PFCC – final report (4th June 2014)

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Summary

“PFCC has taught me the impact that a tight core team, meeting regularly with a clear purpose can have. When that purpose is rooted in improving patient experience, they become an indomitable force.”

(Hesham Abdalla – Consultant in Paediatrics, formerly of Walsall Manor hospital).

Patient and Family Centred Care (PFCC) is a patient-centred service improvement programme. The programme was jointly funded by the King’s Fund and the Health Foundation, and was delivered in partnership with fifteen teams in 11 NHS organisations across England and Wales, all of which operated acute healthcare services (though some also offered community services too) (Appendix 1).

The programme ran from January 2012 to November 2013. It followed on from a previous “prototype” programme, the Hospital Pathways Programme, which worked with 10 teams in 5 NHS acute trusts in 2010/11 (Appendix 2).

This report describes the goals of the programme, the extent to which they were achieved, and the key learning points gained from it. It draws together learning from the eight quarterly progress reports that were produced during the programme.

The key messages from this programme are that to achieve sustained improvement in patients’ experience requires

- Active leadership at the executive level, and strong project management leadership
- Medical leadership from clinical champions, alongside the engagement of the broader medical community
- An infrastructure to support the application of improvement methods
- Staff time to carry out improvement work
- A focus on the lived, direct experience of patients and families
- And ideally, patient and family involvement

Certain key contextual factors strongly influenced success. These included
• The external and political context in which organisations operated
• Local structural changes within the health economy
• Whether there was an organisational imperative behind the work
• Pressure and demands on the system
• Team stability, and
• Strong relationships inside the organisation.
Section 1 – Programme goals and objectives

The following goals and objectives for PFCC were agreed by the PFCC joint King’s Fund / Health Foundation governance group in January 2012.

Overall goals

1. Improve the capability and capacity of NHS organisations to deliver high quality patient (and family) centred care. Improvements will be at the level of the whole organisation and the clinical micro-system (participating team).
2. To provide participating organisations with generalisable learning about how to sustain and spread improvements within their own organisation.
3. Build on the synergies that exist between work in patients’ safety and patients’ experience and other quality improvement work, to enhance the effectiveness of both areas of work in participating organisations.
4. Improve the capability and capacity of NHS organisations to promote improvements in the experience of staff delivering care. Improvements will be at the level of the whole organisation and the clinical micro-system (participating team).
5. Promote patients’ experience as a high priority on the quality agenda alongside safety and clinical effectiveness in participating NHS organisations.
6. Contribute to improvement knowledge, in understanding which interventions work best, and under what circumstances, to improve patients’, families’ and staff experience.

Definition of patients’ experience used in this programme

Patients’ experience includes all aspects of the quality of care, as experienced by patients. The Institute of Medicine (IoM 2001) definition of quality provides a useful definition of quality namely care that is:

Patient-centred
Safe
Effective (therefore encapsulating clinical quality)
Timely
Efficient, and
Equitable.
The IoM further goes on to define the dimensions of patient-centred care as demonstrating all of the following attributes:

- Compassion, empathy and responsiveness to needs, values and expressed preferences
- Co-ordination and integration
- High quality information, communication and education
- Delivering physical comfort
- Providing emotional support, relieving fear and anxiety, and
- Involving family and friends.

This definition goes beyond single aspects of patient-centred care, such as dignity. It is distinct from concepts such as patient involvement in planning and delivery of services more broadly. It is broadly consistent with DH’s (2011) patient experience framework for England, which identifies the following elements which are critical to patients’ experience of NHS services: respect for patient-centred values, preferences, and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support; the involvement of family and friends; transition and continuity; and access to care.

**Section 2 – Programme overview**

The main components of the PFCC programme were

- To apply the University of Pittsburgh Innovation Center’s “PFCC method and practice” – the 6 steps
  - Identify a care experience
  - Form a guiding council to oversee the work
  - Evaluate the current state
  - Set up working groups to take the work forward
  - Develop a shared vision for an ideal experience
  - Identify and take forward the individual projects
• To develop a “driver diagram” (a structured logic chart) for the chosen care experience, in order to
  • identify factors that need to be affected to bring about change (aims) and associated measures
  • draw the links between the improvement initiatives already in place
  • identify current and future priorities for action

• For the PFCC teams to identify specific aims for the projects, supported by locally devised measures to enable them to monitor their own progress against performance.

• For teams to use accepted methodologies, such as the model for improvement to make improvements.

A key part of the methodology was for participants to select a care experience on which to focus their work. Care experiences were chosen for a variety of reasons including
  - Areas of national priority
  - Poor patients’ experience nationally
  - Organisational priority
  - They built on previous work within the organisation
  - A growing burden of disease
  - To build staff engagement in a particular area

Less satisfactorily, occasionally participants selected care experiences because of known problems such as poorly functioning teams or poor staff morale. Experiences that were chosen for negative reasons tended to struggle to engage staff in the work.

Teams were required to set clear aims and associated measures, and were given support to achieve this. Common aims set by teams were:
  - Consistency of clinical care
  - Efficiency, including discharge process
  - Improving communication
- Building staff confidence
- Improving staff experience

It is striking how little focus there is among these on the domains of patients’ experience defined earlier. This demonstrates how difficult it is for staff to view care through patients’ eyes, and their greater comfort with improvement in the sphere of clinical processes of care.

PFCC methods were taken up enthusiastically: especially the commitment to patient shadowing (other than for the end of life care experiences). However, not all of the requirements to establish a clear infrastructure for the work (regular meetings of Guiding Councils and working groups, for example) were reliably enacted.

The programme was delivered through a programme of learning events, webinars and a study visit, supported by written programme materials. The King’s Fund team visited each site at the beginning of the programme and the mid-way review point. The Programme team maintained monthly contact with each team’s key contact, and bi-monthly contact with the organisation’s PFCC Executive Sponsor. We intended this to maintain urgency for progress, identify struggling teams or issues that needed to be escalated, and provide coaching support to the teams. This aspect of the programme was the aspect most appreciated by programme participants (participant survey March 2013). In addition, the two clinical leads for the PFCC programme made efforts to engage regularly with the medical leads in each of the PFCC participant teams, in an effort to maintain medical engagement. These efforts were variable in their success.

Network learning events were evaluated to assess the extent to which they met participants’ needs. Key areas of focus of the first network event (November 2012) were: developing aims and measures, capturing patients’ experiences, and PFCC methods.

The second network learning event (February 2013) identified team building, team working and energising and engaging staff as key objectives.
The third event (May 2013) focused on speaking up in the interests of patients, and on practical problem solving for teams. A theme coming out of the feedback was teams’ appreciation of the opportunity to come together and re-group. One participant described the events as a “safe confessional” – a place to reflect on what was going badly, and an opportunity to “re-charge your batteries”.

The final event (November 2013) was run by the King’s Fund events team, as it had a dual role as a PFCC intervention and a King’s Fund conference. It is not possible to extract responses from participants who were part of PFCC. The following data give a sense of the overall evaluation of the event from the entire audience. However, 86% of participants said the event met their expectations (the rest were neutral), and 80% of participants described as “high” the opportunities the event offered to share good practice and innovation. Two thirds of participants rated highly the opportunity presented by the event to network with peers across the health spectrum. A key theme of the feedback related to the power of stories.

"The presentations that came from the heart of the presenters than just colourful power points. Specially Hiro Tanaka”

"The speakers were recalling genuine experiences. Personal stories are much more powerful than wishes”.

A small number of people commented negatively on the location of events and the cost and time to travel to London.

We asked teams to complete a number of assignments throughout the programme. These were:

- To design the “ideal” patient story
- To construct a “driver diagram” of their care experience
- To produce a suite of measures related to their aims and interventions
- To produce a short project summary for the Health Foundation website
- To give an account of how they were involving patients and carers in their improvement projects
- To complete a local evaluation of their work.
Each team had access to 5 days on-site support from the PFCC improvement faculty. Generally, faculty time was spent on the following aspects of the programme.

- Support with clarifying aims and measures
- Support with staff (particularly clinical) engagement / building resilience
- Engaging with staff to generate ideas for improvement.
- Help with particular improvement techniques, such as Experience Based Co-design
- Support with developing leadership action related to patients’ experience.

Teams largely appreciated the faculty support (100% of respondents to the March 2013 PFCC participant survey agreed that “Faculty had been helpful and supportive”) and the clear focus on aims and measures. However, there were occasional dissenters:

“I felt it was difficult to know how to use the 5 programme days as you need to get into the programme before you understand your needs. I also believe it’s difficult to balance between allowing people to develop and grow with the programme and the monitoring expectations that can become more of a stick than a carrot” (Team evaluation report)

The King’s Fund team and the Health Foundation team met quarterly to review progress. The agendas for those meetings were loosely based on the quarterly progress reports previously circulated.

In addition, the team developed a masterclass for executive sponsors, designed in collaboration with them. This was well attended and well received.
Section 3 – Summary of projects undertaken by participants

Figure 1 shows the location of the participant teams

Table 1 shows the range of care experiences selected by the teams

<table>
<thead>
<tr>
<th>Adults</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>• End of life care</td>
<td>• Care of children attending ED with asthma</td>
</tr>
<tr>
<td>• Care of people with COPD</td>
<td>• Care of children attending ED with acute abdominal pain</td>
</tr>
<tr>
<td>• Care of frail older people attending ED</td>
<td>• Assessment of children with Duchenne Muscular Dystrophy</td>
</tr>
<tr>
<td>• Care of people with dementia</td>
<td>• Assessment of children with complex gastro-intestinal diagnoses</td>
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<tr>
<td>• Care of people with stroke</td>
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<tr>
<td>• Care of people with foot complications of diabetes</td>
<td></td>
</tr>
<tr>
<td>• Care of people with hip fracture</td>
<td></td>
</tr>
<tr>
<td>• Care of people attending ED with acute chest pain</td>
<td></td>
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</tbody>
</table>

Teams produced project summaries for inclusion in the Health Foundation website in December 2012. We invited all participating teams to produce posters for an exhibition at the Transforming Patients’ Experience conference at the King’s Fund on 6th November 2013. (http://www.kingsfund.org.uk/events/transforming-patient-experience)
Section 4 – Techniques used by teams to capture patients’ experiences

The principal mechanism used in PFCC to capture patients’ experiences is patient shadowing. We also supported teams to listen to patients’ and carers’ stories. Although we encouraged teams to collect quantitative data on patients’ experiences as a means of assessing their progress toward PFCC objectives, this was not the predominant mechanism to capture patients’ experience.

There was some scepticism about patient shadowing at the outset. However, the majority of the teams did carry it out, and it was often transformational for the staff involved. Staff found it difficult to do initially. One consultant said “Focusing on the patient is difficult because it makes you confront things you don’t necessarily want to face.”

“It was clear from one experience of shadowing patients that the whole experience could have been much better if someone had sat down for 5 minutes to describe the key events over the next 24 hours.” (Team evaluation report)

“Taking patient stories was an opportunity for parents (in this instance) to describe their experience in their own words and for us it brought the experience to life. Unlike the questionnaire where we identified what we would like feedback on, the parent focused on what was important to them and raised issues that we had not considered.” (Team evaluation report)

In some cases, most notably for end of life care, teams felt that shadowing was not appropriate. In those cases teams listened to patient and family stories, staff’s account of care experiences, and a review of complaints and compliments. One Trust ran a series of “see it my way” events, as a way of engaging staff with the experiences of patients and families.

Teams found it enlightening to discover that what they thought of as priorities for improvement, were not necessarily the things that most concerned the patients.
"Respondents were generally happy with the waiting time for admission from the decision to admit; this is an area where we assumed there would be dissatisfaction." (Team evaluation report)

Two consultants in one team described how the work to hear patients’ stories has really helped them. They told a couple of stories:

- A child with a long-term condition had told them she worried about the costs to their family of the meals in the café etc. when she was in hospital.
- Parents who said they had felt judged by the nurses when they had not been able to visit the child as much as the nurses thought they should.

The feedback they had found especially useful was from staff who used the services: they had been shaken when one staff member said “I expected more”, and another had observed his family had a better experience in India than here.

We asked PFCC participants for their reflections on patient shadowing, both in terms of the value of the process and what they found out by carrying it out. Here is a selection of their responses:

"Patient shadowing, patient stories and other ways of describing patient experience allow staff to examine patient care using a lens with a different focus from other measures of quality of care. The different lenses we use to examine our service allows us to build a comprehensive picture of the care we provide”
John Alexander
Consultant Paediatrician, University Hospital of North Staffordshire

"We continue to champion shadowing at George Eliot Hospital. In fact it was one of my pledges for NHS Change Day. You can see the outcome in my Change Day Video - [http://www.wenurses.com/blog/GEHwifi.php](http://www.wenurses.com/blog/GEHwifi.php)
Patient shadowing is a simple, powerful technique to learn a valuable perspective about your service. It overcomes assumptions and is the first step towards co-producing a better experience for staff and users. Highly recommended!“
Sebastian Yuen
Consultant Paediatrician George Eliot Hospital, formerly Walsall Manor Hospital

"I felt the shadowing was very powerful to do, it made me see things that were always in front of me that on a day to day shift you do not notice until you try to take a step back and see the environment/journey through the patients’ eyes, it was quite humbling really to sit and listen, observe and follow the journey through our department as it opened my eyes to the simple things that are easily remedied to make the journey more streamlined and comfortable whilst in our care. I quickly realised it’s not the big things that as health care providers we need to look at, it’s the small things that can make such a big difference.”
Emma Hughes
Senior Sister / Practice Development Sister, paediatric assessment unit, Walsall Manor Hospital

"When I first heard about shadowing I felt somewhat cynical about it - how could following someone around their care experience possibly help? How wrong could I have been. It is actually one of the most powerful tools that we have at our fingertips and yet the most simple. It helps us to see healthcare through the eyes of the patient, shows us what is important to patients i.e. what are the ‘touchpoints’, but it also, maybe more importantly, grounds us, reminds us of the real purpose of our work and re-boots our jobs. I am on a mission to build it into everything that we do!"
Anna Tee – Patient Experience Manager, Hywel Dda Health Board

“The most I got out of it was to sit by a scared mum, she didn’t know she could ask questions or speak up for herself. It was emotional, I’m a mother, I’ve got two sons. Some of these mums couldn’t speak much English, no-one was giving them much information.”
Annette Killops, Administrative Assistant, Walsall Manor Hospital

“When we started seeing things from patients’ eyes it completely changed the approach we took. My experience has stayed with me very powerfully ever since. It was a mother of a child with asthma. The mother said "the nurses look really busy and I don’t want to disturb them”. She was reluctant to pull the alarm cord."
"It changed the approach to safety on my ward, all triggered by me sharing the experience of care with a patient”

Hesham Abdalla, Consultant Paediatrician, George Eliot Hospital, formerly Walsall Manor Hospital

It is true to say that for some teams, engagement with patients took time to become established. Although (almost 6 months after the first learning event) three quarters of respondents to the March 2013 participant survey agreed that they had a good understanding of what care was like for patients, half felt there was still more work to do, and more than a third felt there was still more work to do to form a shared understanding of what the ideal patients’ experience might be.

Section 5 - Techniques used to engage staff in the improvement programme

Staff engagement was a continual challenge during the programme. As the programme progressed, it became more common to hear from staff that their resources were stretched, and they didn’t have time to do service improvement work. However others reported taking some refuge in PFCC, a way of focusing on their core purpose.

“All members of the team found it difficult to manage the project alongside their day to day duties, particularly when having to also address operational issues that affected the basic running of the service such as a lack of staff, staff capability. Changing processes and roles on top of already identified issues was challenging and at times overwhelming” (Team evaluation report)

The main mechanisms used to engage with staff were:

- Patient shadowing which was energising for staff
- Learning events and visits were intended to create buzz and energy
- Faculty support was also geared toward engaging staff in the work. Three approaches were particularly well received:
• Snorkel events – interactive, fun events intended to engage the broader staff team in the process of generating ideas for improvement
• Staff resilience events – reflective events intended to support staff to develop resilience and reflective practice.
• An all day workshop “Speaking up in the interests of patients”, which was the most highly rated of all programme events.

All 27 respondents to the December 2013 participant survey, when asked whether they “have greater confidence in methods to improve patients’ experience as a result of PFCC” agreed or strongly agreed that they did, with half of all respondents spontaneously mentioning shadowing patients in real time and talking them through their experience as the main mechanism for this. Other ways in which staff mentioned feeling supported was in “setting aims and measures”, and “small repeated changes and measurement rather than a large single project.”

Building team engagement was a principal aim of network learning events. Feedback from those events suggest that they were successful in achieving this, and there was an appetite for even greater opportunities for coming together as a team.

Part of the challenge of staff engagement was the time teams had to meet: the March 2013 participant survey showed some concerns in this area, with a third of respondents who did not agree that their working group met often enough.

Local context was extremely important in determining staff engagement. In some places, there was suspicion of service improvement work (which had been seen in the past as “cost cutting”). One team told us that “when staff feel that change is for the benefit of patients and for themselves they really cooperate”.

Section 6 - Interventions that were used to bring about improvement

As already mentioned, shadowing and patients’ and staff stories were the key impetus behind improvement. Examples of specific initiatives that were used to bring about improvement broadly fell into the following categories:
Transactional – changes in processes of care

- Improvements in the processes of care, designed to improve the consistency and quality of clinical care. Examples include care bundles, checklists, improved identification and assessment of patients
- Improvements in documentation, information and communication, either for clinical staff or for patients, to improve the quality and consistency of clinical care
- Changes in the system of care (e.g., introduction of protected beds on a surgical decision unit, to enable rapid access to surgical opinion for a group of patients who historically have had long waits in the A&E department)

Relational – changes in interpersonal aspects of care

- Changes to clinician patient interactions – these are difficult to evidence, but we were told of consultants reporting “changing the questions they ask” in consultations following shadowing, to focus more on what the patients’ wanted to achieve through their care.
- Changes to care processes with the explicit aim of empowering families to ensure ideal care is delivered
- Follow up calls to bereaved families or families who had recently had a hospital stay
- Staff resilience workshops
- Building relationships with GPs to discuss end of life care for their patients who were currently in hospital
- Building staff awareness of the needs of people with dementia by supporting the training of Dementia Friends.

Transactional and relational

- Improving access to advice and support for relatives – for example via relatives’ clinics, changed visiting times.
- Improvements in staff skills via training
- Environmental improvements, for example the environment for eating, activities on the ward, involvement of volunteers.
- Improving team-working – for example via ward huddles to identify patients who might benefit from end of life care discussions
The forming of a network of participating teams was mentioned as a key to teams’ achieving improvement, both in terms of sharing practical improvement ideas, as well as forming supportive relationships both within participating organisations, and with colleagues from other organisations. One survey respondent said “Taking part in this project has brought the team together”

“Making contacts with other organisations is really important - we are all so very busy trying to manage the day job and we all need to remember to stick our heads up now and again, see what other people are doing, learn from each other and continually ask ourselves how would the patient and family feel in this situation?” (Participant survey March 2013)

Section 7 - The influence of context on the effectiveness of interventions

It is difficult to generalise about context, since different contexts exist at different levels in organisations – at the level of the team, the organisation, within the local health economy and nationally. We identified the following contextual factors that were influential in PFCC.

Positive influences

- Where there was an organisational imperative to take action. An example of this was the publication of the Francis report which made organisations’ responsive to work on quality and patients’ experience
- Where there was a national imperative to work in a particular clinical area, either because of perceived quality issues, or a policy priority
- The importance of a link with credible and independent national organisations (ie The King’s Fund and The Health Foundation) enhanced the commitment to this work
- Where care experiences chosen for this work were already an organisational priority. This meant governance structures and senior
leadership attention already existed and there was a natural “home” for this work

- Where involved, carer and user groups appreciated hearing the conversations about quality that were going on - it really mattered to people to hear how concerned staff were to improve quality. This galvanised the staff
- Although it can be divisive when a care experience straddles separate organisations, a by-product of the PFCC work can be to enhance the engagement between acute and community based staff.

**Negative influences**

- Some teams described their organisation’s agenda being dominated by external concerns (eg CQC, press stories) and this was felt to have a negative impact on their capacity to focus on this programme
- Major changes in staffing at the most senior levels in organisation had an adverse effect on the context for improvement
- Local politics within the healthcare system had a negative impact, particularly when the programme was erroneously identified as the solution much broader issues within the local system. This is linked to the key importance of being clear about the scope of the programme
- At times, the pursuit of Foundation Trust status (or other structural changes within the local system) was described as creating difficulty in maintaining focus on PFCC
- Staff morale / trust in the Board was instrumental in achieving staff engagement in the programme and if it was lacking was a negative contextual factor
- Where relationships between senior managers and senior clinical staff were strained, this impacted on the PFCC effort
- Many of the teams described very heavy winter pressures during the winter of 2012, and increasingly the financial squeeze impacting on their capacity to take time out of direct clinical work to participate in PFCC. Linked to this was perceived staffing levels in some settings (although PFCC did not collect data on this)
• Probably the most influential positive or negative contextual factor was the quality of team-working
• PFCC worked best for teams that already existed and saw themselves (and operate) as a team. Newly established teams could be fragile, and occurrences of ill health or personal issues in one of two key individuals could easily knock things off track.

Section 8 – Did the programme achieve its goals?

We have used the following approaches to assessing the extent to which the programme achieved its goals:
• Programme manager assessment based on routine calls and visits with teams, data returns and programme assignments
• Local evaluations carried out by participant teams
• Two surveys of programme participants
• Evaluation of learning events

Goal 1 - Improve the capability and capacity of NHS organisations to deliver high quality patient (and family) centred care. Improvements will be at the level of the whole organisation and the clinical micro-system (participating team).

Goal 2 – Provide participating organisations with generalisable learning about how to sustain and spread improvements within their own organisation.

Goal 3 - Build on the synergies that exist between work in patients’ safety and patients’ experience and other quality improvement work, to enhance the effectiveness of both areas of work in participating organisations.

Outcome - PFCC supports the development leadership capability and team capability regarding patients’ experience. Achievements are scalable and spreadable
Indicators - PFCC generates persuasive case examples showing how participating organisations:

- demonstrate **organisational** commitment to delivering high quality patients’ experience which is integral to the organisation’s quality strategy
- have practical plans in place to sustaining and spreading the programme’s approach to clinical areas beyond the original remit of the programme.

**Commentary**

Participants described practical plans for sustaining and spreading PFCC. In the December 2013 participant survey, 23 out of 29 respondents agreed or strongly agreed that there were practical plans in place. Examples of these included

“To ensure the principles of PFCC are always at the heart of service design and decision-making and to actively seek out best PFCC Practice”

“Patient shadowing ” and “continuing to involve patients, families and their carers”

“To continue to measure our performance and feedback to staff”

5 of the 11 organisations made significant progress in their approach to patient centred care at the level of the **organisation**. Teams’ local evaluation reports supported this assessment, in that there were examples that the PFCC work had resulted in a change in mindset (or continuation of a mindset that was already strongly committed to patient-centred care) toward patients’ experience in 5 of the 11 organisations. Examples of this progress are described below.

**Alder Hey** – who are considering using the PFCC approach to underpin their work across the trust, as they move into their new hospital. They also demonstrated clear improvements in the experience of children attending A&E with abdominal pain – in terms of speed and organisation of the pathway, pain management and length of stay.
RUH Bath – were already strong, with their Qulturum as the quality improvement resource within the trust, the PFCC programme has strengthened the focus on patient and staff experience.

Aneurin Bevan Health Board – where the organisation has attempted to utilise the PFCC methodology more broadly, forming their own separate relationship and educational intervention with the PFCC team at UPMC in Pittsburgh.

UH North Staffordshire - have used the learning from PFCC to establish a formalised “improvement faculty” within the trust, to continue to support improvement work across the trust. They have expressed the wish to continue to utilise the PFCC methodology for new clinical areas.

Hywel Dda – although slow to make progress on PFCC, have now recognised the need to locate work on patients’ experience within their governance structure, via new “population health groups” each with a clinical chair. This, along with reorganising services along clinical (rather than geographical) lines is intended to increase clinical engagement with quality improvement. The Board is also considering developing a “virtual improvement academy” to support quality improvement.

Ipswich –The work of the PFCC end of life team has now become absorbed into the trust’s proper governance arrangements (reporting to the Director of Nursing). The local evaluation report was submitted to the Trust Board with the commitment to ensure Trust wide learning from the programme, via trust wide work on culture and values to promote patient centred care.

5 of the 11 organisations have made progress in their approach to patient centred care at the level of the care experience and have practical plans in place to sustaining and spreading the programme’s approach to clinical areas beyond the original remit of the programme. Of the 14 local evaluation reports received, improvements in care are apparent in 10, and are likely in a further 2. It is more difficult to systematically assess the direct impact on patients, due to small numbers and limited data sets. However, 7 local evaluation
reports could illustrate impact on patients, and for a further four teams, benefit seemed likely. Examples include:

**Alder Hey** - improvements include improved pain management, and a speedier process of care, with fewer waits and reduced length of stay.

**Walsall** - have already begun to use the PFCC approach with different care experiences within paediatrics. One consultant who has moved to another trust, has already requested the PFCC materials, in order to begin patient shadowing in his new trust. During PFCC they achieved greater reliability of care for children attending with asthma, improved staff confidence, and improved confidence among families.

**Northern Devon** - achieved demonstrable improvements in the care of people with dementia, across an integrated care pathway. They are intending to continue the work once the programme comes to an end, increasing the reach of the dementia work to far greater numbers of staff across the trust, both in the acute and community settings.

**Great Ormond Street Hospital** - some of the staff involved in PFCC have expressed an interest with continuing to use the methodology for other clinics. They made tangible improvements in the experience of families which included changes in clinic organisation to smooth the process, better communication with families (eg texting when results available); improved privacy. Families and staff reported improved clinic organisation, and families reported better care planning. They have plans to continue with family focus groups to sustain improvement.

**RUH Bath** - the end of life team focussed their work on one particular ward. It is clear that this has impacted most on the medical staff, with greater willingness and confidence to discuss end of life issues. There were specific improvements in care planning and communication with families. The trust recognises this work as changing culture, and intends to continue with this work beyond the single ward focus. They have renamed the work "The
“conversation project” and are taking it forward to 5 other wards in the hospital.
End of life care is included in the trust’s quality account and is also a CQUIN.

Two trusts failed to fully complete the programme, in part due to major staffing changes during the time of the programme. Nevertheless they demonstrated positive changes in the quality of care. For example one team, as a result of patient shadowing, improved ward environments, extended visiting hours, established a relatives’ clinic run by a senior nurse to enable relatives to ask questions easily, increased dementia training, and piloted in-reach geriatric assessment in A&E. A second team introduced named doctors allocated to each bay in A&E, clearer staff identification badges, improved pain management, and use of volunteers in the department to support patients. In addition they instituted an ongoing programme of training to build staff confidence in adhering to the clinical protocol for the care experience.

Goal 4- Improve the capability and capacity of NHS organisations to promote improvements in the experience of staff delivering care. Improvements will be at the level of the whole organisation and the clinical micro-system (participating team).

Outcome - PFCC achieves increased priority given to staff experience in participating organisations

Indicators

- PFCC generates persuasive case examples showing how participating organisations are paying active attention to staff experience.

- At least 50% of participating teams can demonstrate evidence of regular monitoring of team function, using an approved survey instrument and action stemming from the results. Examples of appropriate survey instruments include the Healthcare team vitality survey instrument and HSE stress risk assessment tool.

Commentary
"The key message I would like to give is that this connection between staff and patient experience can be positively used to change the way that care is given. I would quote the example of the way that one of our community matrons has changed her practice following her experiences on the project. This allows her to work more collaboratively with the acute hospital teams to ensure that individualised/personalised care is given to patients. In this instance the patient in question had a better planned and remarkably shorter length of stay than would otherwise have been the case."

Andrew Burgess – Divisional General Manager, Northern Devon Healthcare NHS Trust

PFCC did not achieve the metric above, although it did achieve an increase in attention paid to staff experience in participating organisations. In our final survey of PFCC participants in December 2013, 26 out of 27 respondents agreed or strongly agreed that “we paid attention to staff experience as part of this work”.

Particular benefits of this mentioned by respondents included
- Encouraging staff to challenge practice and to seek out best practice from other organisations
- Staff feeling listened to and their ideas and opinions being acted upon
- Recognition of the link between patients and staff experience
- Psychosocial support and staff feeling valued
- Giving staff legitimate time and head space to think differently about what they do
- Building teams and staff engagement
- Building resilience and time for reflection.

There was a common theme throughout the feedback from participants which related to the programme’s role in bringing teams together. The network learning event in February 2013 particularly focused on teams and team work, and this was built on with a webinar in May 2013.
Of the 11 participating organisations, 9 took up the offer of faculty support specifically dedicated to staff experience and resilience. At least 4 of the 11 organisations specifically mentioned plans to continue with the work on staff experience, reflective practice and resilience.

The interventions that took place in participating organisations particularly focused on staff confidence, both in aspects of clinical management, and in communicating difficult news with patients and families. In one trust there was already a focus on building staff empathy (via “See it my way” events), and at two others, relating to building reflective practice. The patient shadowing that was part of PFCC was described as having a major impact on staff’s empathy.

**Goal 5 – Promote patients’ experience as a high priority on the quality agenda alongside safety and clinical effectiveness in participating NHS organisations.**

**Outcome** - PFCC delivers benefit to patients’ experiences in participating organisations

**Indicators**

- 75% of surveyed programme participants in PFCC report greater knowledge of and confidence in use of methods to improve patients’ experience.
- Participating teams can show demonstrable improvements in patients’ experience in the clinical areas included in the programme.

**Commentary**

Although the small number of participants mean the data must be treated with caution, the end of programme survey suggests that programme participants are strongly of the view that this was achieved, with 26 out of 27 respondents agreeing or strongly agreeing that PFCC had a beneficial impact on patients and families, and all respondents reporting greater confidence in their capacity to improve patients’ experience.
Particular benefits that respondents mentioned were:

- "We have listened to what is important in the care experience for patients and making changes based on this information."
- Viewing care from the patients’ perspective and seeing that often it’s the small things that make the difference.

Every participating organisation could demonstrate some improvements in care (this included processes of care, clinical care, and the organisation of care). Around half of the teams could track this through to an impact on patients’ or families’ experiences. For those that could not, this was for a variety of reasons including: the number of patients being too small to be generalizable; patients lacking capacity to communicate experiences directly; and patients and families perceived as being too vulnerable to be asked.

**Goal 6 – Contribute to improvement knowledge, in understanding which interventions work best, and under what circumstances, to improve patients’, families’ and staff experience.**

**Outcome** - PFCC delivers Quality Improvement tools which sharpen the focus on patients’ experience and disseminates them widely. PFCC captures data including the context within which improvement initiatives are likely to be successful.

**Indicators**
- PFCC generates effective quality improvement tools, and disseminates them in a way which maximises the likelihood of them having an impact on patients’ and families’ experience of care.
- PFCC draws on evidence of effective improvement tools from the sphere of safety, and translates these so they can be used more widely to promote improvements in patients’ experience.
- PFCC generates inspiring case examples and material for conference presentations and journal articles, which contributes to, for example the learning about the impact of context on service improvement.
Commentary

The November 2012 learning event focused particularly on sharing the programme methodology and building an understanding of PFCC methods among participants. The event was successful in meeting this aim (with ratings averaging >8 out of 10 in meeting participants aims).

Several PFCC teams gave either keynote or breakout presentations at the King’s Fund’s “6th Transforming Patients’ Experience Annual Conference” in November 2013 which contributed to PFCC’s goal to produce inspiring case studies. The keynote presentation by Hiro Tanaka of Aneurin Bevan Health Board was subsequently one of the most downloaded items.


The keynote presentation by Julie Grice and Joanne Minford from Alder Hey hospital was written up and published in the BMJ.

Patients’ actual care pathways often differ markedly from ... - BMJ.com (www.bmj.com/content/347/bmj.f6728)

Nine of the 11 participating organisations described taking steps to use the PFCC methodology more widely inside their organisations.

Bev Fitzsimons presented the programme methods and findings to the IHI International Forum in Paris in April 2014 in a joint session with Tony Di Gioia from the Innovation Center at the University of Pittsburgh Medical Center, and has been invited to be a keynote speaker at the UPMC Vision Quest event in Pittsburgh in October 2014. The King’s Fund team continues to build and maintain strong relationships with UPMC, to support continued dissemination of this work via contributing case studies (via video) to UPMC events, newsletters and website.

The King’s Fund and the Health Foundation has created an online toolkit in to describe the PFCC methodology and make it available more widely (available at
http://www.kingsfund.org.uk/projects/pfcc). As part of this, a PFCC “Linked-in” group has been established.

**What were the key drivers in achieving results?**

- Executive sponsorship and organisational attention
- The engagement of doctors
- Support for and encouragement of the team (including the focus on staff experience) and team-working within the organisation
- Support, contact and coaching from the PFCC programme
- Help with refining goals, and coaching to improve confidence and competence at measurement
- Focus on driver diagrams, aims and measures
- Significant and unwavering emphasis on the importance of patient shadowing and understanding patients’ lived experiences
- Strong intervention when teams struggle to sustain progress
- Feedback on data and its usefulness for the team
- Persistent efforts to maintain engagement of participating teams through regular contact

**Barriers to success**

The main barriers to success were

- Scope that was too wide or unrealistic
- Where there was a lack of skill in measurement, or a lack of attention to data. Associated with this was a risk to success when teams felt that data were being used to performance manage them, rather than to support them in achieving their own aims
- Measures chosen not relating closely enough to the interventions being trialled
- If leaders didn’t pay sufficiently active attention to the work
- If Boards didn’t act on the results of the work
- If team members didn’t have time to do the work
- If the team didn’t act as a team with common goals and commitment
• If participants believed they already knew what patients were experiencing, and didn’t need to do further work on this
• Patient shadowing was not undertaken by leaders of the work, or was not taken seriously
Section 9 - Learning from the programme

Lessons for NHS organisations participating in improvement programmes

The main lessons for participating organisations related to how teams were established and staff were engaged in the work; arriving at an appropriate scope for the work, clearly distinguishable from (yet connected to) other work taking place inside the organisation; the value of shadowing and coming to understand patients’ experiences; and the importance of developing a vision of the work’s place in the organisation’s way of working, rather than it being seen as a time limited improvement project.

- Teams struggled to identify a manageable scope for quality improvement work, and all teams benefited from support with this
- Effort is required to maintain appropriate focus and avoid “mission creep”
- PFCC was successful in engaging staff in service improvement, and yielded demonstrable improvements in processes of care
- PFCC is popular with staff and there is a high level of commitment, with positive knock on effects on the quality of team working (especially among established, specialist teams)
- Sometimes the PFCC work can be poorly connected to other quality initiatives / patient experience initiatives in the organisation
- It is difficult to disentangle impact of PFCC work as distinct from general quality improvement work that the trust would be doing anyway
- Patient shadowing often generates fear but is revelatory once this is overcome. However, it is important that this is done by senior staff too - junior staff can sometimes aim to please their colleagues in their accounts of patients’ experience.
- The most tangible and distinct change that can be directly attributed to PFCC is the change in attitude and mindset that accompanies placing the focus on patients - described by senior clinicians at one review as “profound work”
- The programme is most successful where it is seen as a way of working rather than just a project
The most successful teams have thought about the future application of the learning from PFCC, and regarded it as capacity building for quality improvement.

**Lessons for external organisations running improvement programmes**

The main lessons for those running programmes such as PFCC related to clarifying goals and ownership of the programme; clearly targeting support towards programme goals; the importance of maintaining communication with both senior leaders and team members; and striking a balance between what is delivered centrally and locally.

- Some use of faculty time was poorly connected to teams’ PFCC goals. Interventions about aims and measures were most likely to be clearly connected to the PFCC goals.
- There is still a sense that some teams carried out tasks as part of PFCC because they had to, rather than because they could see how these would help them achieve their improvement goals. This related to ownership of the programme, which in less successful teams, was seen as external to the organisation, rather than owned by the team. Teams required significant support to enable them to track the improvements through to their impact on patients’ and families experiences.
- Levels of competence and confidence in measurement for improvement were low, and teams required significant support in this area.
- There is a dissonance between what senior leaders say about progress on PFCC and the challenges for front line staff delivering the work on the ground.
- A careful balance needs to be struck between off-site events (such as those held at the King’s Fund, and on-site support. Off-site events provide staff with a welcome respite from their day to day work, and the opportunity to build team relationships (especially on the journey); however people mentioned that cost and time were an issue. On-site support enables more people to be engaged with the programme, but teams found it difficult to schedule these events, and difficult for the team to maintain focus when there were pressing local concerns.
The draw of working with national (“independent” “credible”) organisations is a key impetus for participation - PFCC was seen as a way of providing local communities with reassurance that NHS organisations take the quality of care seriously, and a way of making staff internally “sit up and take notice”

How did teams form and work together?

- There was plenty of enthusiasm and good will for this work. However, medical engagement was variable. In some cases front line staff were insufficiently involved in direct improvements, with the programme focusing too strongly on a small team.
- Teams found it very difficult to make the time to meet, and a key benefit of programme events was the opportunity for teams to spend time together and reflect on their work.
- Some teams over-relied on one person, not always at the right level to exert the necessary influence
- Having different individuals “dipping in and out” of the programme made it difficult to achieve learning that built over the course of the programme. Named team members and a commitment for the same attendees at all learning events and review meetings would help
- Teams were not particularly stable, which impacted on the programme’s capacity to build knowledge and skills. For future programmes the following options could be considered:
  - Emphasise during recruitment the need for participating organisations to field as stable a team as possible
  - Recruit individuals to the programme who will then work as a team

How were clinicians engaged?

There was strong emphasis on the engagement of clinical leaders during the recruitment phase of PFCC. In addition, we set a clear brief for the medical leaders of the PFCC faculty to build relationships and establish contact with doctors in PFCC participant teams. This meant medical engagement was demonstrably stronger in PFCC than in the prior prototype programme. This was
evidenced by the number of doctors attending learning events and presenting the work. Doctor to doctor contact was key to this. Teams’ local evaluation reports and our own assessments suggest that clinical engagement was fair to good in 9 of the 15 participating teams.

How were the public/communities/patients engaged?

We asked teams to carry out an assignment to describe how they were involving patients and communities in their PFCC work. This included how the local community was engaged; how the team went about understanding patients’ experiences; whether and how they used patients as a source of data; whether and how patients or carers were involved in PFCC projects and what examples there were of patients’ involvement having an impact on the work. Examples of the work to involve patients and carers included engagement with local voluntary organisations; teams attending memory cafes to engage with service users with dementia and their carers; PALS engagement as part of the programme team; local focus groups; and trusts’ publicity about the programme locally.

Teams didn’t always find patient and family engagement easy.

"We felt that we wanted to first gain an understanding of the pathway before inviting patients/ carers onto the project. We were apprehensive about how we would take this forward rather than the impact of their involvement. One team member recalled her previous experience leading a project where there was a parent rep that was quite difficult to manage. One parent did express an interest in being directly involved; however this parent was well known to the medical team having had a long history with the service and was found to be extremely negative. Following discussion we felt that this particular parent’s input would have a negative impact on the project.” (Team evaluation report)
Engagement of senior management in participating organisations

Support for Executive sponsorship was strengthened in PFCC. There was a successful teleconference with 9 Exec sponsors in January 2013, and an Executive Sponsors’ masterclass in May 2013. This was rated highly and well attended, which suggests that a tailored programme for executive sponsors would be worthwhile. We also offered executive sponsors a bursary place to attend the King’s Fund annual leadership summit (“Leadership post-Francis”) in May 2013 as a means of strengthening executive sponsor engagement. Seven of the 9 Executive Sponsors incumbent at the time accepted this invitation.

A small number of teams continued to demonstrate weaker executive sponsorship throughout the programme, mostly due to staffing changes. “Replacement” executive sponsors tended not to have as strong a focus on the programme as those who were involved from the start, and who had been instrumental in applying to be part of the programme in the first place.

Plans for Chief Executives dinners as part of the programme were shelved due to low level of uptake.

Active senior commitment to the programme declined over the course of the programme. It was difficult to sustain executive sponsor engagement, and for future programmes executive to executive contact (similar to the approach we took with doctors) and a tailored approach to executives may be worthwhile. Four of the 11 Executive Sponsors changed during the course of the programme. One team member said:

"I became very disillusioned with the Trust senior management with respect to their involvement in the scheme” (Participant survey respondent)

Local evaluations suggested that in some cases there was a gap between what senior leaders perceived to be happening within PFCC, and the perception of front line staff.
If this programme were to be run again what should be done differently and why?

- The programme should be shorter - to avoid drift and the summer period when it is difficult to maintain focus
- Only a single care experience in each organisation should be selected (or themed approach - with all teams working on a common experience) to allow more specific and targeted support
- For teams that are not already established, some focused team building activity should be carried out ahead of the programme
- Team members should be fixed (as far as possible) so learning is built upon
- Even more evidence of organisational / senior commitment should be required
- Regional events should be considered, to enable more team members from each place to attend and reduce the time and cost of attending.
- The learning events should be focused more as “training the trainers” with the expectation that participants themselves teach the course material back at base.

Programme participants were also asked to make suggestions about how PFCC could be improved (participant survey March 2013). Most respondents were happy with the programme and had no suggestions to make. The small number of suggestions made included more programme materials to be supplied, more information about the methods, greater numbers of places at learning events, more practical examples, more time at learning events to work as a team, and a preference for a more directive approach.

Section 10 - Key messages for external audiences

- Getting inside patients’ shoes was transformative for staff
- Senior leadership and medical leadership were essential components of success
• Good management of improvement work was integral to its success. This meant teams must work as teams, with a commitment to a common goal, and with an infrastructure to support the work
• Participants in improvement work must have time to do the work if it is to be successful. It will not be successful if it is merely “added on” to the current job.
• The best chance of making this happen is when an improvement technique is adopted as an organisation’s “way of doing business”.
• The demands on individual staff to take forward improvement work can be lessened by having a broad inclusive approach, which actively encourages involvement from a wide variety of staff.
• Investment in skills in improvement can yield dividends - but must be connected to meaningful activity within the organisation
• Skills in measurement, collection and interpretation of data are essential - but work is needed to help teams to understand data’s usefulness to their core business, rather than for accountability purposes
• Teams that exist as teams are more successful than teams that come together only for the purpose of a service improvement project
• For the benefits of this work to endure, it needs to be integral to the business of the organisation - not a project, and it needs to become the expected way of working, on an ongoing basis

Section 11 – Future plans

In terms of future plans of participant teams, local evaluation reports suggest that 2 of the teams intended to use the approach more broadly as their organisation’s way of doing things; 5 intended to continue with their current PFCC work; 1 intended to transfer the approach to a new organisation; 2 intended to apply the approach to new care experiences. For three teams, the work had simply been noted, or their evaluation report did not propose any specific future plans for PFCC.

In June 2014, the team produced a web-based toolkit of available PFCC resources, to support teams who wish to apply the methodology. Additional
future work on PFCC is likely to be taken forward by the Point of Care Foundation.

Appendices

Appendix 1 – PFCC participating organisations (2012/13)

Alder Hey Children’s NHS Foundation Trust
Aneurin Bevan Local Health board
Barnsley Hospital NHS Foundation Trust
Great Ormond Street Hospital NHS Foundation Trust
Hywel Dda Local Health board
Ipswich Hospital NHS Trust
Northern Devon Healthcare NHS Trust
Royal United Hospital Bath NHS Trust
University Hospital of North Staffordshire NHS Trust
Walsall Healthcare NHS Trust
West Middlesex University Hospital NHS Trust

Appendix 2 – Organisations participating in the prototype “hospital pathways programme” (2010/11)

George Eliot Hospital NHS Trust
Northumbria Healthcare NHS Foundation Trust
Royal Free London NHS Foundation Trust
Salisbury NHS Foundation Trust
Taunton and Somerset NHS Foundation Trust

Appendix 3 – PFCC participant surveys (March and December 2013)

PFCC participant survey 1 (N = 43) (reported March 2013) – all individuals on the PFCC team contacts list were surveyed to assess their views of
- Usefulness of faculty support
- Clarity of aims
- Levels of activity of steering group and working groups
- Clarity of future plans
- Progress on seeing care through patients’ eyes
- Clarity of aims and measures

**Participant survey 2 (N=27) (December 2013)**

The sample consisted of individuals who had attended at least 2 PFCC learning events, so that they would be expected to have more than a passing awareness of the PFCC method and approach. Once ineligible addresses were removed the sample was 49. We received 27 responses (55%). We received at least one response from every participating organisation. Of the respondents, 4 were executive sponsors, 5 were senior medical or surgical consultants, 5 were senior nurses, the rest were patient experience, middle management or administrative staff.

The survey asked

- Whether PFCC had a beneficial impact on patients and families (and if so what)
- Whether there were practical plans in place to sustain and spread the PFCC method (and if so what)
- Whether the team paid attention to staff experience as part of the programme (and if so what were the benefits)
- Whether the individual had increased knowledge and confidence in methods to improve patients’ experience and which ones were most helpful
- Free text – any other comments about PFCC
- Whether the individual would like to remain in touch with a PFCC network.

**References**
