Person-Centred Paediatric Care: Capturing the Experience and Collaborating for the Future
A Patients First Project for NHS Borders supported by the Foundation of Nursing Studies and the Burdett Trust for Nursing

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Duration of project: November 2014 - June 2016
Report submitted: March 2017

Keywords
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Acknowledgements
We would like to thank the paediatric team involved in the implementation of this project and the on-going work in the Borders General Hospital, Jo Odell (FoNS), and the Burdett Trust for the funding that has supported this work.

Summary

Aim: This project describes a multi-disciplinary practice development initiative supporting a clinical team to ‘hear’ the voices of children, young people and their families so that person-centred paediatric care might become a sustainable reality.

Background: Person-centred care (PCC) is now a well-recognised health goal for all. Central to this is listening to what matters most to individuals, responding to this and using the learning gained to build a sustainable foundation for future collaboration. Recently, evaluation of the paediatric service in NHS Borders highlighted that there were no effective collaborative mechanisms to involve children, young people and their families in designing, evaluating and planning future care. An application to the Foundation of Nursing Studies Patients First Programme was successful and supported the project.

Design: This work-based project describes an explorative qualitative approach and the use of Experience Based Co-Design (EBCD) and Practice Development approaches in a clinical setting.

Method: The flexibility of these approaches allows the use of creative methods to engage professionals, children and families as active participants to further understand and explore the concept of PCC. The first stage in the EBCD process is ‘capturing the experience’. For the purposes of this person-centred project ‘experience’ is defined as the individual and personal emotions and feelings children and parents encountered on their healthcare journey. Methods of gathering patients’ experiences around their care included workshops, recorded patient stories, diaries, and a storyboard. A film was also made to share these experiences with a wider audience. This work was conducted over a period of 18 months.

Findings: Engaging all relevant stakeholders took longer than expected, but this time allowed the team to reflect on the existing service and gain confidence in the methods used in the project. The project team were able to agree a definition of PCC and create a shared vision. Initial feedback from children has begun to highlight what is important to them. Further work moving the focus from comment about the service provision towards a more person-centred approach has been the development of the “About Me” diaries and the new storyboard on the ward. Analysis of the children’s and parents’ stories has highlighted the disparity between the views of professionals and families towards illness and its impact on the family. Staff were genuinely shocked by some of the comments and reported that they had not appreciated the depth of the children’s and parents’ feelings. The next stage will be the formation of a collaborative working group to work with families to look specifically at different aspects of work together e.g. admission information and preparation for transition to adult services.

Conclusion: The project has enabled a better understanding of the experiences of children, young people and parents and this will be continued by the working group to inform the design of an effective collaborative person-centred model which can be used to shape future paediatric care. It is anticipated that this work will be used to promote person-centred cultures of practice and give children, young people and their families a clear ‘voice,’ and meaningful involvement in their care. This work will form the foundation for more practice development work in this area and ultimately sustainable improvements in the delivery of quality patient care. The collaborative model, if successfully developed, will be shared with other multidisciplinary groups in UK.

Keywords
Person-centred care, child-centred care, family-centred care, feedback, patient story/stories, patient narratives, collaboration, patient experience and capturing the experience
Introduction and background
This project describes a work-based project supported by the Foundation of Nursing Studies (FoNS) addressing the following problem statement:

“How do we best ‘hear’ patients’ voices and work collaboratively with children, young people and their families to make person-centred paediatric care a sustainable reality?”

Ward 15 is a paediatric ward in a District General Hospital in the Borders Region of Scotland. The ward consists of 2 high dependency beds/cots, 7 inpatient beds/cots and a short stay assessment unit (2 beds/cots) and an ambulatory care unit. Staff care for babies and children ranging from 10 days old to 18 years old, requiring care for medical, general surgical, ear nose and throat and orthopaedic conditions. The ward admits 1,500 children and young people per year and another 1,200 children are seen as day patients in ambulatory care. The average length of stay is now 0.84 days. The child health service within the hospital has been a pioneer with regards to the introduction of Advance Nurse Practitioners and these roles are now part of the established team in both paediatrics and neonates departments.

Recent evaluation of the local paediatric service highlighted that there were no effective collaboration mechanisms for involving children and young people, and their families in designing, evaluating and planning future care. It was recognised that, although the paediatric team aim to provide person-centred care (PCC), this could not be fully achieved without the meaningful involvement of children, young people and their families in the planning and development of health services. This is especially relevant at the moment as health and social care services are now integrated (The Scottish Government, 2014a) and NHS Borders are designing and building a new multidisciplinary integrated paediatric unit.

In the past, members of staff have tried to gather patient feedback on the service. Techniques used have been questionnaires, online surveys (e.g. through Survey Monkey) and exit interviews. These did not yield many responses and generated comments about organisational and procedural processes of hospital care rather than patient experiences. Although there is a place for this type of information it was not possible to answer the question ‘How person-centred is our care?’ For this project, the team wanted to specifically look at what matters to the patients and their families and not how they evaluate the current service. In addition, there has never been a multidisciplinary approach to reflect on the current service. This information will also be used to help other families to tell their stories and voice opinions.

This project describes the effective use of practice development methodologies to draw a multidisciplinary team together, create a shared vision (Manley et al., 2014), and to elicit useful and meaningful information from children and parents focusing specifically on their experiences of healthcare. Patient experience is a complex term but for the purposes of this project ‘experience’ is defined as the individual and personal emotions and feelings children and parents encounter on their healthcare journey. This personal and emotional information has been collected in creative ways to identify ‘touch points’ in the patient journey that can be improved in future practice. Patient narratives increase health professionals’ understanding of the issues that most affect the patient, and their understanding of the priorities of care (Buckley, 2016). This information will also be used to help other families to tell their stories and voice opinions.

It was felt important to ensure a person-centred focus throughout. By applying person-centred working practices, the project team aimed to work towards a person-centred culture and have a
A collaborative approach to planning and delivery of care in the future. The term person-centred care (PCC) was deliberately chosen over family-centred care as the latter has the potential to focus on parents rather than the child themselves and therefore distance the child from the centre and focus of care. In addition, PCC is a more widely recognised and understood concept nationally and internationally (McCormack et al., 2015). PCC is also a key feature of many current health service drivers, and of both local and national policies such as the NHS Quality Strategy (Scottish Government, 2010). It can be defined as the provision of care that is responsive to the personal preferences of an individual when the patient’s needs and values inform all clinical decisions (Scottish Government, 2010). De Silva (2014), in a review for The Health Foundation about the measurement of PCC, states:

‘We want a more person-centred healthcare system, where people are supported to make informed decisions about and to successfully manage their own health and care, and choose when to invite others to act on their behalf... We want healthcare services to understand and deliver care responsive to people’s individual abilities, preferences, lifestyles and goals’ (De Silva, 2014).

Having agreed this, however, there is no doubt that the family remains an integral part of the care process, and it was therefore agreed to seek parents’ views as well, while keeping children as a central focus. It is also important to recognise that parents and children’s priorities are not always the same (Buckley, 2016). The Francis Report (Francis, 2013) recommended that nurses, as part of their annual revalidation, need to demonstrate “commitment, compassion and caring for patients evidenced by feedback from patients and families”. In a response to this, the King’s Fund acknowledged the importance of the patient’s voice also recommending that “NHS leaders should encourage and nurture patient leaders to help build collaborative relationships and develop genuine co-production as a way of improving services” pg. vii (King’s Fund, 2013a). And finally, the recently revised Code of Conduct the Nursing and Midwifery Council (NMC, 2015) emphasises the importance of collaboration, listening and partnerships.

### Aims and objectives of the project

The overarching aim of this project was to conduct a multi-disciplinary practice development initiative supporting a clinical team to ‘hear’ the voices of children, young people and their families to make person-centred paediatric care a reality. This aim was divided into more detailed objectives.

### Objectives

1. Work in partnership with key stakeholders to inform the co-design of a model of collaboration with children and their families, exploring the strengths and challenges in the current service
2. Using experiences provided by the children and their families to shape the direction of person-centred paediatric care for the future
3. Enable the clinical team to take part in experience-based co-design and feel more empowered to deliver person-centred care
4. Facilitate the clinical team to develop a greater understanding of the importance of collaborative working with children and families to improve the quality of care, and view regular feedback as a positive contributor to that process
5. Engage a wide spectrum of health professionals and all those interested in the care of children, young people and their families to design an effective collaboration model to help shape future person-centred paediatric services
6. Provide a supportive environment to enable the voices and narratives of children who are patients, parents and families to be “heard”
7. Inform the development of a model that is usable and transferable and to disseminate the findings to the wider service
Methods
In this section the rationale for the chosen methodologies of evidence based co-design and practice development will be discussed. Project design elements such as personnel, resources, clinical governance, sustainability, and time planning will also be included in this section.

Experience Based Co-Design (EBCD)
EBCD is a unique a 6-stage participatory action research (PAR) design process that seeks to find and use individual experiences of providing and receiving healthcare services to prioritise and implement quality improvements (Bate and Robert, 2006; Roberts et al., 2015). EBCD aims to improve users experience by deliberately focusing on the personal and subjective to identify ‘touch points’ which are defined as ‘the key moments that shape a person’s overall experience’ (Dewar et al., 2010). McIntyre (2008) adds that there are four underlying principles to PAR projects. These are “a collective commitment to investigate an issue; 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” (Adams et al., 2014). When applied to healthcare, EBCD is an approach to bringing service users and staff together to share the role of improving care and redesigning service delivery (Bate et al., 2007, King’s Fund, 2010, 2013b).

The NHS Institute for Innovation and Improvement (www.institute.nhs.uk) has designed a four-stage method of using EBCD that aims to help healthcare providers to use the model to enhance their services. The four stages aim to improve service user’s experiences by (1) capturing the experience; (2) understanding the experience; (3) improving the experience; and (4) measuring the improvement. A central component of EBCD therefore is collaborative working between staff and patients; services are re-designed with rather than for patients.

This project describes the introduction of EBCD and practice development methodologies in a clinical setting. McCormack et al. (2013) found that combining these two approaches provides a more rigorous project framework. They also found this combination ensured that the focus of the work remains person-centred and not merely focused on service improvement. This project was specifically about children, young people and their families’ experiences. By recording people’s experiences through storytelling, drawings and using creative ways to share these findings, the project team could bring staff, parents and children together to work on prioritising areas for improvement and define key actions. The project reported here focused specifically on stage 1 of EBCD – capturing the experience and informing future work in this area. For this stage practice development methods have been used (Diagram 1).

![Diagram 1: The Elements of Co-design used in the EBCD methodology](image-url)
**Diagram 2:** The four Stages of Evidence Based Co-Design

**Practice Development Approaches**

Practice Development (PD) is a well-established approach used by many nurse researchers and clinicians studying health care, change management, and clinical practice (McCormack et al., 2013). PD focuses on understanding the social system of practice as well as empowering individuals and teams to understand their practice and to act to change rather than be led others (Manley et al., 2008 cited in McCormack et al., 2013). It also fosters a transformational culture that ensures all stakeholders are included in the co-design, change processes and implementation of new practices. Practice development is a particularly useful and appropriate framework for this project as the principles focus directly on the patient and their family, and their feelings about the experiences. The values underlying practice development also support and align with the projects aims, for example, to work using person-centred practices.

Practice development approaches that the project team selected as aligning well to this stage of the project “capturing the experience” are listed in Box 1.

| Agreeing ethical processes |
| Analysing stakeholder roles and ways of engaging stakeholders |
| Being person-centred |
| Clarifying the development focus |
| Clarifying values |
| Collaborative working relationships |
| Continuous reflective learning |
| Developing a shared vision |
| Giving space for ideas to flourish |
| Developing participatory engagement |

*Adapted from McCormack et al 2013  pg. 7*

**Box 1:** Practice development approaches

**Project Design**

With the focus on the project’s aims and objectives, the plan was to use the flexibility of the frameworks discussed above to allow the use of creative methods to engage professionals and families to further understand and explore the concept of PCC and the value of this approach to the care of children and their families. Methods of gathering children’s experiences of care include recorded stories, sound bites, diaries, and a storyboard. This work was conducted over a period of
18 months from 2015 to date. The project plan was considered in terms of personnel, resources, clinical governance, and time planning:

**Personnel**
A multidisciplinary steering group was convened to support the project, offer advice and expertise, and to consider which methodologies identified from the literature were the most appropriate to the Co-Design model. The steering group included a Director of Nursing, nurse managers, charge nurse, paediatric consultants, paediatric physiotherapist, occupational therapist and speech therapist and dietician, and other nurses from the ward. Additional advice and facilitation expertise was sought from FoNS.

A core project team was also formed to carry out the work. It was planned to involve not only children and families who have experience of the acute hospital but also children of different ages from local communities. Both these perspectives were important, as a family that encounters the service from an emergency coming to the hospital via A&E, for example, may have a completely different set of needs in terms of support and information compared to a child whose family manage a long-term condition at home with the support of a paediatric multi-disciplinary team. The project team therefore involved a wide range of multi-disciplinary professionals including advanced nurse practitioners, staff nurses, allied health professionals, play leaders, teachers, schools, and social workers.

**Resources**
Financial support of £5000 was available from a FoNS Patients First bursary, with agreement from NHS Borders to release staff and to use ward facilities. Practical advice and support was provided through the FoNS workshops in London, which were attended by members of the core project team.

**Time planning**
This is summarised in the timeline using EBCD methodology diagram 3 in the implementation of the project section that follows.

**Data protection**
Data protection is very important, particularly in relation to the recorded stories (Holloway and Wheeler, 2010). All written, recorded and electronic data was stored securely to maintain confidentiality for those involved. Upon completion of the different phases of the project, recordings were deleted. Participants were informed of this in the information leaflet. To safeguard the children and young people there was always a parent or carer accompanying them.

**Implementation of project plan**
The first stage was to spread awareness of the proposed project and gather together interested staff to assess current practices and to form a core project team and a wider steering and advisory group. This took several “brain storming sessions” trying to gather as many staff as possible allowing for shift patterns and the business of clinical areas. These were, however, well attended and there was clearly an interest and impetus to support this project. With support from nurse managers the application to FoNS was submitted and successful. The project timeline below (Diagram 3) shows the EBCD methodology as applied to this project.
Diagram 3: Project Timeline using adapted EBCD Methodology

Sept 2014
• Gain an understanding through observation and discussion about what is current practice. Meetings with interest parties and gained consent from DoN and local ethics committee.

Nov 2014
• Apply for funding and support to Foundation for Nursing Studies (FoNS)

Nov 2014
• Create core project team and wider steering group

Jan 2015
• Meetings with FoNs facilitator to create initial shared purpose using claims concerns issues to focus the project

May 2015
• Hold Workshops
  • MDT staff – what does PCC care look like for our paediatric service - shared vision and agreed definition
  • Parent stories workshop - record stories
  • Ward team workshop

Dec 2015
• Analysis of recordings of parent stories and themes identified
  • Weighted ‘Wordle’ created to visually represent findings

Jan 2016
• Gather information from children- diaries and sound bites
  • Start recruitment to patient involvement group, using fliers and posters

Jan 2016
• Production of draft film to use to demonstrate touch points from parent stories /parent experience

Dec 2015
• Ongoing development and trial patient diaries
  • Launch new patient Storyboard- “Tell us your story” board on the ward

Feb-June 2016
• Hold joint patient staff event to share experiences and show film to steering group/patient involvement group. Agree improvement areas.
  • Launch collaboration group and decide first goals

Jun 2016 onwards
• Run co-design groups to run over 4-6 months to work on improvements
  • Evaluation phase and sustainability planning

Jun 2016 onwards
• Hold a celebration event
• Present project to FoNS event June 2016 and other IPDC Edinburgh
Meeting with FoNS facilitator

The project team met with the Practice Development Facilitator from FoNS to develop ideas, focus the direction of the project, and begin planning the first steps. With hindsight the project team were initially ambitious and perhaps unrealistic, hoping to include in the project all aspects of the child’s journey through the health system, in-patients and out-patients, and potentially including health visiting, occupational therapy, physiotherapy and community children’s services. It became apparent early in the project that trying to incorporate all the services may have led to an unachievable amount of work within the time frame. There were also concerns that the project had too wide a remit that would potentially become unfocused. This initial session allowed the project team to develop their ideas and concerns and focus their attention on the areas where they were likely to be able to achieve the best results.

Parent Workshops

It was decided to recruit potentially interested parents for a parents’ workshop during the annual children’s Christmas party which is usually well attended by children and families with long term conditions. Careful consideration was given to ensure the recruitment did not overshadow the party atmosphere by giving out information flyers at the end of the party and displaying a poster describing the project rather than interrupting the party to talk about the goals of the project. Those who expressed an interest were asked to leave their contact details. Fourteen parents volunteered.

A ‘special invitation’ event to launch the project was then arranged. A ‘special invitation’ was designed to make the event more interesting and to encourage buy-in. An invitation card was produced and sent out to the list of fourteen parents who had expressed interest. The day was split into two separate sessions: one for parents in the morning and one for staff in the afternoon. This decision was taken as the team felt that both health professionals and parents may prefer to consider PCC within their own distinct groups initially.

In the morning workshop, four parents attended, were welcomed and were reminded of the project’s aims and objectives. They were then asked if they would like to share their stories with the team and were assured of confidentiality. Careful facilitation was used to create a safe space. The session was held in a quiet room in the hospital, everyone was seated everyone in a circle, and Evoke cards used to help the parents link their stories and emotions to a picture. The parents were extremely candid in their recounts of their child’s diagnosis and on-going day-to-day life with a long-term condition. An observer sat outside the circle taking notes about non-verbal reactions to the parent narratives and the group interactions. The stories were all digitally recorded and all parents provided written consent at the start of the workshop.

MDT staff workshop

The staff workshop had sixteen MDT members including representatives from dental health services, physiotherapy, social work, community children’s nursing, occupational therapy, dietetics and health visiting as well as a paediatric consultant and child health line manager. This session was used to explore values and beliefs about what PCC meant and to consider the patient journey (Warfield and Manley, 1990). This led onto group work where posters were made to depict thoughts on PCC using a creative approach. Following this, participants were invited to give feedback.

Ward nursing team workshop

A further similar staff session was arranged to enable participation from more of the ward nursing staff who had not been able to attend the initial workshops. This involved careful liaison with the charge nurse to ensure a suitable date was agreed and time back for staff attending was negotiated. Enabling staff to attend workshops and making sure that information about the project was spread widely and accessible to all, remains an important aspect of the project. There had been an initial
reluctance from some staff to get involved and it was felt that this needed to be addressed at the earliest possible opportunity to avoid a division between those involved and those who felt they were not included (Dewing et al., 2014).

This session was facilitated by the project team lead and followed a similar format to the MDT session. Starting with a values and beliefs exercise individuals considered what PCC meant. The team then gathered common themes and values and invited discussion around them. The group was then encouraged to create posters and collages to depict PCC and give constructive feedback to other groups. The shared vision of PCC was collated and is summarised in a poster in Figure 1.

Figure 1: Values and beliefs workshop summary poster.

This poster was then displayed in the ward and a more formal poster produced and displayed around the hospital to generate discussion about the project and encourage participation and links with other person-centred initiatives in the hospital. Following these workshops the project team used critical reflection to think about challenges, stakeholders, achievements to date, the collection of evidence and anticipated outcomes. We made a poster to share the project with the wider hospital community. Doing this at regular intervals throughout the project time enabled the objectives to be kept central to the work and to evidence and visually display progress. The initial poster made in November 2014 and the latest version is shown in Figure 2.
As well as the workshops, we used a variety of creative methods to try and capture the experiences of children and parents and to capture their experiences start working collaboratively with them. These methods are discussed below.

**Children’s sound bites**
Sound bites were being collected from children and young people using a dictaphone or by writing down what they said. It was important to collect not only what parents said but also what children themselves said about what mattered to them, their feelings and emotions on attending outpatients or on being admitted to hospital. Children and young people are less likely to want to talk about emotions and feelings in a focus group setting, so they were offered the privacy of a quiet room with a parent accompanying them if they wanted. They were given the dictaphone and allowed to record whatever length of sound bite they wanted. They were asked to talk about what was important to them, or to tell us what we (health professionals) need to know about them to help them best. Most said a few sentences and reported that they preferred this method, rather than being asked questions. There is on-going work to record more sound bites from children and young people to highlight these significant moments about their care.

**Diaries**
In collaboration with children and parents in the ward, patient diaries (see figure 3) have been developed. These are for patients to record what has happened to them and how that has made them feel. Younger children can work with their parents on these. This is another way for children to
share with staff how they feel and creatively express themselves. The back page encourages the children to share some of their feelings more publicly on the ward storyboard.

**Figure 3:** Ward patient diaries

![Ward patient diaries](image1.jpg)

**Storyboard**
Parents and children and staff have also collaborated to design a storyboard (see figure 4) that fills a large wall space in the ward area. Children (and parents) will be encouraged to write on the board with whiteboard markers about how they are feeling. These comments will be photographed at regular intervals and the board cleaned. This collection of feelings and comments will be used to inform future care.

![Storyboard for feedback on the ward](image2.jpg)

**Figure 4:** Picture of the storyboard for feedback on the ward.

**Findings**
These results are based on the information available at the time of writing (April 2016) in keeping with the timeline (diagram 3) i.e. soundbites from children and the adults’ recorded stories.
Soundbites: what is important to children?
Children living with lifelong conditions were asked at clinics to describe what is important to them when they come to hospital and to tell us anything else we could do to help them. Answers were recorded and analysed to isolate themes (Box 2). Analysis consisted of listening to each recording and transcribing it, then analysing the transcriptions for common themes. The key themes are listed below. A Weighted Wordle was also generated as a visual way of displaying the results for everyone (both staff and families) to see. This allowed personal reflection, and was a good way of keeping everyone up to date with the project.

Key themes that emerged were:

- That they wished to be treated as individuals and that their questions, opinions and preferences will be considered
- All staff will take time to explain their conditions to them in a way that they understand and teach them how to manage their own health
- That they will be prepared for what will happen e.g. blood test, seeing the doctor and being examined
- Staff will listen to their preferences and accommodate these if possible
- Information is shared with them

<table>
<thead>
<tr>
<th>Emma aged 12</th>
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<tbody>
<tr>
<td>“I like having time to ask questions that are important to me and not feeling rushed. I like to know how I am growing and if I am doing my injections right. I like that I have been taught to do my injections and that I chose which pen to use. I still want mum and dad with me though!”</td>
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<th>Ryan aged 8</th>
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<tr>
<td>“I like when pictures are drawn to explain things to me, and I like when I get asked what my questions are. I never feel silly and I know that it’s about my health so it’s important that I know all about it.”</td>
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<th>Sam aged 6</th>
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<tr>
<td>“When I come to hospital for a blood test we have worked out which is the best place, and so each time the blood gets taken from that place. I like the blood test done as soon as I arrive so we get it over and done – that’s what we do now at the hospital every time. It also says in my notes that I like the magic cream so that I don’t feel the needle going in. I would tell other kids to have that too. I like knowing what’s going to happen and I go back to school and tell my friends about it.”</td>
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<th>Ellie aged 7</th>
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<tr>
<td>“It’s about me and my growing so the nurse and doctor and mum always say that I should sit in the seat next to the desk. I like to ask questions about my body and to see my growing chart.”</td>
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<th>David aged 10</th>
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<tr>
<td>“I know that nothing is going to happen to me unless it has been discussed with me and mum and dad. I like this as I feel that what I say matters and that the doctor and nurse will listen to me”</td>
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<th>Louise age 4</th>
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<tr>
<td>“I like to know everyone’s name and to have mummy and daddy with me. The doctor told me he would look at my tummy. He did but it was fine.”</td>
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Box 3: Selected responses from children seen in the outpatient clinic
Figure 5: Results of children’s sound bites displayed in a weighted Wordle

The results from the children were, in broad terms, like themes reported by Coyne (2015), see Box 4, which particularly included having space to ask questions, receiving appropriate explanations, being prepared for events, and having enough information to understand care. This is reassuring in terms of affirming our own data, and suggests that there may be applicability across a wide range of settings.

<table>
<thead>
<tr>
<th>Coyne (2015)</th>
<th>Current work</th>
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<tr>
<td>• Having time to ask questions &amp; express preferences</td>
<td>• To be treated as individuals and that their questions, opinions and preferences will be considered</td>
</tr>
<tr>
<td>• Being heard and knowing if preferences can be facilitated</td>
<td>• All staff will take time to explain their conditions to them in a way that they understand and teach them how to manage their own health</td>
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<tr>
<td>• Receiving explanations that they can understand</td>
<td>• That they will be prepared for what will happen e.g. blood test, seeing the doctor and being examined</td>
</tr>
<tr>
<td>• Knowing what is happening before it happens</td>
<td>• Staff will listen to their preferences and accommodate these if possible</td>
</tr>
<tr>
<td>• Having guidance and support from parents &amp; nurses on how to prepare themselves</td>
<td>• Information is shared with them</td>
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Box 4: Comparison of findings from Coyne (2015) and current work

Recorded stories: What is important to parents?
The parent group was also instructive. It was surprising how candid the parents were, and how powerful their stories were. Analysis of the patient stories and taking the observation notes into consideration highlighted the disparity between the views of professionals and families towards illness and its impact on the family. Even though parents seemed outwardly to be coping with their child’s illness, their stories revealed that often this is not what they were feeling. They talked of the time of diagnosis as feeling that the ‘bottom had fallen out of their world’ and ‘their family would never experience normal again’. Staff were genuinely shocked by some of the comments and had not appreciated the depth of the parents’ feelings especially around the time of initial diagnosis. Two parents showed signs of emotional distress whilst telling their stories, but insisted on finishing
the narrative despite offers to discontinue. The depth of emotion released was unexpected and perhaps also the extent to which this had been previously suppressed. It was a highly emotional but very illuminating and useful session. It was also interesting that the priorities of children and parents were often different, which validated the reasoning behind asking both groups separately: in general parents were more emotional whereas children wished more information and a greater feeling of safety.

Themes were identified and these are represented in a weighted Wordle (Figure 6). The results have been deliberately reported in this visual way so that both participants and professionals can use this in clinical and teaching settings to illustrate the work of this project and to prompt reflection on clinical practice.

![Figure 6: Results of parent’s sound bites displayed in a weighted Wordle](image)

**Staff workshop feedback**

After the workshop, some staff commented on how worthwhile they had found it and how they had had a chance, through the values clarification exercise with their MDT colleagues, to gain affirmation that they were working towards a shared purpose. It was also instructive to see how the creation of a safe space could allow this information to be shared with real openness.

**Creation of a short film**

The themes and quotes from the staff and parent workshops, together with comments from the children, have also been made into a short film show to parents, families and staff in the future to demonstrate commitment to collaborative PCC. This is now displayed on the hospital website with a link for further feedback.

[https://www.youtube.com/watch?v=A1RaVBERZyU&feature=youtu.be](https://www.youtube.com/watch?v=A1RaVBERZyU&feature=youtu.be)

By using practice development methods and creativity wherever possible, the project has captured experiences from children and parents at different points on their care journeys, and gained some very interesting initial findings. Staff have been shocked at the disparity in their assumptions of what they thought people were feeling, and the reality of what the participants have revealed about important priorities to them. Limitations and future work of the project will now be discussed.
Discussion

The project has been successful in achieving its aim of supporting a multi-disciplinary clinical team to ‘hear’ the voices of children, young people and their families, but has yet to turn that into the reality of person-centred paediatric care. More specifically, 5 of the 8 objectives have been accomplished: working with stakeholders, enabling a team to use EBCD, understanding collaborative working, listening, and achieving a better understanding from service users. The remaining 3 objectives all relate to using the experiences to plan a way forward (shaping the future, considering a longer-term model and disseminating the findings), and these will be discussed further under ‘future developments’ below. The project also brought several challenges and limitations, and these are discussed below.

Challenges and limitations

There was an initial fear of the project from some staff, perhaps based on lack of knowledge - including from some senior staff who felt there was no need for the project and that this kind of working was already in place. The perception that the project was unnecessary proved to be a real resistance to progress, and efforts had to be made to allow feedback to be useful rather than threatening. Thus, engaging all relevant stakeholders took longer than expected, but this time allowed the team to reflect on the current service and gain confidence in practice development methods. The person-centred agenda, collaborative goals, practice development and service improvement aspects of this project presented the project team with exciting opportunities, but also the challenges of engaging the wider caring community, implementing the project alongside our ‘other’ jobs and the geographical spread and different nature of our individual work. There were also some issues with hierarchical tradition and difficulty in releasing staff for meetings. Despite this, the project team were able create a shared vision and agree a definition of PCC.

One limitation for this project could have been our recruitment procedure for parents. The project team involved parents and children from the hospital and community with long term conditions and did not capture the experience of other settings such as general practice or emergency care. In retrospect, the separate workshops for staff and parents could have been organised as one combined workshop, therefore starting collaboratively from the outset. At the time, however, it was agreed not to do this as the project team were using new PD methods of engagement, and there was concern that facilitation might be difficult. It was also anticipated that parents may potentially become distressed and may need support. With more confidence, such groups could be facilitated in the future.

Summary and reflection

Although the Patients First Programme project came to an end in the summer of 2016, the project team have established a collaborative group and it is anticipated that the group will continue to use practice development and the EBCD methodologies to further advance this work. Leading this project has allowed us (the project team) the opportunity to reflect on own contributions. We would all feel more confident to lead a similar project having learnt to trust the team, celebrate team achievements, and not feel responsible for everything that may not go to plan. This process has also taught us to deliberately seek and engage in critical dialogue, and to seek to learn and try more practice development techniques. We, as a team, need to further learn to see the situation and problems from different perspectives and to ask more questions (McCormack et al., 2011). Learning to view the situation from someone else’s “shoes” is very valuable and often allows solutions to be found. Having critical conversations has allowed us to experience this and, through facilitation, to explore ways to move forward (Titchen, 2003). In the future, we feel that we will try and step back from a situation more and ask whether what we are doing is adding value or not. We have also learnt about the use of a critical companion to reflect on our practice in general and not only when involved in a change process.
Future work

It is anticipated that further information from the diaries and storyboard will be available over the coming months, and this will require analysis. This will complete the first two stages of the EBCD model discussed in the methodology section (capturing the experience, and understanding the experience), which are broadly in line with the 5 successful objectives noted above. The remaining 3 objectives are also broadly in line with stages 3 and 4 of the EBCD.

Stage 3, (improving the experience), was not part of this project, but a collaborative group has been formed to take this forward. How this will be achieved is still to be clarified, but key is the dissemination of our findings through a variety of media; to ensure that front line staff will have a better awareness of the needs of children, parents and their families, but can also be used in planning the development of the proposed new facilities. In addition, a long-term group will need to be created to continue to listen, record and respond to family members’ feedback. This may involve capturing the experiences of children, young people and parents in emergency and community settings.

Stage 4 (measuring improvement) was also not specifically part of this work, but it is planned that evaluation will use methodologies including appropriate tools from the Scottish National Person-Centred Health and Care Collaborative Strategy (The Scottish Government, 2014b) and from the King’s Fund Experience Based Design Toolkit (Kings Fund, 2013). A tool specifically focusing on paediatric care using person-centred frameworks suggested and trialled by McCance and Wilson (2015) might also be of value.

Conclusion

One significant, and yet unexpected result of the project has been the staff learning, which has evolved in the last 18 months. There has been a raised awareness of person-centredness, a change in focus of care, a more questioning culture and a willingness to develop culture and to try new approaches. It is finally interesting to reflect that, in the timeframe described, we have moved away from the original definition of McPeake (2015) ‘responding to individual preferences, needs and values’. With deliberate purposefulness, we are moving to a position in which we will be able to say we are responding with individuals so that person-centred practices can be used to improve care. We are all very grateful to the Foundation of Nursing Practice and the Burdett Trust for the learning this project has allowed us and the opportunities it has given us to influence practice.

References


