What are Children and Young People Saying about their Healthcare Experiences?

Person-Centred Care

Information and Feeling Prepared

Relationships

Better Experiences Lead to better outcomes for Children, Young People and Families
Amy Frounks, a member of the NHS Youth forum and a user of Children’s Services says:

“Children, just like adults, desire patient-centred care and have valid thoughts and feelings that need to be listened to. After spending time as an inpatient on paediatric wards, I can vouch that younger people have a different outlook on life and different interpretations as to what good quality care consists of, in comparison to parents or carers. It’s essential to gain that insight from a child’s perspective and collate the information to inform NHS services on what is good, and equally how they can improve the service. Without listening to children alongside adults, how can we truly improve services to suit all?”
The Thoughts of Adsthepoet

I think everybody should have good care, so to help, I thought I would let you know what, from my experience I think makes good care.

In the good hospitals:-
1. Staff talk to me and involve me in decisions about my care. They ask me about what I want and don't want;
2. Staff talk to mum and dad and ask them about me;
3. Staff talk to each other and pass on important information about me;
4. If staff don't know something they are not afraid to say and ask someone who does know, sometimes that might even be me or mum and dad;
5. Staff treat me as an individual and recognise the things I can do, they don't jump to negative stereotypes and prejudices about me, because I am physically impaired;
6. Staff have time for me, they are friendly and chatty and make me feel as if I matter;
7. Staff are friendly and chatty to mum and dad, they work with them, they treat us all as if we matter;
8. I'm never left alone when I'm seriously ill and never in a room with the door closed so staff can't see me;
9. When I'm really ill doctors come quick and do everything necessary to make me better, I'm not left critically ill for hours without care;
10. I always feel that I am getting the best care possible, I'm never made to feel like a second class citizen for whom it doesn't matter if I live or die.

Adam Bojelian, 26th April, 2013 Age 13
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1. Introduction

Report Update: In 2013 the Patient Experience Network published a report entitled Improving Patient Experience for Children & Young People. Eighteen months on PEN have been commissioned to update the original report and highlight any key trends or new work on this very key and current subject. Ideally this update should be read in conjunction with the original report but, accepting that this is not always possible, the authors have included some of the key themes, messages and observations from the original report.

Use of NHS by CYP: Improving patient experience for children and young people (CYP) continues to be a subject which is close to many people’s hearts and one which is still not always receiving the attention and investment that it needs to make continuous progress. Figures from 2014 for children from 0-15 years show that in a typical year …

– Up to half of infants under 12 months and one quarter of older children will attend A&E
– One in 11 children will be referred to a hospital outpatient clinic
– One in 10 to 15 children will be admitted to hospital
– One in 1,000 children will require intensive care

Why Patient Experience: Behind each of these admissions or attendances is a child or young person with a story to tell about their experiences of the NHS. In our last report we said that ensuring a positive patient experience for all groups is a strategic, commissioning and financial imperative for all – it remains just as true today.

Patient experience is a fundamental component of the quality of healthcare and is no longer seen as a ‘nice-to-have’ option. We know there continues to be good evidence for the positive impact of delivering person centred services, in terms of clinical outcomes, staff satisfaction and retention, appropriateness of service use and length of hospital stay – all of which have significant implications for funding requirements for the NHS, its financial health and for delivering best value for public money.

In July 2015 the Care Quality Commission published a landmark document – their first National Children’s Inpatient and Day Case Survey. We have included some of the outcomes of that report in this update. The ongoing review of patient experience for children and young people, and the overall environment in which it takes place, remains vital and drives continuous improvement.

Background: This report was commissioned by NHS England to look specifically at updating the previous report to reflect current good practice on the subject of improving the patient experience for children and young people within the NHS.
2. Executive Summary

**Progress:** The outcomes from the 2015 PEN survey indicate that participants believe that progress has been made since the last survey eighteen months ago, with more respondents reporting positive focus to improve patient experience from children and young people.

**Key findings:** The findings generally support and build upon the findings from the previous survey. The following areas were again highlighted (listed in order of importance): involve children and young people in developing and providing care; improve transition to adult services; provide more timely access to services / improve waiting times; provide a more child appropriate environment; co-ordination – working together across wards, community & acute services, education etc.; restructure service / process to focus on children and young people; provide information in a relevant way; take action on feedback.

**Transition:** One interesting issue to note was how transition had risen up the list of priorities – now sitting firmly in second place. Transition was highlighted in the last report and has been the subject of piece of work headed by Dr Jacqueline Cornish details of which can be found on the NHS England website. Transition is clearly becoming more of a focus and hopefully will result in more examples of good practice from which to develop a strong transition process.

**In Patient Survey:** A key piece of research published in the past year is the Children and Young Peoples Inpatient and Day Case Survey 2014. The survey was conducted by Picker on behalf of the Care Quality Commission (CQC) and encompasses the experiences of nearly 19,000 children and young people who received inpatient or day case care in 137 NHS Acute Trusts predominantly during August 2014. It is interesting to note that, although the CQC survey was conducted within a specific sector, its findings broadly reflected those of the previous PEN report.

**Findings of good care:** The CQC survey found that, as with their previous ‘State of Care’ report in 2013/4, children’s services are generally of a high quality, this also reflected the findings of the first PEN survey and report and is very reassuring. The CQC survey shows that, overall, children and their parents or carers had good experiences of care, as 87% of children (8-15 year olds) and 88% of parents or carers scored children’s overall experience as seven or above out of 10. 91% of 8-15 year olds said that when they had an operation or procedure staff told them what to expect, and 89% of 8-15 year olds said that they felt safe on the ward all the time. Furthermore 82% of 8-15 year olds said that hospital staff talked to them about how they were going to care for them in a way that they could understand and 80% of 8-15 year olds said that when they experienced pain, staff did everything they could to help control it.

Commenting on the results, Dr Andrew McCulloch, the Picker Institute’s Chief Executive, said:

“Everyone using NHS hospitals deserves to be treated with care, understanding, and attention to their personal circumstances – and so it is encouraging that most young people and parents report positive experiences of care. To the credit of NHS staff, it is clear from the findings that young people in hospital are almost always treated with respect and compassion.”
The key findings from the report are summarised in the infographic created by Picker Institute Europe.
2. Executive Summary (continued)

Findings of poor care: The CQC survey highlighted a number of areas where quality could be improved. These include comments on the poor quality of food and the lack of time given to playing with children on the wards. It also found that parents and carers had issues with poor staff awareness of a child’s medical history (41%); lack of involvement in decisions about care and treatment (35%); and staff availability when children needed attention (32%). Concerns were also raised about the quality of children’s discharge from hospital; these centred around information on who to talk to if they were worried about anything when they got home and a lack of written information to take home about their child’s condition or treatment.

The CQC survey found that hospitals were not consistently involving older children in making decisions about their own care (43% of 12-15 year olds), particularly those with longer term conditions preparing for transition into adult inpatient services. A lack of information on options after discharge was also highlighted.

Children with a physical and/or learning disability or mental health condition: The CQC survey found that reports of patient experience were consistently poorer for children with physical or learning disabilities or a mental health condition across all the survey questions analysed. These children were more likely to be negative about the information provided by staff and the quality of their communications with staff. This included questions about whether staff talked with them when they were worried and whether staff always listened to them. The CQC survey also found that there were variations in the quality of care for children across the country with not all Trusts performing well.

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Dr Andrew McCulloch

“"There is cause for concern in the poorer ratings afforded to three areas of care: communication, involvement, and care coordination. Today’s survey shows that more than one in five young people and parents do not feel that staff always listen to them – and this is compounded by the fact that healthcare professionals often appeared unaware of the child or young person’s medical history. Similarly, the survey suggests that much more must be done to involve young people and parents. Patients and families have a right to be involved in decisions about care, but too often, young people and their families are not given this opportunity. This has to improve if the NHS is to call itself a truly person-centred service."”

Kath Evans
Head of Patient Experience – Maternity, Newborn, Children and Young People, NHS England
3. Methodology

**Objective:** The objective of this report is to bring the previous report (Improving Patient Experience for Children & Young People) published in 2013 up to date. The objective of the original report was to examine and comment on the situation as it was then with regard to patient experience for children and young people, challenge existing thinking and suggest possible ways forward; demonstrate ways in which the NHS can provide more positive patient experience for children and young people. Its secondary objective was to celebrate and recognise some of the great work that is already happening, showcasing the wonderful initiatives that today are improving the experience for children and young people.

**Desk Research:** In compiling this follow up report PEN again conducted some desk research, referring to available documents and utilising the latest case studies and information within its own data banks. The desk research, as before, encompassed searches of the internet, review of existing documents and the analysis of information from the PEN database.

**Survey:** PEN also conducted a follow up survey in 2015 amongst its members and other interested parties, requesting their views in response to a number of key questions. These questions reflected the 2013 survey so that we were able to draw some comparisons and conclusions as to how things might have changed or moved forward in the past 18 months. The survey reached 75 participants from 53 organisations representing a wide variety of organisations including NHS England, commissioners, trusts, general practice, hospices, specialist children’s services, charities, networks, councils and user groups. We have used this insight to write this report and compare with the previous survey.

**Event:** During the preparation of the original report PEN held an event on 12th September 2013 in partnership with NHS England entitled Celebrating the Best of Children’s and Young People’s Experience. The event included speakers such as The Children’s Commissioner for England, representatives from the youth forum of the Royal College of Paediatrics and Children’s Health (RCPCH), NHS England and a best practice showcase from Alder Hey Children’s Hospital – the overall winners from this years’ PEN National Awards. During this event delegates were asked to contribute their suggestions and thoughts on the subject – some of the contributions from the event were included in the original report and have not been repeated here.

> I thought the event was very powerful and an eye opener into the variation in experience children, young people and families get and the understanding of complex needs and the principles of good communication which sometimes get lost.

_Mari Longhurst, Senior Commissioning Manager Children and Maternity Services, NHS Merton Clinical Commissioning Group_

In 2015 PEN followed up the original event with three further events across England – one was held in Leeds, one in Birmingham and one in London. The events brought together a wide variety of organisations including CCG’s, Trusts, NHS England and both commercial and not-for-profit organisations all with a desire to improve patient experience for children and young people and with some great insights and practice to share. The outcomes from these events have been used to inform this update.

**Conclusions:** The desk research and review of known best practice was conducted independently of the survey and it was very interesting to note the close correlation of the results – this added weight to the overall conclusions. The events held across the country generated a huge amount of interest in patient experience for children and young people which is now being taken forward.

Please note the research is by no means exhaustive. It is rather a snapshot, taken over a short period focussed on what is currently happening to improve the experience for children and young people. There are many other papers, resources and examples of best practice; this is simply a report indicating some of the great resources and activities that are currently in place, and commenting on common themes and issues.
4. PEN Survey Results

2013 Survey: In the original report the initial survey found that there was an incredible desire and relentless drive from those involved in the care of children and young people to improve their experiences and the experiences of those supporting them. Although the desire was evident but there were often barriers to achieving the best possible results. Whilst concluding that there was still a lot more to be done across the NHS as a whole, evidence indicated that there had been an increase in the involvement of young people, soliciting their views and opinions, looking at how to gain their feedback of their experience of their care, building senates, councils, advisory panels and so on. Less than 50% of the organisations surveyed had a strategy in place for children and young people, a response skewed towards the specialist providers as the number fell to 33% when taking Acute hospitals alone. As the survey was addressed mainly to those who already have an active interest in patient experience this number could be seen to be at the top end of the scale.

The top six priorities identified in the 2013 survey were:

1. Listening to and involving young people more effectively
2. Working together across pathways and partner agencies – to stop working in ‘silos’
3. Specialist staff development – ensuring staff have the appropriate skills and leadership
4. Feedback – Closing the Loop
5. Environment – more child friendly, less scary
6. Commissioning Insight – from including complaints from children to ‘involving CYP in the development of the CCG Transformation strategy’

2015 Survey: In 2015 we saw a small increase in the organisational focus on the experience for CYP moving from 7.03 to 7.39 out of 10. This was driven by a reduction in the number of scores below 5. Interestingly in contradiction there is also a reduction in the proportion of respondents reporting that they have a strategy in place for CYP, dropping from 48% to 38% with a corresponding increase in NOT SURE. This indicates perhaps, a growing awareness of the realities of whether a true strategy exists.

In the survey carried out in July 2015 the top priority remained the same – involving children and young people is the first priority for the organisations who responded to the survey. Below this headline the results changed: involvement was closely followed by improving transition (from CYP to adult services) and improving timely access to services and reducing waiting times. It could possibly be inferred from the results that working across pathways and agencies has some resonance with transition as this requires different parts of the healthcare system to work in harmony, which is clearly not happening effectively at the present time from the respondents’ perspective.

The top priorities in the 2015 survey are as follows:

1. Involve children and young people in developing and providing care
2. Improve transition to adult services
3. Provide more timely access to services/Improve waiting times
4. Provide a child appropriate environment
5. Co-ordination – working together across wards, community & acute services, education etc.
6. Restructure service/process to focus on children and young people
7. Provide information/ communicate in a relevant way
8. Take action on feedback
A growing focus on transition: We covered involvement in more detail in the original report and it is interesting to see transition – also identified in the original report – climbing the priority list. In January of this year the subject was brought into sharper focus by Dr Jaqueline Cornish, NHS England’s National Clinical Director Children, Young People and Transition to Adulthood, in an article published on the NHS England website entitled Improving Transition for Children and Young People.

In the article Dr Cornish said:

“There is a growing movement that recognises that young adults aged 17 years and 364 days are no different to young adults aged 18 or 19. The brain doesn’t finish developing until the age of 25, so there is an argument for building young adult services that meet the developmental needs of young people while they have so many changes in their lives, to make sure there is continuity in their support from those of us in health and support services.

Putting young people at the centre of well planned, integrated and supported transition enables them, and where appropriate those who care for them, to stay in touch with the teams that look after them. Consequently young people are more likely to carry on with their treatment, and continue to develop self-management of their condition. They are more likely to know what to do if they are worried that their health is deteriorating.

As well as the benefits to young people, for example increasing their ability to stay in education, in work, to live independently and achieve their personal goals, this saves money. Reducing missed out-patient appointments, emergency department presentations in mental or physical crisis, unplanned admissions and length of stay, and the need for additional care resulting from preventable complications of their health condition is good news for the NHS and social care and is infinitely preferable to the alternative.”

Out of the work done two tools have been published for commissioners:

1. **Model Specification from Child and Adolescent Mental Health Services**

2. **NHS Standard Contract: Model Transfer and Discharge from Care Protocol for young people with mental health problems in transition from CAMHS.**

For more information please visit:

Play Specialists: In this 2015 survey play specialists also responded and perhaps unsurprisingly they showed an impressive focus on the CYP and shared extensive examples of what is working well. Some of these are covered later.
What is Working Well? Examples from the PEN Survey: One of the most encouraging outcomes from the PEN survey conducted this year was the wealth of suggestions from participants regarding what is working well within their organisations to improve patient experience for children and young people. A selection of these is shown below.

It is interesting to note the variance in support and thinking around children and young people across the survey. This mirrors evidence from other sources which indicate variance across the country. Examples for vulnerable children and young people were disappointingly few and far between, reinforcing the findings in other parts of the report that this group feels under-supported and is less satisfied with children and young people’s services and facilities. The introduction of play facilities was also highlighted in the survey – this correlates very closely with the findings of the CQC In-patient report which found that CYP were unhappy with the levels of play and activity offered in a hospital setting.

We have selected a number of examples from the survey below.

We have some programmes of work that at the heart of the planning and design of services is the experience and feedback of young people. We have created ‘I’ statements that form outcomes to which services should base their service pathways and models on and are a standard to monitor performance against. e.g. ‘I only tell my story once’ ‘I have professionals who come to me in my settings, school, home’ ‘I want to part of the planning of my care and my goals to be taken into considerations’ ‘I want timely access to services to stop things worsening for me’....

Since November I have been involved in a project called the Voice of the Child, which aims at getting the views and opinions of the children. Since doing this, the children and young people really feel like their voices are heard and they are making positive changes for all young people and children using the service.

We have set up a children and young people’s patient experience committee to coordinate all our work in obtaining feedback and using this to improve the services and care we provide.

We currently have a Youth Forum which does some really good work and we need to look at how the wider experience program feeds into the forum and uses this as a resource. The experience of patients when clinical decisions are being made, in terms particularly of environment and allocation of patients are well thought of.

Following introduction of FFT for children and young people’s services, we actively seek views of both children and young people, parents and carers. In the past feedback has been fairly limited to one off surveys or feedback activities. We also now have a number of patient/parent focus groups who we also engage with. We recently introduced ‘Break time with Matron’ where children, parents and carers can come along and chat to matron. Our goal now is to increase the amount of regular feedback from all our areas.
4. PEN Survey Results (continued)

We have a group of young people called our Voice of the Child Ambassadors. They named themselves C.H.I.P.S (children in hospital improvement partner service). They assess and evaluate the service and find areas in which they feel need improvement or change. So far they have made an impact on hospital facilities such as securing Wi-Fi.

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The Pants and Top Display... children to pin on a washing line things that they don't like (pants) and things that they do like (tops). We also have a 'feedback Friday', where children on the ward are asked questions about their experiences. We also do patient events, and parent and children comment on their experiences in a less informal way.

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The children commented that they wanted Wi-Fi and they got it. Also the food has been commented on, so our voice of the child ambassadors did an audit and now we are looking at how we can change it. Parents and patients wanted to meet other families so we now have an events committee in process to organise events for all children with different diagnosis and conditions. Currently only oncology, rheumatology and diabetics have events.

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Feedback from a young person’s project created actions for us, specifically around Transition which we are now moving along with. Young people from a special school asked the question ‘Where would I come if I need to stay in hospital?’ highlighting just how vast and confusing the ‘grey area’ of health care for young people can be between the ages of 16 and 20 especially if they have a LTC or learning disability.

Local branch of National Autism Society visited ward and recommended menus for children who could not read. Menus sent to printers and photos added. New menus fed back to group.

Re-designing menus for children and young people. Re-design patient information to bring in line with what young people and children want to see, engaging with Plymouth College of Art & Design to offer them an opportunity to work with us. Arrangements for parents / carers overnight accommodation at the bedside has been improved to ensure both male and female parents / carers are able to have camp bed to sleep on.

Noisy on the ward at night - now offer earplugs to parents / minimal episodes of noise if possible. Meals - changed menus completely - offer much more choice and timings, own personalised C&YP menus.

Roll out of ‘what matters to me’ work as a pilot on one inpatient ward - now to go department wide. Volunteer play service, providing a team of junior doctors working across weekends and evenings to support play provision for the inpatient areas to supplement the Play Specialist team.

We carry out regular 15 steps assessments with children, young people and families, we also collect feedback via I Want Great Care app on iPads. I work with local schools to gather views on how we can improve our service.

As a team we have produced and implemented Physiotherapy Intervention Guidelines (P.I.G.S) to lead to evidence based and best practice for children and young people, who are using our service, with a variety of diagnoses / conditions.

Break time with Matron directed at both children and parents / carers. Learning disability link nurse / play staff on the children’s ward and Child Development Centre and the Learning Disability Passport specifically designed for children. Patient information booklet for children visiting theatres / imaging.

The ‘you said …’ boards are wipeable so can be changed easily and therefore are updated regularly - rather than having to be typed etc. The school service is excellent and has a real emphasis on integrating children back into main stream at every opportunity and if this is not possible supporting the education teams and the family with the ongoing needs of the child in a very holistic way.
Examples for vulnerable CYP: For the first time we invited examples of what is working well for more vulnerable CYP including Black and Minority Ethnic groups (BME), children and young people with learning disabilities or complex needs, Looked after Children, young carers. There were not as many examples shared for this group, with many stating they have not yet focussed on this audience.

Ensuring we have up to date registers of all people with learning disabilities and ensuring they all receive a full health and well-being assessment

Individually we assess each vulnerable child/adult and make sure that they have the best experiences possible...depending on that specific individual and their needs. We do not treat everyone the same in a particular way but treat them depending on their needs and how we can make each and every patients experience better.

We have many young people with learning disabilities and mental health issues. Young teenage parents are deemed to be vulnerable. BME, LAC are all on this programme.

We do not currently focus on all of the groups mentioned above with the exception of learning disability patients. Learning disability link nurse / play staff on the children’s ward and Child Development Centre and the Learning Disability Passport specifically designed for children.

About to start a wall entitled • "Wellbeing and Resilience" Focusing on young carers, mental health and support.
5. Review of Best Practice

Introduction: A key part of the original report was to look at and celebrate the existing best practice that was already in place - practical examples of how organisations have already tackled some of the perceived, and very real, problems associated with providing excellent patient experience and clinical care for children and young people. We reviewed some of the extensive bank of PEN and other case studies. A selection of these case studies was collated to demonstrate the wealth of practical best practice that already exists – please refer to the original report for these examples.

For this report we reviewed case studies and practices that have come to light in the past eighteen months, or which build on some of the case studies we included in the last report (none of them have been repeated here so please refer to the original report for the original case studies).

Most of the examples we have included here are directly related to improving patient experience for children and young people, however, it is critical – and one of the key conclusions we repeatedly draw – that organisations should not limit themselves to looking at best practice only from their individual specialism. This restricted thinking ensures that some excellent initiatives and practical examples are overlooked on the basis that ‘this does not apply to me’. As we have said before - many of the case studies and examples uncovered are easily adaptable to other settings and should not be ignored. Some of the case studies which show clearly the positive financial benefits of improving patient experience could also be used to more positively influence the budget holders.

The majority of these case studies and examples of good practice have been written by the organisations themselves and may have been lightly edited where necessary. In putting the examples in this report we are in no way taking credit for the excellent work being done – we are merely seeking to highlight and showcase just some of the great work that is out there to improve patient experience and outcomes for children and young people.

My rights as a child are

To have someone I love with me whenever possible
To be told what is happening to me
To ask questions and be given answers I understand
To not be alone if I am sad
To be able to play even if I have to stay in bed And...
That people are honest with me
That the people who care for me understand children’s needs
That I am safe, that my body is my body
That I am respected as a real person with feelings and rights of my own
That my well-being is the most important thing And
I am part of a family

This poem originally appeared in the journal Maternal & Child Health and was reproduced with the kind permission of Manukau Health, New Zealand in a 2004 report by NHS Estates entitled ‘Improving the patient experience - Friendly healthcare environments for children and young people’. It seems as apt today as it was 12 years ago....
5.1 Leicestershire Partnership NHS Trust – ChatHealth School Nurse Messaging Service

Organisation
Leicestershire Partnership NHS Trust (LPT) provides integrated community health, mental health and learning disability services for a population of a million people in Leicester, Leicestershire and Rutland. We have more than 5,000 staff and a passion for quality, integration and excellence. LPT’s division of Families, Young People and Children’s Services (FYPC) provides the School Nursing Service across the area.

Summary

• Introduction - ChatHealth is new texting software that safeguards vulnerable teenagers. It keeps messaging conversations safe/secure to provide timely, confidential access to help from qualified clinicians. Our initiative is improving experiences for patients and staff - who co-developed the system uniquely for the NHS.

• Ambition - Our ambition was to transform access to healthcare for young people. They are leading communications change – almost 100% own mobiles, 80% have advanced phones used to administrate every aspect life. If we fail to provide age-appropriate care in this landscape, they will disengage further.

• Impact - Our ChatHealth school nurse messaging service is now available to 65,000 students aged 11-19 in 90 mainstream schools in Leicester, Leicestershire and Rutland. They no longer have to wait for a clinic appointment or ask a teacher’s permission to attend - they just send a discreet SMS text message at any time and get 1:1 support from a clinician.

• Innovation - Our software proves technology can have large scale, cost-effective impact on improving patient experience – whilst our team is influencing national best practice and actively promoting transfer/dissemination.

Rationale & Context

• Problem - Teens are high risk. In the last 10 years depression/self-harming in this demographic has doubled. Texting provides them with timely, age-appropriate, confidential access to help. It’s widespread technology, offering a far-reaching solution for improving patient experience. Yet it’s rarely adopted in the frontline because staff/managers are risk adverse. The risk of messages going unanswered out-of-hours, losing audit trails and holding sensitive info on handsets, seems to outweigh vulnerable young people crying-out for help.

• Solution - School nurses and young people solved this problem. They co-designed ChatHealth. They imagined pupils in school sending texts from phones as normal, but texts arriving with nurses in a computer-based risk management system that:
  – Ensures no message received ever goes un-answered
  – Sends automated safety bounce-backs out-of-hours, signposting alternative help
  – Is fully auditable and reportable
  – Notifies staff when action is needed
  – Allows nurses to manage messages as a team without giving out numbers for personal handsets

No off-the-shelf product met this specification. So, the Trust employed a software developer to build ChatHealth.
Planning & Delivery

• **Leadership** - The plan was supported from the outset by senior management, ensuring high quality leadership. This enabled tech development to begin – bringing to life the system patients and nurses had co-designed:
  - Chief Executive injected initial funding/created dedicated project lead post
  - Director of FYPC chaired project board to ensure robustly governed approach
  - Commissioners, impressed with initial achievements, contributed £150K funding to widen impact.

• **Objectives** - Project lead was appointed from marketing/communications background, to engage patients/staff and communicate objectives. Aims were clear:
  - Improve patient access to school nurses
  - Enable patients/staff to lead transformation
  - Pilot in 3 schools (4,500 students) until at least 10% contact was delivered by text messaging
  - Assess impact on patient/staff experience, with a view to rolling-out

Impact & Results Achieved

• **Improved Teens’ Experiences** - Staff capacity’s stretched; sometimes students can’t get to see a school nurse. But, some choose not to see a school nurse. They feel more comfortable talking about sensitive issues without meeting face to face (F2F). Because of emotional/cultural stigma they feel more self-confident speaking remotely / anonymously from “behind the screen” (of their mobile device). ChatHealth gives patients a better experience on both fronts

**Improved Outcomes**

- Increased reach/access - 100 additional monthly contacts
- Overcomes stigma of F2F access – half of contacts begin anonymously
- Reaches underserved teens, 1/5 male users compared to 1/10 in F2F clinics
- More 1st time users, broader range of enquiries, earlier intervention compared with F2F clinics
- Improved safety for staff and service users
- Improved interagency working with police/social-care

**Measurement/Verification** - To better understand the impact we examined/discussed patient/staff experiences in a number of ways:

- **Focus groups (30 students)**
  - Student survey (2,000 respondents)
  - Staff reference group
  - “Mystery shopper” anonymous test by appointed service user
  - Patient/staff satisfaction video interviews
  - Peer review; 150 conversation transcripts reviewed by school nurses/managers
  - Reviewers described a thorough, timely, instant, informative, succinct, safe, non-judgmental, sensitive and reassuring service.

- **Testimonials** - See short exert from patient/staff satisfaction interviews:
  [https://www.youtube.com/watch?v=1ZQsCnMkqbM&feature=youtu.be](https://www.youtube.com/watch?v=1ZQsCnMkqbM&feature=youtu.be)
What Makes This Initiative Special?

- **Challenging Climate** - With 1,200 school nurses nationwide looking after 20,000 schools, there aren’t enough staff. ChatHealth is the kind of sustainable solution needed to improve experiences more young people with fewer resources.

- **Efficiency Saving** - School nurses can now provide an industrial-scale messaging enquiries service. We introduced a single point of access triage model, so just one duty nurse handles all enquiries from 65,000 patients across Leicestershire. If all Trusts adopted a similar model, as few as around 30 nurses could handle all messaging enquiries from all UK teens.

- **Cost Saving** - We’re delivering 100 additional monthly contacts within existing capacity. Achieving the same in a traditional F2F way would require two additional nurses costing £70K p.a. Low-cost messaging contacts eliminate unnecessary resource-intensive F2F contacts, saving taxpayers’ money. Furthermore, our duty nurse responds to two thirds of enquiries through messaging; only one third is escalated to F2F colleagues. This releases capacity so more F2F care can be delivered where it’s most needed.

- **Transferability/Dissemination** - The capacity for transferability is infinite - ChatHealth is configurable to multiple services/organizations. We’ve already engaged widely with other Trusts and identified a healthy appetite to adopt the culture/behaviour.

- **Age-Appropriate** - ChatHealth improves the patient experience for teenagers because it’s age-appropriate. Techy young people will become increasingly isolated if healthcare fails to keep up with them – ChatHealth turns that on its head by changing the primary way we interact with patients.

- **Safely Improves Access For Under-Served Teens** - This would be impossible without our unique technology and guidance which ensures safety. Nurses say they speak with more new young people than ever before across a broader range of issues. We get more contact from vulnerable/underserved adolescents who might not otherwise engage with healthcare, particularly boys, for whom we are significantly improving outcomes.

- **Scalable** - ChatHealth is significantly scalable, which we are actively catalysing. This could benefit high numbers of patients.

**Key Elements**

- Improves access – an open channel, available to patients 24/7
- Innovative – more efficient, but simple and safer
- Age appropriate - empowers patients
- Earlier intervention – discreet and timely, removes barriers for patients
Learning Points

- **Challenging Timescales** - We learned software development takes much longer than expected, but results are outstanding if patients/staff are involved from the conceptualisation stage.

- **Patient Choice** - We haven’t set out to replace face to face care – but we learned some young people prefer an alternative. They say they feel more self-confident, less judged, less exposed speaking anonymously/remote.

- **Safeguarding/Confidentiality** - We learned young patients are interested in what we mean by “confidential”. We are clear - we won’t tell parents, teachers, etc. if a student makes contact, unless we have concerns about safety. If a message suggests a young person is at significant risk, we ask the police to help ensure they’re safe. Is this a breach of confidentiality? One patient told us they were just pleased someone cared.

- **Manageable Messaging** - Widening service access has improved our patients’ experiences. We were unsure what would be the impact of this on our already busy nurses, but they say messaging as quick, efficient and manageable. We learned messaging helps them reach more patients within existing capacity.

- **Centralised Working** - Our new single point of access improves timeliness for patients. We thought changing the traditional locality based service model would be challenging. We learned that it flourished. Young people value having direct access and duty nurses say it’s gratifying to support more patients from across the County.

- **Champions Create Champions** - Patients wanted messaging access and many staff were keen to pioneer it. These confident champions were critical to the success of the project, supporting less confident colleagues to engage. The champions approach was so valuable we made it central to the service roll-out.
Organisation - Northumbria delivers integrated acute and community health and social care to the residents of Northumberland and North Tyneside. It is the largest geographical Trust in the UK covering 2000+ square miles. Employing over 9000 staff - together each year we:-

• Care for over 73,000 patients and families on our wards.
• Provide treatment to around 167,000 patients in our A&E departments and minor injuries units.
• Perform almost 27,000 operations.
• See more than 45,000 people for day-case procedures.
• Carry out around 1.3 million appointments with patients outside of hospital.
• Provide adult social care support during 70,000 home visits.

Summary

• This innovative project was developed by a multi-agency group of staff across North Tyneside with the aim to implement a whole school approach to managing self-harm in children and young people in schools across the Borough. The need for the project was based on national research which shows that suicide attempts in adolescents have risen threefold in the last twenty years and that admissions to hospital through self-injury continue to increase year on year. One in twelve children and young people are said to self-harm*. Patient safety is at the core of all nursing care. CAMHS nursing were able to lead on a project alongside a multi-agency group of professionals to look at reducing harm for these children and Young people.
• During 2013 this multi-agency group of staff in North Tyneside gained funding to deliver an early intervention project. The project aim was to implement a whole school approach to managing self-harm in children and young people in schools across the borough of North Tyneside. The project was fully inclusive to all children and young people and included our special schools for children and young people with Learning Disabilities.
• Early detection of the problem and provision of resources and training to manage risk and ongoing care needs was the key focus. The project was based on the NICE Guidance CG16 “The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care”.

Rationale & Context

• Research shows that in the United Kingdom, suicide attempts in adolescents have risen threefold in the last twenty years and that admissions to hospital through self-injury continue to increase year on year. One in twelve children and young people are said to self-harm*. Patient safety is at the core of all nursing care. CAMHS nursing were able to lead on a project alongside a multi-agency group of professionals to look at reducing harm for these children and Young people.

Planning & Delivery

- The initiative involved a collaborative approach across Health, Education and Young Minds Charitable Services.

- Young People from a local school were also fully involved in the Project. The project included:
  - Raising awareness of self-harm management within schools and amongst children and young people achieved through:
    - Development and delivery of a training package (multi agency developed and delivered including staff from Young Minds Charity and several teams across NHCFT) for the early identification of self-harm and the management of self-harm.
    - Development and implementation of resources for use by Education and Health staff with Children and Young people where self-harming behaviours are identified.
    - Resources for use by Children and Young People themselves.
    - The development of a standardised process/guide for the management of self-harm across all school systems in North Tyneside.
    - All schools in North Tyneside (Middle and High school YR7 and above) - including the special schools took part in the training, with a variety of staff attending including:
      - Teachers
      - Learning Mentors
      - Teaching Assistants
      - SENCO’s
      - Educational Psychologists
      - Public Health School Nurses

Impact & Results Achieved

- A base line survey was undertaken at the initiation stage of the project to gain an understanding of school staff’s current awareness and management of self-harm in schools. This was followed by a post training evaluation undertaken to identify if school staff felt their:
  - Understanding of self-harm had increased
  - Their confidence in managing self-harm had increased
  - Their understanding of when and how to seek specialist support had increased

- The findings indicated that the School staff felt that we had been successful in achieving the above aims.

Overall the project approach;

- Increased awareness of self-harm within North Tyneside for professionals, voluntary agencies, parents, carers, children and young people.
- Increased awareness within the Learning Disability Field to ensure self-harm is addressed in the same way as everyone else.
- Provided a clear process for the management of self-harm through the guide developed.
- Increased knowledge and understanding of the services and agencies available to support with the management of self-harm.
- Provided resources to support professionals to open up discussions with children and young people who are self-harming.
- Provided information on wider resources available for support.
- Built resilience amongst children and young people through awareness raising sessions.
The project was an exciting, innovative, proactive opportunity for CAMHS frontline nursing to lead on sharing good practice, utilising a multi-agency collaborative approach. It enabled front line staff to work together to develop coordinated approaches to improve patient safety and ensure an equitable quality approach to patient care. This approach utilised nursing clinical practice, education skills and nursing management/leadership skills.

The project Working Group continue to meet regularly to ensure the sustainability of the work undertaken and to look at next steps. As this was a collaborative approach it has enabled resources to be shared rather than being resource heavy in one area of practice. We have therefore been able to progress on that standing.

Ongoing teaching and training will be in place – to keep all professionals working with young people up to date with management of self-harm. The project group are exploring ways to undertake more direct work with groups of young people into schools re Self Harm. The Resources are available to download from Local Authority Website to ensure continued availability to all staff.

What Makes This Initiative Special?

- This project is key to all areas. It’s vital that self-harm is not seen as only an A&E or mental health issue. All professionals working with children and young people need to understand it and be prepared for when they encounter it. We all have a duty of care to ensure that any Child/young person undertaking self-harming behaviour is supported in a safe, equitable individualised manner to address their needs at a very vulnerable point in their lives.
- All agencies should ensure staff receive training in self harm to ensure we are working to evidence based best practice.
- Further Training is being planned and will be open to all staff from agencies across North Tyneside.
- A base line survey was undertaken at the initiation. The project was developed from a local identified need. The aim was to look at how self-harm could be managed in schools for all children and young people equally. Therefore it included our children and young people with learning disabilities in our special school systems. All resources and materials developed were adapted by members of the project group including CAMHS nurses, Community Learning Disability Nurses, Educational Psychology, Education Staff, Young Minds Charity and special school nurses. This ensured that these resources would be useful to Children and Young People with Learning disabilities.
- The collaborative approach across agencies in North Tyneside also contributed to the success and sustainability of this project. It brought together professionals who were all struggling to manage a significant issue and enabled them to pool resources, skills and knowledge to develop the Training and resources for use in practice.

Key Learning Points

- Multi agency working was key to the success of this project. Agencies need to understand their role in addressing the issue. Taking a multi-agency approach requires perseverance. It can take some time for all agencies to see the need for their input and initial attendance at meetings can be low. Looking at key people to link with and continuing to push forward with the project was eventually successful. The project needs a lead driving it and at least two or three other interested motivated key people to enable it to progress. Admin support is also vital.
5.3 Tameside NHS Foundation Trust
– Engaging with Young People

Organisation

Tameside Hospital Foundation Trust is a mixed-specialty district general hospital. The Trust has over 23,500 Members (Public and Staff) and serves a population of 250,000 people. The Trust employs 2,361 staff (2,050 WTE) and has 542 acute beds.

Our Trust mission statement is:

“At Tameside Hospital ‘Everyone Matters’. Our aim is to deliver, with our partners, safe, effective and personal care, which you can trust.”

Our goal is to become an organisation in which every member of staff understands their role and responsibility in delivering high standard, safe, quality care and works to that goal every day. It is our staff that make the difference and are the key to excellence.”

Helen Howard - Matron for Patient Experience & Quality Improvement

Summary

In September 2014 Tameside NHS Foundation Trust went into new partnership arrangements with Tameside College in offering Student Placements for second year students on their Health and Social Welfare Course (HSC Level 3). The aim of the partnership is to enable students to gain experience and to develop key skills of working in a ward environment within an acute hospital setting, with a view to them undertaking a professional qualification in healthcare. Each Student completes an initial full week on placement then attends weekly through to one final full week placement.

We feel this is an excellent example of partnership working as the collaborative approach across agencies in North Tyneside contributed to the success and sustainability of this project. It brought together professionals who were all struggling to manage a significant issue and enabled them to pool resources, skills and knowledge to develop the Training and resources for use in practice.

As a Trust we will benefit from having students who have an interest in health learning from the staff on the wards and using the skills they are developing in providing care for our patients, thus enhancing the patients experience whilst in hospital.

This partnership working deserves recognition because this model fits with the modern agenda of involving young people in volunteering in hospitals. We have developed a way of ensuring we provide a learning environment for students to enhance their opportunities for education and also ensure they utilise the skills they are learning whilst improving our patients experience in hospital.

Rationale & Context

The aim of the partnership is to enable students to gain experience and to develop key skills of working in a ward environment within an acute hospital setting, with a view to them undertaking a professional qualification in healthcare. Each Student completes an initial full week on placement then attends weekly through to one final full week placement.
Rationale & Context continued

- The students are encouraged to use their classroom learning and bring this into practice within the ward environment. Students are encouraged to engage with patients and may use tools such as memory boxes with patients with dementia.

- Students additionally provide assistance at meal times in the role of Dining Companions. The aim of a Dining Companion is to ensure that patients in hospital receive nutrition in a timely and comfortable manner, where assistance or encouragement is required. When people are ill, elderly or frail, it is especially important that a good balanced intake of food and drinks are maintained.

- The Dining companion project has been predominately with our volunteers but the college students have received training and also engaged with this role. All volunteers and students have attended a comprehensive training programme which is facilitated by qualified specialist practitioners. The Dining Companion initiative has been evaluated as successful in improving the patient experience.

- Participating Students have the opportunity to learn new key skills as a Health care Assistant from hospital based training under the supervision of the Ward Manager and other qualified staff. Working on the wards they are able to achieve the required competencies for their course.

Planning & Delivery

- Prior to commencement of the project a number of meetings were held with the college’s two Placement Officers and their Head of Health and Social Care. Engaging with the Ward Managers has ensured they are fully engaged and supportive of the initiative, and this has been paramount in ensuring the successful implementation of the project. The project has been supported by a HR Project Manager and the Matron for Patient Experience & Quality Improvement.

- Students having completed recruitment checks, induction and mandatory training have been placed on the wards in Adult General Medicine. Each Student completed an initial full week on placement then has been attending daily from the beginning of their placement The placement will continue through to one final full week on placement in February 2015. The students from the college expressed an interest in having their placements in the acute hospital setting and a number of the students wish to continue to become health care professionals.
Impact & Results Achieved

- An evaluation of the student experiences has been carried out. The students, placement officers and Ward managers were asked to provide an evaluation of the placements. The Ward Managers have been delighted with the students and the progress they had made whilst working on their wards and reported they have learnt from the ward based experience, grown into the role and have been welcomed as part of the ward team. The ward managers commented that the students have grown in confidence during their placements and have been encouraged to be proactive in seeking out information and adopt a questioning approach.

- Overall the students have really enjoyed their placements and have gained valuable experience. It has enabled them to become involved in ward routine and see a variety of other professionals at work. They felt welcomed, needed and supported by key members of staff. The evaluation also identified that the students felt valued and respected. It has been pleasing to note the students would recommend the placements to others.

- The carers surveys from the wards where the students have been allocated recognise the positive impact the students have had upon the patients experience. It is also notable that the placements are supporting university applications.

- Overall the Ward Managers, Placement Officers and Students were very happy with how the placements had gone. Benefits were evident on all sides. In light of this, the Placement Officers have requested additional placements to be offered on other wards possibly stroke and/or paediatrics from September 2015 to extend the students experience in areas such as Physiotherapy, Speech and Language, social care, Mental Health and discharge.

Key Learning Points

The key learning points from the project have been to ensure systems are:

- Good communication between both partners.
- Provide a Students Ward Induction Pack supported by a comprehensive local induction.
- Provide the Ward Managers and ward staff with written Student Placement Guidance to clearly identify what a student is able to and is not able to participate in.
- Arrange for Students badges to be available prior to placement start date.
- Ensure students are allocated a supervisor/key worker for guidance at the beginning of and during each placement day. The supervisor/keyworker at the beginning of a shift will provide information on the patients currently on the ward. The Student Supervisor/Keyworker will endeavour to check the Student is able and competent in dealing with the situations they are placed in particularly if this is outside their usual experience.
- Managers to ensure students are aware of where to find information related to patient care. When information is not readily available the students must ask before proceeding—to be covered at local induction.
- Provide information/guidance for students on end of life care.
- Managers will be invited to bring along key workers or send a representative when they themselves cannot attend student placement meetings.
This is an example of a project which could be easily adapted to work with Children & Young People even though this group was not the sole focus of the original work undertaken. It is particularly relevant to the issues highlighted by the CQC survey regarding the poorer results for children with learning disabilities.

**Organisation** - Northumberland is a large county with predominantly rural communities and small urban settlements which are home to around 1800 people with learning disabilities recorded on GP registers.

- 4 integrated Community Learning Disability Teams consisting of LD nurses, social workers, care managers, SALT, OT and community support workers provide specialist support and interventions to around 1300 people with varying degrees of learning disabilities to promote physical and emotional wellbeing and quality of life. The majority of people with a borderline disability or learning difficulty are not known to any specialist services.

- As people are living longer, there are now more adults with a learning disability aged over 45 than under 18 years of age living in the community, rather than in institutional care. Local consultation with a wide range of ages including older people with learning disabilities indicated they often had multiple health conditions, did not understand changes as they aged, sometimes had poor experiences of sexual relationships and exploitation, difficulties in coping with bereavement and with changes in behaviour associated with dementia among friends and family (which is more common in people with Down’s syndrome at an earlier age) and young people.

**Summary**

- National reports (including Healthcare for All (2008)) have highlighted the need for a better understanding of and changes to the way people with learning disabilities are supported.

- Consultation with people in the local area who have learning disabilities and their families told us that they would like support to better understand better how their bodies work, changes such as puberty and the menopause, know how to check for and understand changes, opportunities to discuss relationships, sexuality and sexual health and have more support around bereavement and loss.

- The Josephine & Jack programmes were developed as an innovative way to offer this support by Northumberland County Council and the Community Business Unit of Northumbria Healthcare NHS Foundation Trust (Council delegated Adult Care responsibilities) working together, commissioned through Public Health.

- Josephine and Jack are used to deliver support either individually or via small workshops and feedback has been very positive and there have been requests to extend the referral system to local schools and Northumbria Police.

- As the licence is held by the local authority but managed through the community business unit of Northumbria Healthcare, we believe this is an excellent example of innovatively involving social care to improve experience, giving greater opportunity for integrated use to address individual issues in a very personalised way.
Rationale & Context

• A number of national reports including Healthcare for All (2008) have highlighted the need for better understanding of and changes to the way people with learning disabilities are supported. We know that they are still more likely than the general population to experience diagnostic overshadowing and health inequalities resulting in premature death, more medical conditions such as epilepsy, diabetes or heart problems, be over or under weight, have hearing, visual or communication impairment, develop dementia, experience delays in diagnosis or treatment and be admitted more to hospital.

• During consultation people with learning disabilities and their families told us they would like to understand better how their bodies work, changes such as puberty and the menopause, know how to check for and understand changes, opportunities to discuss relationships, sexuality and sexual health and have more support around bereavement and loss.

• We have 100% sign up by GP practices to provide annual health checks as a Directed Enhanced Service (DES) and continued high uptake (currently 84%). The role of the Community Support Workers and LD Nurses contributes in supporting people with health care appointments in primary care, acute care, podiatry, chiropody, dentist etc. plus health promotion activities and outpatient appointments. While we have increased uptake of breast screening, bowel and cervical screening rates remain low.

• We therefore wanted to look at how we could offer extended personalised support by working together, with people with learning disabilities and their carers, Northumberland County Council and the Community Business Unit of Northumbria Healthcare NHS Foundation Trust (Council delegated Adult Care responsibilities) have therefore developed an innovative approach to supporting people with learning disabilities which is being offered through the Josephine & Jack programmes.

Planning & Delivery

• Josephine & Jack were commissioned through Public Health in response to demand from the Northumberland Learning Disability Partnership Board (Chaired by the local authority Head of Safeguarding and Strategic Commissioning), which reports locally via council committees, into the Health & Wellbeing Board and nationally to iHAL Public Health Observatory on the key targets of the Health Assessment Framework. They are operationally managed jointly through the Learning Development Unit and Involvement & Service Development Team of Northumbria Healthcare NHS Foundation Trust.

• ‘Josephine’ and ‘Jack’ are anatomically correct innovative interactive learning resources used to explore a range of health, wellbeing, relationship and sexual health issues in a confidential and supportive environment. They were commissioned from Them Wifies, under a social licensing agreement and designed to meet the specifications that resulted from consultation with a range of people with learning disabilities across the county.

• Both Josephine and Jack are life-size have all the same body parts are a real person plus some additional features as learning aids. Josephine for example has removable breasts one with a lump and one without to support breast checking. Similarly Jack has interchangeable genitals with a lump in one testicle and the option of a circumcised or retractable foreskin penis. Other features include removable pubic hair, some internal organs and spaces inside their heads where thoughts can be put and explored. They also have accompanying resources including a diary, uterus with baby, sperm, seminal fluid, speculum and emotion faces which can be used to support specific sessions. For example we use the diary to explore permission to read it and discuss scenarios created in it about feelings, events and potential actions.
**Impact & Results Achieved**

- We have established a referral system overseen by senior practitioners who assess referrals and allocate facilitators accordingly to provide small group workshops or individual support, which has seen a significant increase in demand over the last 12 months. We can correlate the number, ages and types of referral by locality including those in safeguarding who are then referred on to the Josephine & Jack project. This helps us identify levels of demand and any trends around patterns of referral and support.

- Feedback from workshop participants has been very positive and has shaped the prioritisation of developing bereavement support in 2014.

- A small group have developed their skills and confidence to be able to present the Josephine & Jack project to wider audiences such as the Learning Disability Partnership Board to feedback on progress.

- As the work with Northumbria Police progresses we will be able to record the number and types of cases where evidence was gathered using Josephine & Jack and any resulting prosecutions and convictions. We are also looking at ways in which we can measure the social return for example in terms of uptake of screening, reduction in the number of sexual transmitted infections, reduction in the number of people taking part in sexual activity without their consent.

**What makes this Initiative Special?**

- The licence is held by the local authority but managed through the community business unit of Northumbria Healthcare as part of our partnership agreement. This gives greater opportunity for integrated use to address individual issues in a very personalised way.

- Both Josephine and Jack can be animated by the facilitators who are trained to utilise them in a drama based approach to workshops. We find people respond and relate very quickly with Josephine and Jack which enables openness about often difficult to discuss issues including safeguarding. So much so that Northumbria Police have now expressed an interest in using these resources to gather best evidence in some cases and we are currently exploring how this might progress.

- The Josephine project was recognised as an example of innovation and good practice in training at the National Learning Disability awards in 2014. As a result we have received enquiries from other local authorities and healthcare providers who are interested in knowing more.

- In the validation process for the 2013 Joint Health & Social Care Learning Disability Assessment Framework it was also highlighted as an area of innovation and good practice: “The Josephine project is a highly imaginative and interactive approach to supporting women with LD to improve their knowledge and understanding of women’s health issues”.

**Key Learning Points**

- We would recommend careful consideration of how resources will be used and managed before commencing to ensure that they have all the features required incorporated into the original design as it is likely to incur additional costs to change them at a later date.

- It is key to have organisational sign up to identify and agree staff with their line managers as the time commitment to training and facilitating can be considerable.
Organisation - University Hospitals Birmingham NHS Foundation Trust is a large acute hospital situated in south Birmingham. With over 8,500 staff, UHB provides direct clinical services to nearly 900,000 patients every year, serving a regional, national and international population. It is a regional centre for cancer, trauma, renal dialysis, burns and plastics and has the largest solid organ transplant programme in Europe.

Summary
- University Hospitals Birmingham (UHB) Orchards and Gardens is a working title for a broad range of community, patient and staff initiatives. It ranges from newly planted orchards, raised beds, a sensory garden, bluebell and snowdrop wood, bee hives, wild flower meadow, fruit and vegetable stall and farmers market. With the ambitious target of planting 2,000 trees and making 16,000 square metres of land available for use by community groups UHB is well on its way to achieving its objectives. Key is engagement with groups to make the site sustainable so we have engaged with a wide range of very supportive stakeholders. Dame Julie Moore, UHB Chief Executive, is a key supporter of the project and the entire Executive Team take an interest in the latest developments.
- Our hope is to inspire other trusts to ‘blur the edges of healthcare’ and engage with their communities, patients and staff in new and innovative ways.

Rationale & Context
- Originally we established a fruit and vegetable stall to make available reasonably priced fruit and vegetables to our local community, patients, visitors and staff. The stall serves approximately 3,000 people per week and sells over 600kgs of fruit and vegetables a week. We then introduced a Farmers Market; designed to support local businesses and provide that ‘something different’ for our local community, patients, visitors and staff. Key was supporting community groups working with disadvantaged people. We soon became aware of groups offering fruit trees, plants and seeds to community food growing groups but availability of land would always be an issue. This is where we came in. Acting as ‘host’ UHB has made land available across a wide range of projects from habitat enhancement, becoming a Nature Improvement Area, opportunities for the rehabilitation of patients and continuing care by supporting the ‘Greening Dementia’ initiatives to different types of food growing.

Planning & Delivery
- Key to the delivery was involving as many local stakeholders as possible to offer us professional horticultural advice on what we could do where. By attending a Birmingham-wide conference on food, we managed to identify key people across the city who could work with us and help the projects become a reality in a sustainable and professional way. Groups include The Trust Conservation Volunteers, National Trust, Birmingham City Council, DEFRA, Public Health, Cofley our PFI partners, The Woodland Trust, local authority Ecologists, Planners and Tree Conservation experts as well as the local Wildlife Trust.
Internally, the project has been ‘team briefed’ and high level support gained from the Chair, CEO and Trust Board, staff and volunteers. As the majority of the UHB site is Roman Fort designated a Scheduled Ancient Monument (SAM), it has been essential that we engage with the local authority and English Heritage (EH). Permissions for every step of the projects affecting the SAM has involved EH and required UHB to seek Scheduled Monument Consent from the Secretary of State for Culture Media and Sport. The planning has had to be detailed and meticulous in order to gain consent.

Impact & Results Achieved

- Results are not easy to quantify, however the fruit and vegetable stall is now a permanent fixture three years after first trialling it. The majority of customers are local people and visitors whose feedback is extremely positive. The farmers market has been trading for two years and become a permanent fixture in the region’s markets with stallholders reporting some of their best trading at any market. Staff feedback is excellent as they have an opportunity in work time to try something different and feel that UHB cares enough to put things on for them. The orchards and gardens have achieved in 12 months what was projected to take 24 months and has seen UHB as a group winner in Birmingham in Bloom and winners of the NHS Forest Awards for most number of trees planted. It is too early to better evaluate other initiatives that are still at the building stage but this will come in the following months and years.

What Makes this Initiative Stand Out?

- It is hard to say what makes this project special because it is made special by the people who are inspired and involved in it. It is through their collaboration and hard work that we are where we are today. I think there are elements that are unique and the site being on a Roman Fort brings uniqueness. There is no doubt that had we not had the Fort on site the land that we are now able to use would have been built on many years ago so the Fort is a blessing.

- The process of consent has been an experience and working with English Heritage has been very positive. Meeting groups and people, discussing the projects leads us into areas we hadn’t thought of. For example the throw away comment about elderly people not having anywhere safe to exercise spawned the ‘walk and talk’ initiative. Connecting with the History department at Birmingham University because of the Roman Fort meant we became aware that our participants could actually handle the artefacts. Our existing collaboration with guide dogs made the connection with blind people handling the artefacts so they could ‘see’ the site in a new way. As we work with each different group we find different ways of better understanding that group and of connecting with them to either better understand their needs or to offer something that might enrich their lives. It is really exciting and a privilege to do.

- We plan to engage with local schools to become a ‘field site’ for history, food production, woodland, pollinators and nature. We have linked with Birmingham University History department to start ‘walk and talk’, our project to bring exercise, knowledge and mental stimulation to elderly people and those with visual impairment. This will see oral historians walking and talking with groups about the Romans, industrial heritage, the canals, medicine over the ages to name but a few. Patients, staff and community groups will be able to handle artefacts that are otherwise behind glass as well as view loaned exhibitions of art and sculpture in the hospital.
Learning Points

- Identify key stakeholders very early on – we were ‘becalmed’ and became despondent very early on we found it difficult to find the right people.

- Research your subject – we are healthcare, we know it and know who to connect with but we didn’t know horticulture.

- Go to people and do not expect them to necessarily come to you.

- Network and ask – this is how we built up the incredibly supportive key group of supporters that have opened up many more opportunities.

- Do not expect to get something for nothing, third sector groups are not established to be at your ‘beck and call’ to provide their expertise and time for nothing.

- Do not be scared to ask for help and sponsorship.

- Expect knock backs as not everyone will share your enthusiasm for your project.

- Engage the Executive Team. Don’t assume everyone in the organisation will be happy to have extra work foisted upon them by your ‘touchy feely’ project.

- Be tenacious and don’t lose the vision that originally inspired.

- Engage your neighbours so they can join in.

- Share the credit – no one likes a ‘big I am’ and this is a team approach.

- Plan for the long term – orchards in particular do not grow over night.

- Tweak the project to appeal to as many people and groups as possible.

- Ensure that you discuss any commercial collaboration so that there are no conflicts of interest.

- Communicate – tell people what you are doing so they can comment and get involved.
5.6 University Hospital Southampton NHS Foundation Trust – Safer Care Checklist

“if you see something, say something”

We know parents are the ‘experts’ in their child and may notice any signs of deterioration or think something ‘isn’t right’ before others.

These films have been created by NHS England to help parents and families to speak up if they see something they are worried about.

Scan the QR codes below to watch the videos:

Family time: ____________________
Family doctor: ____________________

Visit the website at:
www.england.nhs.uk/makework/
patientsafetyre-act

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone 023 8120 4688 for help.

www.uhs.nhs.uk/childrenshospital

Safer care checklist

We want to make sure that you:
1. Understand your child’s care, and
2. Know how to raise any concerns you may have about your child.

This checklist was developed to make sure that:
• You understand why your child is in hospital
• You know which doctor is in charge of your child’s care
• You know how to ask for help if you are worried about your child while they are in hospital

What to do if you are worried about your child while they are in hospital

Sometimes children and young people become more unwell after coming into hospital. Parents and carers often worry that something isn’t right but often don’t feel confident enough to tell us. It’s important you let us know if you are worried about your child, or if any of the following apply:
• You think your child is becoming more unwell
• You think your child is in pain
• You don’t think your child is getting the right treatment

How to do this:
1. Speak to the nurse looking after your child. They will contact the doctor if necessary. If you can’t find them, ask any nurse or press the call bell by the bed. In an emergency pull the emergency buzzer.
2. If you are still worried, ask to speak to the nurse in charge of the ward.
3. In the unlikely event that having spoken to the nurse in charge of the ward you are still worried, then you can speak to the specialist outreach nursing team by calling: 07775 512308. They will come and speak to you, assess your child and contact the senior doctors looking after your child.

Sometimes parents and carers can’t say what they are worried about. If this is the case, please use the tear off slip to alert us that something is worrying you about your child’s wellbeing or the care they are receiving. You can give the slip to any nurse or doctor.

Please use the red slip in an emergency. If you are very worried that your child has suddenly become very unwell, or is slowly getting worse and you think we have not realised.

Hand the slip to a nurse or doctor and they will review your child urgently.

Please share good practice

Please share anything that you felt was particularly good about your child’s care by completing the feedback form available from your nurse.

Knowing what was good about your stay helps us make sure good practice continues.

Be aware

Please alert us to anything that makes you concerned about your child’s care.

Your child’s name:

Time: ____________________
Date: ____________________

Please supply any details that you can:

Stop! Give to any member of staff

I am very worried about my child’s condition and would like an urgent review.

Your child’s name:

Time: ____________________
Date: ____________________
Pull the emergency buzzer behind the bed if immediate help is required.
Introduction

Harvey’s Gang started at Worthing Hospital and was launched in 2014 in memory of eight-year-old Harvey Buster Baldwin from Sompting, who had leukaemia.

The initiative has been offering youngsters who face serious illnesses, like cancer, the chance to tour pathology laboratories to understand things like how their samples are used. Harvey’s Gang invites youngsters with cancer and other serious illnesses to become trainee biomedical scientists for the day and tour pathology laboratories with their families. The project is now taking place in NHS hospitals in London, Kent, and Hampshire and is spreading to others in Somerset, Suffolk, Surrey, Sheffield, Birmingham and Newcastle in the New Year.

The trust which runs Worthing Hospital has announced Harvey’s Gang is now being introduced in countries including Australia and Japan.

Harvey’s mum, Claire Baldwin, said:

“We are totally astounded by how many people have put their hearts, minds and positivity into Harvey’s Gang for the benefit of other children. Harvey would be really chuffed and I think very proud to have left such a wonderful legacy. It’s simply wonderful.”

Harvey received treatment for leukaemia at Worthing Hospital for 18-months and, while staying on the children’s ward, he asked what happened to all his blood samples. Staff arranged for a special visit to the pathology labs where he was given his own white coat, a trainee biomedical scientist badge and shown how to process his own blood.

Chief biomedical scientist, Malcolm Robinson, said:

“It was a real honour to host Harvey for a few hours as he was so interested in all the equipment and how we analyse and process blood samples. However, it was only when they showed a picture of him and me on that special day at his funeral a few months later that I realised just how much the experience had meant to him and his family. Within a week we had named a new blood grouping machine in his memory and Harvey’s Gang laboratory tours for sick children was born.”

How It All Unfolded

Harvey was brought in to A&E on 23/03/2013 Hb 36 g/L, diagnosed, Acute Leukaemia; (Acute Myeloid Leukaemia: (AML). Harvey was AB Rh Positive. Bank Manager, our LIIMS, had been set up for Harvey to receive Irradiated and CMV Negative Blood and Blood products.

We transfused Harvey and he had had lots of samples processed and was curious as to how and why they were done. Staff arranged for a special visit to the pathology laboratories where he was given his own white coat, a trainee biomedical scientist badge and shown how to process his own blood.

Chief biomedical scientist, Malcolm Robinson, said:

“It was a real honour to host Harvey for a few hours as he was so interested in all the equipment and how we analyse and process blood samples. However, it was only when they showed a picture of him and me on that special day at his funeral a few months later that I realised just how much the experience had meant to him and his family. Within a week we had named a new blood grouping machine in his memory and Harvey’s Gang laboratory tours for sick children was born.”

Some of the young patients who have joined Harvey’s Gang at Worthing and St Richard’s Hospitals
Over the past year biomedical scientists at Western Sussex Hospitals NHS Foundation Trust have hosted 21 visits for sick children at Worthing Hospital and St Richard’s Hospital in Chichester.

In September, Harvey’s Gang received national recognition at the NHS Expo 2015 where it was awarded the Kate Granger Team Award for Compassionate Care. The project is now spreading to NHS hospitals across the country and thanks to the support of Ortho Clinical Diagnostics it also heading to Australia, Japan, United Arab Emirates and into the EU.

Harvey received shared care at The Royal Marsden. He had started Chemo and BMT donated from his brother Max. His BMT worked, unfortunately Harvey rejected the BMT and sadly Harvey lost his fight on 6th October 2014 due to Host versus Graft Disease. Harvey had his farewell on Monday 20th October 2014.

At the ceremony the family played Eva Cassidy; “Somewhere over the Rainbow”. Through my tears, I promised Claire, Harvey’s Mum, that we would make Harvey famous. Jon Rabbs, Consultant Paediatrician, also told me that they had a number of kids that would also really enjoy a Lab tour.......... 7 critically ill kids!

#HarveysGang was born

• How can we ensure that we do more, and BETTER?
• We have introduced the “ickle white coat” - very, very cute.
• We give Certificates of Attendance to the youngsters, together with: Ortho Clinical Diagnostics Goody Bags, Lab Cold Penguins, SHOT office; Pens, Tutela Medical; 3 colour Highlighter Pens and SWEETS!

#Harvey’s Gang initiatives are now taking off elsewhere

• Harvey’s Gang embraced by NHS Friday December 4, 2015 Pathology staff at King’s welcome their first Harvey’s Gang visitor, seven-year-old Daniel Ngegba
• Children in hospitals around the country are receiving VIP treatment thanks to #HarveysGang

  We all had a tear in our eyes when we received Daniel’s thank-you note

• King’s College Hospital in London welcomed their first Harvey’s Gang visitor on 17 November, seven-year-old Daniel Ngegba, from Peckham.

• Daniel, who has sickle cell anaemia, has received nearly 50 blood transfusions in his short life and was fascinated to watch how the blood units for his transfusions are selected. He said: “I’ve always wanted to be a scientist, it’s my dream and it came true for the first time ever.”

• The visits also make a huge difference to the scientific support staff working in hospitals who do not usually see patients while carrying out their critical work. Barbara Umlauf, Quality Manager in the King’s Blood Transfusion Laboratory, said: “We all had a tear in our eyes when we received Daniel’s thank-you note – it was a humbling reminder of why our job is important.”

• Hospitals from all around the world will soon be able to apply for ‘Harvey’s Gang in a box’, containing mini white lab coats for the children, certificates and goodie packs including Harvey’s Gang branded LEGO, picture books and DVDs, all funded by charitable donations and corporate sponsorship.

• If you would like to donate and help the project raise £900 please visit: https://crowdfunding.justgiving.com/malcolm-robinson-2
5.8 Southampton Children’s Hospital - Ready, Steady, Go – CYP Transition Programme

Introduction

Issues with transition from child to adult care was clearly highlighted in our original report. The Ready Steady Go programme has been developed by Dr Arvind Nagra and her team at Southampton Children’s Hospital to address just such issues and has been widely acclaimed.

The “Ready Steady Go” transition programme is designed to be used as a preparatory programme for young people with long term conditions aged 11 years and older. The programme is used by the health professionals in conjunction with young people, their families and carers to support the transition from children’s to adult services. The word ‘transition’ is used in this context to describe the process of preparing, planning and moving from children’s to adult services.

The Ready Steady Go transition programme is a generic programme as it has been recognised that many of the challenges faced with each sub-speciality group are similar.

It has been recognised that moving away from a team of doctors and nurses that young people have been with for many years can be a daunting process. The aim of the programme is to encourage the involvement of young people and their families and carers in the transition process at several key phases. Ready Steady Go helps to empower young people by equipping them with the knowledge and skills to confidently manage their healthcare successfully and confidently in both paediatric and adult services thereby allowing them to be more confident about the move to adult services.

Ready Steady Go Hello questionnaires:

The “Ready Steady Go” questionnaires have been designed for young people to complete and discuss with their health care professional. They address the young person’s knowledge about their condition, self-advocacy, healthy lifestyle, sexual health, pregnancy, education/vocation, psychosocial issues and the concept of transition itself.

The questionnaires are designed to be used to check and identify skills, knowledge and confidence levels that are in place or require further support and development. Any issues raised are addressed ‘in small bite size pieces’ - not in one consultation.

The answers are also used as a basis for starting a discussion which reveals whether the extent of the patient’s perception of their own knowledge and skills is justified. Some are prone to misrepresentation - accidentally or otherwise - this should be picked up through discussion and the underlying issues addressed. The questionnaires are also used to help lead to appropriate engagement over potentially difficult issues such as sex and psychosocial concerns. Any issues which may arise are carefully addressed prior to transfer to adult services.

Parents and Carers Transition Plan

The parent and carers transition plan is designed to be completed by the parent/carer alongside the young person’s Ready, Steady or Go questionnaire to ensure any concerns or issues raised by the parent/carer are addressed.

It is designed to help parents and carers develop and feel confident about their knowledge and skills during the period of transition and to help support them as they support their young person through the transition process.
Ready, Steady, Go Transition Plan

The Ready, Steady, Go transition plan is designed to be completed by the young person’s health care team. Any issues raised can be documented and addressed. The transition plan is used to track progress against identified actions and goals.

Where the Young Person has learning difficulties the parent/carer also works through the Ready Steady Go questionnaires with the Young Person engaging as much as possible. This prepares the carers for the move to adult services; the programme allowing all concerns and issues to be carefully addressed and progress monitored prior to transfer.

Transition: Managing your Long Term Condition
‘Hello’ to adult services

Hello Questionnaire

The Hello questionnaire is completed by the young person/adult at their first appointment in adult services. Any issues or concerns raised are addressed by the adult team – in small bite size pieces over a number of consultations.

The Hello questionnaire is completed by the young person/adult annually or bi-annually to ensure knowledge and skills are maintained and any ongoing or new issues are addressed.

Hello to adult services is a follow on programme from the Ready Steady Go programme used in paediatric services and follows the same format.

The Hello programme can be used as a stand-alone programme for any young person or adult first diagnosed with a Long Term Condition in adult services (see Hello user guide).

The programme is used by the health professionals in conjunction with young people and adults and carers and helps to empower young people and adults by equipping them with the knowledge and skills to confidently manage their healthcare successful and confidently in adult services.

The Ready Steady Go Hello questionnaires are designed to be completed by young people and adults who are first diagnosed with a Long Term Condition in adult services. Any issues raised are addressed in ‘bite size pieces’ over a number of consultations not in one consultation. Transition in this case is empowering the adult with the knowledge and skills to successfully and confidently manage their health care.

The questionnaires address the young person’s/adults knowledge about their condition, self-advocacy, healthy lifestyle, sexual health, pregnancy, education/vocation, psychosocial issues and the concept of transition itself.

The questionnaires are designed to be used to check and identify skills, knowledge and confidence levels that are in place or require further support and development.

The answers are also used as a basis for starting discussion which reveals whether the extent of the patient’s perception of their own knowledge and skills is justified. Some are prone to misrepresentation - accidentally or otherwise - this should be picked up through discussion and the underlying issues addressed. The questionnaires are also used to help lead to appropriate engagement over potentially difficult issues such as sex and psychosocial concerns. Any issues which may arise are carefully addressed.

We would like to acknowledge the AQuA Action Ready, Steady, Go user guide for much of the explanation of this excellent programme

The programme has been very well received across the health-care arena and is currently being adapted for a number of different settings and specialisms, including adaptations for learning disabilities.
5.9 NHS Digital Badges

Introduction

NHS Digital Badges are an exciting and innovative way to engage children and young people (CYP) in health and care.

Background information

Digital badges, work rather like Brownie/Guide/Scouts or swimming badges. You do a number of tasks and you earn a badge. However, they have been reinvented for the digital age and Children and Young People are loving earning them!

NHS England has teamed up with Makewaves a safe social media platform and developed 12 NHS Digital Badges for 5-16 yr olds. These are grouped into NHS Explorer, NHS Reporter, NHS Inspector and NHS Citizen. You can view the badges and badge missions at: www.makewaves/nhs

- Digital badges are a fun way for CYP to find out more about healthcare, share their views, get involved in their own health and gain recognition for their achievements.
- The platform can be used for themed health discussions and campaigns so you can share information and hear the voices of CYP.
- Over 4000 schools are already registered on the Makewaves platform providing a unique way to engage with a diverse range of CYP whether locally or nationally.
- Health or youth organisations can join for free, so CYP they work with can earn badges the platform can be used for discussions and campaigns.

Inspire positive health changes in children and young people with health Badge Missions

Digital badges, perhaps could best be described as being similar to brownie or cubs/scout badges – but digital! We know younger children just love to collect things and for older children/young people the badges offer an opportunity to show achievements. The badge missions encourage the development of positive health skills in a fun way using the technologies that young people love to use to communicate. Digital Badges also offer a new way to value and recognise health skills and behaviours.

Two year’s ago, the Department of Health ran a School Nursing workshop exploring ways that safe online social tools could be used to enable positive health messages to reach more children and young people. The co-production workshop brought together school nurses and young people to develop ideas and work together on content – we wanted to ensure the badges worked for young people, school nurses and teachers.

Working in partnership with Makewaves, the safe schools social network of 70,000 children and young people, 10,000 teachers and 3,500 schools, school nurses worked with teachers and young people to develop a series of online ‘Badge Missions’ around key public health themes. A badge mission delivers a series of challenges to students in a fun and interesting format. Students can then respond by submitting their own blogs, films, pictures or podcasts as evidence to show their skills, learning or health tips and qualities in order to earn the badge.

Digital Badges developed by School Nurses, teachers and young people can now be awarded to children and young people in schools and youth groups. This idea of a ‘safe youtube’, and the potential of peer creation and sharing of health messaging by young people came through strongly in the School Nurse social media workshop. It was seen as a strong and effective way forward when approaching early intervention and prevention with children and young people.
The film found at
https://www.makewav.es/story/773399/title/knowyou
rhealthearnthebadges shows the badges in action, and
students’ responses to them. The badges all focus on
key public health issues, the first set of badges to
launch included the Stress Buster badge, Me and My Teeth, Flu Fighter, Know My School Nurse and Health Champion.

Badges currently in development include the following themes: healthy relationships (including sexual health), healthy weight, smoking cessation, dementia friendly and mental health.

If you would like to work with children and young people in your area to earn these badges, enable your school nurses and schools to use these badges or feed in to the development of the new badges you can do this by contacting Sharon Middleton at Makewaves—sharon.middleton@makewav.es

Find out more about the badges at www.makewav.es/health and www.makewav.es/nhs where you can view films of young people earning and creating the badges. We are piloting these badges and working in partnership with school nurses with the aim of inspiring change in young people’s health behaviours. Whether you are a young person, a teacher, a school nurse, or a youth group leader, we want everyone to join us and help build the momentum behind these potentially revolutionary badges.

If you would like to make use of these badges in your area, you can now and we would encourage school nurses to use the badges to promote public health messaging in a fun, creative way. Submitted by Sharon Middleton makewav.es and Wendy Nicholson
5.10 Ipswich Hospital NHS Trust
- Engaging with CYP, ‘Voice 4 Change’ Young Persons User Group

Introduction

2015 has seen the inception of the ‘Voice 4 change’ Young person’s group. Made up of 12 young people aged between 16 and 22, the group has made great inroads in identifying their key objectives, and how best they can position themselves within the Trust to ensure that their voice is not only listened too but also acted upon. Their first objective was to campaign for an ‘adolescent ward’ within Ipswich Hospital, something that they learned about from our colleagues at Addenbrookes who have an adolescent Cancer ward. Their other objectives range from intergenerational work on the Constable Suite, and to actively raise awareness around young people and Mental Health. The future is incredibly bright for the ‘Voice 4 change’ group who have ambitions to represent young people’s health regionally and a proposal to represent young people on the trust board has already been tabled.

If at first you don’t succeed....

CYP Listening Event – advertised countrywide

What Next

The NHS Ipswich and East Suffolk Clinical Commissioning Group has a Young Persons Forum – YEAH! This is a group of young people from local upper schools who share a commitment for health and a passion for making a positive difference to the healthcare services delivered to their peers. At monthly meetings, members inform plans for engagement and how they can contribute to them. We welcome new members from the local area to join us to help in making those healthcare decisions directly related to those aged between 11 and 19.

Intergenerational Gaming / Bingo
Social Networking to tackle Social Isolation

Promoting children and young people’s health and wellbeing across the county.

How We Did It

- Approached local schools/ Colleagues
- Role specific volunteer post advertised across schools/colleges and online.
- Set up Twitter account
- Facebook Group
- Brought friends along
- Grew to 20+ members

Joint venture with Healthwatch UK  Pants & Tops again...
5.11 Fixers – CYP videos

Introduction
Fixers are young people using their past to fix the future. They are motivated by personal experience to make positive change for themselves and those around them.

Real people, real stories, real change.
Fixers have different backgrounds, interests and life experiences, and come from every corner of the UK.

But they do have several important things in common.
They are motivated by a desire to act on an issue that is important to them or a strong desire to help other people.
They also have a voice that they want to be heard, whether that’s on eating disorders, drugs, offending, cyberbullying or any other issue that is concerning them. Becoming a Fixer allows that to happen.

Fixers are heard, understood and respected by others.
Fixers choose the issue they want to fix and, using the skills of a team of creative experts, they work out how to make sure their message is heard by the right people, whether that’s through a unique film, a leaflet or poster campaign, a website, an event or workshop.

Then they use digital, print and broadcast media to make their voice heard as far and wide as possible.

Fixers win awards, meet their MPs and some have even gone on to set up their own charities.

To date, more than 18,340 Fixers from Scotland, England, Wales and Northern Ireland have started - and are continuing - 2,050 unique projects and 785 Fixers projects have been showcased on ITV, UTV and STV regional news programmes across the country, providing more than 50 hours of peak-time exposure to their projects.

Anyone can become a Fixer. You can fix anything you like – as long as you benefit at least one other person.
So, become a Fixer or become a supporter of Fixers today!

Sign up for the Fixers newsletter and stay informed about what we’re up to with regular updates on Fixers' stories, broadcasts and resources.

Videos

Three films were shown at the CYP events which were produced by Fixers – they can be found on the PEN website or by clicking the links below:

Behind The Curtain – Click here for the video

Born Into Intensive Care – Shelley Marsh…..A Mother’s Story – Click here for the video

See The Child. Change The System – Click here for the video
5.11 Fixers – CYP videos

Fixers
25th January 2016

THE FIGURES

18,344 Fixers
400 Fixers per month
2,053 Fixers

9 out of 10 Fixers tackle issues which they have personally experienced

95% recommend becoming a Fixer to a friend

97% gain soft and hard skills

98% There’s a Fixer in local authority areas and every geographic postcode

9% of Fixers are gay, lesbian or bisexual

22% have declared a health issue, illness or disability

9% of Fixers are NEETs

710 private businesses
476 education establishments
1,641 third sector organisations

are supporting Fixers

THE REACH

Monthly reach of 8.4 million across 14 TV regions

52.3 hours of peak air time

8,293 Twitter followers

18,312 likes on Facebook

1,343,942 views across 2,003 films

43,000 unique visitors to www.fixers.org.uk monthly

fixers.org.uk

Patient Experience Network
Re:thinking the experience
5.12 Yvonne Newbold – What I Would Wish For

Introduction

Yvonne Newbold is a writer, speaker and trainer who is passionate about doing whatever it takes to make things better for the families of children who have a learning disability, autism or any other type of special needs. When she was diagnosed with incurable cancer, she knew that the most likely causative factor was the stress caused by nearly 20 years of battling to get her children the equipment, support and care that they needed. Her body was simply worn out. On the same day that she was told she would be likely to survive only another 26 months, she determined to spend whatever time she had left to try and make things better for the next generation of children who need extra help, understanding and acceptance.

Since then, she has written The Special Parent’s Handbook, which is a parenting manual for parents of children like her own, covering every aspect of Special Needs Parenting and sharing all that she learnt about making life easier. The book is an Amazon #1 Best Seller, and she has since won two awards; HSJ Top 50 Inspirational Women in Healthcare and Learning Disability Today Parent/Carer Advocate Champion Award 2015.

Since writing the book, Yvonne has developed a series of workshops for parents, as well as for the people who work with our children. She is now working with a number of schools, hospitals and local authorities in the UK delivering workshops which are helping to reshape services and helping to shift the culture and thinking about how to more positively engage with people who have autism or learning disabilities. Her workshops for parents help to develop their skills to be able to advocate more effective for their children.

What I Would Wish For encapsulates the desires of a parent of children with all kinds of special needs and is a powerful plea for healthcare professionals to really listen to and work with parents of children and young people facing these challenges.

What I Would Wish For

Hospitals will always be a part of our family life – it goes with the territory when you have a child with complex needs. Even though I spend several hours, sometimes several days and nights, in hospital every month, I absolutely dread every minute we’re there, and it gets harder with each passing year.

What one thing would make the whole experience more bearable? That’s easy. I wish that every single hospital employee could learn how to truly listen.

Some health professionals barely listen at all. Others appear to listen, but you soon realise that it was only so they could formulate their reply. Occasionally, we meet someone very special who really listens, and with their whole selves, so they even hear what’s left unsaid.

They’re the ones who make magic happen. As well as absorbing our words, they gain a tangible sense of what our lives are really like in a way that parents like me seldom experience. Time stops still while compassionate kindness soothes suffering. In that moment, something profound happens; my sick child becomes the only thing that matters.

You hear and take my concerns seriously, somehow knowing this is my first adult conversation in days. You make me feel like an equal rather than someone less. You understand all I say even though I’m barely talking coherently. You help me make sense of all of my fears. You acknowledge the essence of who my broken, hurting little boy really is, barely noticing his disabilities and equipment. You make a holistic assessment based on quality of life rather than individual symptoms.

When my child doesn’t co-operate with your examination, you ask for and accept my help. I suggest we turn it into a game, you play along enthusiastically. You offer me a glimpse of the future when all doctors are like you. When we will all pull together on the same side, working in partnership solely to enhance my child’s life.
I can tell by your eyes that you know the things we haven't talked about. You recognise my exhaustion and notice how my hair hasn’t seen a comb for a week, but you don’t judge me or make me feel inadequate. You “get” how my life is. A never-ending merry-go-round of sleep-deprivation, of coping with double incontinence, of tube-feeds, of nasal-canulas, of oxygen-saturation monitors, and of the ever-present vomiting and chest physiotherapy in the middle of the night.

You know how my son’s fragility terrifies me, frightened that his tenuous grip on life could snap at any moment. You feel my guilt that I can’t stop his pain, and you sense how hard I work to keep him alive. You know better than to ask me how I’m coping because you know I’ll always say “I’m fine”. You understand that that’s better than me starting to cry and never being able to stop, so we don’t go there. We don’t have to because for that moment, you were already there, with us and for us.

Yvonne Newbold
October 2014
5.13 Common Room
- Me first: Children and Young People Centred Communication

Introduction

Common Room is a consultancy led by people with lived experience.

They promote collaborative practice and turn children and young people’s lived experience into person centred service, policy and practice improvements across disability, health and mental health. Common Room is a small team of people who engage with a team of 8 paid young advisors with lived experience of disability, long term health conditions or mental health issues who work in partnership with them to co-develop and co-deliver their projects and work streams.

Their work aims to:

- Find the best ways of involving children and young people in decisions about their lives, treatment, support and services- Find the best ways of responding to and supporting children and young people with the issues they experience.
- Support young people to be partners in research, policy, and service improvement programmes - Research and understand the views and lived experience of young people, families, and practitioners about the issues that affect them.
- Common Room works in partnership with or is commissioned by a number of leading organisations including the Anna Freud Centre, National Children’s Bureau, Great Ormond Street Hospital, NHS England, Council for Disabled Children, Child Outcomes Research Consortium, amongst others.

Me First

- **Me first** is an innovative education package to improve communication between children, young people and healthcare professionals.
- **Me first** aims to improve health outcomes for CYP by enhancing the knowledge, skills and confidence of healthcare professionals (HCP) in communicating with CYP.
- Crucially, all of the resources have been co-developed with CYP and have a strong evidence base in research. The centrepiece of the project is the Me first CYP centred communication model - the first designed specifically for and with CYP. The Me first masterclasses and mefirst.org.uk help HCPs to build on their existing expertise and apply the Me first communication model to their clinical practice. Co-delivered with young people, the masterclasses use quality improvement techniques to ensure the learning makes a lasting impact on practice.
- The emerging findings from our independent evaluation are showing a lasting impact on the communication skills of participants. A core aim of Me first is to ensure that the model, resources and learning apply to and can be adopted by all healthcare areas and services. We are determined to transcend organisational boundaries and develop education resources that make a difference to professional practice and to the experience of children and young people across the UK.

Me first aims to:

- Promote the use of a new communication model, tools and approaches to support communication with children and young people
- Increase healthcare professionals’ knowledge of the barriers and challenges to communicating with children and young people
- Build on the existing skills of healthcare professionals and increase their confidence in communicating with children and young people
- Collect and grow a hub of resources to share ideas and expertise in communicating with children and young people
Impact

- The Me first project has been hugely successful. In 10 months we have trained over 200 healthcare professionals, with 100% of participants rating the training and resources as good or excellent.

- The Me first masterclasses have been independently evaluated by the Evidence Based Practice Unit (Anna Freud Centre and UCL), with emerging findings showing improvements in professionals’ exploratory listening, consensus-oriented listening and receptive listening after the masterclass.

- All of the professionals interviewed are now using what they learnt in their practice to make care more collaborative and young person centred. Attendees of the masterclass have said:
  - ‘The training has inspired me to make changes to my own practice and the department I work in.’
  - ‘Excellent course. Very useful having all different professionals present to get a variety of perspectives and ideas.’
  - ‘The day was engaging and creative, with a mix of different activities and time for reflection. We not only learnt the principles of CYP centred communication but how to apply them within our own specialities and practices. A rare and much needed course, I would highly recommend this to any professional working with CYP.’

Comments on our twitter #CYPMeFirst include:

‘It really is excellent, I am genuinely very excited and feel this is part of the solution to so many common themes raised by our young people. Top work! It is up to us to now get using it locally.’

Karen Higgins, Young Health Champions Project Manager, Shropshire CCG

‘Just wanted to say I love everything about MeFirst it’s exactly what we need!’.

Go team Me first!’ Young Person

Me first is the first healthcare communication model designed specifically for and with children and young people – it has the potential to make a significant difference to children and young people’s experience and health outcomes. Children and young people’s involvement in designing, developing, and delivering all aspects of Me first has been the single most important driver for the success of the project.

Funded by: Health Education North Central and East London

Produced by: Common Room Consulting

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The ‘#CYPMeFirst’ model helps health care professionals to get even better at communicating with young people, supporting them to build better relationships with paediatric patients. Take a look at the training, resources and blogs that are available http://www.mefirst.org.uk/. There’s a plethora of helpful hints and tips to dip into.

Quote from Kath Evans
Head of Patient Experience
– Maternity, Newborn, Children and Young People, NHS England
Dear NHS,

Children and Young People make up 25% of the population. The NHS Youth Forum believes that they must play a key role in shaping their own care, and the health service provided by the NHS.

Across the country young people have been working diligently with colleagues in healthcare. We’ve been sharing information, personal experiences and speaking out about the issues that affect young people; but there’s more to be done.

The quality of care that we receive still varies an unacceptable amount. We want you to identify best practice locally while adopting and publicising it nationally.

Young people want to have a voice in the NHS. We challenge you to actively seek out seldom heard voices and involve every CYP on an individual basis by proactively seeking and acting on their feedback.

Finally, there should be an undercurrent of youth involvement throughout the service. From commissioning to delivery and quality assurance, the voices of young people should be a constant presence.

The NHS Youth Forum and young people across the country are ready to work with you all. We are the future, but we are more than just the future – our voices need to be heard NOW.

Yours Sincerely,

the NHS Youth Forum
WellChild Helping Hands is a unique home improvement scheme which, with the support of volunteer teams from local companies and organisations, tackles essential home and garden make-over projects. Our projects make a real difference to the lives of families caring for children and young people with complex care and health needs across the UK.

Caring for a child or young person with complex care needs is demanding. Families find that projects in the home go unfinished, or never get started as their time and finances are so stretched. There are many children and young people who are living in homes which are not suitable for their needs. WellChild’s Helping Hands programme is addressing this by using volunteers from companies and organisations to complete vital home and garden improvement projects — helping families in truly practical ways.

WellChild Helping Hands offers the companies and organisations we work with a unique opportunity to directly impact the lives of their local communities. Companies can use the projects as a volunteering day, a team building experience or an opportunity to work with suppliers or clients in a meaningful and productive format that directly affects the lives of children and families.

What we’ve done so far

We’ve helped hundreds of seriously ill children, young people and their families throughout the UK. Here are some of our achievements.

- Delivered over 200 Helping Hands home and garden make-over / improvement projects across the UK in families’ homes, hospitals and organisations.
- Invested over £20 million in research into childhood illnesses and conditions, including liver disease, kidney failure, diabetes, cancer, cot death, respiratory disorders, neonatal intensive care, sickle cell anaemia and asthma.
- Created 22 WellChild Children’s Nurses with further new posts being confirmed annually.
- Funded health professionals and researchers to focus on improving the care of children and young people with long term health conditions including the WellChild Professor of Community Children’s Nursing
- Campaigned for positive changes in children’s healthcare, with the launch of our Better at Home campaign to get children out of hospital and cared for at home whenever possible.
- Created online communities for families of seriously ill children to come together to support and share with each other.
- Partnered with other charities and organisations on informative tools for parents, carers and health professionals, including the ‘Medicines for Children’ website.
- Provided substantial research grants for creation and development of:
  - The Liver Cell Therapy Unit at Kings College Hospital, London
  - The WellChild Research laboratory at Evelina Children’s Hospital, London
  - The WellChild Pain Research Centre at Great Ormond Street Hospital, London

WellChild - the national charity for sick children
The key worker is defined by NICE (2005) guidance as, ‘A person who, with the patient’s consent and agreement, takes a role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice’ (p 200). Responding to findings in the More than my illness (2009) report, the CLIC Sargent specialist nurse key worker role was aiming to provide holistic care to meet the individual needs of the child and family and facilitate safe care as close to home as possible. They may not deliver every aspect of care personally but will ensure someone is responsible for all elements of care needed. The underpinning report described them as a navigator, an enabler and a coordinator.

Across the United Kingdom (UK), there were 21 posts working with children and young people with cancer and their families as part of the CLIC Sargent Key Worker Project. Their roles are diverse, responding to local need, and developed as the role became more firmly embedded within their individual care settings. There is little information available about different patterns of provision and the determinants for success along with a paucity of evidence to indicate the requirements for service provision to achieve a well-coordinated transition or continuity of care for children and young people with cancer.

The evaluation of the nurse specialist key worker role aimed to:

- Evidence whether there is an improvement in patient and family experience as a result of nursing key worker support
- Evidence whether children and their families have improved emotional wellbeing as a result of nursing key worker support
- Evidence whether children are better able to participate in education, employment and training as a result of nursing key worker support being confirmed annually.
- Evidence whether children and their families are better able to spend more time safely at home during treatment as a result of nursing key worker support
- Identify obstacles to providing care closer to home that may or may not be overcome by the key worker role alone
- Identify the costs and benefits of this new service model
- Evidence whether best practice and learning have been adopted by other practitioners within local teams.

Methods

- The project spanned 18 principal treatment centres in England, Scotland and Wales. A mixed methods approach was undertaken to provide in depth details of experiences and illustrate how the key worker role has been developed. Data collection was face to face and at a distance using questionnaires, interviews and group work. Annual reports from the key workers, job descriptions, other documentation and data collected each quarter on the role by CLIC Sargent (e.g. caseload numbers, contacts with stakeholders) were also included in the analysis.

- In total, 19 specialist nurse key workers, three nurse educators involved in the development of a key worker education resource, 95 parents, 85 stakeholders (individuals the key worker was involved with through their role with families such as community nurses, social workers) and 10 children (six children from an advisory group took part in a group discussion activity) contributed to the study. Evaluation data were collected between March 2011 and March 2015. Key workers were interviewed at two points in time and some took part in a focus group (n=12). Parents from all the sites completed a questionnaire and 23 also took part in an individual interview.
Four children took part in an interview (n=4). Bereaved parents only took part in an individual interview and were not asked to complete questionnaires (n=8). Stakeholders from all the sites filled in a questionnaire. The uniqueness of each case, particular context, issues and story were the focus of this study (Stake 2000). Incorporating a multiple case study approach (Yin 2003) each key worker was defined as a case with the other participants (parents, children, young people, and stakeholders) being linked to them and their practice. The framework approach (Ritchie & Spencer 1994) was used to analyse the interview transcripts and descriptive statistics were reported for quantitative data.

Findings
The presentation of findings is organised in three main sections:

I. An overview of the models of care and how the role was developed in the 18 principal treatment centres (PTC).

II. Realistic evaluation of the models – two scenarios are described:
   a. When it works – when the key working service has the capacity to deliver improved outcomes and influence a positive experience for families and professionals.
   b. When it is challenging – when there are factors that make it challenging for professionals to deliver the role in such a way that it is effective and impacts on families’ experiences.

Models of care
• The key worker was, in the majority of cases, a specialist nurse experienced in Haematology/Oncology and attached to a principal treatment centre.

• Key workers’ caseload composition varied in the number of families they supported as well as the types of diagnoses of children in their care. Parents, children, key workers and stakeholders (health, social care and educational professionals) shared their views about the core responsibilities and roles of a specialist nurse key worker, these included: coordination of care (being the main point of contact in the hospital); knowledge and expertise (information sharing and explaining; training); ability to establish relationships (with families and different professionals involved in the child’s care). These featured despite the variation in the way the role was developed across trusts. Key workers developed their role within a continuum of in-reach and outreach work.

Four main models of care were identified:
1) outreach (visiting families at home),
2) inreach with home visits (key workers who were based in the hospital and who do home visits occasionally),
3) inreach (based mainly in the hospital) and
4) palliative care (reflecting how the key worker role changes in this phase).

The models also vary in key workers’ involvement in direct clinical care. Key workers were all involved in care coordination, but not all were involved in the direct delivery of clinical care.

Realistic evaluation – When it works
Specialist nurse key workers were the main link in the principal treatment centre for professionals as well as families. There was a clear pathway for both families and professionals, enabling key workers to streamline the communication process not only between families and professionals but also between professionals. Key workers liaised with a range of professionals based in education, social services, community teams and other relevant local organisations and voluntary agencies. The role of key workers in liaising with other professionals such as community nurses and with teachers was highly valued by families.
Perceived advantages for parents and children of having a key worker were centred on: having one person to contact about any concerns; someone who was in charge of coordinating services and making sure their needs were met. When in place, there was greater consistency and continuity of care and thus parental stress was alleviated. The key worker helped the family understand the diagnosis, navigate services, continue to support the family and assess their needs using a holistic approach; thus they got to know the family very well. The key worker was the family’s main point of contact and their approachable nature meant that they were the professional that a parent went to with concerns - parents felt they could ask them anything. The impact of the key worker role on families’ experiences is embedded in the relationship they establish with each family. This relationship was one of trust and was built up over time. Parents appreciated having the key worker throughout their journey and although during some phases they might not be as involved, they were still the families’ point of contact; the professional who knows what they have been through, who knows the family and their child. Being able to easily contact the key worker also ensured patients stayed home safely. In general, key workers perceived their role as having a positive effect on the work of other professionals: this view was shared by the stakeholders responding in the questionnaire. They noted that key workers were able to access appropriate support for families and refer to appropriate services. Stakeholders stated that key workers’ knowledge and expertise and coordination of care were linked with a high standard of care.

Realistic evaluation – When it is challenging

The key workers were asked whether they experienced any constraints or problems in their role. The main challenges in fulfilling their role were: time, caseload size, geographical area covered and staffing numbers. The key workers wanted to provide an equitable service to the families on their caseload but sometimes had to focus on the families most in need (e.g. children at the start of treatment, or during end of life care). The inequality of local services also presented a challenge to care coordination for some teams.

Key worker person-centred care in a challenging environment. Key workers developed their role within contexts where there was a lack of resources, pressure of large caseloads and size of geographical areas covered, different levels of competency and staff numbers in the community added to the challenges of care coordination and consequently of care closer to home. Nevertheless, throughout the development of their roles, key workers developed and described examples of good practice of working with families and stakeholders; of information and care pathways leading to quality improvement, of policy development and consolidation of role definitions, among others. These examples serve to illustrate in this report how the key workers’ knowledge, coordination of care and relationship with families and professionals worked well in practice.

Conclusion

- In conclusion, supported by the evidence collected, key working effectiveness is built on three pillars: knowledge, coordination and relationship: when these pillars are in place, a better quality family experience can be assured.

- This research can be applied to all specialities; and highlights the benefits of employing key workers, who offer knowledge, support effective co-ordination processes and relationship building, all of which improve people’s experiences of care.

Improving the co-ordination of care requires ongoing focus and commitment. CLIC Sargent have been heavily involved in supporting key worker positions, and facilitating research in this area. They have identified the improvements required to improve care for children, young people and their families receiving cancer treatment. This research can be applied to all specialities; and highlights the benefits of employing key workers, who offer knowledge, support effective co-ordination processes and relationship building, all of which improve people’s experiences of care.

Kath Evans
5.17 Kat Cormack
- What young people say to me about youth mental health services

How Do Young People Feel About Services?

“If I miss more than three sessions they will kick me off the list- but I’m too ill to leave the house”

“He didn’t talk to me, just at me and seemed to take my mum more seriously than me even though I’m the one living with this”

“He just said I was stressed and sent me away with nothing”

“No one listens, No one cares, No follow up support. It makes me think well if they don’t care about me I can’t be too sick. Maybe I need to be sicker for them to pay attention.”

“I just feel so patronised”

“My GP told me that all girls go through a phase like this = it was full blown Bulimia, I could have died”

“What Do Young People Want

Accessible Services the fit in with their needs and lifestyles

Support

Need support? You’re never alone

- SAMARITANS
- mind
- OCD Action
- YOUNGMINDS
- YOUNG MINDS
- SANE
- CALM
- NAMI
- MIND
- CALM

www = Wild Wild West?

Another Teen Suicide Linked to Ask.fm
Leaves Questions

Number of children who are victims of cyberbullying doubles in a year

Tragedy of girl who secretly browsed anorexia websites: Mother’s warning after suicide of teen with everything to live for

Should you ban your children from using social media?

Patient Experience Network
Re:thinking the experience
Jim Blair is unique in the world of nursing – unique in the fact that he is the only nurse of his kind in the world. His presentation at the recent CYP event in London provided a great insight into some of the work he and his colleagues at GOSH are doing. For the purposes of this report we have shared some of his insights here:

**The focus should be on:**

- Practical solutions to challenging problems
- Thinking differently acting creatively
- Alert flagging systems
- Reasonable adjustments – core and bespoke - how they improve care
- Collaborative partnerships

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**Everybody’s Life Has Worth**

- Beware of missing serious illness
- Find the best way to communicate
- Make reasonable adjustments
- Rely more on visual information
- Give more time for processing

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**How we know improvements are happening?**

**Staff survey**

- 53% have seen significant improvements in learning disability provision in last year.
- In 2013, 17% of staff had seen the hospital passport, in 2014 this has increased to 34%

**Learning Disability Alerts Over 1300 on system since April 2014**

- Make care adjustments
- Monitor outcomes and experiences
- Improve care
Reasonable Care Adjustments
• Involve the child / young person & their families / carers
• Offer double appointment
• Offer first or last appointment
• Family drop in sessions
• Act on the hospital passport
• Change the environment e.g. dimmer switches, quieter areas, sensory equipment, buzzer for waiting
• Make information easy to understand

If the patient is disturbed or distressed in Recovery please consider:
1. Call an anaesthetist to use sedation to induce a relaxed, sleepier state
2. Increase levels of sedation as required

LD Link Leads – 43 across the hospital
• Rolling out of learning disability initiatives across the service
• Monitoring, evaluating and changing services through reasonable adjustments
• Providing colleagues with updates

Experts by Lived Experience
Engage people with learning disability and those who also have autism and their families in
• Service design
• Accreditation
• Delivery
• Evaluation
• Evolution and staff training
• THEN we will get the culture and care right

Improving dignity, care experiences and outcomes
• Passport
• Reasonable adjustments
• LD Our Health Our Hospital
• Involvement – access committee, patient groups, LD Caring Solutions, LD Open Meeting
• Link staff
• Education and Intranet pages
• Protecting beds
• Safer discharges
• Breaking cycles of admissions

The Learning Disability Protocol for Preparation for Theatre and Recovery
• Discuss the patient’s needs with them and their family/carers
• Use ‘comforters’ to relax the patient pre op and in recovery
• Document and handover to colleagues
• Lower levels of noise and light
• Place the patient in a quiet area within recovery
• Ensure parents/carers are present and involved
• Gradually recover observing how the patient is progressing and ensuring pain has been assessed and reviewed

Enhancing care and experiences

5.18 Making Change Happen - Getting Care Right
For People with Learning Disabilities
Being involved – Experts by lived experience

• Be on Committees
• Improve accessible information
• Educate and train staff
• Plan, develop and evaluate service developments and changes
• Be involved in research that leads to practical solutions / change

Partnerships - Making an impact

• Other organisations across sectors
• Trial and share information
• Shaping practice together
• Creating models that work
• Being flexible less protective of ideas / concepts

• INNOVATION – BE CREATIVE

How I can help make change happen?

• What can I do to make care better?
• How can I make sure it happens?
• What else can I do to effect the change that needs to happen?

“It is no use saying, ‘We are doing our best’ You have got to succeed in doing what is necessary.”

Winston Churchill

STOP WAITING FOR THINGS TO HAPPEN GO OUT AND MAKE THEM HAPPEN

CHANGE
STARTS HERE. CAN WE COUNT YOU IN?
What is an ‘environment’ and how can it impact on children?

An environment is defined as: ‘The surroundings or conditions in which a person, animal, or plant lives or operates’ (Oxford University Press 2015).

Why does play and recreation matter?

Children know how to operate in a playful environment – it provides an element of normalisation and control. Play and recreation should be reflected throughout the whole environment.

Although this definition appears to be relatively simple and self-explanatory, Skinner identified the need to break things down into simple bite-sized chunks to make tasks more manageable and to explore deeper meaning (Pound 2005).

The easiest way to illustrate this is to consider how differing environments might make you feel if you were a child accessing the environment for the first time – and how you might operate within each of these surroundings. Add in factors such as the child’s age and developmental stage, their previous experiences, their personality, their state of health, the presence or absence of their parents. All of these factors are known to influence how the child will interact with the environment and impact on their experience of health care provision.

Children’s perceptions differ significantly from those of adults and therefore, the need to find out how children themselves would operate within their surroundings provides a valid reason for asking them, listening to what they have to say and then acting upon their contributions. Providing feedback and showing children what has been achieved as a result of their input acknowledges their time and effort and ultimately leads to better outcomes for all concerned (NCB and the Children’s Commissioner 2013).

So…what’s in it for me?

The Committee on the Rights of the Child (2013, p.3) promotes “the importance of approaching children’s health from a child’s rights perspective” through the UNCRC. Although the Committee identifies article 24 as an ‘inclusive right’, it also advocates a holistic approach to health, requiring utilisation of other rights from the UNCRC to enable fulfilment of article 24.
Key findings of the report - edited

- There is extensive coverage of healthcare design, the role of architecture and the ‘built design’, which occasionally incorporates the views of children. The integration of architecture, design and healthcare planning is becoming increasingly significant and the integration of the perspectives from architects, designers, healthcare professionals and children should inform environment related decisions.

- The evidence base that specifically looks at the impact of the environment on children’s experience of health care is limited, particularly for younger children, whose views are represented through adult proxies.

- Much of the reviewed literature recognises that the views of adults do not necessarily reflect the perceptions or perspectives that children identify as being of significance to them in terms of their experience linked to the environment.

- Children want to be involved in the design, delivery and evaluation of the healthcare environments they inhabit but need the support and facilitation of adults to make this happen, particularly for young children or those with complex needs.

- The environment will affect a child’s behaviour by virtue of the reciprocal influence it has on the child’s thoughts and feelings. Awareness of this can enable the environment to be manipulated to reduce the impact of environmental stressors.

- Developmental considerations need to be integrated into the planning, design, delivery and evaluation of all aspects of the environment. Developmental theory can be useful for ‘understanding’ children’s reactions and interactions with the environment.

- Innovative ways of capturing children’s experiences in relation to the environment should be considered, using examples of effective engagement. This may be from other sectors i.e. education and the early years age range. Effective engagement needs to utilise a variety of methods such as workshops, road shows, photography, the arts, as well as the use of technology, including social media.

- The voice of the child capturing the experiences in general facilities where environments are not specifically designed to cater for children is absent – aside of dentistry, this applies to virtually all primary care settings.

- There are recurring themes that consistently emerge through the literature, but the significance of these change as children grow older i.e. thematic design, colour and the proximity of parents.

- Design elements and design principles provide identifiable features that can be manipulated to produce differing effects within the environment. These features are significant within the initial design of a facility or during refurbishment. However, for pre-existing facilities, there are simple alterations that can be made to enhance the environment i.e. the use of ceiling tiles to reduce noise but also to provide visual stimulation and a means of distraction.

- The role of play and recreation is significant for all children, who want playful activities and facilities reflected throughout the whole environment. This needs to be appropriate to the age and developmental stage of the child and may require separate facilities to be provided i.e. play room for very young children, play facilities for children in middle childhood and chill out areas for young people that offer recreational activities.

- The role of nature is significant and if used effectively it can promote a healing environment.

- The role of art is significant, particularly as a means of distraction and initiating conversation. It covers a whole range of creative activities such as music, dance, sculpture, art projects and photography.

- Children need opportunities to socialise while maintaining their privacy. Although emphasis is put on the needs of young people, younger children also need similar opportunities that reflect their developmental levels.

- For children who stay in hospital, sleep can be problematic due to noise levels that occur as a result of clinical activities. There are mixed messages about room occupancy with some children preferring single occupancy while others prefer multiple bay provision. Separation according to age range is more significant than gender and where possible, settings will take children’s preference into account.

- There is a move away from the hospital as the central point of health care delivery and the emphasis on moving services into the community provides both challenges and opportunities.
5.20 How easy is it to do?
Northwick Park Hospital and Stanmore College

- 4 rooms and a corridor £750… with paint left over
- Work based experience for the students - Priceless

Concept: The idea for this project was generated from collaborative work that was being done between Stanmore College (SC), Northwick Park Hospital (NPH) and the Society and College of Radiographers (SCoR). The aim was to help make imaging departments more child and young person friendly, in line with the Department of Health recommendations that reception, waiting and treatment areas are accessible and young people friendly, comfortable and welcoming. With a new Emergency Department (ED) opening at NPH with a dedicated radiology area it seemed necessary to consider ways to make the environment appropriate for all. Although the specific aim was to improve the environment for children and young people, the affects would benefit all service users as well as staff and carers. Having existing collaborative links helped to shape the process. A radiographer working at NPH and a lecturer at SC were able to approach other members of staff within their respective settings to see if the idea would work in principle. Once this was established the planning was able to begin.

Initial Approach to the College
Claire, a member of Stanmore College gave the art department the connection with Northwick Park Hospital. The lecturing staff (Marshal and Sally) lined up a sight visit, spoke to Jeremy and then worked with him throughout the project. The visual arts lecturers then created a working brief for the level 3 Extended Diploma students. The college and hospital staff met with the students and shared their vision of the project.

Brief
For this project the brief was very flexible. The initial discussion with the art lecturers focused on the idea that the environment needed to be suitable for children and young people but that it would be used by a wide variety of patients and staff so needed to be suitable for all. We therefore knew that traditional ideas/themes such as ‘under the sea’ or ‘the zoo’ would not be suitable. The art teachers went away and discussed ideas that may be appropriate and developed an assignment brief.

Initial thoughts from the students
- Students explained they were “excited about the project because it was out of college and the project had a client that wasn’t a teacher.”
- The students were also excited because it was their “first real project.”

Initial visit for the staff to NPH
The initial visit to the site was made by college staff before the building was completed. The college staff were able to see the layout which helped them with the planning process. The site manager was present and they were able to highlight the building and radiology regulations that needed to be considered. Initial ideas were considered and discussed and these were used to help form the assignment brief.

Room 1 - Student testimony – Keyan
- Investigated the artists Keith Haring and his narratives. We thought about words like joy and happiness to have a positive attitude in the hospital
- The group laid in the poses to fit the words and drew around each other. These figurative shapes were cut out as a stencils.
Room 2 - Student testimony – Romarno • The big coloured shapes in the background were to represent expressive emotions and to flow into one another. They were the background for the outline figures that were inspired by Keith Haring’s hospital project.

Room 3 - Student testimony – Jinisha • Our group decided to make the figure start at the floor and move up to the ceiling and then back down again in a flowing manner. We wanted to express movement as the characters danced up and down. This was also accented by the shapes next to the figures as movement lines.

Room 4 - Student testimony – Rianne • In previously studying Julian Opie I was already inspired by his work. So I decided to research to see if he had any mural work. I used these works as a base for my design. Opie also showed movement in his styled figures so I created movement inspired by those works. • I investigated the art movement Futurism and how they represented movement in repeating shapes and figures over the top of one another. • The multiple coloured shapes are represented where the figures were previously, this gave the illusion of moving figures dancing to music, similarly to the figures that are present in previous iPod advertisements.

Project evaluation – NPH

There are many ongoing benefits that have been identified as a direct result of this project. Importantly, it met the aim, to make the environment more child and young person friendly. The environment is now less clinical and therefore less intimidating. The effect of this is often unconscious but is evident in the demeanour of the patients, staff and other visitors. An ongoing relationship has developed between the two organisations and plans are being discussed for the next project that is going to be completed.

The staff that had contact with the students have commented on their professionalism, enthusiasm and their positivity. A very different view point from the stereotypical idea that is often portrayed by the media. The minimal cost of this project was also a benefit. Only paying for the materials used enabled this project to go ahead. If labour costs needed to be paid then the project would not have been financially viable. The only negative comments have been about the style of the art work. However, art is subjective so not all will like it or view it as necessary. Overall the benefits of this project outweigh any negatives. The positive comments of those using the department highlight its success.

Project evaluation – SC

Engaging with Northwick Park Hospital was a great opportunity for the students to have a working brief that had a very tight time frame. The students had to show the client (Jeremy) their proposal and final design that needed to be changed with the clients specifications. The students had a tight deadline that the work had to be completed by to meet the opening of the department.

The Gold Standard

Image courtesy of Penny Bayliss-Robbins

The new Children’s Unit at Salisbury District The project is described in Waterworld & Treetops It is well worth a read

Who benefits?

Radiology Reception Area, Royal Manchester Children’s Hospital, Image courtesy of Boex
“Drawing on our knowledge and previous experience of how shape, form, colour and light can positively contribute to improving the healing environment...”
(Images and text courtesy of Boex)

Final thoughts... “Children’s perceptions differ significantly from those of adults and therefore, the need to find out how children themselves would operate within their surroundings provides a valid reason for asking them, listening to what they have to say and then acting upon their contributions” (page 4).

It is the simple things that make a big difference

It is often the small, simple things that can often have the most impact.”

As noted throughout the report, the way people react to the environment relates to personal preference, cultural variations and the situation people find themselves in (Kreitzer 2013b). This means there are no ‘hard and fast rules’ in terms of providing generic guidelines, however there are things that can be done, and ‘it is often the small, simple things that can often have the most impact’ (Norton-Westwood 2012, p.9). As healthcare provision moves into the community, it may be useful to consider some of the following points, which emphasise some of the recurring themes that emerged as being significant to children.

- Children’s preferences change as they get older – appreciation of this needs to be reflected through the environment. In particular, children in middle childhood feel ‘trapped’ between resources for young children and young people
- Children perceive the environment through their senses – this can affect the child in positive and negative ways
- Environmental stressors induce anxiety – awareness of what these are helps to minimise anxiety i.e. cover equipment so children cannot see it or reduce noise, especially at night time
- The environment should be used to distract – artwork provides a useful medium which can be integrated as part of the environment or added through the addition of pictures or paintings
- Reflection of nature within the environment is significant and links to the healing process.

A point to ponder...

An NHS Dementia ward

5.20 How easy is it to do?
Northwick Park Hospital and Stanmore College
• Access to natural light and views of nature enhance the patient experience. When this cannot be achieved, symbolic access to nature needs to be provided.

• Thematic design – preferences are for the sea/beach, followed by shiny/metallic, then nature and animals

• Colours – mid colour ranges, particularly blue to green – the depth of colour increases with age from pastels to deeper shades

• Children want to be able to socialise with children of their own age and if possible those who have a similar condition so they can share experiences

• Children want play and recreational activities and facilities to be reflected throughout the whole environment – and these need to be independently accessible

• Altering the environment can be relatively simple by changing colours, lighting and texture • Ceiling and floor tiles as well as wall coverings can be altered, particularly now with the advent of digital printing

• Technology can be used to enhance the social environment and provide a mechanism for capturing feedback

• Children and young people willingly engage in projects that will enhance aspects of the environment through the production of artwork, photography or music

Photo: Boex – leader in design
About ChilyPep

ChilyPep has over ten years experience working with young people to involve them in decision making processes/engagement and influencing work.

ChilyPep (following on from Right Here Project) became CAMHS participation partner for the CYP-IAPT service transformation work.

ChilyPep uses models of participation and peer advocacy to help young people make the changes they want to see in their communities. We run several issue based ‘action’ groups, all seeking to make change for themselves and young people experiencing similar issues.

- 15 years experience in participation and engagement work
- Sheffield CAMHS CYP-IAPT Participation Partner
- Issue based action groups: Mental Health, Young Carers, Healthy Relationships, Young Healthwatch
- Having a voice & making change!!

Why involve children and young people?

- It’s good for their Mental Health and Emotional Wellbeing!
- It’s part of their ‘treatment’ and recovery

- Recognised protective factor for Mental Well-being
  - Enhancing Control
  - Increasing resilience
  - Facilitating participation and inclusion

(MWB Checklist – NMH Development Unit)

“All children and young people have a right to a say in any matter affecting them and for their views to be taken seriously”

United Convention on the Rights of the Child (Article 12)

What is Important?

Participation + Peer consultation

- One of STAMP’s key aims is to raise awareness about mental health and reduce the stigma attached to it. They have carried out a lot of consultation with other young people around what the perfect MH service might look like (peer-peer participation and involvement).
- This led to the development of a young people’s mental health manifesto which the group are now working to and taking forward to influence change for young people and their mental health.

A Young People’s Mental Health Manifesto

1. **STAMP Out Stigma**: Start talking about mental health and give young people the opportunity to talk about, and explore, mental health.
2. **Act now, tomorrow could be too late!**: The mental health system encourages people “to get worse before we can get better”. Help us early on so things don’t get so bad.
3. **Educate don’t discriminate**: Schools hinder rather than help our mental health. Mental health on the curriculum and train staff to spot young people’s mental health so that we can be supported, not stigmatised against or labelled.
4. **Abandoned at 16**: “As soon as you are no longer a child services wash their hands of you”. There is no real service in place for 16-18 year olds. There should be.
5. **A voice and a choice!** Young people’s participation is key; we are the experts in our own mental health and we have a right to be listened to and our views acted upon.
6. **By young people, for young people**: There are a lack of services for young people over 16 that meet their needs - we need a service designed by young people for young people aged 16-25.
7. **Stuck in the mud**: We are often passed from pillar to post - services need to work better together so we’re not stuck in the middle.
8. **We got to fight for our rights**: Getting help is hard, especially if we don’t know our rights. Tell us what they are and offer us advocates to support us.
9. **TREATment not HARASSment**: “Current crisis support desperately needs improving”: Stop turning us away when we are in crisis or locking us up for being ill - support us instead!
Involvement

STAMP have been involved in service design and development:

• CAMHS – you’re welcome standards
• IAPT – user centred healthcare design
• CAMHS – patient journeys

“You’re Welcome” is a set of standards (like rules) on how to make services more young people friendly.

There are 8 parts to the standards:

1. Accessibility – is the service easy to find? Can you get to it easily? Can all young people who need it use it? For example is there wheelchair access?

2. Publicity – are the leaflets, website and other advertising young people friendly and easy to understand?

3. Confidentiality and consent – are young people told about what happens to what they tell workers?

4. Environment – is the building and where you receive support young people friendly?

5. Staff training, skills, attitudes and values – do staff get the right training? Do they have the right skills, attitudes and values to be able to work with and support young people?

6. Joined-up working – do they work with other organisations and can young people get information and support on other issues all at the same place?

7. Young people’s involvement in monitoring and evaluation of patient experience – are young people involved in checking what experiences other young people have had of the service?

8. Health issues and transition for young people – Are young people asked about their own needs? Particularly when they are moving from being a child to an adult (i.e. aged 16-18).
5.22 Friends & Family Test for Children - Monkey WellBeing

- The Friends and Family Test (FFT) has been designed to enable all people who use the NHS to provide feedback on their experiences ‘as a standard part of their care’ in an effort to continuously monitor and improve where necessary, the service being offered (NHS England 2014). From April 2015, it became compulsory to offer all children and young people the opportunity to complete the FFT using a suitable version of the FFT question ‘whether receiving care as an inpatient or an outpatient, in a day ward or accident and emergency department environment’ (Picker Institute 2015).

- NHS England (2014) identified the breadth of opinions being sought which ideally features feedback from a range of services that children use, including neonatal care and perhaps most importantly, those delivered in adult centred settings such as district hospitals, which traditionally provide a less child-centred approach which can be detrimental to children’s overall experience (The Society and College of Radiographers 2015a, Kennedy 2010).

- Ideally, the views of children as well as their families/carers will be captured, both of which are important but from differing perspectives (NHS England 2014). However, ensuring the FFT question can be answered across the age range is important so that the resulting data provides an accurate reflection of people’s experiences (Picker Institute 2015).

- Pilots of the forms used to capture feedback via the FFT have been trialled, using children as part of the review process (Picker Institute 2015).

- This revealed that younger children did not understand the wording of the FFT question used by adults, resulting in changes to the wording, as seen in the version created by Monkey Well-being (Picker Institute 2015). Monkey Well-being has produced a version of the FFT for children and one for their parents/carers, as well as versions covering inpatients, outpatients, GP surgeries and community services (Monkey Well-being 2014). A version is currently being completed for dental services.

These are available in PDF format and are downloadable free of charge from https://www.monkeywellbeing.com/partners/nhs/
VISION

To co-design diabetes services for youth with young people, based on a modern and sustainable approach, achieved through cross-organisational partnership working.

Project Purpose and Justification

- Newham hosts the highest prevalence of diabetes in young people under 25 in the country.
- An UCLPartners sponsored event in December 2014 brought together young people and their families who outlined concerns with the existing service model and made improvement recommendations.

Youth Commissioner Purposes:

- To raise awareness of diabetes
- To reduce stigma, enabling young people with diabetes to live ‘normal’ lives.
- To make a change for youth in the future living with diabetes.
- To gain insight into health care.

Key Milestones:

- **May 2015** – 4 youth commissioners recruited, Newham residents between the ages of 17 and 19 living with Type 1/Type 2 diabetes
- **June-July 2015** – youth commissioners complete training programme, including public speaking and clinical commissioner training
- **August 2015** – community workshops delivered at West Ham football stadium, gathering feedback on CYP diabetes pathway and testing aspirations for commissioning recommendations

- **September 2015** – commissioning intentions outlined to provider emphasising better access developing and improving transition services
- **October-November 2015** – Plan the redesigning of services

Next Steps: December 2015 – finalise delivery and implementation plan, draft business cases as needed

Transitions

- Gradual process
- Co-designed personal plan

Relationship with health care team

- Private appointments
- Three way relationship & communication

Clinic appointments

- Timing (availability)
- Virtual clinics

Peer support and self-care

- Mentor/buddy scheme
- Reducing stigma

Living with Diabetes – from diagnosis to everyday living
Engaging children and Young People in Newham
Richard Mountford, Communications Manager,
Sabeena Subba, Patient & Public Engagement Manager

What is the key driver?
‘Right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice.’

*Article 13, UN Convention on the Rights of the Child*

Newham Profile: A Young Population

- Over one-third of Newham’s population is under 25 years of age, compared to the London average of 30.6%.
- In every primary school in Newham one in ten children will have some form of mental health issue.
- Approximately 12,385 0-18 year olds in Newham will demonstrate early signs of mental disorder.

Peer-to-peer mental health awareness campaign in partnership with Reprezent Radio

CAMHS transformation plan:

- LBN’s Youth Councillors attended 2 day training ‘specialist reporters’
- At Newham Show with volunteers interviewed 100 young people
- Report used to develop transformation plan
- Review draft at follow-up workshop
- Use this link to listen to an audio clip of youth councillors: http://www.newhamccg.nhs.uk/news-articles/Youth-councillors-talk-about-mental-health.htm

- Single Point of Access
- (quicker access to CAMHS with voluntary and community sector support)
- Schools Development
- Self harm and crisis support
- Learning disability and mental health support
- Eating Disorders (A community service for those under 18 years old)
5.24 Kissing It Better

- Launched in 2010 KIB is a charity who are working to enhance patient care through carefully constructed community engagement.

- Organisations use the services of Kissing it Better to supplement the care they already offer. To achieve their objective KIB have several strands to their offer including an interactive website for sharing practical ideas. Following a pilot with Walsall Healthcare NHS Trust in 2011 the main emphasis is their work directly with hospital trusts and care homes to create a programme of activities offering stimulation, companionship and conversation for the patients, residents, and staff that care for them. It could be music, drama, pampering sessions, or something as simple as a cup of tea and a chat.

- The key is that the visits are regular and sustainable. They identify groups with the talent to provide these sessions – usually a school or college – and work hard to build a partnership with the care home or hospital. As they tend to work with young people, they offer training to give them an understanding of the environment they will be working in, and also a basic knowledge of the health conditions that they may encounter, especially ailments affecting older patients. They provide structure and co-ordination for the visits and harness the skills of the local community and promote interaction and understanding between the generations.

- Founder Jill Fraser said “Kissing it Better was set up to enhance healthcare; to make hospitals and care homes the places we would all like them to be. Our aim is to achieve inspirational and practical programmes to improve the healthcare experience for everyone, especially older and other vulnerable people in hospital and care home settings. We are inspired by the work of Florence Nightingale, who firmly believed that simple things can make the world of difference to people who are ill or infirm: a loving touch, an engaging conversation or even a lovely view, can light up the day and lift the spirits.”

- The programmes that are offered by KIB could be easily adapted to suit the needs of children & young people.

http://www.kissingitbetter.co.uk/
5.25 NHS England
Using insight from Children and Young People to drive healthcare improvements

Objectives

- NHS England want to ensure that insight from 25% of the population children and young people is used routinely to improve services at a local, regional and national level.

- The NHS Youth Forum was created to provide direct access to young people to capture their perspective on health care experiences and identify from them solutions that could be collaboratively delivered.

- The Friends and Family Test was rolled out in April 2015 to Children and Young People providing rich insight into their experiences of care that need to addressed.

- The National Children & Young People’s Survey of inpatient & day surgery experiences by the Care Quality Commission was published in July 2015 highlighting that Young People want to be more involved in their care, we need to improve our communication with them directly and critically that Children and Young People with Mental ill-health, Physical and/or Learning Disabilities report poorer experiences of care than those without these conditions.

What information was available and how did patient insight add to the picture?

Whilst there is much anecdotal information regarding children and young people’s experiences of NHS care, until 2015 we have not had access to national data and it has been an area ‘too difficult’ to address. Thankfully things have moved on!

The NHS Youth Forum was able to identify issues that mattered to them relating to Mental Health http://byc.org.uk/news/ministers-value-youth-select-committee-work-on-mental-health.aspx and Communication in 2014, and in 2015 they plan to focus on young carers and transition into adult services of young people with complex/chronic conditions.

The Friends and Family test is offering local feedback to services, often boosting the morale of staff with positive comments. Using the Monkey Wellbeing resources and provided a child centred approach to capturing feedback and even the parents prefer these forms! https://www.monkeywellbeing.com/resources/friends-family-test/. The National Children and Young People’s Survey has provided all providers of Children’s Inpatient and Day Surgery Services with specific feedback relating to their services, areas to action include communication and improvements for children with additional needs. http://www.cqc.org.uk/content/children-and-young-peoples-survey-2014

Specific feedback from a young person on the Shropshire Health Champions led to the creation of this film about how it feels to be a young person accessing NHS services http://www.fixers.org.uk/news/11860-11208/patient-experience.php

A guide to running a youth ‘Take Over Day’ event has been published to embed youth voice and engagement in local services to support local services http://www.england.nhs.uk/2015/07/21/takeover-day-2015-here-we-come-kath-evans/ and

http://www.brook.org.uk/our-work/the-young-peoples-health-partnership

Children and Young People also tell us that environments of care matter, a guide was commissioned to help commissioners address this https://www.england.nhs.uk/2015/07/31/kath-evans-alison-tonkin/ and


The National Association for Health Play Specialists were commissioned to collate the evidence base on play to inform commissioning of its role in health http://www.nahps.org.uk/
What changes were made to services as a result?

The NHS Youth Forum have designed and delivered 3 posters on consent, confidentiality and feedback that are significant issues to young people where they identified a lack of clarity, these are available via the NHS England website


The NHS Youth Forum have influenced the refresh on the NHS Constitution and now in the Complaints section it states young people can complain about services, previously this was ambiguous


A Guide on how to establish a local youth forum has been published


A Free E-book has been published to show case great participation work to inspire Commissioners & providers to involve and use insight from children and young people in service design, commissioning and delivery


A website and education training programme to improve communication between healthcare professionals and children and young people has now been launched to improve care in this area

http://www.mefirst.org.uk/about/

See page 45 for further information

Two brief papers for commissioners based on insight from children and young people in collaboration with the voluntary sector have been published


“When children and young people are seen and heard, powerful discussions happen, they challenge the system, offer new solutions, influence their peers and perhaps most important they flourish personally, if we’re really going to change the future we cannot not capture and action the insight they offer us.”

Kath Evans, Head of Patient Experience Children, Young People and Maternity, NHS England

For more information on this case study, please contact: Kath.evans3@nhs.net
6. Conclusions

Many of the conclusions from the original report hold true in the current climate. They provide a strong foundation and have been combined with those from the most recent PEN survey, the CQC survey, review of good practice and report.

Developing and Using Best Practice:

• There are numerous examples of excellent best practice. More can still be done to highlight and celebrate these. It is pleasing to note that there are increasing examples of good practice across the board (Leicestershire Partnership, Northumbria Healthcare NHS FT) not just in the tertiary centres.

• Many organisations are doing something to improve experience for children and young people. The PEN survey shows that there is more action being taken, and this is great news. There remains too much focus on ‘talk’, and considerably less on identifying existing areas of practical best practice in patient experience and then sharing and embedding it.

• Across healthcare there are many clinical specialisms and settings resulting in considerable tunnel vision i.e. only looking at best practice from within similar settings or specialisms. Much work on improving patient experience is transferrable and/or adaptable.

• There is not enough time or money spent on collectively developing existing (and new) practical best practice.

• There is a wealth of evidence to show that implementing good patient experience practices releases valuable time and resources.

• CYP practitioners face all of the issues that those dealing with adults face, with the additional issues related to age, understanding and parental considerations. Getting it right is not easy, but the issues are not insurmountable as demonstrated by the examples in this report and the CQC survey.

Parent/Carer and Child/Young Person ‘Conflict’:

• In dealing with children and young people the NHS have two differing, and sometimes conflicting, sets of ‘customers’ - the patient (child or young person) and the parents or carers. This is not a unique situation – what can be learned from both within the NHS and from elsewhere?

• Much of the current survey and development work remains centred on the views of adults and not the actual patients (the children and young people). There is clear evidence that a) children’s views differ from their parents/carers and b) children and young people have much to contribute to developing best practice.

• A key example of adult-centred initiatives is complaints procedures. Work still needs to be done to build upon the work done by the NHS Youth Forum to understand what support is required for Trusts to embed these principles and then measure achievement against them.
6. Conclusions (continued)

- Parental and adult considerations are often given more weight than the views of the children and young people – ‘who shouts loudest’.
- Away from the specialist hospitals the emphasis is inevitably on adult provision and patient experience improvement even though children make up a good proportion of patients.
- Scarce time and resources are regularly used as a reason for lack of action.

Transition:
- Transition is a key area where the system still has room for improvement.
- Work has been done to raise awareness of the need to improve transition into adult services and this now needs to be built upon and adopted across the board.

Neonatal:
- We still need to identify more examples of best practice in neo-natal care.
- There are few examples of what is working well in this area.

Vulnerable Children & Young People:
- There is more work to be done to improve services for vulnerable CYP, they are generally less satisfied and perceive a lower patient experience.

Outcomes and Key Findings from CQC Survey:
- Communication, involvement, and care coordination are key areas for concern.
- Young people and parents do not feel that staff always listen to them – compounded by the fact that healthcare professionals often appeared unaware of the child or young person’s medical history.
- Much more must be done to involve young people and parents. Patients and families have a right to be involved in decisions about care, but too often, young people and their families are not given this opportunity.
- Children with physical and learning disabilities or a mental condition have a lower perception of patient experience across the board.
- All trusts must do more to ensure that children with physical disabilities, a mental health condition or those with a learning disability are receiving care that meets their specific needs.
- Food and lack of play provision were identified as areas for improvement.
- Trusts must review how they support patients and their parents and carers during and after discharge.
- Trusts must review their results from the CQC Inpatient and Day Case Survey to ensure that, where it falls below the standard required, the quality of their services improves.

Play, play, play!

“Play is indeed the business of childhood, it’s how children communicate and make sense of the complex world around them. There is evidence that children and young people want us to become more playful in our interactions with them, the National Association of Health Play Specialists (@nahpsofficial) have brought together the evidence relating to play and its importance helps us to keep building our case for play within the health care environment.”

Patient Experience Network
Re:thinking the experience
7. Next Steps

In the initial report we were firmly of the opinion there was a requirement for more visible leadership commitment and engagement to improve both the patient and the staff experience. There was also a need to equip organisations to be much better at measuring and reporting their success, evidencing more effectively the impact of their activities. In addition to these more general issues, in CYP we suggested that the next steps should be:

1. Involve and listen to children and young people (of all ages) more using a broad range of age-specific tools – and act upon their inputs

2. Celebrate the fantastic work that is already happening – and create a positive appreciative enquiry approach to good practice, building on and learning from what works well

3. Make it much, much easier to identify and access examples of best practice in patient experience for children and young people at the point of the need

4. Be open to explore best practice from areas other than CYP, adapt and share it

5. Build on the work by the NHS Youth Forum to develop effective complaints procedures for children and young people that reflect their unique needs

6. Look closely at transition and invest in developing and sharing good practice for example Ready Steady Go Hello

7. Similarly there is a gap for neo-natal that also needs attention

8. Consider the possibilities of working with private sector organisations to deliver best practice improvements in the NHS

9. Ensure that policy makers and budget holders understand that spreading and implementing existing best practice will make best use of and release valuable resources by providing them with concrete examples.

- A key message coming through is that what organisations really want is help in developing and implementing best practice. The key action from the initial report was identifying the great practice already out there and making people aware of it, bringing people together and working with them to make the process easier has to be a priority.

> Children and young people are ready and able to give feedback to help hospitals measure and understand the quality of care they provide. The challenge for the NHS is to ensure that it continues to gather this feedback and use it to improve services.

Dr McCulloch

- It is clear that progress has been made in the past eighteen months with good practice emerging from a wider variety of organisations and more emphasis being placed on developing better ways of engaging children and young people in improving services aimed specifically at them. The CQC report has highlighted a number of issues, a key concern being the discrepancies facing those children and young people with physical / learning disabilities and mental health problems.

- The desire for improvement and the practical examples are out there, we have made a good start and we still have a real opportunity to make a real difference.
7. Next Steps (continued)

How Can This Be Achieved?

- Building on some of the ideas suggested above, there are numerous case studies in existence, some of which are highlighted in this report. These should be ‘sweated’ and made to work harder! Use them to develop master-classes, provide on-line resources, printed and other materials which can be made available across the NHS.

- Individual support can be provided across a range of options including accessing networks and discussion forums, easy access to a library of case studies, involvement in a facilitated Community of Practice, web based training, videos and archive materials.

- Physical resources – PEN have already produced two volumes of case studies of practical best practice and a third is in preparation. Make these volumes, and other such resources, available across the NHS.

- Best Practice Master-classes – utilising existing case studies develop further master-classes similar to those run as part of the Celebrating the Best of Children and Young People series of events at Alder Hey and latterly across three regions.

- Provide training and staff development opportunities based on best practice in practice

- Involve, Listen and Act – There are a number of initiatives and case studies already in existence which can help in this area. 15 Steps Challenge; ‘You Said, We Did’ is widely used and acts as a simple way of informing patients that their contributions have been heard and acted upon. The CYP MeFirst Programme works to build effective communication between children, young people and healthcare professionals and has potential for national adoption.

- Support organisations to identify the pockets of best practice already in existence within their own organisations, and there will always be some somewhere! This can be done in many ways, however, one way could be by encouraging entry into internal and external awards programmes. This has the added benefit of allowing teams to celebrate and share their best practice, gaining recognition for their great work, and involvement in the process has been shown to have beneficial outcomes for patients, staff and future development of best practice.

- Identify and partner with other organisations with expertise which can be used to enhance both organisational performance and improve patient experience for children and young people.

- Build on work already started – transition, complaints procedures, case studies, staff initiatives, awards schemes etc. – placing children and young people firmly at the centre.

Critical to success is creating a mind-set of positivity and self-belief. People can make a difference – often it is the small things that will make the biggest difference.
A call to action that CYP Experience needs sustained Leadership... from @Adsthepoet

LEADERSHIP
by Adam Bojelian

This rhyme is a puzzle, as you will see,
This rhyme tells what a good leader should be.
A good leader respects the young & the old,
A good leader observes & is prepared to be bold.
A good leader is brave & will try something new,
A good leader works hard & gives praise when it's due.
A good leader expects the best from all staff,
A good leader brings happiness & shares in a laugh.
A good leader supports patients & gives them the best,
A good leader teaches staff to be ahead of the rest.
A good leader explains if something goes amiss,
A good leader rejoices in times of great bliss.
If you study this rhyme and look very close,
You'll discover the leader I admire most.
PEN is a not for profit organisation whose ambition is to recognise, celebrate and share what is working well in the experience of care. PEN has written a series of reports to highlight the great work in the maternity experience of care, children’s and young people’s services and the experiences of families with children who are long term ventilated, amongst others.

Re:thinking the experience

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