

National Nursing RESEARCH UNIT

Improving Patient-Centred Care through Experience-based Co-design (EBCD): an Evaluation of the Sustainability and Spread of EBCD in a Cancer Centre

Final Executive Report

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Ethical approval:

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1 Background

A Cancer Centre was formed across two large NHS Trusts in 2006 with the aspiration of delivering internationally renowned cancer services - in the 'top 10 globally' - for patients in the region. In 2008 the Centre began an action research project encompassing several work streams (such as the engagement and training of senior managers) to implement patient centred care (PCC).

This evaluation was conducted between July 2011 and July 2012.

This evaluation was commissioned to specifically examine the sustainability and spread of the chosen quality improvement approach: Experience-based Co-design (EBCD). EBCD is a form of participatory action research involving a 6-stage design process that seeks to harness and use subjective experiences of providing and receiving health care services in order to prioritise and implement quality improvements (Bate & Robert 2007; Robert 2013). Derived from social psychology and phenomenology, participatory action research (PAR) sets out to recognise and directly address complex human and social problems. McIntyre (2008:1) proposes four underlying tenets to the majority of PAR projects. These are a collective commitment to investigate an issue or problem; a desire to engage in self- and collective reflection to gain clarity about the issue under investigation; a joint desire to engage in individual and/or collective action that leads to a useful solution that benefits the people involved; and the building of alliances between researchers and participants in the planning, implementation and dissemination of the research process.

An important component of EBCD therefore is collaborative working between staff and patients; services are re-designed with rather than for patients. Independent evaluations report that EBCD can contribute significantly towards the repositioning of patients from passive recipients to active contributors to quality improvement (Iedema et al, 2008; Piper and Iedema 2010; Farr, 2011). Two particularly crucial aspects of the EBCD approach have been noted: filmed patient narratives (to 'kick start' and secure commitment to PCC work) and skilled facilitation of co-design groups (to enable collaborative working between staff and patients) (Tsianakas et al, 2012).

Theories of organisational change highlight the situated, multi-faceted, dynamic and 'messy' nature of quality improvement processes, particularly in large health organisations (Van Der Ven & Poole 1995; Berwick 2008). In relation to EBCD, challenges of patient recruitment and of sustaining frontline staff engagement for co-design work have been commonly reported, as has perceived limitations of co-design work in aspects of service provision over which participants have limited direct control (Iedema et al. 2008).

As initially undertaken in two breast and two lung cancer services EBCD closely followed an original 6-stage design process; the approach was tailored in different ways as it was then formally disseminated in three other cancer services (two colorectal and one gynae-oncology service) and informally diffused into three community mental health services in a neighbouring healthcare organisation (an Addictions Service, a Psycho-social service and Supported Housing). The ten service studies are summarised in Table 1.

Table 1: The ten service case studies

Service	Study Code	Organisational Study
Breast Cancer (Trust 1)	Service 1A	Sustainability
Breast Cancer (Trust 2)	Service 1B	Sustainability
Lung Cancer (Trust 1)	Service 2A	Sustainability
Lung Cancer (Trust 2)	Service 2B	Sustainability
Colorectal Cancer (Trust 1)	Service 3A	Spread (within organisation)
Colorectal Cancer (Trust 2)	Service 3B	Spread (within organisation)
Gynae-oncology (Trust 1)	Service 4A	Spread (within organisation)
Addictions Service (Trust 3)	Service 5C	Spread (beyond organisation)
Psycho-social Service (Trust 3)	Service 6C	Spread (beyond organisation)
Housing Support Service (Trust 3)	Service 7C	Spread (beyond organisation)

The facilitation of the work in the 4 cancer services is summarised in Table 2.

Table 2: Facilitation of EBCD work in the seven cancer service case studies

Service	Study Code	Facilitation
Breast Cancer (Trust 1)	Service 1A	Programme Manager
Breast Cancer (Trust 2)	Service 1B	Programme Manager
Lung Cancer (Trust 1)	Service 2A	Improvement Lead (A)
Lung Cancer (Trust 2)	Service 2B	Improvement Lead (A)

2 Aims

The three research objectives were to examine:

- (1) whether specific improvements made in the two breast and two lung cancer services as a result of EBCD have been sustained and if further potential areas for improvement continue to be identified and acted upon in these services;
- (2) the impact of the planned dissemination of the approach into three other Cancer Centre services (two colorectal and one gynae-oncology) and the informal diffusion beyond the Cancer Centre (into three services in a neighbouring mental health organisation);
- (3) whether the underlying patient-centred care philosophy of EBCD has had a broader impact within the Cancer Centre.

3 Methods

Research methods used to construct the 10 case studies included: reviewing available documentary evidence in 7 of the 10 case studies; fifty-five 1:1 semi-structured, audio-recorded interviews with key Cancer Centre stakeholders (n=6), quality improvement staff (6), frontline clinical and service support staff (23), and patients (20); non-participant observation (26 hours) of targeted care processes in six selected clinical areas at two hourly intervals over the course of 1-3 working days; reviewing relevant local and national 2010 and 2011 patient survey data (and in particular two selected indicators: 'respect and dignity' and 'treated as a set of cancer symptoms'); and an audit of the web traffic relating to an online EBCD 'toolkit' that was developed and disseminated as a result of the original work in the Cancer Centre.

4 Results

4.1 Sustainability of improvements in four original Cancer Centre services

- Sixty-two quality improvements (or 'co-design solutions') were identified and implemented across the original four Cancer Centre case studies (services 1A; 1B; 2A; and 2B) as a result of EBCD (see appendix 1). These improvements were mapped for each service at the point of their reported implementation (Table 3) and remapped for each of these services two years after their reported implementation (Table 4) to examine sustainability.

Table 3 Co-design solutions implemented in breast & lung cancer services

Service	Service area/point in care pathway	Co-design solutions by service (n)	Co-design solutions by area (n)
1A (Breast; Trust 1)		28	
	Day surgery		9
	Breast clinic		4
	Appointments		8
	Surgical pathway		3
	Written patient information		3
	Survivorship and support		1
1B (Breast; Trust 2)		4	
	Diagnosis/information		2
	Written local information		2
2A (Lung; Trust 1)		21	
	Diagnosis/information/result delays		6
	Written patient information		4
	Continuity of care		6
	Support for chemotherapy side-effects		5
2B (Lung; Trust 2)		9	
	Diagnosis/information		3
	Written patient information		4
	Continuity of care		2

- There were several common co-design priorities across the four services, most notably improving the experience of diagnosis, information giving and availability of written information, continuity of care and information on non-clinical issues.
- However, it is important to note that the two services where fewer improvements, or co-design solutions, were identified were located in the same Trust. Service 1B (4 solutions) and Service 2B (9 solutions) are located in Trust 2 in contrast to Service 1A (28 solutions) and Service 2A (21 solutions) located in Trust 1.
- One-to-one interviews with staff in Services 1A; 2A and 2B, as well as with patient experience improvement staff in both Trusts, indicated that staff in Trust 1 felt far more engaged with the EBCD work, as well as in the Cancer Centre overall, than staff in Trust 2.
- Difference in staff experience of the improvement work is notable for the different cancer service areas. These differences centred on the facilitation of the different co-design groups. As shown in Table 2, two staff, with different levels of experience and commitment to the EDCD project, facilitated the co-design groups within the four service areas. While all staff in Service 1A felt very positive about the facilitation of the co-design groups and the EBCD project overall,

no staff interviewed in Service 2A and 2B felt that the co-design groups were useful, or more useful, than other approaches to service improvement that included patient views.

- Different experiences of EBCD across the services also relates to the organisational structures and divisions into which this innovation was introduced. Front-line staff in Service 2A and 2B were already involved in close clinical collaboration, however, for organisational reasons, they were divided into two different services for the co-design work. Many staff interviewed commented that the co-design groups could have been used more productively to further develop this cross-organisational working.
- A further difference between the two cancer service areas (breast cancer and lung cancer services) was the views of staff on the capacity of patients with different disease conditions to enter into co-design work. Within lung cancer services, in particular, staff often noted the practical limitations of patient involvement in several months of regular hospital-based meetings for co-design work. Our overview of minutes of co-design meetings indicates that fewer patients sustained their active involvement in co-design in Services 2A and 2B (lung cancer services) compared to Service 1A. However, our overview also indicates that those patients from lung cancer services who did continue to participate in co-design work were active contributors to this process.
- Overall, it is notable that the service that was most successful in engaging staff as well as in securing initial co-design solutions was Service 1A. In this service a newly appointed nurse consultant was keen to apply the EBCD philosophy and support the co-design improvements within this service. In addition, this service was involved in a significant and wider redesign project at the time that the EBCD project was introduced here. This service, in contrast to the other services, had the 'key ingredients' for successful service improvement by EBCD.
- No staff from Service 1B replied to the invitation to participate in this evaluation study.

Overall, the key ingredients are identified as: feel engagement in both the trust and wider cancer centre from which improvement work is generated; a service and organisational (trust) environment where improvement activity is on-going; pro-active involvement of key clinical leaders (for example, nurse consultants) to champion change across service areas; facilitation by the improvement (co-design) process by particularly skilled staff committed to the philosophy of that improvement approach.

Overall, 19-22 months after initial implementation, 39 (66%) of the 56 co-design solutions on which we were able to collate data were sustained (Table 4). We were unable to ascertain whether one co-design solution in breast service 1 (pre-op physiotherapy visit), all three co-design solutions in breast service 2 and 1 solution in lung service 1 ('Clinical Trial' information revision) had been sustained or not. The proportion of solutions sustained by service ranged from 57% (12/21 in lung 1) to 78% (7/9 in lung 2) (see Table 4).

Table 4 Co-design solutions sustained by service and service area

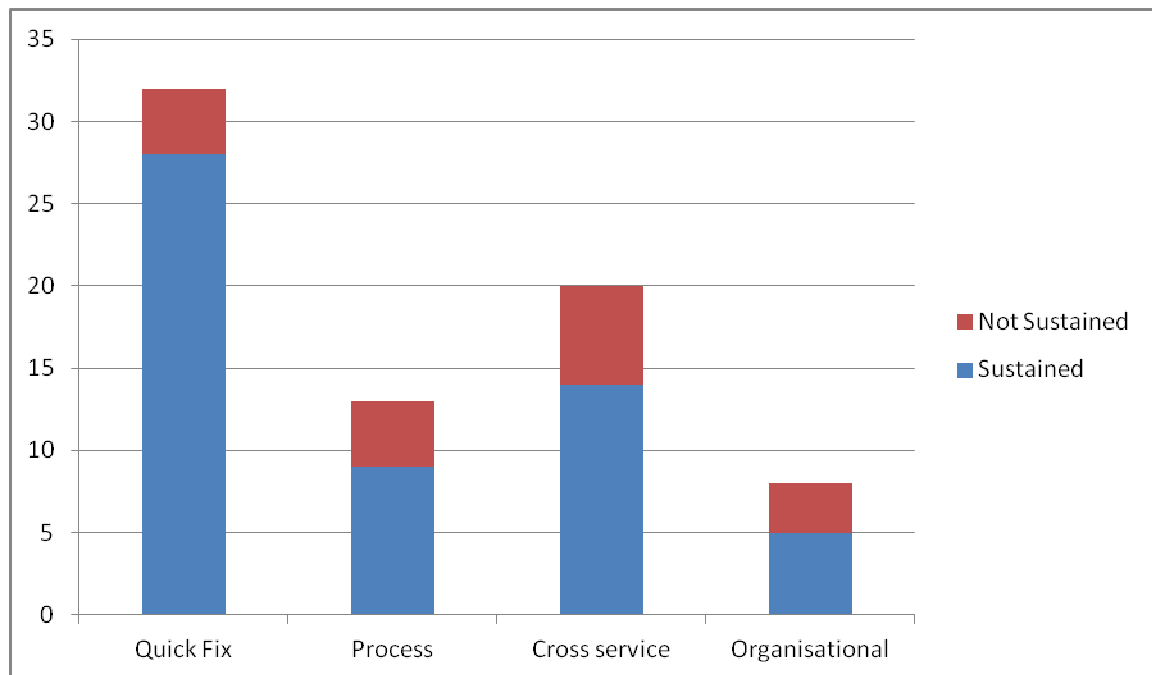
Service	Service area/point in care pathway	Co-design solutions (n)	Solutions sustained (n)
1A (Breast; Trust1)	Day surgery	9	6
	Breast clinic	4	4
	Appointments	8	5
	Surgical pathway	3	2
	Written patient information	3	1
	Survivorship and support	1	1
1B (Breast; Trust2)	Diagnosis/information	2	Not known
	Written local information	2	Not known
2A (Lung; Trust1)	Diagnosis/information/result delays	6	3
	Written patient information	4	2
	Continuity of care	6	3
	Support for chemotherapy side-effects	5	4
2B (Lung; Trust2)	Diagnosis/information	3	2
	Written patient information	4	4
	Continuity of care	2	1

Sustainability was influenced, firstly, by the type of co-design solution that had been implemented and, secondly, by the relationship between the co-design solution and (a) the service context (i.e. if the solution was discrete to the service or spanned service boundaries) and (b) other on-going quality improvement work. Regarding the latter, concurrent changes included: the relocation of parts of the oncology outpatients service from two hospital sites into one; the redesign of the chemotherapy unit and the establishment of an acute chemotherapy service; on-going preparations for the building of the new Cancer Centre (at Trust 1); on-going general patient experience improvement work (at Trust 2 and Trust 1); the development of customer care training for non-clinical general and service staff; and the use of various initiatives to improve general in-patient care experience (at Trust 2 and Trust 1).

The co-design solutions where sustainability is known (56) can be categorized as:

- 'Quick fix' solutions: 28 with 24 sustained
- 'Process redesign' solutions: 9 with 5 sustained
- Cross service or interdisciplinary solutions: 14 with 8 sustained
- Organisational level solutions: 5 with 2 sustained (see Figure 1).

Figure 1: The sustainability of different co-design solutions



'Quick fix' solutions involved little or no change in everyday working practices (for example, revisions of written patient information); process redesign within a service included, for example, new in-service procedures for patient consent; process and structural redesign spanned different services (for example, improving access to pre- and post-operative physiotherapy care); and, finally, there were several organisational level solutions (for example, addressing delays in obtaining PET scan results). The four categories are progressively more challenging to implement. Figure 1 illustrates the sustainability of co-design solution types undertaken within the four cancer service areas and for which evidence is available.

4.2 Spread of approach to other services and organisations

4.2.1 Direct dissemination

The impact of the planned *dissemination* of the EBCD approach was examined for its reception in two colorectal cancer services and a gynae-oncology service. This reception was found to be influenced primarily by service 'readiness for change' in each; notably, wider organisational 'drivers' for improving a service, the vision and active engagement of clinical leaders, and the formal roles of staff facilitating the implementation of the approach.

In the gynae-oncology service 13 co-design solutions were implemented (Appendix 2) and achievements made were seemingly greater than in the colorectal services (Appendix 3). Limited progress was made in the colorectal services because of a lack of involvement of clinical service leads and the co-design process not being implemented. Unlike in the original four case studies, EBCD implementation in the two colorectal services was undertaken without external project funding or research support. In addition, clinical staff were marginal to the co-design work in these services. In contrast, the relative success of EBCD in the gynae-oncology service was enabled by the

work of an 'in service' clinical lead champion - as well as a senior Clinical Nurse Specialist (CNS) - and the alignment of the work with established structures (such as multi-disciplinary team meetings), as well as a recognition that patient experience survey results needed to improve.

Since the early progress of EBCD in the original breast cancer services the patient experience team has been active in promoting the work in a range of contexts. These include:

- Celebration events organised as part of the EBCD process in two initial services (breast cancer services and lung cancer services at Trust 1)
- Update of the initiation and completion of the EBCD work in the Cancer Centre newsletter
- EBCD presentations at the (former) cancer committee (across Trusts 1 and 2)
- EBCD presentations at national and international workshops and conferences external to the Cancer Centre and the two trusts.

Service and patient experience improvement staff agree that the dissemination of EBCD into the Mental Health trust was serendipitous. Influential events and issues were:

- (i) Inclusive organisational development forums for updating on project work;
- (ii) The presence of senior staff (with cross-organisational networks of influence) at such events;
- (iii) The interest of these senior staff in facilitating project dissemination through both formal and informal contacts;
- (iv) The degree of alignment between the EBCD approach and the vision of service improvement staff in 'adopting' organisations;
- (v) The energy and motivation of experienced service development leads in disseminating and supporting learning.

The tailored implementation of EBCD in three mental health services (a supervised self-injecting addictions service, a psycho-social community support service, and supported housing services) was managed and led by the same quality improvement team in the mental health organisation. Implementation of EBCD in this organisation was more focused and innovative than the formal dissemination of the EBCD in gynaecology and colorectal cancer within the Cancer Centre. The work in two supported (mental health) housing projects was ongoing at the end of our fieldwork.

4.2.2 Indirect dissemination

A significant output of the original EBCD implementation in the first four case studies was a free-to-access on-line EBCD toolkit that was made freely available on The King's Fund website. The toolkit was produced and co-authored by staff leading the implementation of EBCD in these services with members of the research team at The King's Fund and King's College London. Following the initial launch of the toolkit in August 2011 - when it received almost 11,000 views - views of the toolkit have averaged 3,500 per month in the period to June 2012; an approximate total of 46,000 views. Apart from the August 2011 launch viewing figures, video views average just less than 120 a month. Figure 2 illustrates the level of interest in the web site generally (by toolkit views) and the use of the video clips specifically (by video views).

Figure 2: EBCD toolkit views and EBCD toolkit video views (August 2011 to June 2012)

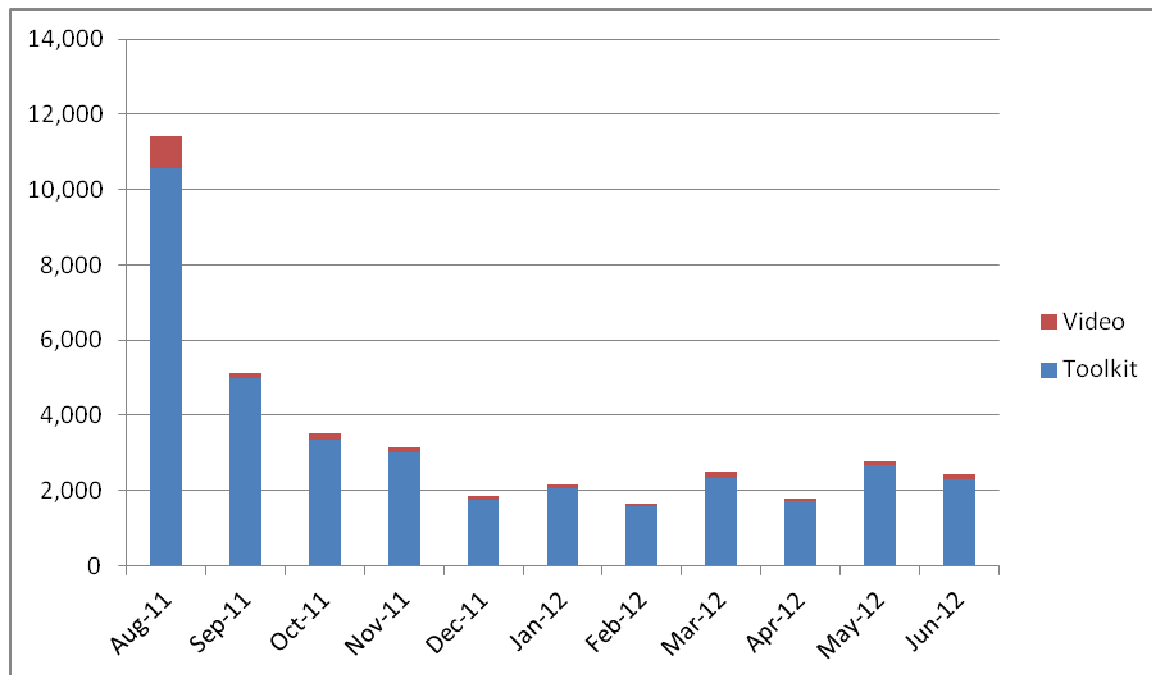


Table 5 lists the 16 EBCD 'steps' that form the structure of the online toolkit and illustrates which particular 'steps' saw the most related documents downloaded to the end of June 2012. Visitors to the online toolkit are less likely to download guidance on the 'co-design' stages of EBCD ('steps' 12, 13 and 14).

There are no available records of the geographical or service location of people who viewed the toolkit or downloaded documents. It is difficult to establish how far the EBCD toolkit has disseminated knowledge of the method and facilitated its uptake. It is likely (as in one known example) that service innovation staff interested in EBCD are attending the NHS Institute for Innovation and Improvement EBD one-day training course along with a selective viewing of the toolkit. We are aware anecdotally that there is interest in translating the toolkit into both Dutch and Swedish; the toolkit has also formed the basis of National Institute for Health Research-funded projects implementing and testing adaptations of the EBCD approach (Locock et al, in press). However, it should be noted that our fieldwork found that many clinical staff in some Cancer Centre services along with the majority of service innovation staff in the adjoining mental health trust remained unaware of the toolkit.

Table 5 Most frequently downloaded resources for EBCD ‘steps’

Tool kit ‘steps’	Documents downloaded (Descending rank order, top ten)
1. Is EBCD for you?	1 st
2. What is EBCD?	
3. Making the case to staff	4 th
4. Developing your project plan	5 th
5. Carrying out observations	3 rd
6. Engaging and interviewing staff	10 th
7. Recruiting patients	2 nd
8. Interviewing/filming patients	9 th /6 th
9. Editing the film	
10. Running the staff feedback event	
11. Running the patient feedback event	7 th
12. Running the joint patient-staff event	
13. Running the co-design groups	
14. Reporting, evaluating and celebrating success	
15. Adapting the approach to your budget	
16. What next for your EBCD project?	8 th

4.3 Patient-centred care in the Cancer Centre

The four initial Cancer Centre case studies (Services 1A; 1B; 2A; and 2B) were also examined for any evidence of sustained, broader impacts on the key drivers of PCC as identified by the Cancer Centre prior to the EBCD approach being implemented. The key drivers of PPC identified by Shaller (2007) are:

- Strategic leadership
- A supported professional workforce
- Collaborative decision-making with patients
- Patient empowerment
- Physical environments of care
- Service innovation (including patient engagement, systematic measurement of performance, and feedback and workforce training).

Our qualitative findings highlight the success of the EBCD approach in supporting *strategic leaders* to promote new approaches to quality improvement in some clinical and operational areas. However, the impact of the EBCD approach in terms of *supporting the wider professional workforce* were less

clear; some subsequent clinician-led attempts to co-design services with patients without wider, formal organisational support and engagement had negative effects on the workforce (and, in some circumstances, on their commitment to future quality improvement work). For example, one senior consultant who unsuccessfully petitioned for additional clinic space for a 'bad news' room for his patients remarked:

"It's just time and resources... and we don't have these... so all this talk about ferns in the waiting rooms... well it's just not realistic" (Service 2B staff interview 1).

With regard to the driver of clinician-led improvement, the local implementation of the EBCD approach in four specific Cancer Centre services was insufficient in isolation – and without strategic-level support - to address the longer-term complexities of team and multi-professional working and - over time - the 'hidden' social and emotional demands of participatory co-design initiatives became more apparent.

For example, staff without the confidence to secure change within clinical teams with disengaged clinicians struggled. Thus experienced improvement staff observed that:

"You've got to have the [service] champions ...there is a difference between saying 'Yes, it would be great to be involved' and really wanting it, they're different things...if I'm honest [the staff involved in EBCD work in service X].aren't leaders...they would not stand up to [the clinical lead] and say, 'This is really important, you've got to be here'" (Cancer Centre staff interview 4).

Whereas a senior staff member in another service noted that:

"The work gave us the confidence to know that we could go for more things" (Service 1A staff interview 1).

The impact of EBCD on *collaborative decision-making with patients* was found to be highly varied across the four case studies and, overall, not extensive (although there was positive evidence of impact in terms of individual clinician-patient encounters). Staff, as well as patients, had a range of different understandings of the nature of collaborative decision-making and what was necessary - or 'appropriate' - for patients.

For example some members of staff felt that the work on decision-making fell beyond their own as well as patients' responsibility and skill:

"I can [say] 'well this is my dream house' but I'm not a builder or an architect [in reality] ...somebody else needs to put it on paper and come back to me and say 'I'll just check with you that it's alright' and then will go off and do it... so with EBCD I don't think that it is our job to be sorting out services" (Service 2A staff interview 9).

While other members of staff considered the emotional demands of working alongside patients as clinicians:

"[The co-design group was] nerve wracking, I was sitting across a [meeting] table from a woman that I knew, I'd looked at her scan and I was going to have to tell her that her cancer had come back in the next clinic... and she's telling me how brilliant her life is ..." (Service 4A staff interview 4).

There was a marked difference between the expectations of senior Cancer Centre staff and the practices of frontline clinical as well as more junior service improvement staff. Thus, one member of staff remarked that:

“[for] the amount of time it takes you need to get some really good stuff out of it...changing [things] a little bit... that’s good, but is that good enough?” (Cancer Centre staff interview 2).

While a more experienced staff member commented:

“[People talk about minor but] How minor? If that minor change affects 100 people that year, and it’s a better experience for 100 people, how wonderful is that?” (Cancer Centre staff interview CS6).

Frontline clinical staff were convinced by improvement outcomes that were more immediate, tangible and larger scale, while senior clinical and improvement staff approached improvement as a longer term and incremental process.

The EBCD approach, when developed for front-line staff only, was insufficient to resolve these differences in expectation. Our findings indicate that the positive views and experiences of frontline clinical staff were secured in the context of broader organisational aims of enhanced *patient empowerment* and collaborative working; both staff and patients were able to elucidate the importance of thinking about such issues in ways that are more responsive to patient need. Improvements in *physical environments of care* were not co-design priorities in the EBCD cancer services; nevertheless patients who witnessed improvements in the built environment of care (for example, a new chemotherapy unit) identified such changes as very important to the patient experience. Finally, evidence for the impact of EBCD on *service innovation* is most difficult to establish because this work often paralleled or became co-joined with other service innovation initiatives in clinical or service areas. Available evidence for the greater success of EBCD in areas where the EBCD work was aligned or co-joined with other service innovations (for example improvements in appointments systems in Breast Service (1); improvements in the Day Surgery Unit) indicates that the impact of EBCD is in informing on-going innovation work.

To further inform our findings relating to our third aim - whether the underlying patient-centred care philosophy of EBCD has had a broader impact within the Cancer Centre - Table 6 reports the Trust-specific and national results of the Cancer Patient Surveys in 2010 and 2012 for two broad indicators of PCC: firstly, whether patients are ‘always treated with respect & dignity by hospital staff’ and, secondly, whether patients ‘did not feel they were treated as a set of cancer symptoms’. These indicators were selected as we judged them to come closest to the whole-person care that underpins person-centred care.

**Table 6 Indicators of a wider PCC approach: Trust vs. National
(Cancer Patient Survey, 2010 & 2012)**

Service	Q: 'Always treated with respect & dignity by hospital staff'			Q: 'Patient did not feel they were treated as a 'set of cancer symptoms''		
	2010: Trust - national (%)	2012: Trust - national (%)	Trust vs. national change	2010: Trust - national (%)	2012: Trust - national (%)	Trust vs. national change
1A (Breast Trust1)	70 - 83	81 - 83	+11	77 - 78	74 - 78	-3
1B (Breast Trust2)	69 - 83	83 - 83	+14	72 - 78	68 - 78	- 4
2A (Lung Trust1)	85 - 82	90 - 84	+5	76 - 79	78 - 77	+2
2B Lung Trust 2)*	---	---	---	----	----	----

* One service (lung cancer services at Trust 2) is excluded from the trust-level survey due to the small size of patient respondents (that also indicates the small size of this service).

As Table 6 shows both breast cancer services saw significant improvements in their 2010 and 2012 survey results relative to the national results for our first indicator of PCC ('respect & dignity'). Conversely, both breast cancer services performed marginally worse in 2012 than in 2010 on the second indicator (treated as a set of cancer symptoms). In the lung cancer service that was nationally surveyed (Lung 1), there were improvements relative to national results for the first indicator of PCC ('respect and dignity') and our second indicator ('treated as a set of symptoms'). These improvements occurred even though the service was performing above the national average in 2012 for these indicators.

Looking more closely at the impact of specific co-design solutions that emerged from the original four EBCD implementations we also undertook a comparison of (a) the implemented co-design solutions and (b) relevant findings in the 2010 and 2012 national cancer patient survey (appendix 4). Clearly there are several limitations to such a comparison; for example, the survey questions do not always directly relate to the identified co-design priorities and there were many concurrent quality improvement initiatives underway at the time of implementing EBCD. Nonetheless, the illustrative findings provide a mixed picture. In the first breast service there was a broad indication of the EBCD co-design solutions having contributed to improvements in several relational aspects of care (for example, amount of time doctor spent; being told sensitively that they had cancer). The impact of co-designed solutions relating to clarity and quality of information provided was less marked. In the second breast service there were very significant improvements in several measures relating to the inpatient experience (a key touch point in the EBCD work); increased sensitivity when being given a

diagnosis was also noted but, as with the first breast service, co-designed solutions to improve information given to patients seemed less successful. In the first lung service, improvements in the survey results were seen in many aspects of patient experience that had been identified as co-design priorities (and in this service these improvements did sometimes relate to information giving), despite many staff feeling disengaged from the EBCD work in this service. Although not presented in detail here, the survey results for the two colorectal services show evidence of significantly positive improvement in all the co-design priorities but in both services it is not known if the early stages of the EBCD work had influenced these; however, it should be noted that CNS staff and the service manager in one of the services were positive in their assessments of the impact of the approach. Finally, the gynae-oncology service saw negative trends in patient experience of GP referrals (despite this having been a co-design priority) but significant improvements in emotional support and relational care within some clinical areas.

Overall the comparison of co-design solutions and the national patient survey results across these seven cancer services suggests that the positive changes affected by EBCD work in aspects of patient experience is more often to do with individual professionals in their interpersonal relationships and encounters with patients. Positive changes were less often to do with the 'whole team' behaviours or systemic reforms.

5 Summary implications for the Cancer Centre from study of sustainability of improvements in four original services

- Service areas in which clinical leaders were actively engaged in the EBCD work were more likely to secure sustained change.
- Staff and patients found 'quick fix' solutions easiest to implement (particularly if managed within a defined service or care pathway area) but not necessarily to sustain in the absence of:
 - Alignment between local quality improvement work in specific services and more formal organisational processes and structures
 - The active engagement of senior managers within and beyond the Cancer Centre with such quality improvement work.
- In some cases, subsequent clinician-led attempts to co-design services with patients without wider, formal organisational support and engagement (as above) had negative effects on the workforce.
- Influential frontline staff across the two Trusts wanted the opportunity to work together on similar co-design priorities to improve service-wide processes but logistically this proved difficult to achieve.
- Staff had different expectations of patients' role in co-design, generally in relation to disease conditions. However, while fewer patients with more debilitating or life-limiting conditions contributed to service improvement work, those who did made a significant contribution.
- The presence of improvement leadership within a service, along with the commitment of this leadership to co-design, was very important for introducing and sustaining the co-design approach within that service.

- Externally positioned quality improvement staff who understand and are committed to the underlying philosophy of EBCD, along with their on-going alliances with 'in service' improvement leads, are very important for introducing and securing change through EBCD.

6 Summary implications for implementation of the EBCD approach generally

- The capability and capacity of local facilitators is crucial to successful implementation.
- Service size, readiness for change and the alignment between shared service values and the values underpinning the EBCD approach influenced outcomes.
- Implementation of participatory quality improvement projects – such as EBCD – should be tailored to (a) the needs of clinical staff, (b) the particular dynamics and challenges of inter-professional team-working, and (c) the changing needs and priorities of patients themselves.

7 Summary implications for quality improvement priorities arising from observational fieldwork in 2011-12

The observational fieldwork identified the following issues for service improvement within particular cancer service areas:

- Review visibility and regular updating of waiting time notification boards in clinics.
- Review experience of breast cancer patients visiting general surgical pre-assessment unit (the social and physical environment of care).
- Review staff photograph boards and name badges in day surgery unit (these boards are not convenient for patients to view; few medical staff wear name badges in recovery areas).
- Review patient information accessibility (for example, regarding sentinel node biopsy preparation) in day surgery unit.
- Review patient experience in the Trust 2 medical wards where cancer patients are sometimes admitted (patient experiences of nursing care, for example, communication about admission, care and discharge plans; hygiene; dignity; patient experiences of housekeeping care, for example, provisioning of suitable meals; room cleaning).

8 Conclusions

Two-thirds of the quality improvements made across the four initial cancer services to implement EBCD were sustained at two-year follow-up. In addition, through pro-active leadership within the Cancer Centre and the support of this leadership within trust-wide leadership networks, EBCD spread from the original four (breast and lung cancer) services to a further three services within the organisation (see Appendix 2 and Appendix 3) and three other services beyond the organisation.

The sustainability of the EBCD approach to service improvement in the longer term will rely on the capacity of trusts and services to support a 'patient-centred approach' to service improvement through 'in-service' and externally positioned quality improvement staff who collaborate to 'drive through' this vision. Without this there is a risk that the spread of the EBCD in the Cancer Centre and beyond will involve slippage from a perspective that values listening to, and working with, patients towards a more organisationally directed view of what constitutes quality improvement. Such sensitive tailoring of EBCD to accommodate different patient groups and the concerns of front-line staff is, in itself, an important dimension of effective co-design.

Fieldwork observations identified a number of potential priorities for on-going quality improvement work to improve patient experiences.

References

- Bate, P. and Robert, G. (2007) *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*: Radcliffe Publishing.
- Berwick, D.M. (2008) 'The Science of Improvement' *JAMA* 299:10
- Farr, M. (2011) *Patient Centred Care and Experience-Based Co-Design: The King's Fund Evaluation Report Executive Summary (Draft)*.
- Iedema, R., Merrick, E., Piper, D. and Walsh, J. (2008) *Emergency Department Co-design Stage 1 Evaluation Report*. Sydney: Centre for Health Communication (UTS) and NSW Health (Health Service Performance Improvement Branch).
- McIntyre, A. (2008). *Participatory Action Research*. Thousand Oaks, Ca: Sage
- Piper, D. and Iedema, R. (2010) *Emergency Department Co-Design Program 1 Stage 2 Evaluation Report*. Sydney: Centre for Health Communication (UTS) and NSW Health (Health Service Performance Improvement Branch).
- Robert, G. (2013) 'Participatory action research: using experience-based co-design (EBCD) to improve health care services'. In: S. Ziebland, J. Calabrese, A. Coulter and L. Locoock (eds). *Understanding and using experiences of health and illness*, Oxford; Oxford University Press.
- Shaller, D. (2007) 'Patient-Centered Care: What Does It Take?' Fund Report. The Commonwealth Fund. www.commonwealthfund.org/publications/
- Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C. and Wiseman, T. (2012) 'Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services' *Supportive Care in Cancer* 12:271.
- Van De Ven, A. H. and Poole, M.S. (1995) 'Explaining Development and Change in Organisations' *Academy of Management Review* 20.3:510-540.

Appendix 1 Details of the sustainability of the 62 co-designed solutions implemented within the four original cancer services

Cancer service	Service area & QI priority	Co-design solution	Sustained?
1A	<i>Day surgery:</i>		
Breast;	- lack of information about operating times/having to wait	1. Dedicated nurse (pre-op)	1. Yes
Trust 1	long hours	2. Staff & staff/patient communication	2. Yes
	- being separated from family & friends too early	3. Notice period before family separation	3. No
	- feeling invisible and alone	4. Pre-op patients wait in own clothes	4. Yes
	- being rushed through recovery	5. Improve continuity of nursing care	5. Yes
		6. Day surgery redesign (single sex accommodation; dedicated consulting room; redecorated pre-surgery and discharge rooms)	6. Yes
		7. Breast cancer awareness (nurse training and liaison)	7. No
		8. Staff photoboard and call bells	8. Yes
		9. Discharge information and protocols reviewed and aligned	9. No
	<i>Breast clinic:</i>		
	- more continuity of care	10. Clinic procedures re-profiled	10. Yes
	- improved relational care	11. Waiting time notification board	11. Yes
	- improved care co-ordination	12. Reception staff customer care training	12. Yes
		13. Staff photoboard	13. Yes
	<i>Appointments:</i>		
	- not receiving letters on time; patients not on lists; lost in system	14. Named clinic clerk contact details on all correspondence	14. Yes
		15. Voicemail message returned in stated time (breast clinic)	15. Yes
		16. Tracking tool to manage new referrals (medical oncology)	16. No
		17. Outpatient Improvement Group to improve inter-clinic communications	17. No
		18. Post-op appointments arranged prior to surgery (breast clinic)	18. Yes
		19. Appointment letters with site maps	19. Yes
		20. Physiotherapy care: pre-op visit	20. n/k
		21. Physiotherapy care: routine post-op appointments	21. Yes

	<i>Surgical pathway:</i>		
	- communication between staff and patients	22. Early/less rushed consent process	22. Yes
	- staff spending enough time with patients	23. Surgery dates on day of results	23. Yes
		24. Review of information flows (pre-assessment to surgery and post-op appointment)	24. No
	<i>Written patient information:</i>		
	- importance of written information	25. Reviewed and differentiated across patient pathway	25. No
	- information about going through cancer treatment and living with side effects	26. Amount of information discussed with each patient	26. Yes
		27. New pre-operative leaflet (sentinel lymph node identification)	27. No
	<i>Survivorship and support:</i>		
	- feeling lost at end of treatment; more information about what happens next	28. Ongoing development of end-of-treatment consultation	28. Yes
IB Breast; Trust2	<i>Diagnosis/information:</i>		
	- way patients are given diagnosis	29. Review information-giving protocols	29. n/k
	- information-giving	30. Refer to Macmillan Centre	30. n/k
	<i>Written local information:</i>		
	- improve patient knowledge through written information	31. Update written local information (chemotherapy symptom checklist and exercise leaflet)	31. n/k
	- improve patient information on local support services	32. Develop database of local information/support services	32. n/k
2A Lung; Trust1	<i>Diagnosis/information/result delays:</i>		
	- how news is broken	33. Review junior medical staff training	33. No
	- CNS presence	34. Extend CNS presence in hospital	34. Yes
	- support & information (clearer management plan for patients)	35. Review local clinic information (include in first letter)	35. Yes
	- physical environment (time/privacy)	36. Dedicated clinic room	36. Yes
	- speed of communication of results	37. Raise in-patient concerns with Clinical Indicators Team	37. No
		38. Review PET scan procedures (reduce delays)	38. No
	<i>Patient information:</i>		
	- information given at first appointment	39. Oncology outpatient and 'Lung Cancer team' leaflets revised (include clinical on-call contact)	39. Yes
	- information needs about financial benefits; homecare; psychological support; after treatment expectations	40. 'Clinical Trial' information revision	40. n/k

	- awareness of palliative/MacMillan nurses	41. Dimpleby Cancer Care information resource promoted by clerical and clinical staff	41. No
		42. 'Welcome video' identified for development	42. Yes
	<i>Continuity of care:</i>		
	- reduce numbers of Drs seen	43. Restructure clinic to reduce Drs seen and wait times	43. No
	- CNS support across hospitals	44. Patient reassurance of MDT working	44. Yes
	- review information flows between hospitals	45. Staff photoboards in outpatients clinic	45. No
		46. CNS networking across hospitals	46. Yes
		47. Information flow review by senior clinicians	47. Yes
		48. Development of EPR portal for cross hospital visibility	48. No
	<i>Support for chemotherapy side effects:</i>		
	- under-reporting	49. Telephone audit	49. Yes
	- need for patients to share knowledge of 'small effects'	50. Preparation of 'checklist'	50. Yes
		51. Unit triage	51. Yes
		52. Acute oncology service	52. Yes
		53. Concerns to be shared with Chemotherapy team	53. No
2B	<i>Diagnosis/information:</i>		
Lung;	- environment for giving news	54. Dedicated space in new MacMillan centre	54. Yes
Trust2	- the way that patients are told	55. Raise awareness & availability of CNS contact details throughout hospital	55. Yes
	- support and information	56. Increase CNS hours	56. No
	<i>Written patient information:</i>		
	- information needs about financial benefits; homecare; psychological support; after treatment expectations	57. Review patient information sheets and appointment letters	57. Yes
	- awareness of Macmillan information & support centre	58. Refer all information solutions to MacMillan centre	58. Yes
		59. Profile Information Centre across hospital	59. Yes
		60. 'Welcome video' identified for development	60. Yes
	<i>Continuity of care:</i>		
	- CNS support across hospitals	61. 'Link nurse' meetings with CNSs	61. Yes
		62. IT work to establish cross-hospital EPR portal	62. No

Appendix 2 Co-design solutions in gynae-oncology service (Trust 1)

Service area & QI Priority	Co-design solution
<p><i>Referral & diagnosis:</i></p> <ul style="list-style-type: none"> - delays in GP referral - waits after referral <p><i>Information:</i></p> <ul style="list-style-type: none"> - little known of brachytherapy - little known of steroid side-effects <p><i>Diagnosis, tests and results:</i></p> <ul style="list-style-type: none"> - waits for diagnosis - diagnosis given by telephone - delayed/lost test results between hospitals - long journeys for simple tests - disorganized PET scan information 	<ul style="list-style-type: none"> GP educational session Women's health afternoon Revise management of scan results Improve diagnosis processes Ensure consistent & timely patient letters (from different hospitals) Revise blood test management
<p><i>Moving through the care pathway:</i></p> <ul style="list-style-type: none"> - chemotherapy: feeling anxious - radiotherapy: feeling alone - outpatients: feeling rushed and excluded by medical staff - seeing too many different doctors - PET scan department; rudeness - left alone/uninformed after treatment 	<ul style="list-style-type: none"> Use patients concerns checklist End of treatment consultation Group follow-up sessions Drop-in clinic system Holistic approach to follow-up in development
<p><i>Physiotherapy:</i></p> <ul style="list-style-type: none"> - delayed referrals 	<p>DVD becomes vehicle for ward staff training</p>
<p><i>In-patient care:</i></p> <ul style="list-style-type: none"> - feeling uninformed - not knowing when to call staff - varied attitudes of nurses - feeling forgotten in single room - long waits at discharge 	

Appendix 3 Co-design solutions in two colorectal services (Trust 1 and Trust 2)

Service	Service area & QI priority	Co-design solution
Colorectal 1	<p><i>Diagnosis:</i></p> <ul style="list-style-type: none"> - being alone when given 'bad news' - receiving 'bad news' in public place 	<p>First visit letter advises 'bring a friend'</p> <p>Senior consultant to be persuaded to give bad news in less public space</p>
	<p><i>Major reconstructive surgery:</i></p> <ul style="list-style-type: none"> - unprepared for effects of surgery (pain & disfigurement) - not knowing the side-effects of anal surgery 	<p>Information leaflets rewritten to include CNS contact information; FAQs; leaflets made available at Dimbleby Cancer Care information office & from CNSs</p> <p>Care pathway for major reconstructive surgery to include pre-admission consultation; information giving; consent process; post-op care guidance</p>
Colorectal 2	<p><i>Colonscopy clinic:</i></p> <ul style="list-style-type: none"> - cramped waiting rooms - undignified care <p><i>Diagnosis:</i></p> <ul style="list-style-type: none"> - feeling alone after diagnosis - needing to ask questions after news of diagnosis <p><i>In-patient care:</i></p> <ul style="list-style-type: none"> - variable nursing care - feeling uncared for at night - poorly managed wards - miscommunication between nursing and medical staff <p><i>Stoma care:</i></p> <ul style="list-style-type: none"> - too rushed to learn self-care <p><i>Follow-up care/discharge:</i></p> <ul style="list-style-type: none"> - no discharge information sent to GP and nurses - poor continuity of wound/stoma care (GP and hospital team) - left alone (need for psychological support) 	<p>Concerns referred to nursing management team</p>

Appendix 4 Quality Improvement ('co-design') priorities by service, local & national Cancer Patient Survey results (2010 & 2011), co-designed solutions and % local improvement relative to national survey results (selected examples only)

QI priority (2009) for 3 case study services where national data available*	Survey question	Survey (2010): Trust/national (%)	Co-designed solution	Survey (2012): Trust/national (%)	Trust change in relation to national change
Service 1A					
(Breast; Trust1)					
<i>- breast clinic: improved relational care; surgical pathway: staff spending enough time with patients; written patient information: importance of written information</i>	Patient thought Dr spent about the right amount of time with them	92/92	Early/less rushed consent process	95/92	+ 3
	Patient felt they were told sensitively that they had cancer	81/87	Improve staff - patient communication	90/87	+ 9
	Given easy to understand written information about tests	87/85	} Written information reviewed; amount of information discussed with each patient	89/87	No change
	Overall, given right amount of information about condition and treatment	87/89		84/89	- 3
Service 1B					
(Breast: Trust 2)					
<i>- inpatient experience: variable nursing care; poor communication to relatives & patients; mixed sex wards; information quality & access: unaware of chemotherapy side effects; not knowing about care plan; diagnosis: poor</i>	Ward nursing staff gave understandable answers to important questions	59/74	} Ward managers viewed films and addressed concerns	68/77	+ 6
	Patient had confidence and trust in all ward nurses	45/74		71/77	+ 23
	Always treated with respect and dignity by hospital staff	69/83		83/83	+ 14
	Patient given written information about the type of cancer they had	75/71	Updated written local information; database established for access to local services	72/75	- 7

experiences of being given diagnosis; no information to take home	Patient felt that they were told sensitively that they had cancer	85/87	Review information-giving protocols; refer patients to Macmillan Centre	93/87	+ 8
Service 2A (Lung; Trust1)					
- <i>information giving</i> : not specific to the person; not easy to understand; varied availability (e.g. for benefits); <i>diagnosis</i> : 'bad news' broken insensitively; feeling unprepared/unsupported; no space or time in busy clinic; no 'take away' information	Hospital staff gave information on getting financial help	59/71	} Dimbleby Cancer Centre (DCC) information resource promoted by clerical & clinical staff; DCC information office access improved; Oncology outpatient and 'Lung Cancer Team' leaflets revised; 'Welcome video' identified for development	69/70	+ 11
	Hospital staff told patient they could get free prescriptions	81/80		83/82	No change
	Given clear written information about what should/should not do post-discharge	92/79		91/82	- 4%
	Family definitely given all information needed to help care at home	63/60		75/62	+ 10%
	Patient given written information about the type of cancer they had	71/61		73/62	+ 1%
	Patient felt they were told sensitively that they had cancer	80/81		82/82	+ 1%
	Patient completely understood the explanation of what was wrong	76/75		75/75	- 1%

* One service (lung cancer services at Trust 2) is excluded from the trust-level survey due to the small size of patient respondents (that also indicates the small size of this service).