

# *Improving Patient Experience for Children and Young People*

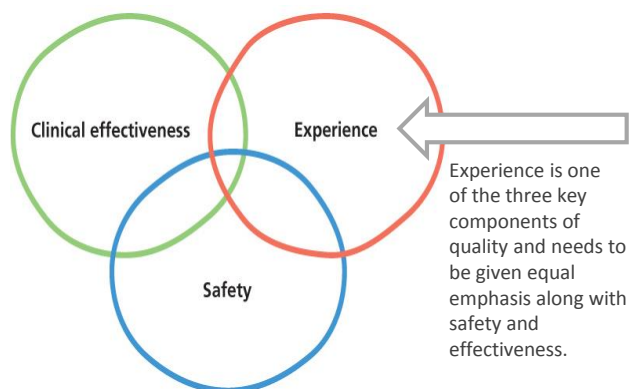
*A Report prepared by  
The Patient Experience Network*

For  
NHS England

Patient Experience Network  
Re:thinking the experience



## Ensuring Neonates, Children, Young People and their Families/Carers have a Positive Experience of Care

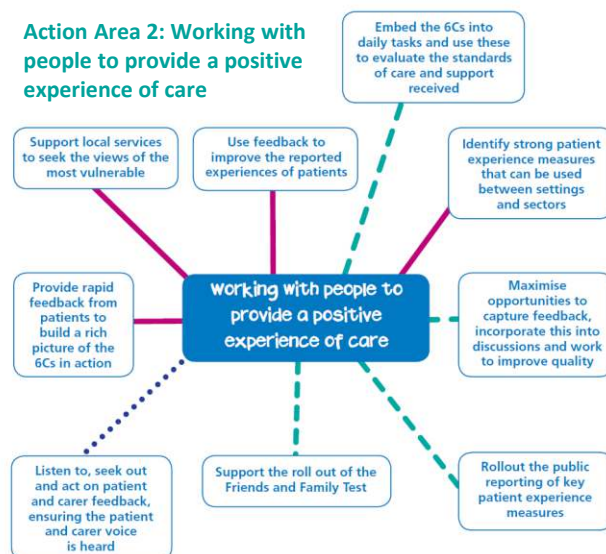


The UN Convention on the Rights of the Child, Article 12 states Children and Young People have a right to have their views heard in all matters affecting them and for these to be taken seriously and in February 2013 the Government pledged that 'Children, Young People and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority', the NHS Outcomes Framework, NHS Mandate and Business plan commits to addressing this.

Dr Maggie Atkinson, Children's Commissioner challenged the NHS in her report 'We would like to make a change' stating 'We found no coherent national programme of activity to proactively encourage local bodies to include children and young people in strategic health service commissioning or other vital decision-making about NHS provision'. Only 28% of 102 local health plans reviewed referenced children and young people's participation in their development, the delivery of what was in them, or the evaluation of whether practice matched their aspirations.



### Action Area 2: Working with people to provide a positive experience of care



### Links with Compassion in Practice, Action Area 2

There are a number of programmes of work in progress at NHS England to ensure participation of Children, Young People and families/carers and experiences of care are focused on:

- Friends and Family test will be rolled out to all CYP areas by 2015 at the latest
- Surveys are currently being reviewed to ensure they capture information from Children, Young People and Families/carers regarding their experiences of care
- Areas of good practice regarding specific experience focused work including use of PREMs, focus groups, schools work etc. are being gathered into a report (Sept 2013)
- A CYP Experience of care community of interest is being established
- We are expanding our network to collaborate widely, including with the voluntary sector, CCGs, Acute and Specialist Trusts to improve experiences of care
- A Youth Forum is being established in collaboration with British Youth Council

We need to learn from the best and inspire services to make sure Neonates, Children, Young People, families/carers experience better care, not just better treatment. Our focus will be on how services are improved as a result of feedback and how such improvement drives clinical outcomes and productivity.

We would value all assistance with this agenda.

Please share any examples of good practice relating to Patient Experience  
[kath.evans3@nhs.net](mailto:kath.evans3@nhs.net) or tweet @kathevans2



# Contents

	Page
1. Introduction	6
2. Methodology	8
3. Executive Summary	10
4. Background to Patient Experience	16
5. Survey	24
6. Review of Existing Best Practice Case Studies	28
• 6.1 Alder Hey – Disability Workshops and Soccer Spa	28
• 6.2 Leicester City – Let the Children Be Heard	30
• 6.3 Salisbury Hospital – New Children’s Ward	33
• 6.4 Birmingham Children’s Hospital – Feedback App for Children	35
• 6.5 North West Ambulance Service – Patient Experience Board Game	36
• 6.6 Northumbria Healthcare – Dental Care – Meeting the Needs of Looked After Children	39
• 6.7 Newham University Hospital – Engaging Seldom Heard Groups – Working with Learning Centres	41
• 6.8 Nottinghamshire Healthcare – Listening to Experience – Transforming Stories into Action Through Technology	44
• 6.9 Birmingham Children’s Hospital – Catering for Children and Young People (Menu Choices)	46
• 6.10 Involving Schools in Design of Environment (Paediatric Intensive Care)	47
• 6.11 Milton Keynes Hospital – Involving Young People	47
• 6.12 Examples put forward by contributors to survey	48
7. Celebrating the Best of Children’s and Young People’s Experience Event	50
8. Who Else Could We be Working With?	53
9. Conclusions	56
10. Next Steps : How Should We be Working to Further Improve Patient Experience for Children and Young People?	58
11. Acknowledgements	60
12. Thank You	61





## Posters

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Through out this report we have included a series of posters that have been made available across various events, including the Celebrating the Best of Children’s and Young People’s Experience event on 12th September 2013.

These are as follows:

- Overview Positive Experience CYP – NHS England Pg.1
- Malala Presents to the Queen Pg.5
- An Integrated Approach – NHS England Pg.7
- What Matters to Me – NHS Greater Glasgow and Clyde Pg.15
- Acting Together Louder than Words – GOSH Pg.23
- The Development and Implementation of a Paediatric Active Care Checklist – Greater Glasgow and Clyde Pg.27
- Exploding Myths and Misconceptions of General Practice with Teenagers – Encompass GP Surgery Pg.49
- Developmentally Appropriate Consultations for young People aged 14-18 in Paediatrics – Northumbria Healthcare Pg.52
- Helping Awareness and Support for Congenital Heart Disease – Anthony Birch Pg.55
- Transition to Adult Care: Ready Steady Go – University Hospital Southampton Pg.57





Picture: Malala Presents to the Queen





# 1. Introduction

Improving patient experience for children and young people is a subject which is close to many people’s hearts and which has not always received the attention and investment that it needs to make serious progress. Ensuring a positive patient experience for all groups is a strategic, commissioning and financial imperative for all. Patient experience is a fundamental component of how we should think about the quality of healthcare. We know there is 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. The ongoing review of patient experience and the overall environment is vital and drives continuous improvement.

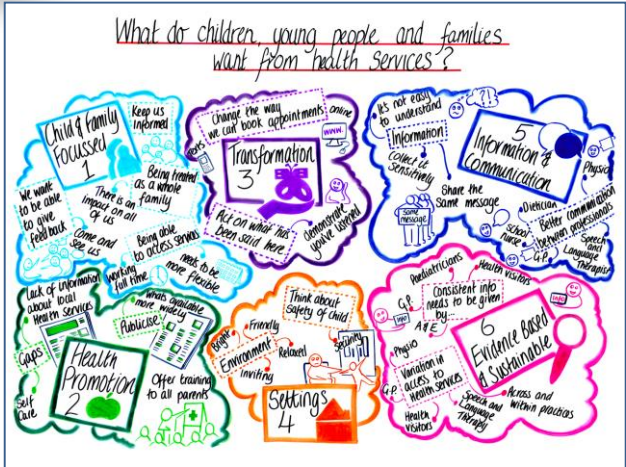
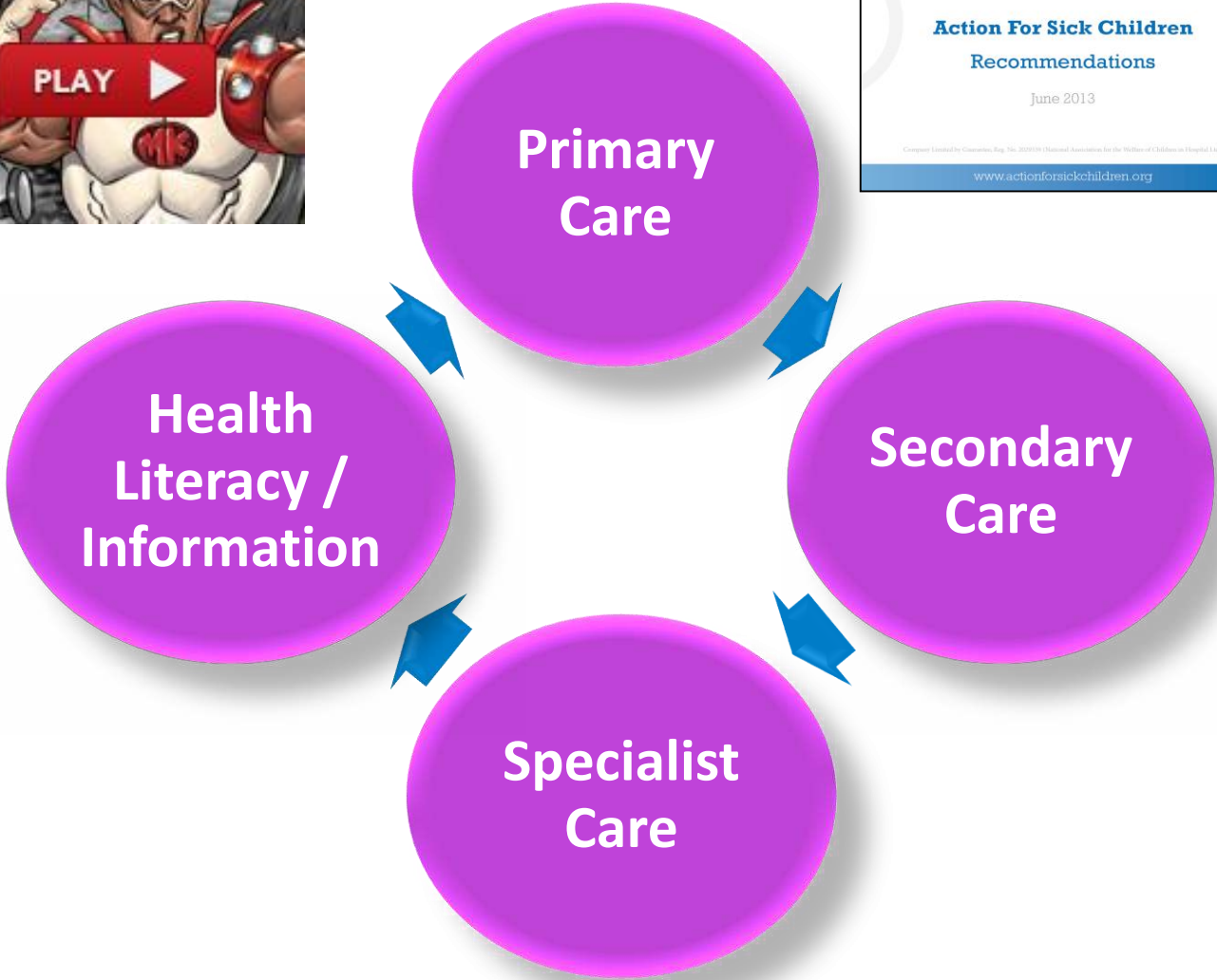
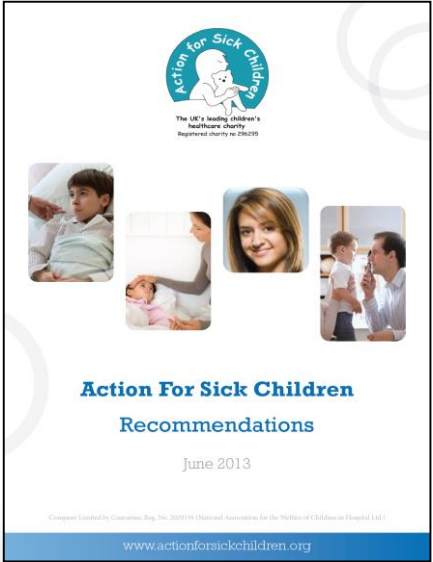
This report was commissioned by NHS England to look specifically at the subject of improving the patient experience for children and young people within the NHS. One comment coming out of the recent survey sums this up very neatly:

*Children need to be recognised as NHS consumers in their own right and there should not be so many hurdles and gatekeepers to accessing their views and experiences of care. Children are conceptualised as a vulnerable group in need of special protection rather than consumers with a legitimate voice and their own world view.*

Jane Noyes, Professor of Health Service Research and Child Health, Bangor University

Clearly things need to change!

Poster: An Integrated Approach - NHS England





## 2. Methodology

The objective of this report is to examine and comment upon the current situation 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 is 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.

In compiling this report PEN conducted some desk research, referring to available documents on the subject and utilising the case studies and information within its own data banks. In addition PEN conducted a survey amongst its members and other interested parties, requesting their views in response to a number of key questions. During the preparation of this report PEN also 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 these contributions have also been included in this report.

The desk research was conducted over a period of one week and encompassed searches of the internet, review of existing documents and the analysis of information from the PEN database. The survey reached 147 participants from 111 organisations representing a wide variety of interested parties including NHS England, commissioners, trusts, hospices, specialist children’s services, charities, networks, councils, local authorities, universities and custody services. One event in particular related directly to the production of this report was attended by almost 100 people from across the NHS and the wider healthcare community. It included staff from a range of settings and job roles from the Children’s Commissioner for England to student nurses. Feedback and comments from other events has also been taken into consideration. The desk research and review of known best practice was conducted independently of the survey and it is very interesting to note the close correlation of the results – this adds weight to the overall conclusions.

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.





### 3. Executive Summary

Patient Experience isn't just an endpoint of care, it should be the start of improving care and ultimately embedded into the culture of an organisation. The evidence shows that more organisations are embracing this philosophy and moving forward, but there is still a long way to go. The overriding need in improving patient experience is to replace the pockets of best practice with an organisation-wide culture of service excellence. Consistency is key both across an organisation and between organisations; patients need to experience that same brilliant experience no matter where they interact with the healthcare system – a big ask in the current economic environment.....but not an impossible one. In this report we are focussing on improving patient experience for children and young people, a distinct group with distinct needs and requirements and one we clearly need to involve more effectively in the improvement process to achieve the desired outcomes.

The report draws from a number of sources including desk research, surveys, events and PEN's own database of information. The report is not intended to be all encompassing but rather is a short overview undertaken as a snapshot of today's status, working on the premise of celebrating some of the positive steps taken to date. The authors have, however, been able to bring together some key strands relating to patient experience for Children and Young People (CYP) and make some recommendations regarding ways to develop and further improve patient experience for children and young people. The key focus for the report was to highlight some of the issues facing organisations in providing the best possible patient experience for children and young people and to give a flavour of some of the great practical best practice currently being undertaken across the NHS and wider healthcare arena.

Several themes have emerged and some learning points were repeated throughout the course of compiling this report.

- **Best Practice:** There are numerous examples of excellent best practice across the NHS. For CYP this is particularly so in tertiary centres e.g. the children's hospitals (Alder Hey, Birmingham Children's Hospital, Manchester Children's Hospital, Great Ormond Street (GOSH) etc.).
- **Involvement of CYP:** There has been an increase in the involvement of young people in improving patient experience; soliciting their views, creating opportunities for their voices to be heard and acting upon their suggestions. However, less than 50% of respondents to the survey had a specific strategy in place for children and young people, and this is from organisations who are particularly engaged in improving patient experience.
- **Focus on action:** Whilst many organisations are doing something to improve experience for children and young people there is still too much focus on 'talk' and not enough on action. Millions of £'s are spent on reports, targets, pledges, discussions and initiatives, and considerably less on identifying existing areas of practical best practice in patient experience and then sharing it. Why re-invent the wheel?
- **Role of leadership:** In addition to the focus on talk over action there is a clear feeling that leadership is not always supportive of initiatives to improve patient experience. This particularly applies to policy makers who are seen as reactive, i.e. responding to the latest 'piece of bad news', and out of touch with what is happening 'on the ground'.
- **Voice of CYP:** Much of the current survey and development work is 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. Take the example of the GOSH patient experience survey in which less than 20% of respondents were children (over several years).

### 3. Executive Summary *(continued)*

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- **Who shouts loudest:** Parental and adult considerations are often given more weight than the views of the children and young people – ‘who shouts loudest’ is one comment, another is that it is easier to elicit the views of adults (parents, carers, ‘experts’ and staff) than of children.
- **Blinkered Thinking / Silo Mentality:** Across the NHS 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.
- **Investment:** There is not enough time or money spent on collectively developing existing (and new) practical best practice and ensuring it is shared across the whole of the NHS. We have included a number of case studies in the report highlighting just some of the great work being done.
- **Lack of action:** Scarce time and resources are regularly used as a reason for lack of action. There is a wealth of evidence to show that implementing good patient experience practices releases valuable time and resources.
- **Variation:** Variations still exist in the provision and quality of services for children and young people both geographically and medically
- **Gap in transition:** Transition (to adult services) is a key area where the system is failing the patient and their families/carers and this is also an area where few examples of good practice have been highlighted.
- **Neo-natal:** We need to identify more examples of best practice in neo-natal care.
- **Generalist Challenges:** 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.
- **Complexities of Children and Young People:** CYP practitioners face all of the issues that those dealing with adults face, with the additional issues related to age, understanding, communication and parental considerations. Getting it right is not easy, but the issues are not insurmountable – and are they really all that different under the surface?
- **Complaints process:** These processes for Children and Young People are fragmented and often based on those created for adults. This can lead to children’s complaints not being properly raised, recorded and actioned. Complaints are a valuable source of information on which to base service improvements and an effective response to complaints often results in complainants becoming strong advocates of an organisation or service.
- **Two sets of customers:** In dealing with children and young people the NHS has two differing, and sometimes conflicting, sets of ‘customers’ - the patient (child or young person) and the parents or carers. The NHS needs to understand and address the needs of both groups without allowing one to overpower the voice of the other.
- **Happy staff = happy patients:** It may be a cliché but strong evidence exists to back this up. PEN have certainly found that patient experience is inextricably linked to staff experience. This has the potential effect of multiplying the benefits of getting it right – but it works equally in the opposite direction.



### 3. Executive Summary *(continued)*

- **CAMHS:** The Child and Adolescent Mental Health Service (CAHMS) provides excellent resources and support services for young people, parents and professionals in relation to mental health difficulties and disorders and features strongly in improving patient experience.
- **Need for Play Specialists:** An underlying theme not reported on specifically elsewhere in this report is the essential role of Play Specialists. Where they are in post they are seen to be a vital part of the team in delivering high quality patient experience to C&YP; where they are not in post there is a plea for the important role of Play Specialists to be recognised.
- **Measurement and evidence:** Supporting deliverers of care to capture evidence of the impact of their improvements more effectively will build credibility, confidence and evidence for the case moving forward.



#### What can be done to improve patient experience for children and young people?

- Involve and listen to children and young people (of all ages) more – act upon their inputs and let them know what you have done, including developing an effective complaints procedures.
- Identify and develop CYP best practice that currently exists and share it - Why does everyone have to plough their own furrow?
- Develop existing best practice from areas other than CYP, adapt and share it.
- Look closely at transition and invest in developing and sharing good practice.
- 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.
- The key message coming through is that what organisations really want is help in developing and implementing best practice. The key action from this report has to be that there is 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. The desire for improvement and the practical examples are out there, we have a real opportunity to make a real difference.
- Support teams to report robust evidence of the positive impact of their actions on other areas e.g. staff engagement, length of stay, health outcomes, reputation as well as improved patient experience.

### 3. Executive Summary *(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 – use them to develop master-classes, provide on-line resources, printed and other materials which can be made available across the NHS

Help can be provided across a range of options including:

- **Web based resources:** Case studies, a discussion forum, web based training, video and archive materials.
- **Physical resources:** PEN have already produced one volume of case studies of practical best practice and a second is planned. It has been well received by those who have seen it. Make these, and other such resources, more readily available across the NHS.
- **Best Practice Master-classes:** Utilising existing case studies develop further master-classes similar to the one run as part of the Celebrating the Best of Children and Young People Event at Alder Hey.
- **Staff Development:** 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.
- **Use best practice effectively:** Identify best practice already in existence by encouraging entry into internal and external awards programmes. This has the added benefit of allowing teams to celebrate and share their best practice, and involvement in the process has been shown to have beneficial outcomes for patients, staff and future development of best practice. For example, following the receipt of the Innovation Award at this years’ PEN National Awards, North West Ambulance Service secured additional funding to develop further games and engagement tools.
- **Work with Partners:** 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.







# What Matters to Me



Jessie Bridges, Senior Clinical Nurse  
Quality Improvement & Patient Safety, NHS

"That doesn't always sit with me I  
was feeling nervous but all they were  
trying to do was make sure I was  
happy and I was able to have a good  
time for the whole  
experience.  
Really well done!" (Age 5 years)

"I am happy to be here  
The staff are so nice  
The food is good  
Really well done!" (Age 5 years)



"Doctors at school are like  
Doctors here but they  
are a bit more like a  
friend and they are like  
the ones that  
I really like!" (Age 5 years)

"They are really nice  
Doctors here but they  
are a bit more like a  
friend and they are like  
the ones that  
I really like!" (Age 5 years)

## Aim

The Scottish Government's Healthcare Quality Strategy (2010) supports the development of person centredness and improved patient experience.

This led to me to ask the question 'Do we really know what matters to the children and young people we care for?' The aim is to provide truly person centred care by uncovering and addressing what is important to children and young people during their hospital stay.

## Methodology

The Model for Improvement (Langley et al 2009) provided the methodology for the project. Three fundamental questions and answers which form the basis of this improvement are:

## What are we trying to accomplish?

The Initiative acknowledges the stress that both children (Coyle 2006) and their carers (Commodari 2010) experience whilst in hospital, and will aim to provide a vehicle to regain a sense of control during their stay. The project will develop a service that does not assume knowledge on the thoughts of patients but rather asks them directly and responds to their needs.

## How will we know that a change is an improvement?

Qualitative data is collected from patient feedback questionnaires. The questionnaires are designed for three groups; parent/carer, young people and children. The data is reviewed every 2 weeks and comments linking to the Initiative are recorded and displayed. Sound bites are also collected and displayed so the multidisciplinary team are able to collectively consider what is important to our patients. Staff feedback is also encouraged.

## What change can we make that will result in an improvement?

Every child old enough to do so will be given the opportunity to draw or write a 'What Matters to Me' list which will be displayed close to their bed.

## Results

Patient feedback has been positive. Often both children and their carers get involved which lends itself well to the family centred care model as well as person centred care. Older children and those with chronic conditions wrote very specific lists outlining personal preferences during their stay. Younger children enjoyed drawing pictures, and often described surprising likes, dislikes and

worries which may have went uncovered had it not been for the Initiative.

## Conclusion

For the cost of just pens and paper this Initiative provides inspiration and insight for hospital staff caring for children and young people. Children and their carers can be confident that their individual preferences are being listened to and addressed. More research is required to analyse the impact of 'What Matters to Me' on psychological stress felt by carers, children and young people whilst in hospital.

## References

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## Acknowledgments

A special thank you to Jane Craig, Linda Vassie, and Alison Jack who alongside the staff of ward 15, Royal Alexandra Hospital helped turn this idea into a reality. Also thank you to the staff and volunteers of the Yorkhill play service who are working hard to embed 'What Matters to Me' for all children throughout Yorkhill Hospital.



## 4. Background to Patient Experience

Patient Experience has been variously defined over the years and it is appropriate to get a flavour of how it has been interpreted for the purposes of this report, and to provide a snapshot of the current landscape in relation to patient experience.

Over the past couple of decades most people would agree that healthcare organisations have recognised that providing excellent clinical care is not enough to satisfy patients. In fact – providing first class medical care is taken as read and the NHS is seen as an excellent example of public healthcare provision the world over. Even today it is very difficult to pin down exactly what makes up the patient experience and many definitions still proliferate. Given the lack of consensus on what ‘patient experience’ actually is should it be surprising that some organisations are struggling to provide ‘excellent patient experience’?

In February 2012 the NHS National Quality Board (NQB) published the **NHS Patient Experience Framework**. This 8 point framework outlines those elements which are critical to the patients’ experience of the NHS. The eight points cover:

1. Respect of patient-centred values, preferences, and expressed needs
2. Co-ordination and integration of care (across health and social care systems)
3. Physical comfort
4. Emotional support
5. Welcoming the involvement of family and friends
6. Transition and continuity
7. Access to care.

In 2004 the Department of Health definition of patient experience included:

- Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way
- Having information to make choices, to feel confident and to feel in control
- Being talked to and listened to as an equal
- Being treated with honesty, respect and dignity.

The Beryl Institute defines patient experience as.....

*“The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions over the continuum of care”.*

.....and this is the definition PEN feels most reflects the essence of what organisations are trying to achieve – it effectively encapsulates patient experience in one sentence. It is not a stand-alone concept, it courses through the whole of the organisation touching every aspect and involving everyone, whether or not they have a direct relationship with patients.

## 4. Background to Patient Experience *(continued)*

There are currently a number of key policy drivers for patient experience in the NHS according to the NHS Institute for Innovation and Improvement – these include The Operating Framework 2012/3 (and ongoing iterations), The NHS Outcomes Framework, NICE Quality Standards, Commissioning for Quality and Innovation (CQUIN), Quality Accounts, NHS Constitution, Section 242 – The Statutory Duty to Involve, Essence of Care, Equity and Excellence – Liberating the NHS (White Paper), and Healthy Lives, Healthy People (White Paper). There is also a tendency for government to react strongly to tragic events and produce further recommendations – recent examples would be following the death of Baby Peter or the recent Mid Staffs fallout – The Francis Report, with its 290 recommendations. Whilst it is extremely important to understand what went wrong in these cases and ensure that it cannot happen again a large number of healthcare professionals feel that many of these inquiries and reports are over-reactive and out of date by the time they come into the public domain, and sometimes point the finger in the wrong direction. Media coverage of the NHS recently has been very negative and this has an extremely adverse effect on staff morale and, potentially, public impressions – making improving patient experience an even more difficult mountain to climb.

Underpinning current patient experience thinking in relation to children and young people, as mentioned by Dr Maggie Atkinson at the recent event at Alder Hey, is the UN convention on the Rights of the Child which states (amongst other important things) **that every child has the right to be heard (including considering children’s views)**.

Patient experience is also inextricably linked with staff experience. In the case studies and work undertaken by PEN this is clearly evident and their findings are backed up by many other organisations. A Department of Health report in 2007 produced by Aston Business School showed strong links between staff survey responses and inpatient survey responses. The report found that staff experience was ‘closely linked’ to good patient experience. It may be a cliché but **happy staff = happy patients**. The link between happy staff and satisfied customers has long been recognised in the private sector.

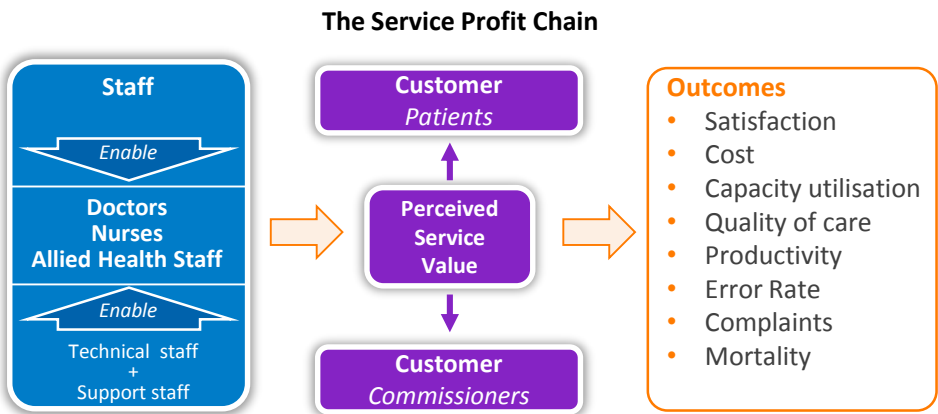
*“It was only when we realised the link between staff and patient experience  
that we started to make real progress in the Trust”*

**Director of Nursing – London Acute Trust**

One of the key recurring themes put forward for a lack of progress in improving patient experience is a lack of leadership, the failure of budget holders and policy makers to understand the real benefits of improving patient experience and not giving it the necessary resources – both time and money – to ensure success. In many ways this can become a self-fulfilling prophecy – as more time and money is spent on day-to-day issues, fire-fighting and reacting to the latest initiative or target less is available to adopt essential best practice which would free up valuable time and resources and produce better outcomes for both the organisation and its patients.

4. Background to Patient Experience (continued)

The business case for investing in improving patient experience is clear – improved patient outcomes, shorter hospital stays, fewer readmissions, improved staff engagement, reduced absenteeism, improved system efficiencies, and improved organisational reputation are just a few examples.



Adapted from: J. Haskett, et al.

The examples given below are not taken exclusively from children and young people’s settings but they have universal application and the evidence is compelling. The key to further investment in improving patient experience across all settings and specialisms, Children and Young People included, is in getting these very positive messages across to the policy makers and budget holders. It may be that we also need to build more evidence specifically from CYP.

- “Patient average length of stay is now 2.5 days – reduced from 5 days”
- “Generated annual savings for the PCT of £1.9m”
- “Saved 1683 bed days at an average cost of £250 per night – that is a saving of £420,000”
- “Improved attendance at clinics – DNA’s down from 24% to 3%”
- “The project has already made a positive impact on Trust reputation and more women are choosing to come to the Trust”
- “Patient falls have reduced from 63 to 16 – especially those resulting in injury”
- “100% of patients have shown an increase in function following supported discharge”
- “The service has allowed service users who may not have come into a clinic to have access to healthcare”
- “Trust-wide 30 day mortality has reduced....by 31%”
- “Staff now feel more empowered and confident”
- “There has been over 50% reduction in staff resignations”
- “Staff absence has reduced from an average of 8% to just below 2%”

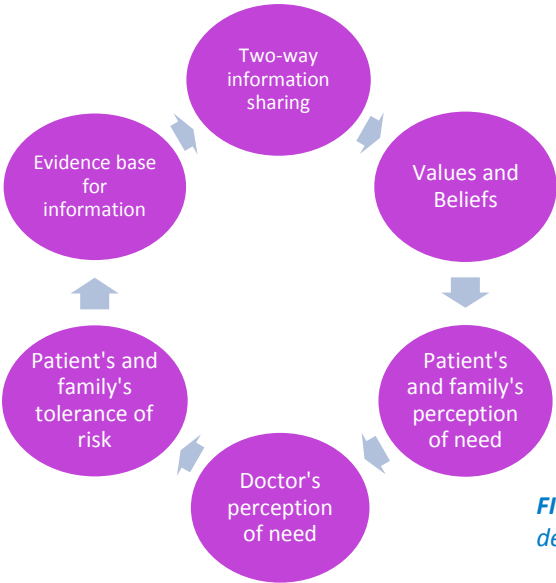


In 2012 an NHS Atlas of Variation in Healthcare for Children and Young People was published, with a subtext of reducing unwarranted variation to increase value and improve quality. One key part of the report linked the success in reducing the variations that exist to improving patient experience through shared experience.

The report indicated that variations in the quality of service and in clinical outcomes persisted despite the work on quality improvement that has taken place in the NHS and that the value of guidelines, metrics and clinical governance in promoting high-quality care was clearly understood.

#### 4. Background to Patient Experience *(continued)*

The report stated that the process must be a) Grounded in the patient and/or family being well informed; and b) Sensitive to the individual’s and/or family’s needs and values (see Figure A below); and that shared decision-making holds the key to maximising quality and efficiency in these circumstances. The evidence showed that patients and their families, making a choice using patient decision aids and the evidence available, often choose an option that utilises less resources and results in a better patient experience.



**FIGURE A:** Key components in shared decision-making

Clearly not all variation arises as a direct result of service design and delivery: ease of access and outcomes in children and young people are also affected by pre-existing health status and socio-economic factors. To promote child health the report concluded that it is vital for the NHS to continue to work in partnership with other professionals, and to approach reducing variation as a multi-professional inter-agency process. This point was also made by Dr Maggie Atkinson in her presentation at the CYP event covered later in this report

Improving Patient Experience has received a lot of attention over the past few years and it is clear that great progress has been made, PEN alone has more than 250 case studies in its archives and work has been, and continues to be done by many organisations including the Offices of the Children’s Commissioners, NHS England and many other bodies. However it is also clear that best practice in patient experience is not universal, there are pockets across the country and even within organisations – at a recent conference one speaker referred to a need within his hospital group for pharmacy to now work more closely with discharge procedures. PEN was able to put him in touch with a pharmacist from his own hospital group who had recently won a PEN National Award for just this. Knowing what is out there and having it easily accessible is key.

Patient Experience is not an exact science and it is continually evolving, each year patients’ expectations increase and the NHS needs to view improving patient experience as an ongoing priority, not just a passing fad, today’s imperative. Standing still is not an option.



## 4. Background to Patient Experience *(continued)*

In February 2013 a pledge was signed by the government and 19 other organisations covering many aspects of healthcare for children and young people in the UK. The pledge commits them to improving health outcomes for children and young people, providing a framework for them to become world leading. Best practice in patient experience can be easily identified in relation to each of the pledge ambitions below:

- Children, young people and their families will be at the heart of decision making, with the health outcomes that matter most to them taking priority
- Services, from pregnancy through to adolescence and beyond, will be high quality, evidence based and safe, delivered at the right time, in the right place by a properly planned, educated and trained workforce
- Good mental and physical health and early interventions, including for children and young people with long term conditions, will be of equal importance to caring for those who become acutely unwell
- Services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health care in adult life
- There will be clear leadership, accountability and assurance and organisations will work in partnership for the benefit of children and young people

Complaints form a key part of improving patient experience across the board, and children and young people's services are no exception. Concerns exist that not enough focus is given to children and young people within the NHS Complaints process and the Office for the Children's Commissioner produced a report into the issue in September of this year.

Key United Nations Convention on the Rights of the Child articles that relate to complaints systems include: Article 2: non-discrimination; Article 3: best interest of the child; Article 12: children and young people's right to have their voice heard and taken seriously.

The following principles were developed based on the views, experiences and voices of children and young people, as well as discussions with professionals who have a responsibility for complaints (2013). A number of key organisations, including the Department of Health, the General Medical Council, the National Youth Advocacy Service and the Youth Justice Board all signed pledges to make key improvements.

1. All organisations working with children and young people should value and respect them, and develop positive and trusting relationships.
2. All complaints from children and young people should be seen as positive, valuable service user feedback and considered from a safeguarding perspective.
3. Children and young people should be involved in the development and implementation of the complaints process they may wish to use.

## 4. Background to Patient Experience *(continued)*

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4. All children and young people should have access to information about complaints processes. This should be provided in a variety of formats, including online, and should be age appropriate and take account of any additional needs that a young person may have.
5. All children and young people should be able to make complaints in a variety of ways.
6. Written responses to complaints should be timely and where possible discussed with the young person. The young person should always be given an opportunity to provide feedback.
7. Staff should be well trained and have access to training in listening to, and dealing with, complaints from children and young people.
8. Children who need support to make a complaint should have access to an independent advocate.

Patient experience for children and young people is a vital component of improving both the quality and efficiency of the NHS. It touches the entire organisation, staff both on the front line (doctors, nurses, receptionists and healthcare practitioners) and behind the scenes and has a direct impact on improving the depth and quality of services. Finding and implementing areas for improvement is vital to ensuring the effective development of services for children and young people.



# Poster: Acting Together Louder than Words – GOSH

## ACTING TOGETHER! LOUDER THAN WORDS!

### A patient experience, listening event led by young people

Great Ormond Street **NHS**  
Hospital for Children  
NHS Foundation Trust

#### Background

Great Ormond Street Hospital (GOSH) has three priority areas that form part of its vision and strategic plan and they are as follows:

- **Safety** - to reduce all harm to zero
- **Effectiveness** - to demonstrate clinical outcomes
- **Experience** - to deliver an excellent experience

GOSH aims to consistently deliver an excellent experience for their service users - patients, family and carers. The hospital seeks to provide the best possible services to patients and their families who come from diverse backgrounds and from all parts of the UK and abroad.

Internally the hospital had talked of some form of Commitment which was shorthand for motivating a major cultural change that involves agreed actions by everyone connected with GOSH.

Communications between patients, families, staff and local services underpins every activity at GOSH. Improving the provision of timely, relevant and easy to understand information and advice is a continuing goal in ensuring a positive experience.

Great Ormond Street Hospital NHS Foundation Trust commissioned SMSR Ltd an independent research company to plan, facilitate and deliver a Listening Event which would enable the hospital to discuss and to better understand the current patient and family experience and start the process of engaging stakeholders on the concept of a GOSH Commitment.



#### Aims and Objectives

The main aim of the Listening Event was to explore and generate feedback on developing a set of actions and behaviours, rather than empty promises and platitudes, that all GOSH stakeholders – but critically patients, their families and staff, can share, motivate, and implement to ensure an excellent experience for all. Underlying this was an aim to better understand these stakeholders' current evaluation and perception of the patient experience.

The key objectives of the Listening Event were as follows:

- To gather perceptions of the positive and negative aspects of the current patient/family experience
- To understand what a Commitment should entail/look like
- Identify the key priorities/challenges to be addressed
- Assess the level of support for the proposed Commitment and reasons for this
- Assess the levels of belief for a proposed Commitment
- To understand how the Commitment can be implemented successfully

The young people were considered the most important voice of all stakeholders and to ensure they had the space and confidence to speak openly and honestly a separate session was carried out on the day with this group: the objectives of this session were slightly different as was the approach. The session built around the suggested 'dozen or so heads of agreements/actions that will be implemented by everyone at GOSH' and was aimed to give the young people in attendance the opportunity to contribute to their design and provide feedback on how they could contribute to a Commitment and change the current way of thinking and delivering.

#### The Listening Event (Young People)

##### Promises

Promises, promises explored young people's confidence in the creation of the Commitment. It attempted to explore what a Commitment would look and feel like for them. The working definition of the Commitment for the day was:

"To create a culture of GOSH where everyone is equal and young people are trusted to contribute to what the hospital experience should be like for patients – from the moment you walk in, to the moment you leave."

The young people defined the three key variables in this process as being themselves, families and GOSH staff. They discussed the strengths of this as a platform on which to build the Commitment while providing an insight into the opportunities to develop.

##### Empowerment

This was the theme that underpinned all of the aspirations of young people involved in the GOSH Listening Event. As a group of stakeholders in the hospital it was felt they could significantly add value to any shared goal.

"Being empowered to take ownership within GOSH" was a central theme of the Listening Event and young people described a desire to not just feel like, but have a genuine stake in any initiative. Adding substance to the discussion was the reflection on current practice and possible opportunities missed. Young people illustrated the discussion by describing the re-design of the GOSH entrance, including its shop.

##### Resilience

Resilience was a characteristic felt to be present among young people within GOSH and a characteristic that would benefit any mutual Commitment established within the organisation.

Young people participated in an exercise to illustrate their ability to 'prototype' and demonstrate the benefit of capacity building through trial and testing. The 'Marshmallow Challenge' (build a marshmallow mountain) offered an opportunity to develop an insight of the strengths in 'prototyping' when working collaboratively on a new initiative read in this instance as the GOSH Commitment. The ability to 'learn through trial' is a trait often prevalent in young people, from both the practical exercise and preceding discussion it was a sentiment shared by the young people on the day.



##### Voice and Influence

The working group of young people was asked to consider the subject of voice and influence which was referenced as: "If being empowered will give you the chance to make changes at Great Ormond Street, Voice and Influence is about giving you a chance to say what those changes would be".

The group having previously suggested specific changes within GOSH, discussed the importance again of a holistic approach to patient care. A key message was summarised by one attendee as follows:

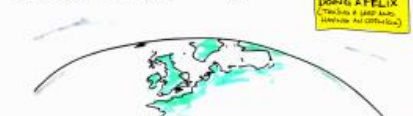
"I wonder if staff understand what children think is important about making their time in hospital better?"



#### Key Messages

Young people likened the implementation of the Commitment to a leap of faith and the plea from these young people to the management of GOSH was 'just go for it' and 'jump' (they compared it to the space jump of Felix Baumgartner) and not to spend hours planning to account for every eventuality but instead to just get on with it. They felt it is better to make meaningful and real changes (and mistakes) than to talk and do nothing.

From their perspective the overall need is for GOSH to recognise that the development and roll out of the Commitment is a three way process involving staff, families/carers and patients and not just a process between staff and family/carers. For this to occur they felt it is essential that patients (along with their families/carers) are empowered and are given an active and definite role.



#### Overall Recommendations

The primary recommendation is for GOSH to embrace the findings of the consultation and commit to improving the current family/patient/staff experience to a level that is comparable to the clinical experience. To achieve this there is a need to 'Commit to the Commitment' and this will require systems, processes and resources to both develop it (and ensure that it is relevant, believable and achievable), implement it and measure it.

The systems and process will need to prioritise the multitude of issues arising, the two key measures being 'ease of implementation' and 'level of impact' focusing on those that score 'easy/high' rather than 'difficult/low'.

Finally there will be a need to monitor and measure progress of the Commitment's implementation and to assess if it is having a meaningful positive impact and how to identify and address barriers to its implementation or impact where they exist.

For this to be done effectively it is essential that it not only embraces and empowers all staff but families/carers and patients and a significant aspect of the challenge is to create a role for young people with this process.



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## 5. Survey

The full results of the survey have been submitted in a separate document so we do not propose to cover the results in their entirety in this report. However, the survey forms a major part of the overall conclusions for the report so it is appropriate to reiterate some of the findings and conclusions.

In a nutshell the survey found that there is 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. The desire is there but there are often barriers to achieving the best possible results. Whilst concluding that there is still a lot more to be done across the NHS as a whole, evidence indicates that there has 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 have a strategy in place for children and young people, a response skewed towards the specialist providers as the number falls 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.

What is clear when you consider comments from the event at Alder Hey on 12th September 2013 and other sources, is that much of the work is being done ‘in isolation’ with individual trusts working up their own solutions and not understanding that there is extensive existing best practice which could be tapped into and adapted.

When asked what the main priority was for improvement within their organisation respondents resoundingly answered – listening to and involving young people more effectively. Solutions included simply ‘Listening to what the children want’ and ‘Giving them support to air their views’ to ‘Following up their concerns’. Working out how to involve children and young people in all decisions that affect them was a key area, especially the need to find child-friendly ways to ensure that children and young people feel heard, recorded and respected. Add to this the comments from the young people at the event – ‘we want to see that you have taken notice and taken action’ and we begin to build the picture.

The next five priorities identified were:

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

The survey backed up desk research findings that the specialist children’s organisations make children and young people, together with their parents, carers and families the absolute focus of the whole organisation. One organisation commented that “We are driven by the needs, wishes and preferences of children and young people; it is built into our care planning and evaluation and we actively seek and respond to feedback from children and young people”. These organisations also exhibit a genuine recognition of the need to constantly improve, even if it is not always an easy path to tread.

## 5. Survey *(continued)*

In more generalist settings the survey found that there was a sense that they are trying to engage more with children and young people, but that there are more barriers to achieving their aims. Resources and priorities are cited as reasons for not making the desired progress. With so many demands on time and resources, and with new reports and recommendations coming out all the time and grabbing the headlines, the more generalist organisations find it hard to square the circle. One respondent commented that with “the diversity of work we do and our patient groups (general paediatrics, mixed specialities, HDU etc. in one small area)....it is difficult to know which group of patients to focus on at any given time, and which part of the service needs development. Future planning of services is also very difficult to achieve as much of the work we do is reactive to the given situation”. Another commented that “It has been difficult to get a focus on children’s services recently because of Trust focus being on Emergency Care Standards, and 18 week RTT and Cancer targets too”.

In these settings there is a clear desire to focus on the experience of children and young people but that other demands on time and resources seriously limit the opportunities. Combining these comments with the desk research and other sources it is clear that there is a significant level of frustration – not just limited to children’s services – that staff cannot achieve the standards they would like to because they are not given the time, resources and support they need to make a real difference. The message that providing excellent patient experience not only doesn’t drain resources but, more often than not, it in fact frees up valuable resources, is clearly not getting through strongly enough to the budget holders.

### *Examples of Best Practice put forward by respondents to the survey include:*

*“We have worked really closely with some of the haematology patients, who did not meet some of the criteria for our specialist teams. Through their input, via questionnaires and the user group, we have now changed our practice and included them in the care provided by the oncology team. They have helped us write patient information and have set up a parent support group, through the user group”*

*“We have also implemented ‘Beads of Courage’ which is a fantastic way for children to receive rewards for procedures and commemorate their achievements through their treatment”*

*“Our Transition Service has recently been given runner up in the Welsh Allen Awards. Her work has achieved fantastic outcomes in transition of Young People with complex needs, which is an area of great anxiety for parents and can be difficult in managing expectations”*

*“We aim to incorporate play in all aspects of care. This can be from building dens above beds, or using on-line resources such as Nature Detectives to bring the outdoors inside, teaching children at an age appropriate level to enhance their education”*

*“The CNN service have set up a nurse-led asthma, eczema and constipation clinic. Children and families have told us that they prefer seeing us as we give them a longer appointment which allows them to tell us their story, it’s usually the first time someone has listened to them and explained what the condition is and how it can be managed”*

## 5. Survey (continued)

*“MYA is made up of a number of projects which use youth projects to support children and young people in reaching their full potential. Two health-focussed projects are:-*

**Healthline** – *Delivers health awareness programmes to young people using interactive group work, as well as 1:1 when required.*

**Voices in Partnerships** – *works with children, young people and parents who need access to CAMHS services and gives them a voice by bringing them together to explore their experiences”*

*“Children in care developed an 'all about me card' to be completed by foster carers to virtually introduce themselves to young people prior to the start of the fostering arrangements”*

*“We decided that we wanted to develop a Health Passport for Looked after children and this has been designed by young people themselves”*

One more detailed example given was: Admission 1- A patient with learning difficulties was prepared for surgery but unfortunately it didn't go as planned and she was suddenly confronted with staff she hadn't previously met or had time to talk with. All these new faces bombarding her overwhelmed her. As she started to receive anaesthetic she panicked and attempted to run. M was required to receive her second surgery sometime in the near future.

*Admission 2 -Having had some support from CAMHS, M was assigned a Care Worker to work toward her upcoming surgery. The Care Worker, S, was introduced and spent time getting to know M and attempt to help the next surgery be a much less traumatic event. S worked with M until a date for the surgery was known. S also worked with staff at the hospital to make M's surgery go as smooth as possible and put together a short book, with pictures that M could use to understand her surgery a little better as well as tick off the various stages as they happened so nothing was a surprise to her.*

*On arrival at the hospital the father said "we were immediately introduced to a fantastic young Staff Nurse, she was outstanding at making M feel relaxed in an environment that she was absolutely terrified of being in." M was introduced to the surgery staff also and a Doctor, who introduced herself and spent a few minutes chatting with M, and importantly about the items she would see when entering the anaesthetic room. M was fast tracked through, and as Dad described ..."other than a slight panic going under... the whole process was a breeze compared to last time.*

*I believe the work pre-empting problems carried out by S, especially the book, and the hospital staff taking time getting to understand both M's difficulties and M herself really helped. I want to pass on my sincere thanks to everyone involved ....in making this the smoothest possible experience for M and putting her previous experience somewhat out of her mind.*

*The full survey results and report are available separately and form a key part of the background to this report. Many of the issues and actions highlighted were also mirrored in the results of the desk research, archive material and feedback and contributions from the Alder Hey Event.*

## Poster: The Development and Implementation of a Paediatric Active Care Checklist – Greater Glasgow and Clyde

## The Development And Implementation Of A Paediatric Active Care Checklist



## Authors

Jennifer Rodgers, Quality Improvement and Patients Safety, Acute Paediatrics, NHS Greater Glasgow and Clyde  
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## Introduction

In 2012 the Prime Minister, David Cameron, expressed his concerns regarding standards of nursing care in the UK. He called for a wider uptake of 'Intentional Nursing Rounds', 'Intentional Rounding', introduced by The Studer Group Florida USA in 2007, is an evidence-based, structured process for the delivery of care. The implementation of which resulted in significant decreases in the incidence of falls, pressure ulcers and medication errors (Studer Group, 2007). It also saw an overall increase in patient satisfaction. Nursing staff also reported an increased calmness and control to their care delivery, increased job satisfaction and more timely detection of any deterioration in their patients' clinical condition. In NHS Greater Glasgow & Clyde 'Intentional Rounding' was introduced as a standard of care for all wards for this organisation. However it quickly became evident that the fully duplicated 'active care checklist' was unsuitable for the paediatric population.



**Figure 1.**

<p> <input type="checkbox"/> <b>Passive:</b> I never listen to the radio or CD's when I am driving.  <input type="checkbox"/> <b>Active:</b> I listen to the radio or CD's when I am driving.  <input type="checkbox"/> <b>Check:</b> I listen to the radio or CD's when I am driving.         </p>	<p> <input type="checkbox"/> I have not listened to the radio or CD's when I am driving since I was 17. Based on the previous week's trial and error, I am going to:         </p> <table border="1"> <tr> <td>1. Date: _____</td> <td>Frequency: _____</td> <td>Speed: _____</td> <td>Notes: _____</td> </tr> <tr> <td>2. Date: _____</td> <td>Frequency: _____</td> <td>Speed: _____</td> <td>Notes: _____</td> </tr> <tr> <td>3. Date: _____</td> <td>Frequency: _____</td> <td>Speed: _____</td> <td>Notes: _____</td> </tr> <tr> <td>4. Date: _____</td> <td>Frequency: _____</td> <td>Speed: _____</td> <td>Notes: _____</td> </tr> </table>	1. Date: _____	Frequency: _____	Speed: _____	Notes: _____	2. Date: _____	Frequency: _____	Speed: _____	Notes: _____	3. Date: _____	Frequency: _____	Speed: _____	Notes: _____	4. Date: _____	Frequency: _____	Speed: _____	Notes: _____	<p> <b>NHS</b>  <b>HEALTH SERVICE</b>  <b>UNITED KINGDOM</b> </p> <p>         Name: _____          Address: _____          City/Town: _____          Date: _____       </p>
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## Method

A collaboration between tissue viability and quality improvement nurses formed the basis of this work, while the methodology was driven by The Model For Improvement (Langley et al 2009). The three fundamental questions which form the basis of this improvement are:

*What are we trying to accomplish?*

Every Patient, Every Time:

- Have their pain assessed and managed
- Are comfortable, no avoidable pressure ulcers
- Have age appropriate activity options
- Receive help whenever they need it with personal cares.
- Have their fluid and nutritional needs met
- Are aware of buzzer system and how to call staff
- Are kept up to date

*How will we know that a change is an improvement?*

Both process and outcome data were collected. The process data measures firstly if the active care charts are present and secondly if they are completed correctly.

The outcome data collects information directly from patients and their families relating to each aspect of the set goals. In short, a nurse will ask 20 families a month on each ward if they were ever left feeling sore/ were always comfortable/ always had something to do, and so on. This not only provides a breakdown of how well each area is doing on all aspects of being 'well looked after' but builds capacity to collect data and ownership to act on improvements both locally and across the organisation.

**What change can we make that will result in an improvement?**

An overarching goal was set with a clear timeline of 7 months:  
 >95% of paediatric patients will receive all elements of active care  
 throughout their hospital stay by July 2013.

Testing began in one area who kindly volunteered to pilot the project. Following input from staff, patients and carers the 7th version of the tool was accepted as final (Fig 1). Both the tissue viability nurse and quality improvement nurse completed face to face training ensuring contact with at least 50% of all in-patient hospital nursing teams.

## Results

All paediatric areas are now reporting both process and outcome data fairly consistently at 95% and above (Fig 2). However it is early in the process to claim reliability. Any dips in both process and outcome measures are considered by the team and where possible improvements are made. Feedback from ward staff is mixed. While the paper work load has increased, the system provides structure to, and evidence for the good care they provide. The structured and documented process is reassuring for both the team and families they care for.

Fig 2



## Conclusion

Utilising a collaborative approach alongside the Model for Improvement is effective in implementing an active care checklist within a paediatric hospital. Striking the balance between the paperwork burden and providing evidence for intentional rounding / active care is challenging. Future progress will include testing an electronic version of the document.

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## Acknowledgements

Thanks to all the nursing staff, parents, carers and children involved in the development of this checklist.

Thanks to Medical Illustration for their assistance in the design of the checklist.



## 6. Review of Existing Best Practice

A key part of this report is to look at and celebrate the existing best practice that is 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. For the purposes of this report we reviewed some of the extensive bank of case studies PEN have either uncovered or made themselves aware of. A selection of these case studies has been collated to demonstrate the wealth of practical best practice that already exists. As there are well over 200 case studies in the archives – all relating to improving patient experience, but not necessarily directly related to children and young people, we have selected just a few. Most of the ones we have used here are directly related to improving patient experience for children and young people, however, it is critical – and one of the key conclusions of this report – that organisations do not limit themselves to looking at best practice only from their individual specialism. This blinkered thinking ensures that some excellent initiatives and practical examples are overlooked on the basis that ‘this does not apply to me’. 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.

These case studies have been written by the organisations themselves.

### 6.1 Alder Hey – Disability Workshops and Soccer Spa

#### Overview:

At last years’ PEN National Awards the overall winner was Alder Hey Children’s NHS Foundation Trust with a fascinating entry which showed just how the NHS can work effectively with other organisations to deliver something extra special for both staff and the family / caregivers in the difficult field of children’s medicine.

#### Introduction:

Children and young people with disabilities can often feel marginalised and excluded from public health messages. Their parents can feel very protective and this can lead to further exclusions. The programme Alder Hey, Everton in the Community and Woodlands Beauty Spa have developed is aimed at being fully inclusive. It enables those with a range of disabilities to be active, receive information on healthy lifestyles, see positive role models in action and help parents understand that their children are able to exercise and take part in main stream activities without any harm. It also improves the patient experience and provides parents and families an opportunity to look after themselves by receiving a holistic therapy on site to aid relaxation and reduce stress during an extremely difficult time in their life.





## 6. Review of Existing Best Practice *(continued)*

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### Summary of Outcomes:

*“The Therapies help to lift the mood and enable parents to deal with the day to day stresses of being in hospital”.*

**Manager**

One of the patients who took part in the workshops said “The programme encourages me to take part in physical activity; it gives me the chance to get certificates which makes me work harder as I get a sense of achievement. The workshop gives me variety in my day and a chance to see and talk to new people, which I really love. It is exciting and because of this, it gives me something to look forward to. But most of all it makes me feel valued by people outside my family and carers and it is FUN!”  
Jessica

*“To work alongside Alder Hey enables us to complement the way they care for the children by offering some pamper time, to see the smiles on the patient’s faces with a little sparkle on their nails or face painted is a sight to be cherished”.*

**Woodlands Beauty Spa Staff**

The sessions are promoted well within the organisation, and are delivered using a rota system to ensure that all areas, departments and clinics have engagement with this activity at some time. Alder Hey also hold the Soccer Spa’s in the parent’s accommodation enabling siblings, parents and other carers, especially those who are longer term patients enjoy the benefits.

Alder Hey have been delighted to have such a positive and pro-active partnership with Everton Football Club and Woodlands Beauty Spa, and feel confident that this programme can be replicated throughout the country by other football teams. The support they have received in challenging health inequalities in line with Public Health Strategy has been enormous and it is clear that other Hospitals can learn from this to develop similar programmes.

As the Football workshops and Soccer Spa are funded through Everton in the Community and Woodlands Beauty Spa there have been no cost implications to the trust. The Woodlands Beauty Spa beauticians kindly volunteer an afternoon of their time a month. Through their partnership with Everton in the Community patients have also experienced days out from the hospital to Everton FC football games. Everton football players have also attended some of the sessions to participate in the workshops with the children.

### How It Was Achieved:

Through feedback from female patients Alder Hey developed their Soccer Spa workshops in partnership with Everton in the Community and Woodlands Beauty Spa, which seek to bring spa therapies alongside, football workshops to children and young people as well as to their families and carers once a month. There are a range of therapies available to choose from: gentle massage for mum or dad, a hand massage for dad or grandma, face painting or nail varnish for the patients. In developing this programme, Alder Hey has recognised its responsibility of not just treating patients but treating their families to help them to relax and take care of their health and wellbeing. Soccer Spa enables the Woodlands Beauty Spa staff to use their wonderful gifts as holistic therapists to make a difference to the lives of the children and their parents/carers who are suffering illness or stress.

Soccer Spa activities are specifically designed to allow all children to take part, regardless of age, ability or physical circumstance. The workshops ease the children’s obvious anxieties about their treatment, and for parents the workshops aid to break up the tedium of long-term hospital care.



## 6. Review of Existing Best Practice *(continued)*

The Football Sessions were initially delivered once every alternative week for 2 hours, but due to the positive feedback from parents and families this has been increased to up to five sessions per week. The impact of the football workshop programme has been huge with over 1500 patients every year taking part.

During the sessions children, along with their families and carers are given the opportunity to openly discuss their thoughts and ideas around health and wellbeing. More significantly the workshops provide a platform for social interaction and laughter, easing the children’s obvious anxieties about hospital, whilst breaking up the tedium of long-term hospital care. In addition, the positive brand of Everton Football Club inspires many of the children to engage with the Everton in the community staff in a way that other health practitioners find difficult.

### Learning Points and Tools:

- Children and young people with disabilities can feel marginalised and excluded from public health messages.
- The programme allows all children to take part regardless of age, ability or physical condition.
- The programme helps to relieve the children’s obvious anxieties about their treatment and for parents the workshops help to break up the tedium of long term hospital care.
- Therapies on offer include massage, face painting and nail art. Activities cover a range of football related tasks
- Alder Hey has recognised its responsibility of not just treating patients but treating their families in order to promote their health and wellbeing.
- Don’t be afraid of approaching outside organisations – you may be surprised at what can be achieved

### 6.2 Leicester City – Let the Children Be Heard

#### Overview:

The consultation was co-designed with the end-user group and followed by true engagement as the strategy was designed based on patient feedback. The process can be used by NHS/public organisations as well as external private organisations. It is a simple model to use, gaining invaluable feedback, which is easily transferable into any project. Because of the accessibility of the information patients were more willing to provide feedback, making the engagement process smooth and gratifying. The materials used can be developed for the evaluation of any service used by children and young people as the questionnaires and presentation images are appropriate for the user, simple and easy to adapt.

#### Introduction:

Leicester City believe that children and young people should be given a clear voice to help improve the health services they access and need. When NHS Leicester City needed to redesign its strategy for Child and Adolescent Mental Health Services (CAMHS), it turned to its Engagement team to discover how young people felt about the existing service and where improvements could be made. The engagement work that followed resulted in a new service specification that better meets patients’ expectations, based on young people’s feelings about using the service.



## 6. Review of Existing Best Practice *(continued)*

To design the most appropriate service, a public consultation took place over four months. The aim was to listen to what young people:

- think of the service
- want from the service
- want to be prioritised regarding treatment
- think are major issues that need addressing.

The engagement team then wrote a strategy to reflect the findings from the public consultation, reflecting the priorities and service changes that were fed back.

### Summary of Outcomes:

From the results of such a robust process, undertaken with the full involvement of children, young people, their families and carers, alongside experienced and knowledgeable health professionals, a new strategy was written, and service changes made, with principles chosen to reflect the children's views. NHS Leicester City is confident that the CAMHS strategy developed has ensured continuous involvement and service improvement. The young people involved have had their voices heard and their thoughts acted on, which has proved to be an overwhelmingly positive experience for them. As well as meeting the needs of patients, the efficiency of the service locally has improved dramatically.

### How Was It Achieved:

In order to design the most appropriate and effective consultation, Leicester City used the insight and knowledge of young people. The consultation was designed by a young person who joined the engagement team on the Takeover Leicester Day, with input from other young people and supported by YoungMinds, a charity for children's and young person's mental health promotion. The young people suggested who should be approached for comments, the style of language to be used and advised on incentives that would trigger the best response. This knowledge and information proved invaluable in creating a genuine engagement process. The resulting questionnaire design was simple to understand and complete, asking children for their thoughts on the rules of the service and what the priorities should be.

Leicester City then evaluated the existing service and developed the engagement plan with children and young people, identifying the priorities and guidelines by involving stakeholders at every key stage of the process.

The consultation ran for 4 months and was publicised through the Partnership Network (a children's and young people's network in Leicester City, Leicestershire and Rutland), Big mouth (a forum where disabled children and young people can air their views), CAMHS nurses, youth councils, Leicester Local Involvement Network (LINK) and NHS memberships to be certain that we were engaging with those who had experienced the services.

Other consultation publicity included press releases, NHS Leicester City's website, articles published in the local media and questionnaires displayed in city and county CAMHS locations. NHS Leicester City membership also played a key role alongside people attending city family events, such as the health corner at the Christmas lights switch-on ceremony.

There were two elements of this project which were very unique; the integration and influence of patient feedback into the project and strategy as a whole, and the engagement design itself.

## 6. Review of Existing Best Practice *(continued)*

From project initiation to the strategy design through to the final documentation, the patient was placed at the heart of the service and objectives were included that were viewed as real and able to improve the patient experience. Throughout the process there was real influence from patients, carers and local children and young people which was a rewarding experience, creating a completely accessible strategy.

The engagement design used experience-based patient involvement from the very beginning. The look, feel, tone and method of engagement was all influenced by the end user – children and young people all played an integral role in the design, language, communication channels, questionnaire and presentation design which made it easier for communication and made the strategic process understandable for people involved. This allowed the engagement team to collect excellent, beneficial feedback that was meaningful to the organisation and the strategy design.

The strategy itself outlined the future progression of CAMHS and laid the foundations to continually improve patient experience. The team at Leicester City ensured that the plans developed were fed back to interested stakeholders and complied with the standards of engagement for all partnership organisations of CAMHS. An agreed priority was for CAMHS staff to continually gather patient feedback on service delivery. A real success was that there is now on-going engagement by the service itself as part of the delivery strategy. Taking a ‘whole family approach’ to treatment involves including carers and family members in future care and this approach was highly supported by the consultation and by CAMHS staff.

The feedback has also had an influence on the future action plan for CAMHS. This is to be fulfilled by 2014 when the strategy is to be reviewed. By this point the future GP lead Clinical Commissioning Groups (CCGs) will be responsible for the review, and they were made aware of how successful this process has been.

### **Learning Points and Tools:**

There were many learning points from this particular project. They included very small factors and some overarching principles which the organisation has used on projects since the project debriefing.

The most valuable learning experiences which were key to the project’s success were:

- Ask questions; do not be afraid to ask service users for advice on what they want.
- Use best practice; the design phase was made easy and was quick and simple by using best practice materials such as artistic pathway design (NHS Leicester City), experience based design (Institute of Innovation), and easy read (LDICN).
- Test and test again; using the questionnaire as an example, the first questionnaire was not the final one. We used practice questionnaires to develop a final questionnaire which could be delivered by people who may not have known CAMHS well.
- Hear what people say; we didn’t just listen to what patients were saying, we heard what their problems were. Some issues raised were not necessarily the problem itself, but an underlying cause. We explored these using a focus group which proved successful.
- Take time; this was a long process, allow the project time and remind people that it is happening. This removes the tokenistic approach and allows the organisation to gather meaningful feedback.



## 6. Review of Existing Best Practice *(continued)*

### Tools Available to Share:

- Engagement and Communications plan
- Take over Leicester information on CAMHS project
- Questionnaire 1 – for children and young people
- Questionnaire 2 – for CAMHS service users
- Presentation to focus groups with annotations
- Report on feedback including demographic feedback
- Get involved newsletter article
- CAMHS Strategy

### 6.3 Salisbury Hospital – New Children’s Ward



#### Introduction:

The project involved re-locating the children’s services to a central location bringing inpatient, outpatient and therapy services together in a modern environment. The aim - more efficient services and a clinical environment better suited to the needs of patients, parents and staff. Stars Appeal funding gave a unique opportunity for a higher quality environment with children, families and staff at the heart of the design process.

This initiative fitted into the long term Trust strategy for rationalising the hospital site and modernising services and facilities and was therefore fully supported by the Trust Board. The following benefits were identified: Improved patient experience, reduced infection risks, improved privacy and dignity, improved facilities, increased efficiency in use of rooms, increased opportunity for clinical assessment, improved wayfinding, reduction in time wasted during clinics, and improved patient experience (teenagers).

#### Summary of Outcomes:

The steering group process enabled children, families and staff to tackle many design challenges in a safe, fun and rewarding way through the use of experienced artists as co-designers. The results of this inclusive approach captured the imagination and commitment of the staff and local community. It brings with it a thorough, well thought out patient environment that is its own reward for all the hard work in fundraising for the Stars Appeal. Additionally the links with schools remain in place and will continue to benefit both the Children’s unit and the Trust as a whole for the future.

A paper and website survey was carried out before the start of the project, to assess patients’ satisfaction with the old facilities and expectations for the new unit. A repeat survey of staff and patients has been carried out after the project (and is ongoing). Responses are coming back from children, parents and staff and the results are overwhelmingly positive, and indicates how much the work the Trust has put in to get these part of our services right are appreciated by users.



## 6. Review of Existing Best Practice *(continued)*

Some tangible examples of the many improvements:

Action	Results
Better placed reception desks and flow of patients - e.g. DAU no longer requires patients to travel the length of the ward to get to the unit	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• Reduced infection risks</li><li>• Improved privacy and dignity</li></ul>
Increased number of ensuites	<ul style="list-style-type: none"><li>• Reduced infection risks</li><li>• Improved privacy and dignity</li></ul>
Latest bedside TV units with touch screens and customised child friendly design	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• Improved facilities</li></ul>
Integrated design helps Therapy staff carry out clinical assessments – with the help of a trail of turtles, pebbles and starfish built into the vinyl floor the patients enjoy and understand more quickly how to take part in a running, walking or throwing tests	<ul style="list-style-type: none"><li>• Improved facilities</li><li>• Increased efficiency in use of rooms</li></ul>
Bedrooms have individual themes and fun images that help the play specialist distract and amuse children	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• </li></ul>
Waiting areas are filled with interactive features that relax, delight and distract children and offer clinicians a chance to observe children in more natural play which	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• Increased opportunity for clinical assessment</li></ul>
Playdeck allows direct access to the outside via the playroom (previously patients had to go through the DAU waiting area)	<ul style="list-style-type: none"><li>• Improved patient experience</li></ul>
A dual purpose room provides a Therapy space and teenagers’ recreation room	<ul style="list-style-type: none"><li>• Improved facilities</li><li>• Improved patient experience (teenagers)</li><li>• Increased efficiency in use of rooms</li></ul>
A sensory room for patients with special needs is a new resource	<ul style="list-style-type: none"><li>• Improved facilities</li><li>• Improved patient experience</li><li>• Increased opportunity for clinical assessment</li></ul>
Wayfinding floor designs plus children’s drawings as wall panels in each consulting room makes the visit to Outpatients more child friendly	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• Improved wayfinding</li><li>• Reduction in time wasted during clinics</li></ul>
Interactive LED lighting in ensuites, bathrooms and consulting rooms allows children to take control of their environment and bring a personalised feel to their visit or stay	<ul style="list-style-type: none"><li>• Improved patient experience</li><li>• Upholding Trust Environmental policy</li></ul>



## 6. Review of Existing Best Practice *(continued)*

### 6.4 Birmingham Children's Hospital – Feedback App for Children

#### Introduction:

Birmingham Children's Hospital launched the NHS' first smartphone app to enable children, young people and their families to quickly and easily deliver anonymous feedback to their ward or area they have visited. The application allows patients and families to leave feedback and comments in a quicker, easier and more effective way than ever before. It was designed to enable people to interact with the hospital in an innovative new way. It featured in an ITV news story which summarises and explains the app:

<http://www.itv.com/news/central/story/2013-02-20/app-for-hospital-patients/>

#### Summary of Outcomes:

How does it enhance patient experience? Michelle McLoughlin, Chief Nurse, who led the project, said: "The app enables us to gather feedback in a way that our patients and families want to give it so we know immediately what we are getting right and what we need to improve to make their time with us the best it can be".

*"The response from patients and carers has been extremely positive, the speed of response has been appreciated and service users feel that the Trust is taking more of an interest in their concerns."*

The feedback has also had a positive impact on staff as the feedback given via the app is far from all negative, in fact much of it proved very positive and this had a positive effect on staff experience. Ward Managers are now used to the quick response times and find the real time element and visibility can be very beneficial in enabling them to deal with issues quickly and effectively.

#### How Was It Achieved:

The app can be used by anyone with a smartphone, blackberry or other mobile device. The questionnaire was designed in conjunction with young people to ensure that it was as user friendly as possible whilst delivering high quality qualitative and quantitative feedback.

Responses are fed directly to the ward or area being commented on and are posted live (filtered but not moderated) onto the Trust's website (9-5 Mon to Fri) with 'out of hours' comments being held in a holding area before being posted. Ward staff respond, usually within 24 hours, with responses again being highly visible.

Posters are placed around the Trust explaining the new app and how to use it – these are replacing the 'No Mobile Phones' signs.

Robin Vickers from Digital Life Sciences told ITV News Central the new smartphone app for patients at Birmingham Children's Hospital was being used for constructive feedback, despite originally thinking it would be used by patients to complain and moan. Digital Life Sciences were one of the partners which developed the app.

## 6. Review of Existing Best Practice *(continued)*

### Additional Information on How It Was Achieved – Taken from the BCH website

#### Patient and Family Feedback

- We are constantly working to improve your experience at our hospital and to make sure we achieve this we need your help.
- Your feedback is vital to us so that we can improve the areas that need improving and make sure we keep doing the things we are doing right.
- To make things as easy as possible for you we offer multiple ways for you to give your feedback and help us reach our goal of providing the best possible care.

#### Feedback app



Our feedback app is the latest way that you can tell us what you think.

It allows you to comment on all aspects of the service here and your feedback goes straight through to the manager in charge of the area that you or your child has been treated in, so we can respond right away.

We are dedicated to being open and transparent about the feedback we receive which is why we publish the messages live on our website here in real-time for others to view. Find out more and read the comments .

Download the app for:  
Android >>  
iPhone >>  
Blackberry >>

#### Learning Points and Tools:

One piece of advice that BCH would give is that the system is for feedback and not for dealing with specific complaints and this needs to be made clear in responding to feedback given.

### 6.5 NW Ambulance Service – Patient Experience Board Game

#### Introduction:

The North West Ambulance Service NHS Trust (Nwas) is the largest ambulance service in the country. It provides a 24 hour, 365 days a year emergency service to those people in need of emergency medical treatment and who are most vulnerable. Nwas also provides a non-emergency service known as the Patient Transport Service for patients attending hospital who are unable to make their own way to and from the hospital due to medical needs.



## 6. Review of Existing Best Practice *(continued)*

### Summary of Outcomes:

The board game has proved to be a cost effective engagement tool which NWAS has used with a range of ambulance stakeholder patient groups including, community and reference groups.

Following any engagement using the game, the Patient Experience Team contacts the community group lead for initial feedback on how they thought the engagement had been perceived, and in all cases, feedback from this has shown to be very positive. Since the implementation of the Board Game in 2011, the Trust has not received any negative feedback in relation to its effectiveness. Please see below for examples of feedback:

*"The interactive and fun board game which North West Ambulance Service introduced our visually impaired members to during their visit, proved to be fully accessible (for those with a visual impairment and learning difficulties) and a positive method of encouraging people to speak out about their experiences and opinions of the Ambulance Service, hopefully offering some insight into where improvements are required and where skills and talents lie within the current service. Great Job!"*

***From Justine Watson, Charity Coordinator, Bolton Society for Blind People.***

*"When I first saw that the ambulance service was coming to play a game I wasn't interested. In the end I decided to attend and I am glad I did. I really enjoyed playing the game and giving feedback about the ambulance service. Too often we get classed as binge drinkers. In actual fact, we are not binge drinkers and instead have an illness. It was good to share this with the ambulance service by playing a game to give feedback. I will definitely promote this to the other residents when you come back again."*

***From resident DISC, support and treatment for people drug/alcohol dependencies.***

For a consistent approach when measuring feedback, in line with national requirements, the Trust has adopted the NHS Patient Experience Framework measures (recently adapted by NICE), a modified version of the Picker Institute Principles of Patient Centred Care. Feedback is analysed against:

1. Provision of a responsive service.
2. Accessibility - Availability of service, reduced health inequalities.
3. Communication/Information - Verbal, written, customer service.
4. Treatment as an individual - With dignity and respect, taking account of individual needs.
5. Listening - Questions were answered and concerns addressed.
6. The quality of care received.

*Some of the outcomes from the programme include:*

- Information communication sheets for hospitals and patients to ensure there is clear understanding about waiting times.
- A communication checklist for hospitals to support patients who are ready for collection when the ambulance arrives at discharge.
- A standard guide for all staff to ensure the communication provided to patients is consistent during their journey.
- A CD made available for the blind community providing information communication about the ambulance service verbally.
- To ensure all staff have information on quality standards and can communicate patients concerns in this area.
- Information is produced for staff to remind them of the various tools to support communication with diverse groups e.g. pictorial handbook, language line, community handbook.



## 6. Review of Existing Best Practice *(continued)*

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### How Was It Achieved:

The Trust's Patient Experience Team developed the board game in conjunction with AKD Training, a company who specialise in producing large-scale board games primarily for staff training purposes. It was developed to be used in the wider community to find out what patients want to know, how and when do they want to receive that information, and to gather that feedback and experience in a fun, stimulating and innovative way through the use of a board game.

- The game consists of a large board, an oversized dice, square tiles which have issues and comments and cards centred around different themes such as patient involvement, information, staff attitude, communication and medical care - all open for discussion.
- An NWS Patient Experience Team member facilitates and leads the group in a session with the game and is supported by an assistant to record the feedback information and assist with the exercises.
- Depending on numbers attending, participants are split into four teams and team captains can be selected. The teams will compete against each other to get the most points in the time provided.
- The idea of the game is that everyone involved should have an opportunity to give their experiences – both excellent and poor and share their needs and expectations of the ambulance service.
- All patient experience information received for improving services is included as part of the Trust's patient experience programme for the year.

### Learning Points and Tools:

The board game initiative can easily be used by ambulance services and NHS Trusts across the country to simplify cost effective engagement within communities.

A patient experience toolkit featuring the board game has specifically been developed by the Trust, the first one of its kind for an ambulance service. This was recently launched to communities and NWS staff at the Trust's annual AGM Open Day event attended by over 300 individuals. The toolkit is now available to view on the Trust's website and has also been shared at national ambulance forums. A PDF electronic version has been developed further to requests.

The board game stimulates large discussion on set comments and questions and it is important for facilitators to identify if there are specific concerns for individuals that may not be being addressed by the questions that are being asked and to ensure that those individual concerns are also addressed.

Keeping to a set time is important to manage as groups can become engrossed within the game with some of the discussions can develop and stray 'off course'. It is also important to ascertain whether individuals in the group may have translation requirements and to ensure this service is available. In NWS' experience, where translation is required, the host group will usually have this facility available in their own setting either through carers or through group leads.

## 6. Review of Existing Best Practice *(continued)*

### Tools Available

- Toolkit: <http://www.nwas.nhs.uk/getting-involved/involving-our-community/involving-you-in-our-work/patient-experience-toolkit/>
- Posters.
- Explanation of how to work with focus groups on the board game and also with regard to facilitation and recording feedback.
- Board Game to view electronically.
- Good practice examples of how to measure feedback against the NHS Patient Experience Framework.
- Trust Patient Experience Community Engagement Plan.
- Reference quotes.

### 6.6 Northumbria Healthcare NHS Foundation Trust - Dental Care – meeting the needs of looked after children

#### Introduction:

Children and young people who are looked after are less likely to access dental services. Research illustrates that children in care were less likely to participate in routine dental care than a non-looked after children cohort group.

All children and young people are required to have a dental appointment booked within 7 days of entering care. This care is normally accessed from general dental services and sometimes from salaried community services. However, this approach has resulted in a number of issues:

- Reliance of foster carers to feedback information about attendance at the dentist to the appropriate health and social care services.
- Gaining appropriate consent for dental treatment.
- Challenges of accessing NHS dental care for some carers.
- No information regarding the oral health needs of children/young people and dental treatment included within the health record of children and young people (unlike other health issues).
- The opportunity for oral health promotion activities with children, young people and their carers.
- The reluctance of some general dental practitioners to provide care for children/young people with emotional and behavioural issues, resulting in missed appointments and a lack of cooperation when receiving dental treatment.



With the aim of addressing the identified issues, it was decided to develop a dental service that was designed to meet the needs of looked after children and young people, providing a clear dental care pathway for children and young people entering care in North Tyneside.

#### Overview:

A pilot project was planned that would deliver a bespoke dental service to this population of children and young people. The framework for the delivery of this service was developed by a multi-agency steering group that was formed specifically for this purpose.

The service design adopted a structured approach that would support effective communication between all those involved in the care of looked after children and young people. At the same time the design adopted was considerate of the individual needs of each looked after child and young person i.e. providing longer appointment times, acclimatization visits and appropriate timing of appointments (start or end of a clinical session).

## 6. Review of Existing Best Practice *(continued)*

### Summary of Outcomes:

The team also receive a copy of consent for dental care from the appropriate person i.e. birth parent or social worker. In the past this has been an issue for the dental team who have had to attempt to locate the appropriate individual to provide consent for dental care.

### Improved Communication and Partnerships Between Professionals:

- The administration processes include on-going communication with key professionals i.e. social workers and the RHLAC team. The dental team informs professionals of appointment dates, cancellations and failed attendance.
- Non dental professionals also report that the dental care now feels “linked up”. They now feel they have somewhere to go if they have concerns regarding issues such as missed appointments or concerns relating to the oral health of the children and young people.

*“I think the great advantage has been the linked up service and I have got other people to go to if they do miss appointments or if I have concerns about their dental health, or concerns about how their teeth have got into that state”.*

*“Obviously we try and let them know if young people are not going to attend, but umm that can be a very short space of time beforehand and there has been massive understanding around that”.*

- Professionals now feel more confident that the initial dental appointment and resulting care are being addressed in a timely manner.

### Customers Service:

- Residential managers and carers report that they now have a clear pathway of dental care for the children and young people they care for. Beforehand they felt this was not the situation and would sometimes struggle to access care.

*“The main thing of course, is that this service means that children coming into care can get quick access to dental care and sometimes that is what they need”.*

- Continuity of care, children and young people who have returned home have continued to attend the service for care if they wish to.

*“Children who have returned to their parents have then continued to access care here with their parents”.*

- Professionals and foster carers report the service provides speedy access to care, an improvement to earlier experiences. Carers report that children are treated with respect at all times irrespective of their behaviours or poor attendance history. They feel that the dental team is flexible and responsive to the needs of the children and young people e.g. providing longer than average appointments for some, understanding of last minute appointment cancellations, and accommodating the needs of carers and sometimes birth parents.

### Improved Knowledge and Behaviours:

- Carers report improvements in the oral health behaviours of the children and young people they care for. All children, young people and their carers that attend the service receive appropriate oral health advice and toothbrushing instruction from the dental team. Due to the pressures of time this intervention is not always possible in general dental services.
- Carers also report improved levels of cooperation when attending for care. It is felt this is due to the attitude of the dental team and support provided i.e. acclimatization visits.

## 6. Review of Existing Best Practice *(continued)*

- An audit of current service provision for looked after children and young people, by community dental services across England has been conducted by the Cardiff University research team. This revealed that only one other community service had a clear pathway of care for the looked after children in their area.
- This model of care could be used externally for looked after children in any part of the UK. The model is also transferable to both community and general dental services. Adoption of the model would facilitate a consistent provision of dental care for looked after children irrespective of where they access care i.e. community or general dental services.
- In particular it would facilitate effective partnerships with general dental services and those professionals responsible for the care of looked after children.

**Learning Points and Tools: The learning gained from developed this service include:**

1. The importance of consulting with the frontline staff responsible for the delivery of the service. Meetings with the clinical team provided a number of key features of the service delivery that would not have been considered by the multi-agency steering group.
2. Effective promotion of the service with foster carers is essential. Initially some foster carers were reluctant to access the service and it was felt that the steering group should have spent more time promoting and educating foster carers of the features and benefits of this service before it started.
3. Ensuring that the all key services are represented within a steering group. Promotion and awareness of the project may have been more effective in the early days of the service pilot if there had been a member of the social work team involved in development of the service.

The materials developed as result of this service include:

- a) A service handbook including standard operations for administration.
- b) Service paperwork e.g. initial contact letter, treatment planning and summary documents.
- c) Information flyers promoting the service with foster carers, children and young people.
- d) Research information sheets, consent forms and topic guides.

### 6.7 Newham University Hospital – Engaging Seldom Heard Groups – Working with Learning Centres



#### Overview:

Our work with young people is especially unique as the young people are becoming empowered to engage with the Trust differently. The formation of a Youth Engagement Team ensures that young people are given a voice in the Trust. This work has meant that any service development can be truly understood and commented on by local people. The merger has had youth input right from the merger proposal stage to ensure youth are at the forefront and fully integrated following the merger.



## 6. Review of Existing Best Practice *(continued)*

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### Introduction:

Newham is one of the most diverse boroughs in the UK and as such presents specific healthcare challenges and inequalities. The aim of this initiative was to find a way to engage and involve the diverse local communities in their local healthcare, especially the seldom heard groups such as the homeless, refugees and migrants. The initiative built on existing engagement work by the engagement team going out to audiences that would not normally interact with the Trust. Newham also has one of the youngest populations in the country and this initiative has allowed the Trust to bridge a gap between these different audiences and the Trust.

### Summary of Outcomes:

Newham are reaching those who were not able to engage with health services in the past and work in partnership with the local community organisations. They have also raised awareness of the Trust and its feedback systems. Engagement materials were provided to English teachers who plan to include it in their teaching material for future students.

It highlighted issues with management of expectations, as there were similar themes in most of the adult learning centres. The patient experience feedback was shared with relevant departments and actions were taken. The feedback was also used in staff induction and training.

The success of the initiative was measured based on the number of groups and variety of backgrounds that the Membership and Engagement Team were able to reach. This was supported by many people from the sessions signing up for Trust membership and deciding to become volunteers at the hospital.

Comments from one of the ESOL class teachers: “The sessions were really informative. Learners were encouraged to voice their opinions and views and many want to get involved. Thank you and we look forward to continued working together.”

In their work with young people, Newham forged close relationships with the local schools and removed the barriers for young people to engage with the Trust, resulting in more young people and student leads from local schools participating with the Trust. One of the youth representatives also decided to become a volunteer to work in the Membership and Engagement Team on regular basis. She was also involved in working with the merger team of the proposed merger of the three Trusts. A Shadow Youth Engagement Team has been put in place.

### How Was It Achieved:

Initially the idea was presented to the Deputy Director of Nursing from where secured internal board level approval and support to move the initiative forward. Following this the Chief Executive of the Newham Renewal Programme (NRP), a charity organisation that supports the homeless, refugee and migrant communities, was approached. The initiative was presented to the NRP, highlighting the specific benefits to this audience (engagement and involvement in their local healthcare and to empower them by raising awareness of our how to provide feedback). From the very start the NRP proactively encouraged their staff to support this initiative.

As part of the initiative a user friendly presentation and printed materials were developed, which included information about the hospital and ways of providing feedback including formal complaints, attendees were able to take away this information and during the session an open discussion and feedback session allowed all attendees to participate fully.





## 6. Review of Existing Best Practice *(continued)*

The NRP identified suitable groups for the Trust to work with and the membership and engagement team presented to a range of groups at housing associations and at the carers' network. They found that learning centre students were particularly keen to get involved and were pleased that the Trust was taking the time to visit community settings to find way to meet their needs. Prior to the sessions it was clear that these groups did not know how to get engaged or provide feedback and they left feeling empowered to do so. The teachers at each venue supported the sessions and provided interpreting where needed to ensure that communication barriers did not lessen the quality of information available for attendees.

Following the success of the sessions with ESOL students the English teachers were also keen to work with Newham as the interactive sessions, presentation and documents were useful teaching materials. Newham therefore expanded the initiative and started working with learning and resource centres. The Team also ran sessions at various training course and learning centres in the borough, which included ESOL, IT, Business, and craft classes.

As well as running sessions with the hard to reach groups identified by NRP, the Trust was keen to improve engagement with young people. A young person was identified (someone who had in fact approached the Trust to get more involved) and was invited to become a patient representative. As part of her role as a patient rep she participated in PEAT inspections, attended the Food and Nutrition Group, shadowed staff in the Patient and Public Engagement work and attended and supported public focus groups. This empowered her and she chose to become one of Newham's patient ambassadors to represent the Trust and raise awareness among other young people. She has been invaluable to our work with young people and has been helping to set up a Youth Engagement Team.

This work encompassed liaising with local schools and holding meetings with young representatives to get them on board. This was really successful and the attendees thought it was a brilliant idea to have the Youth Engagement Team to enhance services for the youth. They were keen to be core members for the team. The school staff were keen for this work to go ahead and provided support. They were also keen for Newham to do further outreach work at their schools. Newham also started taking student on placements and work with other schools to attend student events/council meetings/assemblies.

### Learning Points and Tools:

- Approach organisations with ideas even if they seem impossible or less likely to be taken up ( I did not expect learning centres to co-operate)
- Outreach work - go out into the community, forge relationships and partnership work – in the current climate lots of organisations are working closely across previously unconsidered boundaries.
- Show respect to young people and their opinions
- Empower and mentor patient representatives, let them take the lead where appropriate

### Tools Available for Sharing

- The training pack used for the sessions was made available to share.

## 6. Review of Existing Best Practice *(continued)*

### 6.8 Nottinghamshire Healthcare NHS Foundation Trust – Listening To Experience: ‘Transforming Stories into Action Through Technology’

This case study has been included because, although the setting is for older people, it focuses on mental health and the methodology, outcomes and learning points could be easily adapted to a children and young peoples setting



**Overview:**

Ward B 50 is part of the Mental Health Services for Older People Directorate based at Queens Medical Centre. The service delivers care to older adults with functional mental health issues with a recovery focus in a supportive environment.

Ward B50 and its team led by Helen Forrester, Ward Manager, provide assessment, treatment and therapy to people who require an inpatient admission.

**Introduction:**

B50 ward staff felt they could do more to encourage communication with patients, carers and families by feeding back about their experiences and make suggestions for service improvements. They were keen to know what was important and make changes based on what patients and carers thought would make the experience on B50 a positive part of their recovery. Feedback from patients, carers and families provides insight which is endlessly valuable to teams in improving the care they deliver; ensuring the service they provide is responsive to its patients.

**Summary of Outcomes:**

The involvement of staff at all levels in patients’ meetings has encouraged an openness and belief by patients and carers that they are really listened to. Open and friendly responses to stories and feedback plus the immediacy of using Patient Opinion compared to more traditional feedback routes have added innovation and meaning to the Trust’s feedback mechanisms.

Our ‘light bulb moment’ of opening up the ward meetings has reaped benefits in the ward culture creating better two way dialogue. Meetings often have the patients talking more than the staff! We feel this initiative, demonstrating how patient experience is core business will have lasting influence. It is making a difference to how people feel about being a patient who tell us how they feel visibly, publicly, good and bad. The dynamic between staff and patients has shifted; people feel more comfortable raising issues as staff are responsive and grateful for the feedback. The culture on Ward B50 is being replicated on wards such as Silver Birch. A healthy and constructive relationship between staff and patients is being maintained.

12 change stories on B50 were recorded on Patient Opinion. As the site records and evidences changes it was easy to implement. This activity is reported to the Trust Board( e.g. see ‘Doctors appointment times on the ward)

This is not a ‘one off’ approach, it will be sustained and it is not staff dependent. The ward manager has encouraged staff to get involved. Helen registered her team to receive PO alerts via e-mail so that any ward staff can print stories to show patients. Stories are placed in the ‘feedback folder’, on notice boards and discussed at patient meetings.

## 6. Review of Existing Best Practice *(continued)*

The ethos of recovery is enhanced by the informal feedback process as patients say what they want from their patient experience. The Involvement Team reinforces the Trust's commitment to recovery by signposting information about the Nottingham Recovery College and Involvement centres where patients can continue having a say in service improvement after they leave hospital and undertake courses to sustain their recovery. The ward is proud to have its first volunteer recruited to the Involvement centre and he said in a recent letter ...'I've been given another chance at life and that's wonderful'.

The launch of the NHS Patient Feedback Challenge has chosen Ward B50 as a beacon of good practice to inspire others.

### **How Was It Achieved:**

The ward team needed to increase patient/carer feedback by improving the existing dialogue between patients and staff. By extending this approach to senior staff and the wider Trust; patients found out more about services recognising that the involvement of senior staff was crucial to create an open culture with 2-way dialogue. The Involvement Team was invited to the ward to allow technical expertise and internet "know how" to re-invigorate traditional patient/carer ward meetings. We needed to take an innovative approach and we wanted to develop a 'horses for courses' strategy suiting the needs of everyone.

The Involvement Team, staff and feedback champion volunteers along with three Trust Governors, gathered feedback from patients and carers with face to face conversations and stories but using iPad technology alongside. Increased participation got people talking and feeding back about issues and services putting forward their own suggestions for improvements

The use of Patient Opinion (PO), an independent feedback website means postings of concerns/issues can be tackled in real time and in a public domain. An immediacy of response addresses issues rapidly and are visible to everyone using the PO site. The nature of mental health services means that people often feel disconnected isolated and may also feel disempowered. Knowing that their feedback is being heard not only by the staff but by wider audiences on the web and the Trust reassures patients that they are being taken seriously. For the ward staff, this has become a way to hold themselves to account on their commitment to improve services.

Ward staff of all grades have been involved plus staff from the wider Trust; the support of service user volunteers working with the Involvement Team has increased patient/carer confidence in feeding back. It has proved important to have both volunteers (who are, by their position a supportive and understanding conduit rather than a representative of the Trust) and a feedback system which is independent.

Who is involved? Patients, carers, families, ward manager, patient activity coordinator, hotel services, clinical staff, service user feedback champions, involvement team, environment coordinator, health care assistants, three Trust Governors, voluntary services, and students.

### **Learning Points and Tools:**

The initiative is easy to replicate and doesn't have a high cost to adopt. Building on this success, we were selected as guest speakers at a partnership event for older people's services. Silver Birch Ward is replicating ward B50's approach as the team was inspired by the achievements on B50.



## 6. Review of Existing Best Practice *(continued)*

Patient Opinion East Midlands stakeholders’ event invited the ward manager to speak about her role and skills as a responder to organisations starting out on their feedback journey. The initiative was supported by the Trust and feedback enabled by the people who work in front line services. The ward presented at two regional events to communicate the success of the initiative in Sheffield and Leicester.

- *Start small. Make one change in ‘real time’ it’s a real motivator for everyone.*
- *Communicate one change as a result of speaking to patient carers and families.*
- *Model the change you want to see on a small scale. This helps people to see the value of the initiative/approach and encourages others to contribute.*
- *Feedback can be life enhancing for the patient, carer or family; being listened to is empowering and integral to recovery. “I have had excellent treatment on Ward B50. This ward has given me a new life”.*
- *Staff learn what patients find important. This informs aspects of care and personalises it.*
- *Empower staff at all levels to generate or respond to feedback. It is everyone’s business benefitting everyone*

**Tools include:**

- Ward suggestion box
- You Said - We Did posters
- Service User Carer Experience (SUCE) forms
- PALS and Complaints information
- iPads for access to Patient Opinion and iSurvey
- iSurvey for the electronic SUCE form
- Patient Opinion literature
- Feedback champion volunteers
- Feedback champion role description

### 6.9 Birmingham Children’s Hospital – Catering for Children and Young People (Menu Choices)



**Overview:**

The Trust introduced a new electronic food ordering system (MAPLE). Hand held tablets on each ward are used by patients to select from menus which are tailored to their need. For example, a patient with special dietary requirements will only be able to view choices which are relevant to them and not the general menu. The choices are accompanied by a realistic image of the dish or item to help them with choices. There is also a portion size option. The system also allows for monitoring of the nutritional value of the food being ordered to ensure that a healthy balance is maintained and recovery improved



## 6. Review of Existing Best Practice *(continued)*

### Summary of Outcomes:

#### How does this enhance Patient Experience?

Children and Young People like the method of ordering and the ability to see what they are getting. Expectations are effectively managed with less waste and better meal completion. Nutrition is more easily monitored and managed than before and patients feel more satisfied and recover more quickly

#### How does this enhance Staff experience?

Initial responses from the ward staff indicated that the system was more time consuming to administer, although this appeared to be mainly due to the novelty of the system. Further down the line time savings became clear as catering staff received real time data that was more easily interpreted and collated than the original system.

### 6.10 Birmingham Children's Hospital – Involving Schools in Design of Environment (Paediatric Intensive Care)

When an expansion of the Paediatric Intensive Care Unit was planned the Trust ran a competition with a local school to design parts of the interior. The winning team worked with the interior designer to finalise the design and see it through to fruition. The work is now complete and feedback from both staff and patients/carers has been very positive.

#### How Does This Enhance the Patient Experience?

Links have been established with local schools and schoolchildren – many of whom will have interactions with the Trust in the future. The unit has been designed by patients, for patients and satisfies many of their needs and requests

#### How Does This Enhance the Staff Experience?

Staff have an exciting new environment to work in, they have improved interaction with the patients

### 6.11 Involving Young People – Milton Keynes Hospital

#### Overview:

Milton Keynes recognises the importance of involving young people in developing services and involves them in a number of ways:

1. The hospital regularly invites children from local schools to take a look around the hospital and wards (especially paediatric) and make comments – what do you think of the wards, are we providing the right kinds of toys/entertainment, what do you like, where can we improve?
2. The hospital encourages 6th former to act as volunteers in children's wards and providing links to other area of the hospital e.g. A and E. Young patients are often more comfortable with someone of a similar age

### Summary of Outcomes:

#### How does this enhance Patient Experience?

The hospital has made a number of changes in response to suggestions and children's services have improved as a result – the Net Promoter score is used to monitor this. We have found that children are often more comfortable with someone of a similar age and are less worried about their interaction with the hospital. Children involved in the project are more comfortable should they actually need to come into hospital in the future and are more positive about the services offered

### Learning Points and Tools:

One piece of advice – It is the little things that really matter and involving local children has enabled the Trust to see things from a different perspective



## 6. Review of Existing Best Practice *(continued)*

### 6.12 Examples put forward by contributors to the survey include:

- Children with complex palliative care needs – experiences of advance care planning:  
<http://ncbi.nlm.nih.gov/pubmed/22384400>
- Costing and commissioning children’s palliative care services based on young person/family preferences:  
<http://www.ncbi.nlm.nih.gov/pubmed/23617814>
- Children’s Health Information Needs:  
[http://netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1718-145\\_V01.pdf](http://netscc.ac.uk/hsdr/files/project/SDO_FR_08-1718-145_V01.pdf)
- Young People with epilepsy – experiences of knowledge exchange and engagement with professional:  
<http://www.ncbi.nlm.nih.gov/pubmed/21194484>
- Evidence into practice – evaluating a child-centred resource with children and young people with type 1 diabetes – report in press Nov 2013:  
<http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1704-211>
- NHS Institute for Innovation and Improvement and AhHa Publications – Monkey:



The NHS Institute together with the Association of Chief Children’s Nurses (ACCN) worked with AhHa Publications and parents to produce a suite of resources for use in primary schools to educate and engage 5-11 year olds about emergency and urgent care services ‘fronted’ by a friendly character called ‘Monkey’. It encourages healthcare professionals to work with teachers in schools.

## Exploding myths and misconceptions of general practice with teenagers



### Background

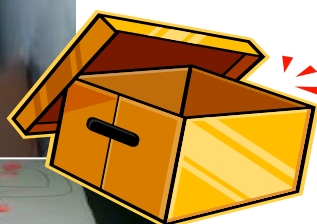
Young people have a poor understanding of general practice. (How do teenagers and primary healthcare providers view each other? An overview of key themes. Jacobson et al BJGP Oct. 2001)

### Aim

To improve young people's understanding of general practice

### Method

- Adult free agenda days were held for young people registered at a health centre.
- A young people's involvement group called "Teen Talk" developed from this.
- The young people identified Personal Social Health Economics (PSHE) lessons in school as being a good time to learn about:
  - general practice,
  - health issues,
  - their rights in health settings.
- Working with a local school and the young people we delivered PHSE lessons to approximately 350 Year 8 (12-13years olds) students over three days.
- During the lesson to promote discussion and learning we used:
  - body maps,
  - videos
  - anonymous questions box
  - games
- Pre and post lesson questionnaires after the first day were used to assess the effectiveness of the lesson.



Body Map

"Would you turn me away if I turned up by myself?"

"Can they answer questions about cancer if its not you who has it but you're worried?"

"Why when you go with an adult do they talk to them and not you?"

"Can I completely trust my doctor?"

### Results

Themes that emerged from the agenda days included poor understanding of:-

- confidentiality
- young people's rights
- what GPs do.

During the PSHE lessons discussions also included:-

- young carers
- re-presenting if symptoms don't resolve
- concerns about cancer
- mental health
- keeping healthy.

We also received positive feedback from the school.

### Questionnaire results.

"Do you understand your right to 'Confidentiality' and what it means?"

Pre PSHE Lesson



■ Yes

Post PSHE Lesson



■ Yes

### Discussion

- We saw, alongside other practice improvements, an increase in young people accessing general practice.
- This work also highlighted the need for GP practice team training in this area.
- With involvement from "Teen Talk" we held a training session for local GP practices covering:
  - young peoples rights
  - their experiences of general practice.



So- are we listening to our young people? They have a lot to ask us and a lot to tell us too.

Felicity Shenton  
Michelle Morton  
Sharmila Parks



## 7. Celebrating the Best of Children and Young People’s Experience Event

The Celebrating the Best of Children and Young People’s Experience Event grew out of an initial idea that PEN had to share some of the best practice work it has unearthed since it started its work almost four years ago. Over this time PEN has amassed a large database of best practice, which it has shared in a number of ways and this desire to share led to the idea to run a series of Best Practice Master classes being developed. The first master class was developed with Alder Hey – the overall winners at this years’ PEN Awards, which sparked an interest from the CYP directorate at NHS England, allowing the day to be developed and offered to a wider audience. We decided to include some of the outcomes from the day in this report as we felt that they would provide an interesting insight into what people who regularly work within the CYP arena are really looking for – which has proved to be the case.

The event included a keynote speech from Dr Maggie Atkinson, Children’s Commissioner for England, and presentations from Kath Evans of the CYP Directorate at NHS England, representatives of the Royal College of Paediatrics and Child Health (RCPCH) Youth Advisory Panel, parents from BLISS the neonatal charity and former child and youth patients. The afternoon was given over to Alder Hey Children’s Hospital to showcase the excellent best practice they have developed including an overview, the Everton Disability Workshops and Soccer Spa Case study, Spiritual Care at Alder Hey, the Children and Young People’s Forum and the Dance and Movement Project. In addition to the speakers there were a number of poster exhibitions during the day with ample opportunity provided for networking, discussion and consideration of practical best practice.

The event was extremely well received and comments on the day included ‘This is an excellent way of hearing about and sharing best practice, please let me know when the next one is being run’

### Other feedback from delegates and contributors included:

*“Positive energy and diversity of approaches”*

*“The message of sharing, every conversation helped”*

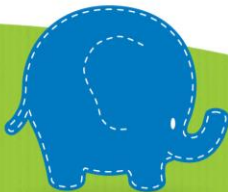
*“Increased awareness of the huge amount of ongoing initiatives and examples of best practice relating to children and young people – there is a clear need for someone to take the lead in sharing and spreading best practice, bringing people together – joining up the dots”*



*“Practical examples of how to tackle the issues surrounding children and young people’s experience”*

*“Ideas, great insight into some good CYP engagement projects – there is a lot going on and we need to let people know”*

*“Consider young people’s opinions and demonstrate it is being done”*





7. Celebrating the Best of Children and Young People’s Experience Event (continued)

*“Patients have the answers – we need to give them the opportunity”*

*“How to deliver excellent patient care to put children at the forefront of decision making by listening to them”*

*“Always lots of information that we don’t know and is really helpful”*

*“It’s about the patient, quality. Listen, act and improve on it”*

*“The passion, drive and commitment of the presenters and their teams has been truly inspirational and contagious! Lots more to do to improve patient experience but there are some wonderful examples for us to look at”*

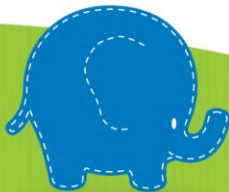
*“Pointers to various documents and resources available. Inspirational! Soccer spa – will see how we might replicate in Wolverhampton. Examples of good practice. There are barriers to be overcome – not a new concept but application of theory is important. Everton in the Community working with the hospital is an example of a well-motivated team with the interests of children at its heart”*

*“Examples of current practical initiatives to involve, improve and obtain patient experience. Good to have re-iterated key principles of best practice work with children and young people by RCPCH youth advisory group. Highlighting relevant future documents and reports”*

*“Really found the Everton in the Community work inspiring. Thinking about our students and what they can do”*

*“Appreciated hearing about the joined up working with Everton FC and Woodlands. Enjoyed hearing Maggie Atkinson speak”*

*“Networking very beneficial – good ideas re how and what benefits of CYP involvement”*





## Developmentally appropriate consultations for young people aged 14-18 in Paediatrics

### Background

- Adolescence – rapid biological, psychological & social development
- Coincides with move from paediatric to adult health care
- Failure to provide developmentally appropriate consultations can result in poor engagement & worsening self-care & health outcomes

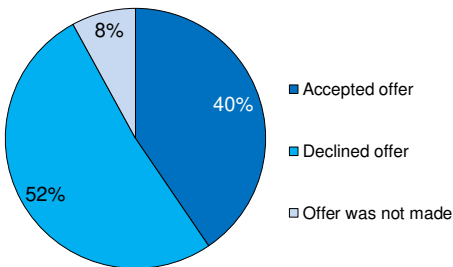


### Organisational foundations:

e.g.

- Support from CHBU Senior Management Team
- Support from Quality Improvement Council
- Existing momentum in Trust (e.g. You're Welcome)

### No. of YP who opted to be seen alone



- 92% of young people offered time alone.
- Drs who had mostly 'yes' responses had followed this practice prior to start of project.
- Suggests that Drs and families might need time to get used to the change in practice.
- Further need to explore how confidentiality and health promotion was approached.

### Next steps

1. Email survey of HCPs (July-Aug 2013) – Facilitators & barriers going forward.
2. Young Peoples' feedback (Jan-Feb 2014) – What are their experiences of the provision?

**Contact:** NTGH ext 4193 - Gail Dovey-Pearce  
on behalf of project team:  
Gill Turner, Tracy Scott, Janet Hughes, Jacqueline Story, Naomi Jones, Fiona Gay & Jonny Cardwell.



## 8. Who Else Could We Be Working With?

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Scarce resources are often cited as reasons for not making progress across all aspects of the NHS and improving patient experience is no exception. Some of the case studies PEN has identified, Alder Hey in particular, show how the NHS can effectively work with outside organisations to deliver cost neutral programmes for improving patient experience – but who else could the NHS be working with? PEN was involved with the recent Patient Feedback Challenge, run by the NHS Institute for Innovation and Improvement, where one key element was to explore working with non-NHS partners.

Potential conflict of interest is an obvious concern and the public sector has long held a certain level of suspicion about working with private sector organisations. Nothing should be ruled in or out until the need and opportunity has been identified, it is important to be open-minded about the type and range of organisation project teams could work with. PEN itself has a huge amount to offer in terms of improving patient experience for children and young people and in addition has experience of managing grant funding and identifying and bringing organisations together.

To provide some basis for discussion we have identified the following headline areas.

### By Organisation Type

- PLC's, large and small limited companies and partnerships e.g. John Lewis, Everton Football Club, Woodlands Beauty Spa, Fairtrade
- Public bodies – police, social services, teachers
- Social Enterprises - businesses or services with primarily social objectives whose surpluses are principally reinvested for that purpose in the community, rather than being driven by the need to maximise profit for shareholders and owners.
- Mutuels - exist for the purpose of raising funds from their membership or customers (collectively called members), which can then be used to provide common services to all members of the organisation or society. A mutual is therefore owned by, and run for the benefit of, its members - it has no external shareholders to pay in the form of dividends, and as such does not usually seek to maximise and make large profits or capital gains.
- Community Interest Companies
- Third Sector – we should not overlook the potential value of working with companies from within the Third Sector

### By Locality

- Geographic accessibility and fit relative

## 8. Who Else Could We Be Working With? *(continued)*

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### By Area of Expertise

Overall these fall into 4 broad categories:

1. Leadership – visibility, credibility, ongoing commitment
2. People – have they been given the capability and authority to deliver excellent patient experience? Are they being continually developed to allow them to sustain the progress? Team working and interdepartmental relations.
3. Process – creativity, is there flexibility in the system to permit, enable and encourage creativity? Are the processes reinforcing continued improvement or are they getting in the way? Lean management thinking for the NHS – how can the processes be improved to release valuable resources?
4. Experience of children and young people, working with them, understanding and addressing their issues

### *Specifically key areas of expertise might include:*

- Effective Spread and Adoption
- Delivering excellence with reduced numbers
- Freeing resources and delivering better value
- Retaining staff whilst delivering more and better quality patient experience
- Identifying and removing barriers within organisations
- Customer focus – both internally and externally
- Systems and procedures – identify
- Commercial management – understanding cost/benefit and the value attached to the improvements being made
- Measurement and effective use of data to inform process improvement - Developing measurement criteria that can evidence and deliver true value into the service chain.

Poster:

*Helping Raising Awareness and Support for  
Congenital Heart Disease*



*O2 Music Experience  
G.O.S.H Clinic*



## 9. Conclusions

The message coming out of the work we have done over the past month is loud and clear, and it really isn't rocket science.

1. There are numerous examples of excellent best practice (both clinically and in Patient Experience) across the NHS. For CYP this is particularly so in tertiary centres e.g. the children's hospitals (Alder Hey, Birmingham Children's Hospital, Manchester Children's Hospital, Great Ormond Street Hospital etc.). More can be done to highlight and celebrate these.
2. Whilst many organisations are doing something to improve experience for children and young people there is still too much focus on 'talk' and not enough on action. Millions of £'s are spent on reports, targets, pledges, discussions and initiatives, and considerably less on identifying existing areas of practical best practice in patient experience and then sharing it. Why re-invent the wheel?
3. Much of the current survey and development work is 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. Take the example of the GOSH patient experience survey in which less than 20% of respondents were children (over several years).
4. A key example of adult-centred initiatives is complaints procedures. Work still needs to be done to understand what support is required for Trusts to embed these principles and then measure achievement against them
5. Parental and adult considerations are often given more weight than the views of the children and young people – 'who shouts loudest'.
6. Across the NHS 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.
7. There is not enough time or money spent on collectively developing existing (and new) practical best practice.
8. Scarce time and resources are regularly used as a reason for lack of action. There is a wealth of evidence to show that implementing good patient experience practices releases valuable time and resources.
9. Transition is a key area where the system is failing both patients and their carers.
10. We need to identify more examples of best practice in neo-natal and transition (to adult services).
11. 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.
12. Complexities of dealing with Children and Young People – 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
13. In dealing with children and young people the NHS had two differing, and sometimes conflicting, sets of 'customers' - the patient (child or young person) and the parents or carers. Not a unique situation – what can be learned from both within the NHS and from elsewhere?

*"No-one talks to you about transition"*  
Shannon

*"I felt lost and confused. It felt like I was surplus to requirements - it was very difficult and bewildering"*  
Shannon's Mum



# Transition to Adult Care: **Ready Steady Go**

Dr Arvind Nagra, Tricia McGinnity, Denise Franks, Judi Maddison, Amanda-Lea Harris

Southampton Children's Hospital, United Kingdom

SOUTHAMPTON  
Children's Hospital

University Hospital Southampton  
NHS Foundation Trust

## What is transition?

A purposeful, planned process for young people with a long term medical condition that equips them with the skills necessary to move successfully from child to adult orientated health care.

## Why is it important?

Good transition reduces morbidity & mortality and can help improve vocational success.

## Who is it for?

Young people aged >11yrs with a chronic medical condition.

**We suggest that good transition can be achieved by using the **Ready Steady Go** programme**

## Background

Studies show that effective transition between paediatric and adult care improves long term outcomes.

Many of the issues faced by young people across sub-specialities with a chronic medical condition are generic. We have developed and implemented a transition programme called Ready Steady Go (RSG) to address these concerns.

RSG ensures the medical, psychosocial and vocational needs of the young person are addressed by following a structured, adaptable transition programme.

By working through a series of questionnaires RSG shifts the emphasis from preparing the adult service for the patient to preparing the patient for the adult service.

A key principle of RSG is to empower the young person to take control of their life and help equip them with the necessary skills to function independently and confidently in adult services.

## Objectives.

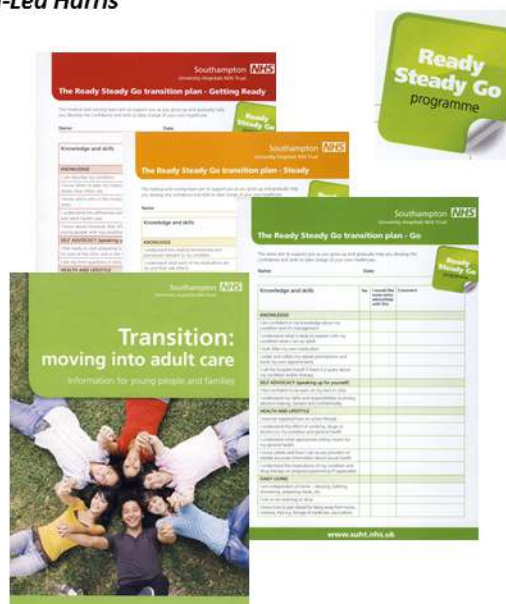
To assess the effectiveness of the RSG programme

## Method.

A questionnaire was designed to assess the effectiveness of the documentation that underpins the RSG programme. This gauged whether the documentation:

- was simple to understand
- was easy to use
- aided the transition process
- improved clinical practice

The questionnaire was completed by patients, carers and healthcare providers who were part of the RSG programme.



[www.uhs.nhs.uk/readysteadygo](http://www.uhs.nhs.uk/readysteadygo)

## Results

93 completed questionnaires completed (see table)

—40 patients

—31 parents

—22 healthcare professionals

Questions	Responses
"Transition: moving into adult care" information leaflets helped patients and family understand why they are starting RSG	93 agree
RSG questionnaires were easy to understand and use	93/93 strongly agree/agree
RSG questionnaires helped focus the consultation and address difficult issues	90/93 agree
RSG helps ease the process of transition	93/93 strongly agree/agree
RSG improved my practice	21/22 strongly agree/agree
Any questions that would help improve transition?	93/93 – 'No'
Any comments?	<ul style="list-style-type: none"> <li>• Time issues</li> <li>• Relevance of some questions e.g. patients with learning disabilities</li> </ul>

## Conclusion.

RSG is simple to understand

RSG is easy to use

RSG addresses the key issues for a good transition

RSG is useful in easing the transition process

RSG improves clinical practice

**The Ready Steady Go programme is an effective tool for delivering optimal transition to adult services.**

Dr Arvind Nagra, Consultant Paediatric Nephrologist  
Arvind.Nagra@uhs.nhs.uk



## 10. Next Steps: How Should We Be Working to Improve Patient Experience for Children and Young People

Across healthcare, in our opinion, there is a requirement for more visible leadership commitment and engagement to improve both the patient and the staff experience. There is 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 suggest 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 today – 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. 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
7. Similarly there is a gap for neo-natal that also needs attention
8. Understand that spreading and implementing existing best practice will make best use of and release valuable resources
9. Consider the possibilities of working with private sector organisations to deliver best practice improvements in the NHS
10. 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.
11. The key message coming through is that what organisations really want is help in developing and implementing best practice. The key action from this report has to be that there is 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. The desire for improvement and the practical examples are out there, we have a real opportunity to make a real difference.



## 10. Next Steps: How Should We Be Working to Improve Patient Experience for Children and Young People *(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 hard! 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 one volume of case studies of practical best practice and a second is planned. 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 the one run as part of the Celebrating the Best of Children and Young People Event at Alder Hey
- 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.
- 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. For example, following the receipt of the Innovation Award at this years’ PEN National Awards, North West Ambulance Service secured additional funding to develop further games and engagement tools. A key element of an internal programme is unpicking what ‘good’ looks like to enable it to be embedded, sustained and spread more widely.
- 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 – 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.

## Additional Acknowledgements

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- NHS Atlas of Variations in Healthcare for Children and Young People
- NHS England
- Nursing Times
- ‘Little Voice – Giving Young People a Say’
- Great Ormond Street Hospital website (and others)
- Swallow et al – various documents
- Francis Report
- Victoria Climbié Inquiry Report - Summary
- Bliss
- Royal College of Paediatrics and Child Health
- Common Principles for a Child Friendly Complaints Process (Children's Commissioner 2013)
- [http://www.childrenscommissioner.gov.uk/content/publications/content\\_715](http://www.childrenscommissioner.gov.uk/content/publications/content_715)
- <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>

# Thank You!

And finally a heart-felt THANK YOU to everyone who is working so hard to improve the experience for our children and young people, together with their families and carers.

Thank you also to everyone who has shared what is working well, for your willingness to share for the greater good.



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