

# Report of Survey Findings:

## ***Celebrating the Best of Children's and Young People's Experience of Care***

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September 2013

Patient Experience Network  
Re:thinking the experience



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## Introduction

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This is a summary report of a survey that was undertaken by PEN in partnership with NHS England. The survey was prepared to support a Best Practice event and a report celebrating the great work that is in place today to improve the Children and Young People's experience. It was open for responses from 21<sup>st</sup> August 2013 until 22<sup>nd</sup> September 2013, and was an on-line survey. Both Ruth Evans of PEN and Kath Evans of NHS England extended invitations to their network to take part.



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.

Professor of Health Services Research  
and Child Health

## Executive Summary

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- In total 147 participants from 111 organisations, representing a huge range of interested parties including NHS England, commissioners, providers, specialist children's services, charities, networks, councils, local authorities, universities, custody services. [See Appendix 1](#) for more information of the break down.
- As a rule the more specialist the organisation is the more detailed the responses.
- Parents, young people, consultants, GPs, heads of nursing, matrons, patient experience managers, professors, directors, student nurses, co-ordinators, physiotherapists, health visitors are just some of the backgrounds of the participants.
- Acknowledging that this report may potentially be skewed by the nature of the survey and the audience who have been approached, what shines through these responses is an incredible energy and relentless drive to improve the experience for children, young people and those supporting them. There is a desire to improve and a commitment to work 'tirelessly' to continue to improve.
- 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. Overall respondents scored their organisations at 7.06 when asked on a scale of 1-10 how would you rate your focus on the experience for children and young people ([see Appendix 2](#))
- Less than 50% of the organisations who responded have a strategy in place for C&YP services ([see Appendix 3](#)). This number reduces to 33% for the Acute providers. Strategy is not always deemed important:  
*"No specific strategy but this aspect is built into other strategies and we have begun to collate an action plan based on the feedback from clients on their experience of the service to action any aspects we do not do well or could have done better."*  
but for others it would be a useful asset:  
*"I am just a small voice trying to advocate for children's voices and would relish a strategy that is widely available to staff of the organisation and informs practice."*

## Executive Summary *(continued)*

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- Despite all the great work that is reported in the survey in terms of involving and engaging young people, when asked what are the most important areas for improvement for your organisation regarding improving the experience for children and young people, listening and involving young people and children more effectively is the resounding priority, with 43 mentions ([see Appendix 4](#)). This includes simply *“Listening to what the children really want”* to *“Giving them support to air their views”*; *“Following up their concerns”* and working out how to *“Involve children and young people in all decisions which affect them”*; *“Finding child-friendly ways to make sure the children and young people feel heard, recorded and respected.”*
- The second priority is working together effectively across pathways/ partner agencies, with references to *“too many people working in silos”*. This is not unique to children’s services and this is an ambition across many facets of healthcare.
- Interestingly, while not coming out in the priority number one spot, when looking across priorities two and three, Specialist staff development is ranked 3rd overall in terms of mentions. So it is not the top priority but is a critical enabler where the respondents felt there were areas for improvement including *“having the appropriate skills in the workforce to deliver the care the children need”*; *“Supporting leadership development for children’s health clinicians”*; and recruiting and retaining specialist skills for example a play therapist.
- With 13 mentions Feedback and closing the loop is ranked 4th. This includes using child appropriate feedback mechanisms, and then actually taking action on the feedback and closing the loop for young people.
- Joint 5<sup>th</sup> are the environment and commissioning insight. In terms of the environment this is simply referring to ways to make the environment more child-friendly, less scary including for example the operating theatre. From the commissioning perspective this includes elements such as including complaints from children and *“involving C&YP in the development of the CCG Transformation strategy”*.
- Other areas were mentioned as key priorities and some of these are covered in more detail in the following pages as they were recurring themes across the survey answers.

## 1. Specialist versus Generalist

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- For specialist children's organisations there is a sense that children and young people, with their parents and families, are the absolute focus of the entire organisation:
  - *“The child and family are at the centre of everything we as an organisation do”*
  - *“Putting families at the very heart of their care in a holistic way is paramount. We are driven by the needs, wishes and preferences of children and young people, it is built into our care planning and valuation and we actively seek and respond to feedback from CYP”*
  - *“We keep the child and family at the centre of everything we do most importantly our services are not just for the sick child we also support families, siblings and grandparents with a very flexible quality service”*
- There is a genuine recognition in specialist organisations that there is a constant need to improve, and it is not always easy:
  - *“We have some excellent practice and people are extremely committed to making this as good as it can be. I think it is intrinsic to most practice but actually implementing this all the time is tricky”*
- In more generalist environments, perhaps unsurprisingly there is a sense that although they are trying to engage more, there are barriers to achieving this:
  - *“Focus is on the care Children need but we often feel we are boxing around systems and restrictions to deliver the best care. This is particularly true with regard to budget constraints and service patterns”*
  - *“I think we aim to be focused on the experience of children and young people but sometimes time and resources limit this ability”*
  - *“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”*
  - *“We have some very strong partnerships working with children and families in particular but in other areas these are particularly weak. It is in my opinion partly related to the diversity of the work we do and our patient groups. (General Paeds, mixed specialities, HDU etc.. in one small area) as 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”*

## 2. Feedback

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- There is a very real sense that in terms of feedback organisations are shoe-horning 'adult' feedback mechanisms to fit the needs of children services and a very real sense of frustration that these are not delivering the desired insight and outcomes for the organisation – *"The Trust's focus is on the Friends and Family Test which is not necessarily child friendly or focussed on the needs of children."*
- Where changes have been made as a result of feedback they do not tend to be transformational – rather they are environment changes, which are of course important as every single improvement matters, however, the feedback does not seem to be contributing to wide organisational or cultural improvement.
- There is a disconnect commented on frequently around the FFT tool kit in terms of its use for reporting children's experience of care, and overall there is a move toward social media. Although this is recognised as the way to move forward, it is not being embraced, with several organisations commenting that they wish to move ahead with this but they are finding the organisation is not ready; one respondent commented that they are not allowed to use Facebook. This is a spectrum however as one CEO is reported to use Facebook and Twitter regularly.
- Disappointingly there are still some organisations who report that their leadership seem to take no action on feedback.
- On a more positive note child-friendly or innovative examples such as Twitter, Facebook and other social media, 15 Step Challenge, sibling event evaluation, use of art to portray experiences, craft feedback activities are cited. These seem to be in the minority and most appear to miss the teenage and adolescent year groups. Use of apps, smart technology and social media other than Twitter are rarely mentioned.
- We have developed feedback mechanisms for children, worked with young people's panels and provided solutions tailored to different ages of child

### Stated Priorities

- Acting on feedback.
- Find better ways of collecting feedback from children and acting on the feedback.
- Use of IT to be developed more for feedback.

### 3. Feedback Moving Forward

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- In terms of plans to change the way of collecting feedback in the future a surprising number (23%) commented that they were unsure or that there were no plans to change.
- Where there are plans to change 12% mention moving to tablets, i-pads or electronic data collection via website etc..
- 13% are considering social media (Facebook, Twitter) apps or sms.....
  - *“I would like to see us have a Facebook page for the service to enable a dialogue”*
  - *“We have looked at Social Media tools but have met some resistance from the organisation about how this would be monitored”*
  - *“Using social media following on from local YP feedback”*
  - *“Had not thought about Facebook, Twitter etc. - will try to investigate with service/ Trust”*
- In reality there are very few who are considering rethinking the whole approach to feedback to relate more to their younger audience. So despite the frustration with the current unsuitable systems, there appears to be a resistance to thinking outside of the ‘adult’ box....
  - *“To start from scratch, I would engage with youth advisors and ask them what tool they would like to use to feedback their experience, and then look at the options available”*
  - *“We need to look at novel ways of getting feedback such as using social media”*
- The root of the problem may be what difference in reality the feedback makes. When asked **‘How is the feedback used in your organisation?’** there is a range from *“I am not sure”* to *“not constructively”* to *“at twice yearly meeting to Trust governance and safety meetings”* or *“fed into user group meetings and trust board”* to *“feedback is used to commission and shape services”* or *“any feedback is discussed and considered with view to improving the service we provide”*. There are very few organisations operating at this latter end of the spectrum.
- Respondents were asked to consider what action had been taken as a result of feedback in the last 3 months. Actions are listed in [Appendix 5](#) and it is clear that the feedback is actually being used to positive effect in many organisations.



## 4. Engagement with C&YP

There is a wide range of mechanisms in place to involve and engage with children and young people, and there is sense that some of this is making a difference, however, this remains the most important priority for the respondents moving forward:

- *“About to re-launch children’s board.”*
- *“We have a Children’s and young people’s pathway group that feed directly into board level.”*
- *“Young people have been to talk to the trust board on their experiences, which has enhanced peoples understanding of the needs of this group.”*
- *“CYP on work experience assessing services”*
- *“Use of YP from local colleges”*
- *“We are moving in the right direction and have made some real good progress with the recruitment of children’s ambassadors attached to healthwatch and we have our own local reference group”*
- *“During baby clinic we have children’s programmes playing on some computer terminals to engage children and help with compliance such as during immunisations.”*

### Stated Priorities:

- Involve children and young people in all decisions which affect them
- Building a cohort of C&YP who can work with us to help us shape our approaches at every level
- Involving children and young people in development of services
- Consulting children and young people when changing or adapting the environment
- Listening to children's voices regarding their care planning
- Developing mechanisms for C&YP to engage in review and performance management of services
- Putting C&YP experience at the heart of any service redesign or change.

## 5. A Growing Sense of Connection

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In this area of care, as an independent observer, there seems to be a stronger connectivity across sectors – exemplified by the breadth of contribution to this survey; this has also been seen through some of the anecdotal comments. It does though rank 2nd as a key area for improvement:

- *“We are developing our children's focus, linking in with the local providers and we have access to the LA Children's network - as and if required”*

### Stated Priorities:

- Coordination of care particularly with the acute services avoiding the stress of case management for the family.
- Services working together.
- Working together effectively with partner agencies.
- Agencies sharing information.
- Preventing the family from having to retell its story over and over again.
- Sharing information and eliminating barriers to services.
- The right person for the right intervention at the right time.
- Develop a Multidisciplinary teamwork culture (too many people working in silos).
- Good communication between all paediatric healthcare professionals community and acute care.
- Making connections with local groups, especially local Youth Advisors.
- Link with Local Authority work.

## 6. Specialist Staff Development

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Although not listed as the main priority for improvement, when assessed across all priorities mentioned, staff development was ranked 3rd overall, clearly identifying this as a key area, which although not top of mind, is essential for success:

### Stated Priorities:

- Supporting leadership development for children's health clinicians.
- A good skill mix with experienced clinicians.
- Having the appropriate skills in the workforce to deliver the care the children need.
- Play specialist involvement - we don't have one but would be highly recommended.
- Recruitment and retention of care staff.
- Appropriate staffing levels of sick children's nurses.
- HCA or play therapist to be part of the team.
- Healthcare professionals in paediatrics and adult services need training on how to deliver age appropriate information.
- Incorporating children and young people's views in training and education of medical professionals.
- Connecting with and enthusing clinicians for this.

## 7. Emergency Department

Although not a top priority when asked specifically the question, ED frequently comes up as an issue across the responses:

- *“I work in an Emergency Department that does not have a separated Paediatric A&E despite having just over the 16000 stats that would indicate a requirement”*
- *“We have a designated children’s area in our emergency department (which is locked and separated from the adult services) and have 14 paediatric nurses employed in our team. We work hard to have joined up working with child health to provide the best service and user experience. The department is, however run by adult services (not part of child health). We do not have a doctor allocated to the paediatric area which causes a lot of frustration for the children and families and there are times when staff/ resources are taken from the paediatric area to cover the rest of the ED which can also impact on the experience for the children and young people”*

### Stated Priorities:

- Provision of emergency nurse practitioner service and look at potential ANP service.
- Cramped A&E facilities with no stand alone PAU.
- Patient Environment/Experience in Emergency Department.
- Reduce waiting times by allocating a doctor to work in the paediatric emergency area.
- Fully open Paed ED 24/7 - planned for autumn 2013 now open 10.00 -00.00.
- Flow from Paed A&E.
- Reduce waiting time in Paediatric Assessment Unit & A&E dept.

## 8. Commissioning

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Commissioning came up as a recurrent theme across the survey responses:

- *“I think children’s commissioning has had a very low profile to date and been very reactive to the needs of secondary care providers. This is improving in our organisation but we have a significant way to go”*
- *“The CCGs which I am working for are evolving as commissioning organisations and seeking to develop mechanisms and forums for engaging with C&YP and seeking their views”*

### Stated Priorities:

- Commissioning based on children's and family's experience.
- Ensure CSU/CCG's include complaints and feedback from children in their procedures.
- Involving C&YP in the development of the CCG Transformation Strategy informing the CCGs Priorities and direction of travel as a commissioning organisation.
- Measuring CYP outcomes and using them in the commissioning cycle.
- Commissioning high quality services that meet needs with clear outcomes.
- Feedback used to develop quality markers for services commissioned, also there is an expectation that provider will develop and deliver action plans in response surveys and feedback from users.
- In every service that we are commissioning now for children we are embedding public/user engagement.

## 9. Transition

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Although not in the top five in terms of stated priorities, transition is evidently a common day-to-day challenge that is being faced, both in terms of the actual transition in terms of their age, but also when children and young people are exposed to adult elements of their journey:

- *“We focus little on adolescents, there is no specific area for them or activities for them to do whilst they are in the department”*
- *“We do try and use the skills and experiences of our adult colleagues particularly in District Nursing, this is particularly important in delivering equitable care around transition”*

### Stated Priorities:

- Transition to adults.
- Joint funding of young people's short break services when they leave children's services.
- Early management of any unrealistic expectations of adult services during transition process.
- Healthcare facilities for children and young people that are separate from adult facilities.
- Ensure the environment is suitable for Children and young people when not in a Children's ward.

## 10. Mental Health, Learning Disabilities, Complex Cases

The additional challenges of communicating with C&YP who have communication issues due to learning disability, mental health or other were consistently flagged up as a priority to be addressed. When adolescent mental health and communication with C&YP with complex cases are considered together these would be ranked joint 4th:

- *“Being part of a Mental Health Foundation Trust should mean we are focused on the emotional health and well-being of young people but there is no dedicated time engagement with young people, but the lack of understanding of the SN role and that we are health professionals not based in schools is widespread. There are specific areas where we do well as in the focus on Looked After Children but there are so many children in poverty whose needs are neglected and not dealt with until crisis point. This results in a high turn over of Social Workers who do their best but get frustrated by the long historical context of family issues”*
- *“Although we have the child and young people at the heart of our service it is clear that those with Mental health issues this service does not meet their needs”*

### Stated Priorities:

- Better provision for CAMHs patients - improved access 24 hours per day. Stop CAMHs patients coming into acute paediatric medical beds.
- More research that involves the participation of children and young people with learning disabilities.
- Importance of developing and maintaining relationship with GP for children and young people with complex needs.
- Communicating with children with communication difficulties.
- More flexible support groups for children living with complex needs/disabilities to have peer support and opportunities to experience the same activities as other well children in a safe supported way.
- Attitude towards 16-25 year olds especially those with long term conditions.
- Ensuring that the experiences of children with cognitive impairment are better.

## 11. 24/7 and Flexible Hours

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Being available for the families and young patients in their hour of need was an ongoing theme running through the responses. Some have successfully tackled some of the issues ([see Appendix 5 and 6](#)), but this area was ranked 6th in terms of the stated priorities:

### Stated Priorities:

- Flexible working allowing more care to be delivered at home 24 hours a day when needed.
- Flexibility to meet needs in a variety of settings: hospice, child's home, school and hospital.
- Out of school hours meetings.



## 12. Research, Best Practice, Learn from Each Other

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Learning from each other, having the opportunity to share best practice, and indeed not so good practice was deemed important, being ranked 8th. The participants indicated a real desire to share and the majority have expressed interest in joining a Community of Practice:

### Stated Priorities:

- More qualitative research into the experience of children and young people.
- Effective learning, including sharing learning, from Serious Case Reviews.
- Recognise the importance of children's research for developing high quality and child centred health services.
- Define appropriate benchmarks of quality in children's research for REF so that children's research is not marginalised.
- Quality improvement research that considers all the 3 elements of quality together and lessons learnt. This type of research literature is sadly lacking ,try looking for it, it doesn't exist.

## 13. Safeguarding

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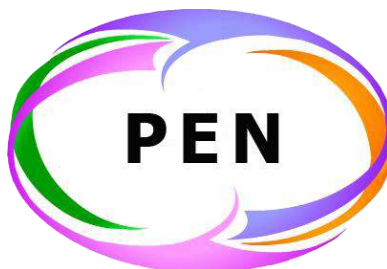
Just making it into the top 10 priorities, safeguarding was frequently mentioned, as there are some concerns about the need to focus on the more basic safeguarding concerns, and that this can cloud the issue. Safeguarding is not synonymous with patient experience:

- *“Lack of investment in School Nurses means a programme of safeguarding and immunisations only”*
- *“Whilst we have safeguarding in place and developing I am unsure of this area specifically”*
- *“Safeguarding is sometimes impacting on our ability to improve the experience”*

### Stated Priorities:

- Better implementation of safeguarding roles - posts filled and areas of responsibility clarified.
- Safeguarding with a focus on improving early intervention.

# Appendices



## Type of Organisation

Organisation Type	TOTAL	%
Acute/ MH Trust	28	19
NHS England	19	13
Foundation Trust	19	13
Community Trust/ CIC	14	10
CCG	12	8
Children's Hospice/ Charity	10	7
Education	7	5
Children's Hospital	6	4
Service Organisation	4	3
Councils - children/ youth services	4	3
Networks	4	3
CSU	3	2
CAMHS	2	1
Other	15	10
<b>TOTAL</b>	<b>147</b>	<b>100</b>



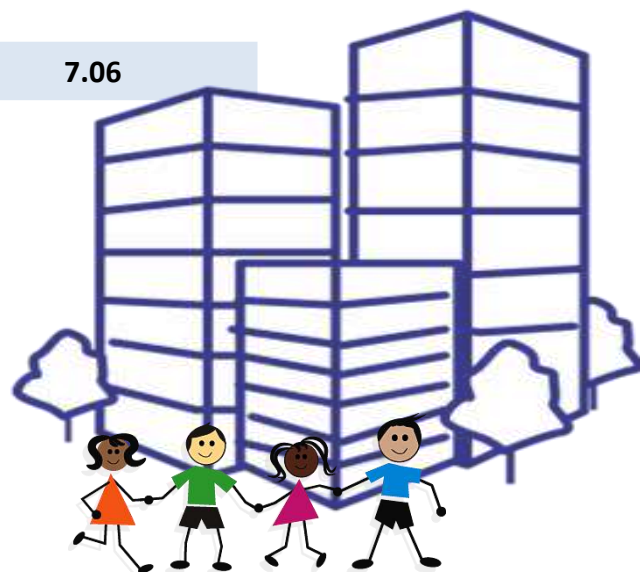
## Overall View of Organisational Focus

Thinking about your own organisation, how would you rate your focus on the experience for children and young people? Please rate your organisation on a scale of 1 to 10 where 1 represents 'We do not focus on this at all' to 10 'This is built into everything we do'

Answer Options	No. of Respondents
1 (We do not focus on this at all)	4
2	2
3	4
4	3
5	9
6	3
7	14
8	19
9	15
10 (This is built into everything we do)	12
Don't Know	1

Response Count	86
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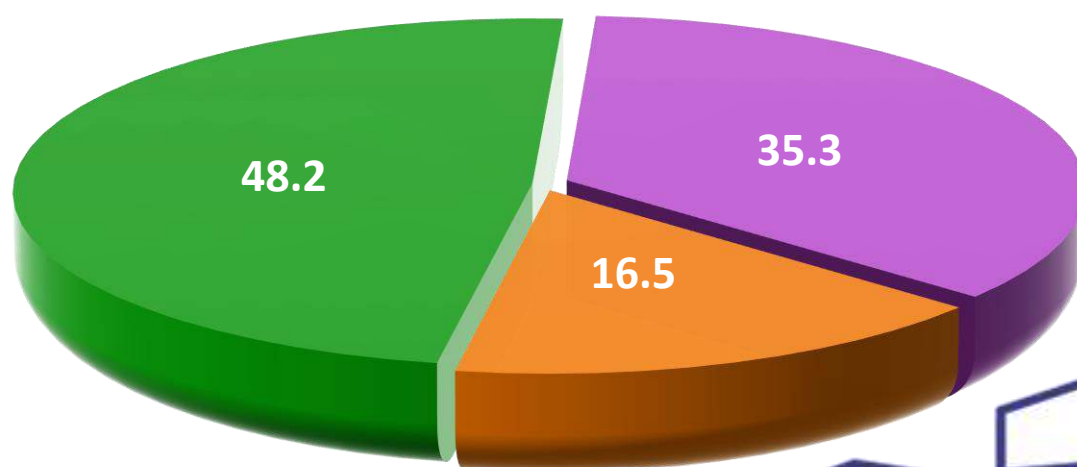
Rating Average	7.06
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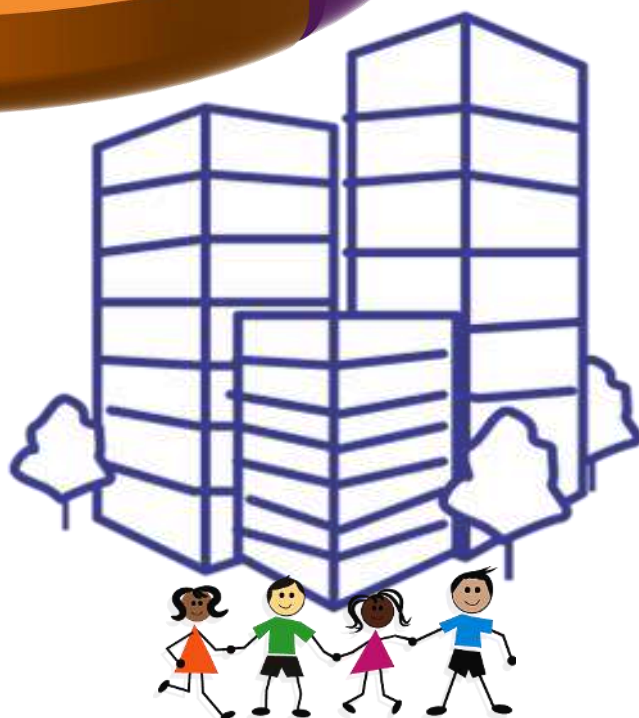
## Strategy for C&YP

Still thinking about your organisation, do you have a strategy focussed specifically for children's and young people's experience?

■ Yes      ■ No      ■ Not Sure



Response Count: 85



## Priorities for C&YP

Issue	Mentions
• Listening and involving young people more effectively	43
• Working together effectively across pathways/ agencies	19
• Specialist staff development	17
• Feedback and closing the loop	13
• Environment	10
• Commissioning insight	
• Flexible hours - 24/7 out of school etc.	8
• Adolescent incl. Mental health	
• More relevant qualitative / quantitative research	
• Emergency Department	7
• Transition	
• Age appropriate service	
• Communicating with children with complex needs	
• Accessibility improvements	5
• Share best practice/ learn from each other	
• School nursing service	
• Safeguarding related concerns	4
• Primary care - improve focus	
• Develop strategy	
• Have fun	
• Deliver the promise	3
• Food	
• Separate dept. for children	
• Use of technology	
• Palliative care	2
• Ambulatory Care	
• Flow	
• Theatre provision	
• Continuity and sustainability	1
• Providing Information	
• Short stay assessment beds	
• Eradicate inequalities	
• Monitor across areas	
• Self care management	
• Looked after children	
• Community Nursing	
• Admission process	
• Confidentiality	
• Build resilience	
• Emotional health and well being	
• Dentists and Optometrists	
• Discharge planning	

## Action On Feedback in Last 3 Months

**Respondents were asked to consider what action had been taken as a result of feedback in the last 3 months. Actions included:**

With the past three months, a number of complaints have been made regarding the state of ward decor. As a result, the ward is currently undergoing redevelopment.

Feed back from homeless families that they are not receiving healthy start vitamins has resulted in changes being mooted both within the organisation and taking it up nationally.

The allocation of care, timing of visits, number and variance of staff visiting, care planning.

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.

Modifying the pathway for booking appointments in day ward.

Parents have commented that they do not know how to get in touch with their Health Visitor. We have introduced one central number for each team and have this printed on labels which we stick in the front of the PCHR.

School students did not like the room being used for School Nurse drop-ins as it had a window and they felt other students could see in. School have provided a more private space for these sessions after negotiation.

During a one to one yearly review of care with the family, a parent fed back that they were overwhelmed with the number of new people introduced to their family. (the size of the care team has trebled during the last 6 months). We were able to strip back to a core team of 5 that would work with the family at home and be rota'd on to care for the family when they stay in our hospice.

Teenagers felt they were not being taken into account in the waiting room. Provided teenager friendly games and books but these have to be locked away and given out if asked for. Laminates in the dept instruct them on how to do this.

Recent engagement exercise with children and carers led to new service specification and tendering approach to CAMHS services locally.

Parent during school holidays wanting more flexible dropping off and picking up of children for short breaks at hospice looked at staff working different hours on shift to allow this to happen when possible.

Families having problems transporting in and picking up children have taken on some volunteer drivers to help with transport if families do not have a car or having problems affording petrol rural Norfolk.

Summer holiday activities for children and young people.

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



## Action On Feedback in Last 3 Months *(continued)*

**Respondents were asked to consider what action had been taken as a result of feedback in the last 3 months. Actions included:**

Admission 1- 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 parents/ carers of children with complex needs requested that the process for dissemination of information about their children was made as easy as possible to avoid repetition of medical history and to support the nursing care that their children require. We have introduced a health passport as a result so that staff can see a quick summary of child's needs and condition at glance based on the traffic light system.

Patients requested that we had a system of highlighting that their children had additional health needs prior to them arriving in hospital so that staff were fully prepared for hoisting, gastrostomy feeds etc. Children and Young People with complex needs are 'flagged' on PAS so staff are highlighted at the point of referral.

Health and justice team are linking with a prisoners patient group re opening hours in the prison healthcare centre.

We moved doors within a corridor to improve privacy and reduce noise for young people staying in nearby bedrooms.

We have started txt messaging parents to remind them of their appointment which parents prefer.

Changes to layout and decor of CAMHS clinic.

## Examples of Best Practice

**We welcomed all examples of best practice related to children and young people's experience:**

We have worked really closely with some of 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.

The User's talking to the trust board has been a fantastic way for them to feel like they are being heard, especially when they are fed back changes from these meetings.

MYA is made up of a number of Projects which use youth work 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 support when required.
- **Voices in Partnership** - works with children, young people and parents who need to access CAMHS services and gives them a voice by bringing them together to explore their experiences.

A children's hospice service providing short breaks, end of life care and symptom management to children and young people not expected to live beyond their 19th birthday. Our care philosophy is at the centre of everything we do as an organisation.

1. We respect the rights and individuality of all children, young people and their families, both within their own homes, communities and within our hospices, throughout each family's individual journey.
2. We aim to provide a flexible approach to caring for all families based on their individual needs and safe resources, to ensure that the best interests of the child are paramount.
3. We acknowledge that families are experts in their child's care. We will listen to and work together with families to strive to maintain their chosen way of caring for their child. We will be responsive to changes in their medical, psychological and care needs.
4. We acknowledge the diversity and uniqueness of the families we support and endeavour to meet the needs of all family members – including their physical, emotional, religious, spiritual, social and cultural needs – in a sensitive, safe and professional manner.
5. We advocate that the children should receive the highest standard of care possible. We promote and encourage partnerships with all those working with the children and their families to provide consistency, quality and safety of care.
6. We ensure that all staff who work for Shooting Star CHASE are professionally trained, guided and supported to ensure our continued commitment to delivering the highest quality of care for all families using our services.

Setting up young people's executive to run alongside governors board.

## Examples of Best Practice *(continued)*

**We welcomed all examples of best practice related to children and young people's experience:**

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.

Our Children's Community Nursing service provide end of life care 24 hour per day when required which has received very positive feed back from families and professionals involved.

Our Diabetes team are working to achieve the best practice Tariff and the structured education sessions which the nurses provide particularly the one focused on the transfer from primary to secondary school has been well evaluated.

Our respite care unit has a glowing parent survey which reflects the excellent care delivered there.

### Pain management and distraction

We use a range of procedures for nurses to see, treat and discharge patients without them needing to see a doctor.

Collaboration between medical and nursing staff on developing guidelines.

Close working between A&E and Paediatric in the Children's Emergency Department.

My research looks at sleep hygiene education as a way of treating behavioural sleep problems in children with developmental disabilities. Within this there is a significant qualitative element, looking at the experiences and perceptions of families of children with developmental disabilities of sleep hygiene education - looking at how this intervention is delivered, how much support is offered etc.

Patient experience is key to the nurses on our ward to ensure that children are receiving excellent care. We know that for children coming into hospital is scary, new routines and scary unfamiliar faces! Play is an integral part of the care delivered. We are currently developing a website for children and young people coming into hospital to include videos and information on what to expect.

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

You're Welcome - School Nursing Service have initiated.

We provide Hospice care for children and young people up to the age of 21years. This includes short breaks/respite for the child with or without their family. Symptom Management and access to Consultant in Paediatric Palliative Care and specialist nurses. Step down from hospital care and End of Life Care. All offered at 2 hospices and by the hospice at home team covering parts of London, Surrey and West Sussex. We have a large Therapy Team including Physiotherapist, Occupational Therapist, Complementary Therapist, Art Therapist, Play Therapist, Music therapist and Counsellors. We also provide a range of group activities and therapeutic groups.

We have run a poster competition with our local acute trust. The posters are currently being put into an animated DVD to use at our next Governing Body. The children were asked to make comments about their hospital experience. this will be shared with the acute trust.

## Examples of Best Practice *(continued)*

**We welcomed all examples of best practice related to children and young people's experience:**

### *Involving young people in:*

Assessment of service impact, Service evaluation, Service reviews, Commissioning, Young inspectors, Qualitative interviews, Focus groups to explore issues of importance, supporting young people to co deliver conferences, customer satisfaction, Service design, development, working with elected / non elected user groups

DSH assessments, Screening referrals/ signposting, Group therapy, Risk assessments, On call service, Joint care planning, Recognising the family / young person as central in our approach, establishing a therapeutic relationship, being open, respectful and thoughtful, evidence based practice, creative practice

Integrated hospice at home and inpatient service.

A key working care co-ordinator for all families who is a constant for the families. They co-ordinate a core team of staff to work with that family in the place of their choosing.

Hospice at home to facilitate choice of place of care and choice of place to die.

Higher level nursing skills such as Nurse Consultant role, independent prescribers and clinical assessment skills to offer more responsive care throughout the 24 /7 period in the absence of medical staff.

On-call service throughout evenings and weekends.

Family choice of time of respite care at home, including evenings and weekends.

Generic role of care team in response to family feedback about needing help with daily activities such as making meals, ironing, cleaning and washing.

Use of family support volunteers to reduce the burden of some household tasks so families can spend precious time together.

I am clinically based senior sister. I lead the team here and work clinical shifts along side them

I ensure policies and pathways are up to date and are being adhered to.

I will audit care in the department on a 3 monthly basis.

I collect evidence to present to continue to push for a better paediatric service.

I respond to all the data and complaints regarding children attendances.

I work closely with the Adult team and assist in advising or advancing their knowledge and skills with children.

A sibling support group is being developed to provide parental guidance and support during early admission period, and particularly through a bereavement period.

In Gynaecology, a paediatric and adolescent Gynaecology service has been established to provide appropriate care in a non threatening environment and also support during the transition period.

In Maternity a young parents group is well established to support young mums and their parents / carers.

## Examples of Best Practice *(continued)*

**We welcomed all examples of best practice related to children and young people's experience:**

Important when caring for children with complex disability to observe child and make a note of what the child enjoys; which rooms they like, detailed plan of sensory room/play activities that they like and what will help with development. Important to get as much detail from child/family /school so all following same plan excellent communication. Good open honest dialogue with families based on trust they need to know they can contact us when in crisis.

We offer 24/7 support and symptom management with increasingly complex needs it is frightening for families to keep children cared for at home and not just bouncing back to hospital they need community based services over 7 days a week.

I've been awarded a clinical research fellowship to develop an intervention for children and young people with epilepsy. The systematic review we did found no evidence about what helps children and young people to take their medicine, so I am applying for ethical approval to interview children and young people (who have difficulty taking their tablets) to find out what they think about taking tablets and what the difficulties are. Then to design an intervention using ABA to test in an RCT in the future.

### The Health Passport design

We have also asked a group of young people to design and run a survey about services that they would use if they had any problems with their emotional health. His report has just been received and will help us to design a comprehensive CAMHS service.

This is a new area for us but we have an action plan in place which includes trying to get feedback from all our patient groups - acutely ill , chronic and long term users, adolescent.

We are trying to develop a way of talking to 'well' children through local schools and school councils, guide / brownie groups etc.

Audio-visually separate department for children in the ED - child friendly.

Dedicated team of 14 paediatric nurses- all PILS trained- access to APLS/EPLS.

Joined up working with child health to share pathways and ensure good patient flow and experience across the emergency admission pathway.

Complex Needs Steering Group with parent representation and families forum for children with complex health needs are our best examples of family involvement.

Peer Support Workers in CAMHS short-listed for Nursing Times Award.

Children are involved through an art project that involves the acute trust and schools .

National youth project visited the acute unit with interactive sessions regarding roles of professional and how we can improve services for young people. This is a type of project that can involve young people in schools locally.

## Examples of Best Practice *(continued)*

**We welcomed all examples of best practice related to children and young people's experience:**

The hospice children and young people from birth to 30 years of age with a life limiting or life threatening condition and their families, including those who are technology dependent. We provide both in-house residential care that includes palliative care, symptom control, end of life care and short breaks. We also have a therapies team that delivers physiotherapy, hydrotherapy, complementary therapy, music therapy and specialist play activities. We have a family support team that provides psycho-social care, spiritual support, a cultural link worker, sibling support worker, outreach play, complementary and music therapy and a bereavement care co-ordinator.

We are running a programme of Young Health Ambassadors working within Healthwatch in the region, which we inherited from previous bodies and are now taking forward.

As PPP Lead I am exploring how to get young people's voices into our work and specifically into the Citizens Senate I am setting up for the East of England.

To this end I am holding a workshop with the Hospital and a group of pupils from a local school.

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

Parents have said that they don't ask Doctors questions as they don't feel comfortable whereas they feel comfortable talking to a nurse & asking questions.

As part of my MSc I completed a dissertation evaluating the role of the Children's Community Matron. The service evaluated very well. Parents asked for a 7 day service which we have now implemented.

Below are a few examples of our work to feed into the debate.

Children with complex and palliative care needs – experiences of advance care planning:

<http://www.ncbi.nlm.nih.gov/pubmed/23384400>

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://www.netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1718-145\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1718-145_V01.pdf)

Young people with epilepsy - experiences of knowledge exchange and engagement with professionals:

<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>



## A Few Words About PEN

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The Patient Experience Network (PEN) is a not for profit organisation. We were set up in 2010 to recognise, share and celebrate the great things that are happening to improve the patient experience. By doing this our aim is to help organisations sustain and embed their best practice and be more effective at demonstrating their success.

We welcome individuals and organisations across all facets of healthcare; our common ambition is to improve our patients' experience. By joining PEN, members acknowledge that we will do our best to share their best practice and to help them recognise and celebrate the work their teams are doing.

Patient experience has at its heart an understanding that this is all about ordinary people overcoming everyday obstacles to do extraordinary things.

To find out more please visit our websites:

[www.patientexperiencenetwork.org](http://www.patientexperiencenetwork.org) or [www.patientexperienceawards.org](http://www.patientexperienceawards.org)

Or contact **Ruth Evans** on **07798 606610** or [r.evans@patientexperiencenetwork.org](mailto:r.evans@patientexperiencenetwork.org)



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Patient Experience Network

Re:thinking the experience

