, it was felt that the topics discussed may be too sensitive to cover in a group setting.

Services and support around hair loss: a database has been set up for patients at the information centre so that they can access appropriate local services. The wig service was reviewed and changes were made. Patients now have access to better wig services at the hospital, and a partnership with a top hairdresser has been developed for wig cutting services. Investment in a scalp cooling machine has led to better hair protection and less discomfort for patients.

Some of this work was in process before the co-design groups. However, understanding patients' experiences in this area has facilitated a much wider review that has supported these changes.

Communicating diagnosis

(Developed during co-design events at King's College Hospital)

Communication and information at time of diagnosis could be improved: this co-design group only met once. A second meeting was planned but did not happen due to an over-running case conference. No further information is available.

The new Macmillan Information Centre should go some way to addressing patients' information needs.

Inpatient experiences

(Developed during co-design events at King's College Hospital)

The standard of nursing care and communication with patients varies, and communication with relatives could be improved: one co-design meeting was held at King's College Hospital and it was agreed that staff from the wards would be invited to attend. However, no further meetings took place. Some work was done with managers of inpatient wards, who were shown the DVD that highlighted patients' experiences on these wards. Managers were glad to have seen the film and explained that they would highlight and discuss the problem areas with ward staff.

Some anecdotal evidence suggests that the inpatient experience may have improved, but staff are also aware of ongoing problem areas. The latest survey of patients' experiences (Quality Health 2011) suggested that further work may need to be done.

Single-sex ward accommodation is now a national requirement. Information about compliance and the improvement action plan can be found on the King's College Hospital website.

Quality Health (2011). *National Cancer Patient Experience Programme 2010 National Survey: Guy's and St Thomas' NHS Foundation Trust*. London: Department of Health. Available at: www.quality-health.co.uk/cancer-reports (accessed on 28 July 2011).

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