Best Practice Report

Children & Young People

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By Patient Experience Network

Welcome

At the Patient Experience Network (PEN) we are privileged to run the Patient Experience Network National Award (PENNA) programme. 2023 will be the 13th year that PENNA has opened for entries, and we are amazed each year to receive so many incredible and inspiring examples of best practice, things people and organisations are doing to improve the Patient Experience. This includes the experience of care for not just patients, but families, friends, loved ones, carers and service users. As the staff and their experiences are key to delivering a great Patient Experience, we also include examples where the focus has been on improving the Staff Experience.

In this Best Practice resource, we have collated examples from our finalists and winners over the recent years which have a focus on the experience of children and young people. These include any examples of best practice submitted that were short listed, where the focus was on improving the experience for children and young people, regardless of which category they entered. As you will see we have 40 examples in this resource.

Format

This is a rich resource full of thoughtful and thought-provoking content. Organisations submit their best practice to us and are encouraged to include the following information:

- An introduction to their organisation
- Some general information about the context and project
- Rationale and background
- What planning and preparation was undertaken
- The impact that the project made.
- Suggestions about relevance to others
- Any standout information
- Key learning points

Weighing Babies and Well Baby Clinic Pathway
Ashford & St Peters NHS Foundation Trust
PENNA 2015
FINALIST – Personalisation of Care

Organisation

Originally established in 1998 from the merger of Ashford and St Peter's Hospitals, the Trust has been on a long journey of development and improvement to its current position as the largest provider of acute hospital services to Surrey residents, and having become a Foundation Trust in December 2010.Ashford and St Peter's Hospitals NHS Foundation Trust serves a population of over 410,000 people and employs 3,700 individual members of staff with a turnover of £263 million. The Trust provides a whole range of services across its two hospital sites in Surrey - Ashford Hospital in Ashford, and St Peter's Hospital in Chertsey. The majority of planned care, like day case and orthopaedic surgery and rehabilitation services, is provided at Ashford hospital, with more complex medical and surgical care and emergency services at St Peter's Hospital. Our vision and strategy Our vision 'Creating excellent joined up patient care' captures our ambition to join up care within our hospitals and care into and out of hospital, stressing the need for excellence and putting patients at the centre of everything we do. This year we revised our Trust strategy and key objectives to deliver this vision, with two over-arching missions:

- To develop integrated care for our local population – working to join up care pathways with primary, community and social care
- Deliver high quality specialist services in Surrey – with our aim to become an Emergency Centre for Surrey.

These are underpinned by our four strategic objectives; Best Outcomes; Excellent Experience; Skilled, Motivated Teams; and Top Productivity.

General Summary

The Infant feeding team (IFT) was put into place in June 2014 under the directive of the head of Midwifery. On joining the team as the lead midwife, I noted that there were many babies being re admitted on to the ward from community with weight losses of just above 10% and jaundice issues. By reviewing and auditing every readmission it was found that main reason for these weight losses were due to feeding issues, including tongue tie and Jaundice It was felt that with a support line, robust guidance and a referral clinic in place for the community midwives and health care workers these babies could be cared for in their homes. After presentation of the audit results and much discussion with the management teams the weighing baby guideline was then written and the well-baby clinic was launched in January 2015. Babies who presented with weight loss above the expected % and query Jaundice could be referred into our clinic, by appointment daily between 13.00 and 15.00pm, and if relevant would be referred back into community with a feeding plan to be followed up by the community teams in the family home. Feedback from parents and community staff regarding the difficulty in securing frenulotomy appointments in the community, the resulting feeding issues, and the frequent cessation of breast feeding due to tongue ties evidence was also presented to management and after much research training was secured for the midwives on the team and the tongue tie clinic became part of the daily well baby clinic.

Rationale

The main reason the well-baby clinic, its pathway and infant feeding team mobile service came about was to prevent unnecessary admissions into hospital for mother and baby dyads for issues surrounding feeding and also to provide an advice line for staff in the community in order that the community teams could support the dyads in their homes. This has avoided long waiting times on the wards to see Paediatric doctors' avoidable readmissions and improved patient satisfaction. The tongue tie clinic was added in response to user and community staff feedback and the difficulty accessing free, local and timely specialist support for babies with tongue ties that affect feeding.

Planning

The planning started with the recognition of multiple issues around feeding in the community and the lack of a central point were the users and staff could turn to for advice and to refer. This led to me approaching my line manager with the idea of the well-baby/tongue tie clinic and then taking the idea to the management team followed by consultation within the multidisciplinary teams. Discussion at the MLSC with the users on their thoughts on the project. Next came the writing of the weighing baby and well-baby clinic pathway which was then circulated to supervisors of midwifery, Obstetric and Paediatric leads for ratification. Once ratified circulation and structured teaching within the unit for all the clinical and community staff within Obstetrics and Paediatrics. The Well-baby clinic began in January 2015. The tongue tie process involved researching training for the infant feeding team midwives. With a 2-year waiting list for the university courses in house training with the maxillo facial unit was secured and the tongue tie clinic was added in March 2015. This has avoided long waiting times to see Paediatric doctors' avoidable readmissions and improved patient and staff satisfaction.

Impact

The readmissions continue to be audited and the results published against previous year's results. Auditing the care plans enables learning points to be identified and the relevant staff informed of these points in a timely manner in order to provide continuous improvement in patient care and the patient experience. The impact has seen a downward trend in readmissions of approximately 20%. This not only ensures better user satisfaction, as staff released to give timely and efficient care to those patients on the ward. The initiative has also made financial savings for the trust due to unnecessary readmissions.

Relevance to Others

The impact has been noted by external agencies who report less attendance to the drop-in feeding clinics. This has enabled the sure start centres to re-focus their resources were needed. Community staff express satisfaction in the ability to arrange appointments for mothers and babies in the community in a timely manner, previously this was a very stressful part of their jobs.

Standing Out

This project is special as it has gone from idea to fruition in a short time with instant auditable results. Commitment from our head of midwifery and obstetric and paediatric leads has made the process uncomplicated and strong line management support has allowed the infant feeding team to focus on the planning and implementation of the project. The community leads recognised very early on the impact that the clinic and pathway would have massive benefit for not only the mother and baby dyads but also the community midwives and support staff who would have a central point for advice and referrals regarding feeding and tongue tie issues. Previously this had been a difficult and stressful process.

Key Learning Points

- Ensure management support at all levels
- Identify clinical space to run the clinics.
- Investigate in house frenulotomy training where possible as external course costs may inhibit and delay the start for clinic providers
- Approach internal and external agencies early on for their input.
- Put a robust training program in place for all staff using the pathway.
- Ensure all multidisciplinary teams are aware of clinic start date.
- Regularly update all staff of the monthly audit results.

Creating Memories in Children
Barking, Havering and Redbridge University Hospitals NHS Trust
PENNA 2018
FINALIST - Personalisation of Care

Organisation

Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT) is a large acute Trust in the south east of England. We run two hospitals – King George Hospital in Good Mayes and Queen's Hospital in Romford – and also serve clinics across outer north east London. Working closely with our partner organisations, our 6,500 staff and volunteers care for a diverse community of 750,000 people.

General Summary

BHRUT Treasured Memories Appeal was set up in 2006. It provides support to children and young people whose family members/friend has a life limiting illness. Treasured Memories believes in an open and honest approach to support children/young people, enabling them to share their anxieties and feelings in a trusting and safe environment. Before this project started there were limited spaces available in the Trust to conduct these types of conversations. Dennis's Den was created to provide a dedicated space where this type of work could be carried out.

Rationale

The Trust Mission Statement for End of Life Care (EOLC) written in 2013 states that "care will be delivered by staff that is knowledgeable and compassionate in surroundings that provide comfort and dignity". Staff tried to accommodate for patients to have an opportunity to say goodbye to loved ones especially with young children. The BHRUT EOLC Strategy ambition no. 3 states that the hospitals will work towards ensuring that the hospital environment does not add to the distress experienced by people at this difficult time and that all necessary steps are taken to ensure privacy and dignity for those approaching the end of their lives. For example:

- A young cancer patient dying in hospital unable to go home, two young children 2yr & 5yr wanted to give their mum a cuddle and say goodbye. This was done however the only privacy was behind a curtain in a four bedded bay. This led to both health care professionals and patients feeling less than satisfied with this environment.
- A 63-year-old patient who died on the cancer ward in the Trust 5 years ago with a cancer diagnosis unfortunately was unable to go home. Like a lot of patients nationally there are still 51% of patients dying in hospital, and at BHRUT we have on average 7 adult deaths a day. This patient had a young family, and they were extremely supportive to him but if meant spending a lot of time in the hospital and trying to accommodate lively children, but it was important to him to see his grandchildren frequently. This promoted the Specialist Palliative Care Team to look at a child friendly space within the Trust which would enable families to create memories at the end of life.

Planning

A project task and finish group were devised, and they researched the available resources available. A proposal was submitted to the Trust board to find a suitable space within both hospital sites. A patient's family who had died in the Trust engaged with the SPCT to fund raise to support the project and became part of the working group as they felt very passionate about this project succeeding. The led CNS discussed the idea of the project with local hospice family support team and the national child bereavement Trust to seek their advice. Once the funds had been raised an implementation plan was put together and presented to the Charity and Trust board for approval. The working group worked in collaboration with estates, charities, patient's family and the Trust board to deliver the project. Smaller working groups were set up within the SPCT to source the furniture and to make the room look more like home and accommodating for children.

Impact

Over the past five the project has gained momentum as other health care professionals have a better understanding of the important of preparing children for the death of a loved one. Creating memory boxes with patients and their families/carers has increased dramatically and feedback from families has been

positive... Since the opening of the dedicated space (Dennis Den) patients now have a protected area where difficult discussion can take place and spend some time together before heading back to their bed space.
Patients are now able to skype family and friends, so they do not miss out on important experiences
Able to read children a bedtime story as well as completing memory boxes,
Write feelings on stars that can be tied to the blossom tree, they can also decorate and leave a message on a star which they can tie them on the tree together to add a positive stance to a negative experience which is essential for bereavement care.
There are aids within the room to help children discuss their worries and feel supported
Memory boxes can be completed without being disturbed by the business of the ward.
The room has sensory lights to help create a more calming environment for those that might have special needs Quotes from family members:

- “Just being able to be together as a family off the ward environment” patient
- “A beautiful room to hold our wedding service, a time I will always remember” wife of a patient “
- Thank you for giving me time away from the ward to tell my 10-year-old daughter that my cancer had returned and have family time together that was never possible before” Patient
- “After telling young children that their mother was going to die very soon, it was a great space for them to be able to cuddle and share a pizza that they always usually do together, it helped me a professional to feel that we had been able to make a difference” staff member
- “Feels rewarding to make a small difference in a difficult time” staff member

Relevance to Others

The opening of the Dennis den has taken a number of years to put into place and the family who had completed the majority of the fund raising were very proud of this and his wife quoted “It’s a great legacy to him, it’s amazing to see it and other families will be able to benefit from it”. It has generated other fund raisers to be interested in providing funds for a great cause. As many patients are deteriorating and dying in hospital as their preferred place of care it is important that this space is continued and that further resources become available to replicate this not only in our other hospital site but in other Trusts. There has been interest from other local and international organisations to re-create the memory tree in particular in their workplace.

Standing Out

In EOLC it is the small things that make a huge difference. This project has enabled patients who are going through a difficult time to have some pleasures by being able to create memories with their loved ones (particularly children and young adults). Historically there are usually dedicated spaces in areas like A&E, maternity and ITU but not for the general wards. This project has enabled our Trust to stand out as they believe that this is important for patients who are nearing the end of their life. The feedback from the patients has been heart-warming and extremely positive. One lady had been in hospital for 8 weeks and had not been able to get outside, she was able to be wheeled into this room on her bed where there is a blossom tree and even though artificial, she felt overwhelmed with emotions and gratitude.

Key Learning Points

•It is important to get Trust executive buy in from the start in order for the project to move forward
•Work in collaboration with local businesses to raise funds
•It helped having a vision form a family whose relative had died and had a negative experience as they were driven to improve future care.
•Implementation plan is vital in order for everyone to know who is doing what.

Journey Through Treatment for Children and Young People with Eating Disorders
Barnardo's
PENNA 2016
FINALIST - Access to Information

Organisation

Since April 2009, Barnardo's Helping Young People and families to Engage (HYPE) service has been working in an innovative, pioneering partnership with the Community Children's Health Partnership (CCHP) – an NHS staff group of 900 in Bristol and South Gloucestershire making children, young people and their family's participation meaningful in NHS services. These services include all mental health, child health and universal nursing services.

This NHS Barnardo's partnership is about bringing together the different skills and expertise of an NHS and national voluntary sector organisation to create high quality services that have the best evidence based clinical care with the best service user experience.
HYPE, a service of 7 FTE works with children, young people and their families/carers, commissioners, health practitioners, professional leads, service and senior managers, education and Voluntary sector to raise aspirations about what service user participation can achieve. We have shared our learning and achievements nationally.

This collaborative approach led to the rare accolade of "outstanding service nationally" from Care Quality Commission in 2015. This CQC rating was strongly predicated on our attention to building the evidence base demonstrating the impact of this way of working.

Young people have strong ownership of the HYPE service and took charge of creating a mission statement for CCHP as part of a participation strategy they developed with clinical staff.

"It's our mission to make sure we always listen to you and understand what your experience of healthcare is".
We have been developing a 'whole systems approach' to embed CYP and family's participation at every level of the CCHP. This has included significant attention on creating a positive culture of service user participation. We have gone from a position where services and individuals resisted engagement processes with service users to services now actively engaging in service user participation and generating their own ideas for change with service users.

From April 2015 the new NHS providers that form CCHP are a triumvirate of Avon and Wiltshire mental health NHS Trust, Sirona care and health and Bristol Community Health.

General Summary

The findings from a consultation with families affected by eating disorders gave an overwhelming message about the complete lack of information and understanding they had at the beginning of the process of receiving services. They reported the impact of this as creating long lasting barriers in their ability to access and engage with services.

Prior to this feedback provider services thought their communication and materials on eating disorders were adequate.

Barnardo's continued to work with the families involved in the consultation and linking with a small, enthusiastic group of clinicians we started to map out the information families identified in hindsight as being useful.

We knew from young people that as a starting point paper-based information was too heavy and inaccessible. Families were coming into service with huge stress levels, feelings of being out of control and needed something digestible.

Scoping the use of digital media in this area we identified a lack of information that showed the whole journey from the point of view of the family and clinician. In discussions with families this gap seemed to fit with what they felt was missing.

We then set about engaging with GPs, Bristol Children's Hospital, Adolescent Inpatient unit, CAMHS and adult mental health services together with families. A plan was then developed for a suite of video and audio digital media showcasing all possible aspects of the pathway with a family's story as the central narrative.

This media was published online in 2015 and provides a CYP focussed story with all the services around the child in an accessible and unique format. Responses from family's were instantly positive and reports that it radically changed their conversation with professionals.

See webpage with all associated video and audio materials. The main film has had 5.5k hits since June 2015.

http://cchp.nhs.uk/cchp/explore-cchp/eating-disorders

Rationale

In 2011 commissioners, CAMHS providers and Barnardo's HYPE started meeting to improve understanding of the experience of CYP with eating disorders and their families.

The care pathway for these families didn't always run smoothly and there were increasing numbers of complaints from parents about the distress the lack of consistency and working with multi professionals caused. Shared training and liaison between the agencies were being established but there were still gaps in services effectively working together.

Barnardo's HYPE service worked with CAMHS providers in Bristol and South Gloucestershire to make contact with a random sample of the families seen in the past year for eating disorders.

Barnardo's then embarked on a programme of home visiting 25 young people and their families both separately and together.

An overwhelming message from families was the complete lack of information and understanding they had at the beginning of the process, creating long lasting barriers in their ability to access and engage with services.

From this we set about working with families and senior leaders and clinical stakeholders to create information that was accessible and fit for the 21st century.

Planning

This was led by Barnardo's, planned with families and key senior leaders from CCHP. For efficacy other stakeholders were involved on an individual basis.

We stripped information back to its bare bones starting again with the story told to us by a young person with eating disorders and her dad.

We produced an audio of this story with the real young person and parent and hired actors to play their parts on film thus creating an authenticity while maintaining their anonymity.

We added in commentary and film from all the different professional groups involved in this family's journey to explain the purpose and function of their care and treatment.

Supplementary audio and video media were then developed to give more detailed information on:

- Children's hospital
- GP role
- Adult mental health
- Different parent perspective

- Different young person perspective
- Riverside adolescent unit
- The family-based approach

These materials are all available online and are additionally promoted via clinical staff in CAMHS as well as via local health watch.

Parents then helped us to develop an information pack which they saw as the next step in understanding the detail on the complexity of the illness and its treatment. This pack is being piloted in one of the CAMHS teams before it's rolled out see attachment. Feedback so far has shown significant benefit for parents who are supported by the clinical team to get to grips with the information a bit at a time.

Following this success, we have produced further video material for the Riverside Adolescent Inpatient Unit – this is a CYP led film shown to new CYP before admission. Again, this has hugely helped to smooth the transition into services.

http://cchp.nhs.uk/cchp/explore-cchp/riverside-adolescent-unit

Impact

The audios and videos have been evaluated through survey monkey in 2016 and received feedback from both local families and clinicians and clinicians across the country. See attached document. This has generated lots of positive feedback as well as suggestions for exploring this work further.

We chose this method as respondents can by anonymous and has a wider reach than internal questionnaires.

We also use the CYPIAPT session by session monitoring within eating disorder patients locally and this is giving us very important feedback about the role of the clinician in supporting this information which we have then used to promote it to a minority of clinicians who are not as engaged. The main findings from this monitoring are:

75% of parents felt informed about the purpose and approach of the different eating disorder services

60% of young people felt able to watch the film within the first few sessions and it reduced their anxiety about what was going to happen

Families also now report feeling more informed and able to join in discussions about their care.

We have had more young people with eating disorders involved in participation activities and wanting to develop these resources further.

Relevance to Others

As part of the dissemination of these resources we contacted the Royal College of Psychiatry who enthusiastically endorsed the digital and audio media and included information and a web link to every psychiatrist in the country in their summer 2015 newsletter.

This has generated lots of interest in other CAMH services and reports that they are using this information with their families despite the local differences.

Families we work with who receive services from disability child health professionals are very keen to develop similar media to support understanding of different conditions and we have started work on a cerebral palsy film using the same format.

Standing Out

- Young people's and parents' views were central from the outset and throughout the process.
- Senior leadership supported the process across all the different organisations working with eating disorders.

- Clinicians prioritised family’s views over their own unless this went against the evidence base
- The resources are innovative and provide an emotionally powerful and engaging experience
- Combining the clinical and family perspective in this way is unique
- There was significant national and local interest
- These resources continue to stimulate new ideas of how to reach more aspects of young people’s lives e.g., school and friendships.

Key Learning Points

- Listen to families
- Bring their ideas to life with them.
- Work with senior as well as front line practitioners
- Give your work a platform through social media
- Pay attention to supporting the coordination for those involved to make the most of their time
- Think about who will benefit from your work nationally/externally
- Involve families and staff in celebrating your success.
- Bring in other expertise such as film making is you don’t have the skills in house – don’t see that a reason not to try something new.
- Keep being open to feedback to improve what you’ve produced

Baby View – Neonatal Intensive Care Video Conferencing Project
Bradford Teaching Hospitals NHS Foundation Trust
PENNA 2016
WINNER - Innovative Use of Technology

Organisation

Bradford Teaching Hospitals NHS Foundation Trust is responsible for providing hospital services for the people of Bradford and communities across Yorkshire. We operate over several sites, including Bradford Royal Infirmary, which provides the majority of inpatient services, and St. Luke's Hospital, which predominantly provides outpatient and rehabilitation services. Employing 5000 staff, covering a large and multi-cultural population we aim to be responsive to the needs of both patients and their families/carers. We look for new ways to improve patients experience; this joint collaboration between the Information Technology, Neonatal services & the Chief Nurse team is an excellent example.

General Summary

There is often delay of a few hours before parents of critically unwell neonates can see their babies in Neo-natal Intensive Care. We have implemented and are using a state of the art and ground-breaking video conferencing facility through a secure platform, allowing parents of sick babies to be able to see the baby and converse with the clinical team looking after the baby from anywhere in the world. This technology has enabled parents to be able to see their infant's real time and engage visually with the clinical team. This process has decreased parental anxiety, enhanced family integrated care with the additional health benefits to the infant. Parents can make a video call from PC, Laptop, Max, Smartphone or Tablet to the team looking after their sick baby. Feedback from parents has included I used this at night-time and could see that my baby had settled before I went to bed, and I was in a different hospital to my baby for three days and this eased the anxious feeling. Feedback to date has been 100% positive from parents and neonatal staff. Approximately 40-50% of families with sick babies in the unit are using the system.

This project is very special, it was based on a concept and driven forward with passion and commitment, and it proves collaboration between teams can work effectively. Both clinical and non-clinical staff and management, were absolutely of the belief that it was the right thing to do for patients. Each member of the team brought different knowledge and skills to the project. The end goal was to enhance integrated family care. We are the first unit to develop and implement this service in the region and possibly within the country. With the overwhelmingly positive feedback from both families and the staff, we believe that this intervention will help us support parents through a long and potentially distressing neonatal journey.
Rationale

This is an NHS wide issue, with parents of ill children sometimes finding that they live in one place, and have babies in separate Neo-natal Units, because of clinical requirement. An example identified early in the concept was of parents living in York, with one baby (twin) at Leeds and the other at the Bradford Neo-natal unit.
The Bradford Neo-natal unit has 31 cots and provides intensive care services to sick neonates born within and outside the Yorkshire Neonatal Network. There are about 600-700 admissions every year and most are admitted to the unit within minutes after delivery. This means that the babies (some of whom are critically unwell) may spend most of their first few days away from their parents, while the mothers are recovering either in the delivery suite or the postnatal wards. There are an increasing number of babies who are transferred to the unit from other hospitals in the region. This is a very distressing time for parents and the challenges of not getting to see the babies as early or as often as they would like to disrupt early bonding, influence early expression of breast milk and adversely affect their overall experience in the hospital.

Planning

Project team established comprising:
Assistant Chief Nurse, Neo-natal Consultant, Neo-natal Clinical Nurse Specialist, Network & Security Services Manager

- Scoping parental interest and needs through informal discussion. Engagement with IG and development of local policy, to ensure the solution meets all requirements and is approved at board level
- Source finances, paid for through Charitable Funds
- Promotion of the idea and involvement of all key stakeholders, to ensure buy-in from all disciplines (clinical and non-clinical)
- Neonatal staff training and education, use of the technology as well as the need for the process through patient stories and demonstration.
- Identifying teams within the organisation for financial, technical and practical solutions and providing evidence of positive impact on patient experience.
- Market research and engagement with suppliers, allowing the ability to implement a potential solution on a trial basis. Testing of new technology, to ensure reliability and sustainability and capitalise on joint interests with suppliers to deploy a third-party solution
- Develop parental information leaflet to facilitate access to videoconferencing, continuing evaluation and feedback.

Impact

- Positive parental feedback and satisfaction survey (100% positive – All parents found this a very beneficial experience and did not have any technical difficulties) evidenced by numerous testimonials
- Staff experience survey – 100% staff identified this as a process to enhance patient experience and demonstrated need for further investment (i.e., more video units to facilitate multiple calls at the same time)
- Technical validation of the solution – IT department ensure reliability and usability

- Frequency of use – monitoring regular use of the facility
- Significant local media interest, also showcase opportunity. Showcase Event to the Chair of the CQC who visited the trust in October.
- This gives a very strong message that our organisation is innovative and committed to our patients care and wellbeing. This has created a great deal of interest from other departments within the organisation who have thoughts and ideas about how technology can help them

Relevance to Others

The system is working well and is firmly embedded in the department. We are now keen to expand this into other services. Currently the Bradford area has a low breast-feeding take-up and the traditional service face to face service is not showing the desired/needed increases. A secure, simple to use video conferencing facility would mean that patients could dial in when they had a problem, or needed some support with breast feeding, which is expected to provide more focussed support to new mothers. Other services have also registered interest into how Technology might support their services. Any enhancement to improve patient experience will be considered.

Whilst a number of pilots using solutions like Skype have been used for other NHS video conferencing applications, the Foundation Trust rejected these because they felt that they were not secure enough. The FT was also looking for a simple solution and the Cisco Jabber solution fully meets this. The secure technology has created much interest from a lot of other services in the organisation and also created media interest from local media. There was high profile interest from the Care Quality Commission Chair who visited the Foundation Trust in October 2016. The solution could be used for remote clinics, supportive outreach clinics such a breast feeding. The use of technologies in supporting patient experience will be included in our engagement vision over the next few years.

Key Learning Points

Understand what the need is and what the solution might be, in this case it was secure useable technology.

Created a project team who are all committed to the end goal, this cannot be about individual achievement. There were challenges along the way which we worked together to solve. For example:

- Identifying an appropriate and user-friendly platform (for parents / clinicians), engaging with necessary supplier
- Information governance and IT security
- Parental support and engagement
- Staff support and engagement
- Multidisciplinary staff involvement and motivation
- Resources particularly finances

The project group was small we worked on short term achievable actions, meeting on a regular basis to keep the momentum. We purposely managed the project ourselves, to prevent creating a level of bureaucracy.

Most importantly keep the focus, there are currently so many other challenges and constraints in the NHS. Seeing first-hand the effect on families and reading the feedback was the best motivator for our team

Noah's Star
Birmingham Women's and Children's NHS Foundation Trust
PENNA 2019
FINALIST - Partnership Working to Improve the Experience

Organisation

We are Birmingham Women's and Children's NHS Foundation Trust – proud to bring together the expertise of Birmingham Children's Hospital and Birmingham Women's Hospital. Our Trust is the first of its type in the UK, formed in February 2017 to drive forward our commitment to providing the highest quality, world-class care that women, children and families want, and deserve. Uniting our hospitals means more seamless care; more investment to make greater advances in our specialist treatment and world-leading neo-natal and foetal work. Importantly, it also gives us a greater voice in shaping the future of family-centred care.

With more than 641,000 visits from patients each year, we are a busy Trust and pride ourselves on the commitment of our 6,000 strong team, which works tirelessly to provide the very best treatment and support to our women, children and families. We are one of only two dedicated women's hospitals in the UK, with the busiest single site maternity unit, delivering more than 8,200 babies a year. We also incorporate children's mental health and wellbeing services offering truly integrated care. We have one of the largest Child and Adolescent Mental Health Services in the country, with a dedicated inpatient Eating Disorder Unit and Acute Assessment Unit for regional referrals of children and young people with the most serious of problems (Tier 4) and our Forward-Thinking Birmingham community mental health service for 0–25-year-olds.

Every day our UK and globally respected surgeons, doctors, nurses, midwives and allied healthcare professionals provide some of the most advanced treatments, complex surgical procedures and cutting-edge research, to improve care today and develop even better care for the future. Home to the country's leading teaching centres, we're passionate about nurturing and developing the skills of our present and future workforce, along with investing in the very best training and education to foster life-long learning.

General Summary

Noah's Star is an initiative to create partnership working between the hospital and an outside organisation in order to create an additional specialist voluntary service to complement the work already being done by the volunteer service within the hospital. Careful collaboration has resulted in clear guidelines and robust checks to ensure the high standard of volunteering is maintained.

To date, Noah's Star has provided over 50 volunteers to play with siblings of babies who are residing on our neonatal unit, this provides parents with an opportunity to give their time and attention to their babies in the knowledge that their older children are being cared for. This has had a big impact on parents, who describe the relief at not having to feel guilty about spending enough time with one or other of their children. This service has expanded in the last 12 months, offering more activities and support and reaching in excess of 700 children.

Rationale

Noah's Star was created by a mother who gave birth to twins whilst already having an older child. Her babies were on our neonatal unit, and she felt her time was torn between her babies and her older child with no existing specialist sibling play provision within the hospital volunteer service.

Sadly, one of her babies, Noah, passed away and she felt strongly that she wanted to create a service in the hospital to help other parents who were juggling time with siblings and tiny babies, so she named the initiative Noah's Star. It provides volunteers to play with siblings of babies in our neonatal unit, in order to give parents, the confidence to spend quality time with their babies, knowing their older children are being well cared for.

Planning

Once the rationale for a service was agreed work was carried out with the neonatal unit, volunteer service and Noah's Star to devise the parameters of the role, paperwork and relevant checks required.

Initially we began recruiting and offering a basic play service within limited time slots.

As numbers increased, the range of activities and time of availability has increased.

Current tasks performed by Noah's Star volunteers:
Sibling support, family support, drinks, beads of courage, holding and comforting babies, provide each family with a book to read to baby, hand and footprint kits, entertainment bags for siblings, family pizza nights, themed sessions, memory making arts and crafts, Easter egg hunts, Santa's grotto, mermaid and pirates party, beach party, Disney PJ party and more! All within BWH at our Children's and Women's Hospitals.

The BWC Trust Volunteering Service supports the infrastructure to ensure that Noah's Star volunteers are compliant with all Trust policies and procedures. There is regular communication to ensure that new volunteers feel welcomed and supported. Staff who work on the Neonatal Unit are also highly supportive and really value the work that Noah's Star do. It makes their roles easier on the ward knowing that siblings can be occupied, entertained and can understand more about their family's situation.

Impact

We now have a team of team of 50 plus volunteers.

We calculate that 3100 hours of support time have been given at BWH NICU (we do also now support Ronald McDonald House and New Cross Hospital, but we record those hours separately).

We calculate that 745 siblings have been looked after by volunteers from Noah's Star at BWH.
A new 'Stay and Play' group started monthly from November 2019 for families who have been discharged – 78 families have attended this so far.

Some quotes from families who have been supported by Noah's Star:

"This is an amazing team helping and supporting me through such a difficult time"

"My little one was only on the NNU for 48 hours, but the kindness of Noah's Star and help was lovely, thank you to the lady who took the first picture of my baby for me and looked after my daughter in the creche"

"Brilliant service"

"Noah's star has been amazing for our 4-year-old during our NICU journey, it really takes the pressure off entertaining a young child at your baby's bedside, I can't recommend or praise the volunteers enough – thank you"

"Kind and reliable people who help and care when needed – you all do an amazing job"

"I never knew such a service existed, but it is invaluable and one I would scream from the rooftops about now - a great asset to the neonatal unit"

Relevance to Others

This has strong relevance to other organisations who wish to involve specialist partner agencies to improve the patient, family or staff experience.

We have a number of specialist partner agencies in our Volunteer Services portfolio, and we are happy to share the ways we have developed working relationships.

It is important to recognise the dedication and value of small charities working to improve the lives of others and this project, Noah's Star, truly demonstrates that.

Standing Out

Vision – this was the vision of one mother who was determined to help others through the story of her own journey.

Dedication – the number of families served, and the expansion of the project demonstrates the needs that existed, that our now being met through a dedicated group of specialist volunteers.

Wider benefits – families often sacrifice their own lives to ensure the best possible outcome for their children. This project demonstrates the needs of the whole family and ensures that sibling's needs are prioritised safely without the family feeling guilty.

Ability to replicate – There must be many more specialist needs across the healthcare system. There are often charities or support groups set up to address the needs of patients. This project encourages a wider scope of the difficulties caused by serious illness.

Key Learning Points

- Scope – Take time to investigate all the issues for setting up a new volunteering project. There will be a lot of paperwork and administration, so don't underestimate all of this.

- Support – Support your partner organisation to understand the perspective of a health provider. Eagerness may mean that potential barriers seem negative and unwelcoming.

- Praise – Ensure you keep in mind the kindness of volunteers wanting to make a difference in their communities. This is so valuable when healthcare is facing so many pressures.

- Share – Help others to access your resources and the processes and plans that made your project a success.

Young Adult Volunteering
Birmingham Women's and Children's NHS Foundation Trust
2019
FINALIST – Strengthening the Foundation

Organisation

We are Birmingham Women's and Children's NHS Foundation Trust – proud to bring together the expertise of Birmingham Children's Hospital and Birmingham Women's Hospital. Our Trust is the first of its type in the UK, formed in February 2017 to drive forward our commitment to providing the highest quality, world-class care that women, children and families want, and deserve. Uniting our hospitals means more seamless care; more investment to make greater advances in our specialist treatment and world-leading neo-natal and foetal work. Importantly, it also gives us a greater voice in shaping the future of family-centred care.

With more than 641,000 visits from patients each year, we are a busy Trust and pride ourselves on the commitment of our 6,000 strong team, which works tirelessly to provide the very best treatment and support to our women, children and families. We are one of only two dedicated women's hospitals in the UK, with the busiest single site maternity unit, delivering more than 8,200 babies a year. We also incorporate children's mental health and wellbeing services offering truly integrated care. We have one of the largest Child and Adolescent Mental Health Services in the country, with a dedicated inpatient Eating Disorder Unit and Acute Assessment Unit for regional referrals of children and young people with the most serious of problems (Tier 4) and our Forward-Thinking Birmingham community mental health service for 0–25-year-olds.

Every day our UK and globally respected surgeons, doctors, nurses, midwives and allied healthcare professionals provide some of the most advanced treatments, complex surgical procedures and cutting-edge research, to improve care today and develop even better care for the future. Home to the country's leading teaching centres, we're passionate about nurturing and developing the skills of our present and future workforce, along with investing in the very best training and education to foster life-long learning.

General Summary

The most complex and ambitious of all our volunteer programmes, the structure of the Young Adult Volunteer (YAV) programme is designed to give volunteers a real insight into the working environment of the NHS, with significant opportunities for personal development.

With a strong focus on widening participation, our YAV programme's strategic aims are to raise participants' aspirations, encouraging greater volunteer diversity and to engender a lifetime commitment to social action.

YAVs undertake 72 hours of volunteering, completing a varied programme of volunteer activities improving the patient and staff experiences. Activities may include Ward/Clinic Support, Welcoming/Wayfinding, project support, administering surveys - depending on their programme and the needs of the Trust and its individual Wards, areas and services. YAVs have been instrumental in growing our capacity for 'core' volunteering services - by adding YAVs into the Welcoming and Wayfinding rotas, we were able to cover 50% of all available hours during 2018/19.

Using this format has impacted our long-term offer bringing increased service resilience through ensuring volunteers have experience of a number of different aspects of the whole hospital's operation. It has ultimately brought volunteer population closer in age to service user population in our Children's Hospital, which is a huge benefit.

Rationale

From before conception to adulthood, children are at the heart of what our Trust does. A decade ago, the Children's Hospital was a pioneer in developing its own Young Person's Advisory Group (YPAG) and in 2017, our 0-25s mental health service, Forward Thinking Birmingham relaunched its own youth advisory panel, Think4Brum. Incorporating a youth strand to our Volunteering Service in response to the #iwill campaign was therefore a natural step for us. Today we are pioneers again in having developed the NHS's first structured volunteering programme for 10-16s alongside an ambitious supportive programme for individual volunteers aged 16-25.

BWC received a generous two-year grant to support the development of youth volunteering from the #iwill Fund.

Based on our previous experiences working with university-aged students, the guiding principle of our six-month Young Adults Volunteering programme for 16-25s was to offer volunteering in short bursts to make it easy for young people to connect with us.

The YAV programme was soft launched early in 2018 by beginning to accept under-18s who were already applying to the Adult Volunteering programme.

The programme's strategic aims are to:

- Raise aspirations among hard-to-reach groups by engaging at least half of all young volunteers from areas of high deprivation within the Birmingham conurbation
- Encourage greater diversity and local representation in the applicant pool for NHS jobs, particularly within our own Trust, by raising awareness of the range of NHS careers and providing Young Adult Volunteers with training and tools that contribute to their personal development
- Encourage a lifetime commitment to social action and volunteering by engaging with young people in a meaningful way at the earliest possible stages and providing follow-on opportunities

Planning

The YAV programme was conceived and recruited key staff members and external colleagues to support its development over two years, enabled by the #iwill Fund grant.

To ensure health and safety, compliance, efficacy and overall good management, we created an internal #iwill Steering Group, involving Heads, Managers and others working in the following clinical and non-clinical areas, with access to other colleagues as necessary.

As the YAV programme has extremely long-term goals, retaining appropriate data for the purpose of attempting to track volunteers was a significant consideration. We wanted to track YAVs to see whether they engaged with us in another capacity, either through further volunteering, YPAG or Aspire; and/or applied for a job in the future. Working with our Information Governance Manager, we drew up a data retention schedule that allows us to retain the minimum amount of personal information needed to identify a YAV moving within our programmes until their 30th birthday.

Ongoing governance for Youth Volunteering is achieved via the same channels as Adult Volunteering: through reports received at Patient Experience Committee and Patient Experience Operations Group meetings. There are also several standing items regarding youth volunteering on the weekly Volunteering Team meeting agenda. Finally, we have maintained an ongoing dialogue with staff and volunteers with the aim of learning and improving through positive comments and constructive criticism.

Two Volunteer Services Coordinators (one per hospital) have supported the increase in volunteer applications and the management of a larger volunteer service, while a Youth Engagement Officer leads on the recruitment to and administration of the programme.

Impact

The well-known patient benefits afforded by individual volunteers of any age include reduced feelings of loneliness, isolation and stress (e.g.: Ward Hosts, Care Cart), increased engagement and well-being (ego: Play, Breastfeeding, Nurturing), and greater levels of comfort and efficiency within the hospital environment (e.g.: Meet and Greet, Wayfinding).

The additional benefits of Young Adult Volunteers, aged 16-25, are that patients can interact with people much closer in age and life experiences to them. YAVs also bring a freshness and enthusiasm to the volunteer force: "He was a great help volunteering to support improvements in the food provided to inpatients at Parkview Clinic [Forward Thinking Birmingham]. … He was really helpful in chatting to the patients and engaged them in a way we would find hard to do, being much older than them." Sodexo Catering Services Manager.

In both years, the YAV programme has been oversubscribed. 102 against a target of 100 at the 9-month mark during year 2.

In August 2019, we recruited our 250th YAV. Young Adult Volunteers have now been integrated into the Service's core offer and form nearly 50% of the volunteer team at BCH.

"The volunteers played with my daughter … I couldn't believe they were 17 and 18.… They were really patient and took time with her. They were super-positive about their volunteering experience, and how it will help

them in the future. … I've been with my daughter 24/7 since we arrived, and I had 5 minutes stress-free to myself while the volunteers played with her…. they are the best volunteers of the ward".
Mother, about YAV Volunteers (aged 17 & 18)

YAVs currently account for around 28% of the total volunteer force at BWC and 46% of the volunteer force at BCH.

Relevance to Others

Although not unique, the YAV programme has been of interest to many trusts due to its potential to change the nature of the Trust's workforce by widening the applicant pool.

In our capacity as a 'Beacon site' for #iwill, we have already shared widely our experiences of setting up the YAV programme with Trusts in our region and further afield. We have made our policies and documents freely available to anyone interested in setting up a similar programme and have circulated our first-year report. We hosted a regional forum for 18 months and plan to invite members to our closing #iwill event in April.

We intend to extend our youth volunteering further at our Women's Hospital and Forward-Thinking Birmingham mental health and wellbeing service. We intend that this will offer more choice to potential volunteers with more options for learning and developing their skills. We are currently planning a training and development programme for all of our Trust volunteers.

Standing Out

Meaningful opportunities for young people have helped to raise the Trust's profile within the sector and among volunteer applicants. An additional and significant benefit, especially with respect to diversifying the applicant pool for Trust jobs, is the enhanced understanding and appreciation of the NHS and its career paths.
"What a shift! The staff were incredible … I heard of a parent that had received some bad news which was difficult to hear but I think in turn that made me realise how amazing the staff are and how much I want to be a part of the NHS. I can't thank you enough for this opportunity it has been phenomenal." Katy (aged 18)

The YAV programme provides a useful tool in workforce preparation and diversification at a time when recruitment is a focal point. For instance, an ongoing exit survey shows the positive impact of volunteering on YAVs' understanding of the world of work, revealing that, after volunteering:

- 62% are more aware of the diversity of careers in the NHS
- 73% are more aware of the personal qualities and skills that would be needed to pursue an NHS career

Through various local and national networks, we are able to liaise with other organisations, NHS Trusts and healthcare providers.

Key Learning Points

- Our overall administrative load is higher due to the rotations. We have learnt from this and in our next phase of development we will reduce rotations from three to two.
- High volume of applications – this needs preparation and strong management. It helps to prepare people in advance.
- Increased level of personal support / development required in a higher proportion of cases than in 18+ adults. This can be mitigated by a strong induction, training and mentoring.
- Coordination of rotations; especially given YAV cohorts' multiple start dates. Term dates, exams, mocks, public holidays and school or college holidays will all affect this. Mitigation can be to organise around the terms.
- Continual staff support and liaison required for the most successful integration of young adults

Some useful statistics:

- Over 35% of our YAVs volunteer because they have a passion for healthcare, but nearly 10% have been a patient and want to give something back.
- Over 87% of the YAVs completing our programme Entry Survey think they might like to work in the NHS.
- 73% of YAVs answering our Exit Survey said being a YAV had made them want to volunteer again.

- Over 22% of Exit survey respondents now want to take their education further than when they started the programme.

Young Carers in Schools Award
Cardiff and Vale University Health Board
PENNA 2019
RUNNER UP – Integration and Continuity of Care

Organisation

Cardiff and Vale University Health Board is one of the largest NHS Organisations in Wales and employs approximately 14,500 staff. The organisation is complex and multifaceted as we care for not only acute patients but also those under Mental Health and Primary Care, as well as tertiary services. The Health Board services the population of and works closely with two local authorities.
Carers Trust South East Wales is the largest charity for carers in Wales, providing practical services for unpaid carers and people with care needs across South East Wales.
In 2011 the national census identified 1,579 young carers within the Cardiff and Vale of Glamorgan, however, it is recognised that this number is an underestimation of the numbers of young carers when compared with other surveys of school children across the UK.

General Summary

Young carers' play a huge part in support provision, but it is estimated that only half have a particular person in school who recognises their role and helps them. Many young carers feel there is a stigma attached to their role, highlighted by 68% reporting having been bullied in school. Therefore, initiates put in place to identify young carers early is beneficial to their educational and future outcomes.
The initiative was commissioned through strong partnership working between Health, Local Authorities, the Third Sector, and based on what our young carers have told us. Through raising awareness of young carers within schools we can support them before they reach crisis, and also educate their fellow students to be more mindful of the challenges they face. Successful outcomes have been an increase in the numbers of young carers identified and full engagement of staff and students. The transferability of this initiative is highlighted through the Carer Friendly Award in Health, Social Care and Third Sector settings, which was developed from this work.

Its sustainable is paramount and supported by its main aim to help not only staff, but also students to understand, inform, identify, listen and support young carers in school.

Rationale

In 2017 Cardiff and Vale Health Board, both Local Authorities and Third Sector representatives met to work together to develop a Carers Strategy to meet the three national priorities set out by Welsh Government:

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

It was identified early on through this work that there was a gap in support for young carers and more needed to be done to increase awareness of these carers and supporting them through their education. Thus, giving them the opportunity to gain the best educational outcomes for their future, and continue their own lives alongside their caring role.

In addition, work had already been undertaken with young carers across Cardiff and the Vale who were surveyed with regards to the services and support they receive. The questions for the survey were developed in partnership with Vale of Glamorgan Council, Cardiff and Vale Youth Services and young carers. Results highlighted that young carers felt there was a lack of awareness of their role as well as a lack of support both with practical issues and issues regarding their health and emotional well-being. Many young carers reported having experience bullying, social isolation and increases emotional and physical demands being placed on them. All of these issues alongside their role as a young carer have huge impacts on education and future opportunities.

Following on from the Carers Strategy work and findings of the report and feedback from young carers a Young Carers Action Plan was developed. This identifying that engaging with school settings was an ideal place to begin to tackle some of the concerns that young carers had. With this in mind the Young Carers in Schools Award project was commissioned. In partnership with Carers Trust South East Wales a pilot of their Young Carers in Schools Award was rolled out in a small number of high schools in both Local Authorities.

The Young Carers in Schools Award, which was developed by Carers Trust and The Children's Society in 2015, The award consists of three stages: the basics, beyond the basics and best practice, with each stage having five standards, which schools will need to achieve and evidence in order to gain the award:

- 1 Understand – Assigned members of staff who will take responsibility for understanding and addressing carers needs.
- 2. Inform – Awareness raising amongst colleagues, sharing knowledge about carers
- 3. Identify – Carers to be identified
- 4. Listen – carers are listened to a, consulted and given time and space to talk.
- 5. Support – Carers are supported and signposted to resources and services.

All evidence is reviewed by a Peer Review Panel made up of young carers. The panel review and discuss the evidence submitted by schools and decide if an application is successful.

Once the pilot phase was completed and evaluated the award was offered to all secondary schools across Cardiff and the Vale of Glamorgan.
Planning
Once commissioned Carers Trust South East Wales employed a full-time School Development Worker to facilitate activity with schools. Firstly, to gather baseline data, via questionnaire, from all the 26 High schools in Cardiff and the Vale. This was to identify how many known young carers they had and the type of support they provided. They also met with young carers service providers such as the YMCA, to discuss current partnership work with the schools and the framework of the Young Carers in Schools Award.

After the baseline data was collected the focus was to work with 8 secondary schools across Cardiff and the Vale of Glamorgan. These schools were asked to identify the best person to be a young carers lead and to meet with the School Development Worker who took them through the first level of the award providing training and tools to help them identify and support young carers in their schools.

Impact

Since it began in 2016 the number of schools participating has increase year on year. In Cardiff 61% of the secondary schools are participating and 75% in the Vale of Glamorgan. The programme has seen a dramatic rise in the numbers of young people identified, in schools as carers, from the baseline audit in 2017.

In addition to date 12 secondary schools across Cardiff and The Vale of Glamorgan have passed The Basics level of the accreditation and 3 have achieved the Beyond The Basics level.

"The work we have put into school has already highlighted four other young carers that are transferring to us in September. We can now put some support in place all ready for them to have a smooth start to 'big school'." Carers Lead, Radyr High School.

The initiative has also given a voice to young carers in their school, many of whom had not previously identified themselves to the school as carers and built their confidence.

"Being part of the panel has given me a newfound confidence in my knowledge as a young carer – so much so that it has pushed me to consider becoming a Young Carers ambassador for my school" Young Carers, Carers Trust South East Wales Carers Panel

Relevance to Others

Partnership working on this initiative allowed us the identify early on, as we understood each other's roles within the carers journey, how beneficial it would be to adapt the Young Carers in Schools Award criteria to be used in other settings such as, care homes, Wards, with social care teams and within third sector organisations. By adapting the criteria for the setting in which it will be used, it has allowed all of the Partner organisations to raise awareness of carers of all ages, increase staff knowledge in a variety of organisations and improve and increase the information which is provided to carers within many aspects of our communities, ultimately supporting carers of all ages to have a life alongside caring.

Standing Out

Strong partnership working between the organisations involved and the young carers themselves has meant that we have developed an initiative that is sustainable and transferable across sectors and ages. This has allowed us and others to reach carers in aspects of their lives we normally wouldn't have been able to. Working in Partnership has allowed us to pool not only our resources but also our experience and expertise to support young carers in a setting that is most relevant to them.

More importantly young carers are at the heart of this initiative they have been involved from the outset from identifying a need for the initiative through to their involvement in assessing and awarding the schools.

Key Learning Points

- Communication: Schools take time or do not responding to emails – to help this this although it can be time consuming, schools were often contacted by phone
- Time: this was a big factor for schools and staff who often didn't have the time to develop awareness raising information, to support this exemplar templates were developed for schools, this included awareness raising posters, presentations to train staff and classroom activity suggestions.
- School inspections: It is important to remember that schools often have inspections and a number of schools involved were undergoing their Estyn inspection. Inspection time is understandably a busy time for staff so this should be factored into any plans.
- Recognise the Work of Schools: It was important to make sure that all the schools were getting the recognition for the work that were undertaking, so it was decided to have four events each year where schools can come along with young carers to receive their awards. The event also helps schools come together and share their achievements and good practice.

Identifying the Unwell Child in the Community Settings
Central Cheshire Integrated Care Partnership
PENNA 2019
FINALIST – Using Insight for Improvement (Other NHS Funded)

Organisation

Central Cheshire Integrated Care Partnership (CCICP) brings together three organisations that aim to transform, develop and deliver community health care services that are focussed on delivering high quality, safe care in the right place at the right time.
CCICP is a unique collaboration between Mid Cheshire Hospitals NHS Foundation Trust (MCHFT), Cheshire and Wirral Partnership NHS Foundation Trust (CWP), and the South Cheshire and Vale Royal GP Alliance, which covers 29 local GP practices. It was first developed in 2016.

More recently, CCICP has aligned its services into different geographical locations creating Care Community Hubs. These have become a central point of contact and allow referrals to be made in a more efficient way.

Paediatric Services form a significant part of the CCICP workforce. The team is made up of:

Paediatric Therapies (Physiotherapy, Occupational Therapy, Speech and Language Therapy)
Special Needs Nursing (Special Needs Nurses within special schools, Children and Young Person's Continuing Care Team)
Advanced Paediatric Nurse Practitioner

Children receive assessment and intervention in a variety of settings, including mainstream and special schools, clinics, Nurseries and Early years settings, and also their own homes.
The Paediatrics Service have strong links with the Local Authorities across Cheshire East and Cheshire West and Chester, enabling some movement towards integrated working.

General Summary

Following a CQC visit in April 2018, it was identified that staff needed to be more skilled in the identification of unwell children within community settings – particularly in regard to the potential symptoms of Sepsis. The Standard Operating Procedure was completed in December 2018 and agreed formally at Integrated Governance. The SOP was developed in line with pathways provided by the UK Sepsis Trust to ensure consistency. There are 3 pathways - <5 years of age, 5-11 years of age, and 12+ years of age.

To launch the SOP, all paediatric staff based in Community settings have received training around the embedded pathways. This training has been delivered by the APNP & Paediatric Service Manager and is scheduled to be delivered on an annual basis. Any Community staff completing visits have received their own thermometer as part of the screening tool and have copies of the pathways to easily refer to, as well as cards to hand out to parents and carers to alert of potential signs and symptoms of sepsis. Staff working within clinic bases have access to an 'Identification of the Unwell child' Clinic Box, which also contain a thermometer and copies of the pathway.

Rationale

Following the CQC visit in April 2018, it was identified that there was not a formal Standard Operating Procedure for identifying Unwell Children in Community settings. The complexity and numbers of children that frontline staff within CCICP are now assessing and treating is continuing to increase, which is subsequently leading to an increased risk of managing children who are unwell and potentially demonstrating signs of sepsis. This is particularly evident in our special schools across South Cheshire and Vale Royal, where the numbers of children and young people accessing these settings is continuing to increase. As the number of pre-term babies born that are now surviving with advancements in medical care, more children and young people are presenting with complex conditions, and as such are at additional risk of becoming unwell in community settings.

The paediatric staff within community settings, work incredibly hard alongside the child/young person and their families to ensure that they can access an education setting and live a normal and independent life as possible.

By creating the Standard Operating Procedure, the service wanted to equip staff with standardised pathways and Point of care testing equipment so that children demonstrating symptoms of being unwell could be identified early and receive the most appropriate care at the right time, rather than families consistently accessing A&E departments when not indicated, or vice versa making sure that they do access emergency care when they do immediately require it.

Sepsis, in particular, has had additional local and national News coverage over the last few years. Public knowledge of this condition is increasing, however there still remains instances where key signs and symptoms are being missed. Although it has been stressed to paediatric community staff that they are evidently not experts in this area, they can add another screening step into the process, and again heighten awareness of potential signs.

Planning

Following identification that a SOP needed to be completed, the APNP, Paediatrics Service Manager and Sepsis Lead for Sepsis met to discuss evidence-based practice and review information that had been researched by the UK Sepsis Trust. The SOP was collectively produced following this and pathways embedded. A case was submitted to demonstrate the importance of staff having thermometers to be able to accurately complete the screening tool, which was ultimately accepted. This led to a significant investment by the Trust of over £10,000.

Community based paediatric Therapy and Nursing staff were identified, and appropriate training dates were organised to roll out the training behind the SOP. Individual thermometers were assigned to staff working independently in community settings away from a clinic base. Alongside the thermometer, staff were given copies of the 3 pathways embedded within the SOP for quick reference, and also signs of sepsis cards to be able to give to parents/carers for reference should urgent care not be immediately required. Within clinic bases across the CCICP footprint, boxes have been created containing a thermometer, copies of the pathways, and additional cards.

Within a 2-month timeframe, all staff had been trained and had relevant equipment in place. The SOP was also shared with GPs locally to advise of processes, and also the local A+E department. Through sharing this best practice, the paediatrics services can screen children with potential signs of sepsis and ensure that they access the correct areas – whether this be in A&E, GP or monitoring with their parents/carers.

Again, we have stressed to paediatric s staff that they are not experts in this area, but the fact that they have been trained to identify potential signs of the unwell child, and have easily accessible pathways to follow, means that they have an increased awareness of when further care may be indicated. They can also play a key role in the education of parents and carers, and signpost to appropriate information and resources should this be required.

Our APNP is now taking a Sepsis Lead position for CCICP and will be linking in with the Acute Trust to ensure that consistent best practice is maintained, and that further training resources could be implemented moving forwards to ensure staff have the most up to date knowledge for their roles.

Impact

One of the most significant impacts of the implementation of the SOP is the confidence that the teams now have in regard to managing children that may potentially present with symptoms of being unwell. Although previously aware of the dangers of Sepsis, specifically in nursing teams, the training and implementation of this SOP, has significantly increased the knowledge and awareness that, particularly therapies, teams have. To be able to provide them with a thermometer as part of the screening tool has further increased confidence.

The paediatrics staff can also play a key role in the education of parents, carers and children/young people by being able to potentially identify the signs of an unwell child. Staff should now be equipped to discuss this with all involved in the child's care, highlight areas of concern, and signpost/refer on as appropriate.

There have been 2 recent patient incidents that have been managed by the paediatric Nursing teams, where potential signs of Sepsis have been identified, and the pathways have been followed to ensure the correct care was given. In both instances, an ambulance has been called, and the children have been taken to A+E for formal assessment. The outcomes for the children in both instances have been positive. They received the assessment and treatment early and did not further deteriorate. The feedback provided to clinicians by Paramedics and Acute Trust staff was extremely positive and demonstrated that the pathways worked effectively.

The larger scale impact on the numbers of children and young people presenting at A&E and out of hours departments still remains unclear, but as a paediatrics service, we appreciate that at this moment in time, the level of impact that we currently intend to have is around increasing awareness of the signs of an unwell child for both staff and also for parents/carers. There is a larger piece of work that is just about to commence around the development of a 'Child Community Hub' in the Cheshire East Place. This will add more focus on avoiding GP appointments and inappropriate hospital admissions, in order to reduce the demand on A&E departments. As this work develops, this pathway will undoubtedly form a solid foundation of what we are trying to do, as the services are aiming to ensure that the community hubs would be the first single point of access for children and their families, who could then be appropriately screened and referred on as appropriate.

Through education of parents and carers by highlighting signs and symptoms of the unwell child, we can also ensure that they are aware of these signs and symptoms in any future instances. This would again promote that the child or young person accesses the right care at the right time.

Relevance to Others

There is potential for this work, including training and documentation, to be shared across different Community services to optimise consistency of the approach. As the 4 Cheshire CCGs have just agreed to merge, this will provide additional potential to be able to share and implement the approach, and also learn from best practice from other areas if appropriate. Early work has commenced with East Cheshire NHS Trust, Cheshire and Wirral Partnership NHS Foundation Trust, and the Countess of Cheshire NHS Trust, to start to share best practice, specifically within therapy. This SOP is easily transferable and can ensure that children and young people are consistently accessing the right care at the right time when needed.

As previously mentioned, it has already been shared with GP representatives and our colleagues at Mid Cheshire NHS Foundation Trust to ensure that we have a consistent approach in the CCICP footprint.

Standing Out

From speaking to the Sepsis lead for CCICP, it would appear that this kind of initiative is rare. Being able to provide staff with information and equipment to recognise signs and symptoms of the deteriorating child ensures rapid access to the appropriate services following early intervention. All evidence base highlights the importance of early intervention and escalation, as well as promoting education of the awareness of the symptoms of sepsis to families.

The buy in from staff, and the understanding of the importance of an initiative like this has significantly contributed to its success. The service has managed to significantly increase awareness and educate staff to a level that they feel able to manage a situation.

As indicated above, the SOP is easily transferable, as it uses the underpinning evidence from the UK Sepsis Trust. As such it can be replicated in different NHS Trusts locally and across the country if there isn't anything in place.

Key Learning Points

- Research the latest evidence

- Gain a baseline understanding of team awareness and where training needs to be targeted
- Invest to save – through being able to provide staff with the appropriate equipment and knowledge, this will ensure that early identification occurs, and that children and their families are directed to the right care at the right time
- Importance of buy in from GPs, Practice Managers – The Clinic boxes are being housed in Community receptions of GP surgeries. It is therefore important that they are aware of the relevance and need for these to be present to allow staff to screen children appropriately.
- Consistent approach between acute and community services

Child Health Hubs
Cheshire East Integrated Care Partnership
PENNA 2020-21
RUNNER UP - Integration and Continuity of Care

Organisation

Cheshire East Integrated Care Partnership (ICP) is an alliance of NHS providers of health and care services who work together to deliver care by agreeing to collaborate rather than compete. These providers include hospitals, community services, mental health services and GPs, as well as social care.
By working together in this joined-up way, we will be able to help local people receive the health and care that is sensitive to their needs, as close to home as possible.
Our approach will be to work through the eight care communities in Cheshire East. The eight are coterminous with the nine Primary Care Networks, with the exception of Crewe, which includes two PCNs.
The ICP is overseen by a board of partner organisations and hosted by Mid Cheshire Hospitals Foundation Trust. The ICP is not a separate organisation, so there is no HQ, no buildings and no full-time staff, it is run as a partnership.
The area covered by the ICP is co-terminus with Cheshire East Council, serving a population of nearly 400,000 people.

The 8 Care Communities:
Care communities are a virtual team of health and care professionals who work together in and near people's homes in partnership with the Primary Care Networks of general practices. They cover populations of 30-50,000 people, though the focus is very much on ensuring care is wrapped around the individual.
Staff are based within their own organisations, though working as a team to support patients. Each has a clinical leader and support from a manager. Some of the care communities have existed longer than others, with each covering its own unique population, which have different demographics and needs. An early priority for the ICP is to develop the four themes highlighted by the Transformation Plan [LINK TO BE ADDED]

The care communities are:
- Bollington, Disley and Poynton (BDP)
- Chelford, Handforth, Alderley Edge and Wilmslow (CHAW)
- Congleton and Holmes Chapel
- Knutsford
- Macclesfield
- Sandbach, Middlewich, Alsager, Scholar Green, Haslington (SMASH)
- Crewe
- Nantwich and Rural

The ICP covers two historically different healthcare systems divided by the M6 motorway. People from the east tend use Macclesfield Hospital and the community services provided there, with those further south using Leighton Hospital and its community services. Social care has also been delivered from east and south bases.
As we look to develop the ICP and care communities to deliver equitable services across Cheshire East, we have highlighted four care themes where we are outliers and could therefore improve services. These are:
- Mental wellbeing and social prescribing
- Children's health
- Cardiovascular health
- Respiratory health

The learning from these target areas will help us develop the ICP and shape who we do things in the future.
Development of the care communities will also include support with:
- Business intelligence
- Project management
- Workforce and organisation development
- IT
- Finance
- Estates

General Summary

The project group were tasked with 2 main targets – develop 2 children's health hubs, and to reduce A+E attendances / GP appointments where these could be managed in other ways. The project is designed around the Imperial Child Health Model, which is centred around developing more effective communication between primary and secondary care through regular MDT sessions and learning opportunities.

Despite the pandemic, we have achieved a significant amount over the last 12 months. We have 2 established child health hubs that are based within Children's Centres in Crewe and Macclesfield. We have successfully implemented Prolonged Jaunice and unsettled infant clinics within the children's centre in Crewe, and also have a paediatrics bloods service operating from Macclesfield, which are completely run by Advanced Paediatric Nurse Practitioners or Community Nursing services. These have all received excellent feedback from parents due to ease of access and location.

MDTs are also starting to be well established between primary and secondary care colleagues. We have to date discussed retrospective referrals but are looking to continue to develop this offer into prospective referrals, as well as specialist MDTs around complex care and CAMHS.

Rationale

Our project has quickly developed the aim of 'Delivering care closer to home through implementing new models of care and adopting a whole system approach to child health'

From a review of the baseline data, we were able to identify that 0-day admissions and A+E attendances for paediatric patients was increasing annually, and the strain on the acute services was continuing to broaden. Through the sharing of success from the Imperial Child Health Model, the 'Improving Me' Programme was setup within the NW Community Hubs network, aiming to provide funding to local areas to develop children's health hubs. The health hubs are intended to increase connections between primary and secondary care and reduce inappropriate referrals into secondary care settings. We are also keen to ensure that parents only tell their story once, and that we can connect services to ensure that the patient journey is as positive as we can possibly make it.

Through moving acute based clinics into community settings, utilising our Advanced Nurse Practitioners, and upscaling our Universal services we believe that we are able to deliver on the key objectives set out above.

Planning

The project group initially started as a small group consisting of a project lead, programme manager and clinical leads. The initial ideas around moving the prolonged jaundice clinic into the community and establishing the Unsettled Infant clinics followed soon after. The project group membership has significantly extended since and is continuing to do so. We now have representation from the following areas:

- -GPs
- -Consultant Paediatricians
- -CAMHS
- -Local Authority colleagues including the children's commissioner
- -CCG
- -0-19 service
- -Care Community coaches
- -Transformation leads
- -Trust executives
- 3rd party sector

We established governance structure within the group and have a clear reporting pathway into both Acute Trusts as part of the ICP, in addition to the ICP Transformation Board. The project has project plans, risk logs (and how we plan to overcome risks), terms of reference that are continuously reviewed, and project group meets on a monthly basis to review progress. We are reviewing the progress of the project using PDSA templates. There are now currently 7 operational workstreams that are operating in the following areas:

- -Prolonged Jaundice
- -Unsettled Infant
- -Integrated care
- -Development of the ANP
- -Obesity
- -Peri-natal mental health
- -Respiratory

We are also relaunching existing services such as the CATCH app which aims to provide Universal information for parents of children under 5.

The success of the project in Year 1 has been underlined by the successful application for funding for Year 2 of the project, and consistent positive feedback from all involved.

Impact

We set out to deliver the right care closer to home, and from the feedback that we have received to date, this is certainly something that has happened. We have seen over 40 children in our unsettled infant clinic since it started in February. These children would previously have either attended A+E or needed to have gone to their GP. We have also seen a similar number of children in the prolonged jaundice clinic, which has received positive feedback in regard to its accessibility and location within the children's centre. There are over 90 children that have accessed the paediatric bloods service in the children's centre in Macclesfield, all of which would have been on a waiting list in the acute trust if it were not for this service. All of these services have received praise from GPs also in regard to ease of access. Feedback from clinicians running the clinics is also extremely positive and has led to improved job satisfaction.

One of the key successes of the project has been bringing together health, Local Authority and 3rd sector workers to share best practice and link services together to ensure that there is no duplication and that parents are truly only having to tell their story once. We have been able to encourage health staff to share information on Universal services that they previously didn't know existed, whilst parents attending clinics at children's centres have started to now access some of the Early years services which are operating out of the same site.

MDT sessions have identified that retrospective referrals have been appropriate but have flagged opportunities for educational sessions to promote shared learning. These are being implemented currently for GP Colleagues.

We have also promoted co-production wherever possible. Parent carer representatives have an invite to attend project board on a monthly basis, and a service user survey was completed in the summer to ensure that we have worked with parents to identify areas for development.

Quotes:

Staff - "I think the environment is perfect for children. It is easy for parents to park their cars; it is a relaxed child and family friendly waiting area. The feedback from parents has been positive."

Parent: "The Children's Centre is a fantastic resource for children having blood tests - it is easy to park, doesn't feel like a hospital, and the staff are amazing. We were in and out really quickly"

Relevance to Others

This project has several key links with other groups and projects, which has been identified through the increasing number of stakeholders that we are recruiting to the project group. We are linking in with CCG workstreams around Smoking in Pregnancy and Obesity in Year 2 and coordinating a joint approach in both areas.

The joint working that we have established with the Local Authority means that we can also share a great deal of work done across Local Authority workstreams also, with the focus more recently being in Early years.

The ICP Transformation Delivery Board that we sit on allows sharing of best practice and highlights with other project leads for different projects. We are able to discuss what strategies have worked well and provide some constructive feedback around areas for development / how to achieve goals.

Groups such as the Maternity Voices Forum, and Parent Carer Forums allow us to widely share the progress with service users and keep them up to date with new developments whilst canvassing opinion.

We are also part of the Connecting care for children forum, which aims to join up best practice and sharing of the Imperial Child Health Model. This allows continuous reflection of where we are in our journey against the marker that we initially set out to achieve.

Standing Out

All stakeholders involved in this project have all commented on its pace, organisation, and most importantly its success. We have managed to achieve a significant amount of progress even during the height of the COVID-19 pandemic, which is testament to all involved, particularly our clinical leads who have been on the 'frontline' throughout. The feedback that we have had from stakeholders involved in the project is extremely positive, and they generally feel that we are making some great strides in improving children's health projections in Cheshire East.

One of the key elements that stands out for us as a project management team, is the truly collaborative nature of the project. We have successfully managed to connect several different NHS trusts, Local authorities and 3rd party sectors together in achieving the same goal of bringing care closer to home for the children and their families. The improved communication and connections between primary and secondary care departments has also been invaluable and will only continue to grow as we provide definitive paediatricians to each care community.

The feedback that we have received from parents and carers in regard to the clinics that have been established has also been excellent. They are consistently pleased to be able to access important appointments at an accessible venue, with excellent parking, a personable clinician, and then have the opportunity to see what other activities are taking place at the Children's Centres.

Key Learning Points

- Have clear Clinical leadership and guidance. We have allowed our clinical leads to provide the suggestions on the areas that could be enhanced initially and supplemented this with service user feedback also.
- Governance structure is key. Methods of escalation up to board levels – both in regard to progress / issues and risk is vital to ensure that a project moves forwards quickly
- 'Thinking differently' – if the COVID-19 pandemic has taught us anything in the NHS, it is that we shouldn't say an immediate 'no sorry that can't be done'. We have tried to think outside the box, join organisations together and connect pockets of work that have been existing in silos.
- Networking- be prepared to have lots of stakeholders, and welcome them into the group – they will help push things forward and connect the work together
- Share resources and knowledge across organisations, remove barriers
- Active reflection and reviewing of new initiatives – PDSA cycle is vital to review and evaluate impact.

Beads of Courage
Cambridgeshire Community Services NHS Trust
PENNA 2016
WINNER - Personalisation of Care, FINALIST - Continuity of Care

General Summary

The Beads of Courage programme was introduced to the UK, from America, through the paediatric oncology units. The beads are a concrete visual representation of each intervention a child has undergone during their treatment, helping them talk about their condition, fears and hopes. As a Community Children's Nursing team, the children and young people (CYP) we support with cancer started to receive the beads supplied to us by the Regional centre.

Mags Hirst, our play specialist, recognised the benefits of this scheme and was passionate about extending it locally to the many children we care for complex and life-limiting illnesses, but who do not have cancer. As the beads are not funded by the NHS, as a team we identified funding streams to ensure sustainability and to ensure local CYP could continue to benefit from these. The Beads provide them with a unique approach to personalising care by working in partnership with CYP and their families, enabling them to understand and talk about the impact of their condition and treatment on their daily lives.

The beads and the story they tell are unique to each child, their siblings and their families. The beads build a picture and a memory for each family that they can keep and reflect on. It gives credibility to their journey in a concrete and understandable way that can be used to explain to a child, when they are older, what had happened to them, or as memory for the family if their child is no longer with them.

We were the first team in the UK to introduce the beads for children and young people with a non- oncology diagnosis, and the celebration annually of the children and their beads is a spectacular, happy, exciting event. With the positive attitude and leadership demonstrated by Mags, a willingness to identify unique elements of each child's journey, and our ability to share a joint, team vision, keeping children and families at the centre of what we all do, we have been able to work together to truly benefit children. These benefits are achieved at the most challenging time in a family's life and through the most painful journeys they will ever have to face, providing a platform for them to express their own, unique stories and paths

Rationale

As a service we aim to provide individualised, compassionate care and believe that the Beads of Courage, in a small way, can give credibility to the child and their family of the challenges they face on an almost daily basis for, what is often, a lifetime.

The Beads of Courage embrace and celebrate each child's unique experience and personal journey with regards to their complex or life limiting condition.

The beads are a physical reminder of each child's personal story; their treatments, every hospital attendance, every visit by a community nurse, every intervention they have to have, and gives CYP the opportunity to build a visual representation of their personal journey, supporting their emotional, social and spiritual needs. The beads also provide a way to open and improve dialogue not only within families but with those around them, such as friends at school and other professionals who may not have the broad understanding of the challenges and achievements each CYP has on their journey

We also provide beads for siblings. These recognise the challenges siblings face with having a brother or sister who is unwell and who is often away from home. They also provide a way to celebrate and acknowledge the support siblings provide as carers and recognise the impact having a child with a life-limiting illness in the family can have on siblings, for example when parents are away from home with the poorly child or miss family and school activities.

Planning

Mags Hirst provided the leadership for introducing this innovation for children with life-limiting illnesses. She contacted the programme lead and explored the use of the beads in a wider context. We were informed that the licence was available for CYP with life-limiting, non-oncological conditions and complex health issues. We then sourced initial funding and became the 1st team in the UK to provide the beads outside the oncology world.

We identified a pilot group of CYP already known to the team, and in partnership with the children and their parents, discussed if this was an innovation they would welcome. The feedback was incredibly positive with universal agreement that this was something to be rolled out and which would benefit their child, as well as the wider family and friends.

Our pilot consisted of 8 CYP and we provided families with Bead diaries to help us understand and evaluate the benefits of the beads in terms of family memories and recall, as well as the costs involved in providing the beads retrospectively to the point of diagnosis. Without exception, each family enrolled on to the pilot programme was able to comprehensively complete their child's diary, one family being able to recall 9 years of complex care.

Through our initial investment, Mags was able to purchase the beads required to commence the pilot and complete these CYP bead collections. Each family has reported back the positive benefits and the therapeutic value of threading the beads alongside their children. The therapeutic value reported included enabling families to remember and talk together about the detail of the treatments received, including the pain experienced and courage shown by the children and the great pride parents had in their child's ability to face these challenges.

Our electronic records incorporate a care plan which highlights the beads programme as an intervention in itself, so that we can ensure all children and their siblings, who are eligible for the beads, are considered for the programme and the beads offered

Impact

The positive impact of the beads cannot be emphasised enough. Children and young people now have a voice that they may not have had previously. They are able to discuss and articulate their own, individual, stories in words and language they understand. The children, and their families, are able to take their unique combination of beads to hospital and clinic appointments and express what has happened to them since they were previously seen.

The impact on professionals has been astounding, most have never contextualised what it means to be a child or young person with a complex or life limiting condition. To see the beads, threaded together, is a very humbling experience for both clinicians and non-clinicians and is a reminder of why we all work in the roles we do and that all of us are working together to ensure positive experiences of health care for our patients or client group.

We wanted to give the CYP a voice, a way of talking through their experiences, fears and successes. We have evidence of a young girl who was selectively mute, as a result of her fears and worries due to her ill health. Using her beads as a platform to speak, she was able to explain to people what scared her and what she has endured and earlier this year she was supported by Mags to stand up in school assembly and talk about her journey.

We are measuring the beads in terms of cost and report 1/4ly on this to our financial team and donors, to ensure effective and appropriate use and ongoing sustainability of the beads.

The greatest measurement we have is qualitative from the feedback and engagement from the children and their families both in terms of engagement with the initiative, a positive expectation that the children will receive their beads from the nurses who visit them, the accumulation of retrospective beads for interventions by professionals outside of the team and increasing attendance at our annual tea party for children and families where we celebrate the immense courage and bravery the show each day.

Key Learning Points

- Be open and honest when discussing the purpose of the beads with families and children before they start on the initiative
- The reflection needed can be painful for families and this needs to be supported
- The ongoing funding needs to be considered as this needs to be sustainable, families and children will discuss and compare, so there needs to be equal access
- Storage, you will need lots of storage!

Children's Key Worker Service Evaluation Project
CLIC Sargent
PENNA 2015
FINALIST – Bringing Patient Experience Closer to Home

Organisation

CLIC Sargent is the UK's leading cancer charity for children and young people. The charity provides clinical, emotional, practical and financial support for children and young people with cancer and their families, so they can cope with their cancer diagnosis and get the most out of life. In 2014-2015 CLIC Sargent:- supported over 6,800 young cancer patients- had an income of £25.04 million CLIC Sargent employs approx. 530 staff (including social care staff, nurses, fundraisers and central support staff) that are based in over 60 paediatric principle treatment centres, teenage and young adult principle treatment centre, shared care hospitals, homes from home and offices across the England, Scotland, Wales and Northern Ireland.

General Summary

Childhood cancer care exists in a complex environment, involving chemotherapy, surgery, radiotherapy, radiological assessments, and support therapies. In the hospital alone families meet a multitude of healthcare staff. Treatment and follow-up last many years across Principal Treatment Centres, Shared Care Hospitals, Community Services, home and school life, impacting on every family member. It turns family's upside down and they feel overwhelmed. CLIC Sargent's (2009) More than My Illness report and NICE (2005) Improving outcomes guidance for children & young people with cancer highlighted the need for better coordination of care, suggesting a key worker approach. Little evidence existed for such roles and limited understanding of how best to deliver this style of working to maximise outcomes and improve experience. The project aimed to help the NHS understand and test this approach. It was independently evaluated by London South Bank University. Findings demonstrate that, when the model works well, it can reduce stress for families and facilitate care closer to home. It can improve communication and partnership working with families and between healthcare workers, social workers and teachers to provide efficient and appropriate care. The evaluation also identified what makes the role more challenging and offers learning to maximise best practice.

Rationale

The CLIC Sargent (2009) More than my illness report and NICE (2005) Improving Outcomes Guidance recommended that cancer services for children and young people should have processes in place to ensure effective coordination between professionals and organisations involved. Care should be integrated and coordinated throughout the patient's cancer journey: working in partnership across primary, secondary and tertiary care settings, across statutory and voluntary sectors, and across health and social care settings. The key worker role was identified to provide this service and meet this recommendation. The key worker is defined by NICE as, 'A person who, with the patient's consent and agreement, takes a role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice'. Despite the recommendations, little evidence existed on service user outcomes using the key worker model of care. The project aimed to support key workers funded in the project to work in partnership with the family on assessment and care planning, coordinating and navigating services, having access to specialist cancer nursing support and information, and empowering the child and family. The approach was independently evaluated by the London South Bank University Team, funded by National Cancer Action Team in England and CLIC Sargent in Wales and Scotland, against service user outcomes and experience, and aimed to inform best practice in partnership working.

Planning

CLIC Sargent funded 21 specialist nurse key workers across all Principal Treatment Centres in England, Scotland and Wales between October 2011 and March 2015 (18 had a patient caseload and 3 were educator posts). Funds were raised by a partnership with Tesco Charity of the Year in 2010, to test what impact the key worker role could have on young cancer patients and their families. Key Workers were employed by the NHS and supported 3,556 children with cancer, 0-18 years, over the three years across the UK. CLIC Sargent managed the project and supported nurses through study days, newsletters, facilitated networking, and contract meetings. Project management aimed to enable nurses to share good practice and identify and problem solve challenges. The evaluation of the specialist nurse key worker role aimed to evidence whether:- there is an improvement in patient and family experience as a result of nursing key worker support- children and their families have improved emotional wellbeing as a result of nursing key worker support- children are better able to participate in education, employment and training as a result of nursing key worker support- children and their families are better able to spend more time safely at home during treatment as a result of nursing key worker support- obstacles could be identified in providing care closer to home that may or may not be overcome by the key worker role alone- best practice and learning have been adopted by other practitioners within local teams

Impact

18 specialist nurse key workers, 3 nurse educators, 95 parents, 85 stakeholders (e.g., community nurses, social workers, GPs, teachers) and 10 children contributed to the evaluation. Evaluation data were collected between 2011 and 2014. Key workers were interviewed at two points in time, and some took part in a focus group (n=12). Parents from all the sites completed the questionnaire and 23 took part in an individual interview, 4 children took part in an interview and 6 in a focus group. Bereaved parents only took part in an individual interview and were not asked to complete questionnaires (n=8). Stakeholders from all the sites filled in a questionnaire. A mixed methods approach was used to illustrate how the role developed. Data included analysis of annual reports and quantitative quarterly data collection recording the support given to 3,566 children. The published evaluation found that 69.7% of parents questioned who had a key worker had an improved peace of mind, with 55.8% feeling less stressed. Through working in partnership with parents the key worker model was felt to “decrease parents’ feelings of isolation and increased their confidence to care for their child.” Children felt “less scared” and valued support with return to school. Overall the report demonstrates that the specialist key worker role can and (when it works well) does achieve the following outcomes; - Improvement in the child’s and family’s experience of their care and treatment- Families are able to spend more time at home, and children with cancer can be cared for closer to home- Improved emotional wellbeing- Children/young people are better able to participate in education- Best practice and learning is adopted by local hospital teams For key working to work well three pillars have to be in place: knowledge, relationship and coordination. Knowledge: the key worker being a specialist nurse with knowledge, experience and expertise in childhood cancer and services available led to a higher standard of care, and helped families have the confidence to care for their child at home. Relationships: the relationship between the key worker and the family over a period of time enabled trust to grow; families felt like they were supported by someone who knew them as a family. In addition, the relationships between key worker and staff in different services improved understanding of roles and fostered partnerships in which coordination could thrive. Coordination: the key worker worked effectively with a range of hospital and community professionals, coordinating children’s care and supporting them to live as normal a life as possible. They were seen by parents as a reliable, consistent, approachable source of support. When these three pillars are in place and the role is embedded in the children’s cancer multi-disciplinary team, and is understood and supported, the key worker can make a better contribution to achieving these outcomes for children with cancer and families.

Relevance to Others

The structure and methodologies outlined in this projected provide learning for other charities to evaluate the models of care and opportunities for partnerships and collaborations to maximise project outcomes. The successful project structure validated questionnaires and data collection tool utilised in this project mean there is scope for this project to be replicated. This could be within children’s cancer services to explore how the model has been sustained or adapted over time. There is also scope to replicate with other disease groups or for different age ranges, e.g., Teenage and Young Adult Cancer services. Such studies would add to the evidence base and enable comparisons or contrasting findings to be identified for different groups. The project was UK wide and included posts from all Principal Treatment Centres (with the exception of Northern Ireland). Aside from replicating over time or in other ages, the model and evaluation structure could be used to evaluate similar services in other countries.

Standing Out

Benefits for children with cancer and their families through partnership with families and coordinating partnerships across settings and agencies: The evaluation report demonstrates that specialist cancer nurses using the key worker model of care can help families of a child with cancer to manage the complex environment they find themselves in during treatment. It also supports survivors of childhood cancer make the right life and health choices by providing clear signposting, information about re-accessing services, knowledge of their journey so far, support though transition and into follow up care. For bereaved families there was a clear indication that the coordination, relationship and knowledge pillars were vital to families having everything set up for care in a location of their choice. Families valued honesty and trust and was perceived by parents to enable individualised support. The key worker approach facilitates resilience in families; by providing them with the right support at the right time, partnership working and scaffolding information over time. Benefits for the NHS and wider children's cancer community: The evaluation provides evidence that NHS managers and commissioners can use to further develop the specialist nurse key worker model in their area, providing the evidence base for improved patient experience.

Key Learning Points

In addition to the learning from the evaluation itself, the value of partnership working is a key learning point for anyone doing something similar. The whole project epitomises collaboration and partnership; - between the NHS, university researchers and the charity sector to drive change and gather evidence- between the charity, commercial or corporate sponsors and NHS bodies to raise funds for innovation and evaluation. - between specialist nurses, children, families and other care providers to deliver quality outcomes- across health, social care and education to ensure a comprehensive and holistic impact on patient experience. Other learning includes the importance of structured project management processes particularly when working to timelines across multiple NHS sites and with partners.

Me First: Children and Young People Centred Communication
Common Room in Partnership with Great Ormond Street Hospital for Children
PENNA 2015
RUNNER UP - Communicating Effectively with Patients and Families, WINNER - Personalisation of Care, OVERALL WINNER

Organisation

Common Room is a consultancy led by people with lived experience. We promote collaborative practice and turn children and young people's lived experience into person-centred service, policy and practice improvements across disability, health and mental health. Common Room has a small team of three, including the Director, as well as a team of 8 paid young advisors who have lived experience of disability, long term health conditions or mental health issues who work in partnership with us to co-develop and co-deliver our projects and work streams.

Our work aims to:

- Find the best ways of involving children and young people in decisions about their lives, treatment, support and services
- Find the best ways of responding to and supporting children and young people with the issues they experience.
- Support young people to be partners in research, policy, and service improvement programmes
- Research and understand the views and lived experience of young people, families, and practitioners about the issues that affect them.

Common Room works in partnership with or is commissioned by a number of leading organisations including the Anna Freud Centre, National Children's Bureau, Great Ormond Street Hospital, NHS England, Council for Disabled Children, Child Outcomes Research Consortium, amongst others.

General Summary

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

Me first is an innovative education package to improve communication between children, young people (CYP) and healthcare professionals. *Me first* aims to improve health outcomes for CYP by enhancing the knowledge, skills and confidence of healthcare professionals (HCP) in communicating with CYP. Crucially, all of the resources have been co-developed with CYP and have a strong evidence base in research. The centrepiece of the project is the *Me first* CYP centred communication model – the first designed specifically for and with CYP.

The *Me first* masterclasses and mefirst.org.uk help HCPs to build on their existing expertise and apply the *Me first* communication model to their clinical practice. Co-delivered with young people, the masterclasses use quality improvement techniques to ensure the learning makes a lasting impact on practice. The emerging findings from our independent evaluation are showing a lasting impact on the communication skills of participants. A core aim of *Me first* is to ensure that the model, resources and learning apply to and can be adopted by all healthcare areas and services. We are determined to transcend organisational boundaries and develop education resources that make a difference to professional practice and to the experience of children and young people across the UK.

Rationale

'I should be the one involved in decisions because it's my body'

'When they talk to my parents, it feels like they're the one with the condition, not me.'

Improving communication and decision making in healthcare is an issue consistently highlighted by CYP as a priority. 43% 12-15 years olds said they were not involved in decisions about their care, with CYP with long term conditions more likely to have poor experiences of communication, including not feeling listened too. The

HEE mandate is clear that improved training in communicating and involving children and young people in decisions about their care has a significant part to play in improving their health. *Me first* seeks to improve health outcomes for children and young people through the delivery of an education programme and resources designed to enhance the knowledge, skills and confidence of healthcare professionals in relation to communicating with children and young people. The primary audience for *Me first* is healthcare professionals and healthcare support workers working in predominantly adult settings, who will come into contact with children and young people in the course of their work. However, we have learnt from the pilot phase that members of the children's healthcare workforce have also found the resources useful in their own practice, in addition to supporting the development of good communication practice with trainee healthcare professionals or non-paediatric colleagues.

Planning

Partnership working has been the foundation of *Me first*. Funded by Health Education North Central and East London (HENCEL), Me first has been developed by Common Room and Great Ormond Street Hospital with the support of Birmingham Children's Hospital Young Peoples Advisory Group (YPAG), East & North Hertfordshire NHS Trust, Dr Cathy Street & Associates, Evidence Based Practice Unit (UCL and the Anna Freud Centre), and Nutshell Communications. Following a review of the research, we held a national stakeholder event and also undertook extensive interviews with professionals experienced at working with CYP from a range of backgrounds, and with CYP with experience of healthcare, in order to gather evidence and top tips for use in practice and to ensure the project was informed by and worked across disciplines.

We worked with a team of young advisors to synthesize this and co-develop the full range of resources, including:

- The *Me first* communication model, which provides a practical framework to support children and young people-centred conversations in healthcare. We believe this is the first healthcare communication model of its kind, designed for and with children and young people.
- The *Me first* website (mefirst.org.uk) contains an interactive communication model to enable healthcare professionals to build their own conversations and apply the model to their practice; a resource hub, which enables users to share tools, projects, and ideas from throughout the UK; and practical advice and tips from children, young people, and healthcare professionals about how to put the model into practice.
- The *Me first* masterclasses, which are co-delivered with young people and support healthcare professionals to apply the *Me first* communication model to their practice. The training builds on attendees existing skills and expertise and utilises quality improvement techniques to enable healthcare staff to embed learning in their clinical practice. The resources were developed and piloted, before being rolled out nationally in 2015.

Impact

The *Me first* project has been hugely successful. In 10 months, we have trained over 200 healthcare professionals, with 100% of participants rating the training and resources as good or excellent. The *Me first* masterclasses have been independently evaluated by the Evidence Based Practice Unit (Anna Freud Centre and UCL), with emerging findings showing improvements in professionals exploratory listening, consensus-oriented listening and receptive listening after the masterclass. All of the professionals interviewed are now using what they learnt in their practice to make care more collaborative and younger person centred.

Attendees of the masterclass have said:

'The training has inspired me to make changes to my own practice and the department I work in.'

'Excellent course. Very useful having all different professionals present to get a variety of perspectives and ideas.'
'The day was engaging and creative, with a mix of different activities and time for reflection. We not only learnt the principles of CYP centred communication but how to apply them within our own specialities and practices. A rare and much needed course, I would highly recommend this to any professional working with CYP.'

Comments on our twitter #CYPMefirst include:

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

‘Just wanted to say I love everything about *Me First* it’s exactly what we need! Go team *Me first*!’ Young Person

Relevance to Others

Improving communication and decision-making with children and young people has significant benefits across healthcare, including reducing fear, anxiety, and resistance, increasing adherence to treatment, and improving health outcomes. Thus, from the outset, the aim has been to develop a model and resources that can support CYP-centred communication across the full range of healthcare roles, professions, and services

To achieve this, we have:

- Developed the communication model, training, and resources based on extensive interviews with practitioners across a wide range of healthcare professions and services to ensure applicability and acceptability.
- Resource section and website are free and promoted nationally to ensure they are widely accessible to healthcare professionals across England. Submitting funding bids for two impact studies in partnership with other organisations to explore and evidence the impact of *Me first*.
- Seeking endorsement from Royal Colleges to increase the perceived relevance of *Me first* for specific professional groups.

National Young Peoples Forums - Advisory Group Meet Up
Great Ormond Street Hospital
PENNA 2017
FINALIST - Partnership Working to Improve the Experience

Organisation

The Great Ormond Street Hospital's Young People's Forum is a group of current, ex and siblings of patients who are aged 10 to 21. We have over 67 members currently, which is exceptionally good for a tertiary national hospital. Our member who travels the furthest comes from Newcastle! The YPF have a strong voice in helping to improve the experiences of teenage patients who are treated by GOSH. They get to voice their opinions and make suggestions on a range of topics and issues. They use their own experiences to guide and support the Hospital. They meet 6 times a year to discuss what they think the hospital should be taking action on, what the hospital is doing well, and get updates on how their views and opinions have impacted care and services. Meetings are as much about us learning new skills as well as facts and information about the hospital. Key projects include making improvements to catering and making sure there are adolescent spaces in the new buildings.

General Summary

This application is to recognise the National Young People's Forums/Advisory Group Meet Up event which was held on the 14.10.17.The event was organised by young people, for young people, with the help of the Great Ormond Street Hospital (GOSH) Patient Experience team, more than 80 young people (150 with adults) came together on Saturday 14 October to discuss the big issues surrounding their health and hospital care. The morning kicked off with laughter at a Q&A session with comedian and ex-GOSH patient Alex Brooker. Alex shared positive memories of his time at GOSH and told young people that they play an important part in their healthcare, and if they stay quiet, they won't be able to have an impact. At the next session, young people were divided into groups, which mixed up ages and youth forums, for a 'share and steal' activity. Patients shared their 'Our first ever Big Youth Forum Meet Up' thoughts on the rights of children and young people in healthcare, practical issues for children and young people in hospital and emotions of children and young people in hospital. At the end of the day, attendees chose a workshop to participate in. They could choose from a tour of GOSH, first aid and CPR training, a course on advocating for themselves, public speaking skills and more. To close the first ever Big Youth Forum, Meet Up, everyone voted on the issue to be taken forward by the NHS Youth Forum. They decided that everyday mental wellbeing should be everyone's responsibility and that communication should be a two-way conversation amongst equals. For more of the day search #NHSCYPMeetUp on twitter. Why does this event deserve recognition?-It was the first time, in this format that all the National Young People's Forums/Advisory Groups across the country have met up.-It was the first time a number of representatives of all youth forums had met in one place and voted on issues which came out of their discussions to work out what the big issues are facing children and young people in healthcare.-The event was planned by young people, every couple of weeks from April up until the day there were conference calls to decide on the agenda, who to invite etc.-Even the event logo was chosen by young people as a brand company came up with a number of ideas, these were sent to forums across the country and they chose their favourite theme

Rationale

The YPF have wanted to bring all forums across the UK together to learn from each other and share and steal ideas, e.g., what good campaigns have other hospitals run on catering – can we borrow some of their materials or tactics? To hold an event like this funding was needed, so after years of hoping, a new Patient Experience Team lead at the Trust put together a funding application and a grant was awarded from the GOSH Charity. Our moto in the GOSH Patient Experience Team was that not one size feedback method fits all and whilst there are national surveys and an NHS England youth forum (20) people, there is not a mass event where all who want to come and share their ideas on healthcare can congregate – so we made one! This means our vote on what is the most important issue to you as young people were interesting as the young people had free reign, there were no set questions from the Care Quality Commission or anyone else. Although the YPF is not a support group, there is an unintended side effect that young people find comfort in meeting those who have for example missed their first school trip or have a rare condition. So, bringing a number of young people who have/have been through similar situations was another reason for the day.

Planning

As stated above the event was planned by young people, every couple of weeks from April up until the day there were conference calls to decide on the agenda, who to invite etc. Young people were led by staff on suggesting what decisions should be made but the young people made the decisions after being given facts e.g., we have X money are we going to spend it on food or party bags. Even the event logo was chosen by young people as a brand company came up with a number of ideas, these were sent to forums across the country, and they chose their favourite theme. Support was given from the-Patient Experience Team-Charity Team-Volunteer Team-Catering Team-IT Team-Art Team

Impact

The young people produced a portfolio of all the ideas/campaigns from around the country and shared their challenges and successes. The young people identified that there were 2 key themes for young people in hospital that needed to be focussed on: everyday mental wellbeing should be everyone's responsibility and that communication with clinicians and hospital staff should be a two-way conversation amongst equals. It was determined that these would be communicated to the NHS Youth Forum for further follow-up.

Relevance to Others

The experience of running the event and the results gained will influence young people's care in the future.

Standing Out

This was the 1st national Young People's Forum meeting, bringing together young people from all over the UK to share their experiences. The involvement of the experienced team at GOSH meant the young people were able to focus on contributing to the event.

Key Learning Points

Starting early-there was a considerable amount of liaising that had to be done. Ensuring information is held regarding allergies etc for all young people and is accessible to a number of people.

Hetty's Hospital
Global Initiative
PENNA 2017
WINNER - Communicating Effectively with Patients and Families

Organisation

Global Initiative is a digital agency in the heart of Oxford. Founded in 1999, it is directed by Gareth Nixon and Chris Sinclair and now comprises 14 staff. Specialising in start-up and enterprise software, Global Initiative supports various projects through its Initiative 100k Fund for those that will have a positive social impact.

More information about the fund:
https://www.global-initiative.com/article/100ksocial-digital-support-fund-launched/

Hetty's Hospital was conceived by two paediatricians, Drs Ria Evans and Rebecca Duncombe. They won runner-up in the TVWLA 2023 Challenge. The project was awarded funding to complete a releasable trial version of the app. Global Initiative translated and developed the idea into an app for tablets and mobiles. They also funded half of the project through their Initiative £100k Fund for socially impactful digital projects.

General Summary

Hetty's Hospital began as a solution to the turmoil that any parent taking their child into hospital faces: how can we reduce the anxiety for our children going into hospital and make the experience as worry-free as possible? The solution is the brainchild of two paediatricians: a storybook app with games teaching kids all about the hospital experience. Through the narrative of the eponymous Hetty and her three friends, the app mixes key, informative messages with wacky, mess-galore games such as the sick-bucket and wee-in-the-pot games. As graphic as these games might seem to grown-ups, it was demonstrated as the most effective way of captivating our target audience. The app, which is freely available on iTunes and Play Store, has received nearly 1,000 downloads in the time since release. Designed to be played before or during a child's hospital visit, allowing for unscheduled appointments and parental involvement. The team has been approached by other organisations to contribute ideas and funding for new stories. It is optimised for tablets but works on smartphones.

https://play.google.com/store/apps/detailsid=air.com.globalinitiative.HettysHospital&hl=en_GB
https://itunes.apple.com/gb/app/hettys-hospital/id1082996251?mt=8

Rationale

Hospital can be an intimidating experience for many adults, but, for children – despite the best efforts of parents and dedicated staff – the idea of going into hospital can be fraught with anxiety. Paediatricians Dr Becky Duncombe and Dr Ria Evans realised that there was a genuine need for something that could reduce the stress of children going into hospital and, if well executed, could actually make the experience enjoyable. The format of a downloadable app was chosen for accessibility; Becky and Ria were determined to make something that could be freely available in order to meet the overall ambition that every child in the UK going into hospital could benefit from playing Hetty's Hospital. Becky and Ria came to Global Initiative after receiving funding from the NHS 2023 Challenge, but we soon realised the budget was still a long way short from what it needed to be to create anything that would do the idea justice. Because we were so instantly inspired by the project and already felt such affinity with what the doctors were trying to achieve, we decided to sponsor the project ourselves with Global Initiative's dedicated £100K Initiative Fund.

Planning

Working directly with Rebecca and Ria from the very beginning, a dedicated team at GI began to evolve the concept of the project, iterating and refining the idea and characters until there was a viable solution that could satisfy the team's aspirations. The next stage of planning was the creation of storyboards which would map out the entire experience of the app from start to finish and provide a foundation for the rest of the team to work from. The storyboarding process was led by GI's Head of Design Niki Forecast, who, as well as leading the creative throughout the project, also makes a cameo appearance as the voice of Nurse Ethel – as do many of the team involved. The team at GI also consisted of Gareth Nixon who helped conceive and lead the building of the app and was also responsible for the development of the game technology.

Chris Sinclair led the project delivery and Ben Walton was responsible for the fantastic animations that bring the app to life. The app was launched on the iOS App Store and Android Play Store in October 2017, and, although this was a momentous occasion for everyone involved, this is very much just the beginning for Hetty. With funding for Phase 2 secured from UCLH, we are already underway creating dedicated storylines for cancer, diabetes, allergies, and dentistry.

Impact

We've included results from a feedback survey that was sent to a focus group of 20 children to test Hetty's Hospital. As you will see, the results were compelling: with 80% of the group saying they had learnt something from the app and 90% of them saying they had either enjoyed or really enjoyed playing it. The launch was timed to coincide with National Play in Hospital Week 2017. The reaction was exciting; the first social media post was shared almost 400 times. The app was posted by parents and doctors alike in relevant forums and social media channels. The app reached 3rd place on the iTunes store for medical apps in the UK and ITV Meridian has approached us to further publicise Hetty's Hospital. Users not only feel the results of the app are helpful and supportive but are spreading the word.

This popularity also translates into downloads, with nearly 1000 downloads on the iOS App Store and Play Store combined in the short time since its release. It is worth considering that up until now, the majority of marketing surrounding it has been via word of mouth – we are very excited at the prospect of what more publicity could bring in the new year.

The first phase of the app covers some common procedures for kids in hospitals including an ultrasound, an X-Ray, and an MRI scan. However, we soon realised the enormous potential of the app for helping kids with far more chronic illnesses, things that are incredibly difficult to talk about.

After securing funding for the second phase of Hetty's Hospital from UCLH, we've already started work on four new storylines, including a child with diabetes and a child with cancer. We want the app to have as much resonance as possible and believe it could be the best solution for explaining some these difficult topics for children suffering from such life changing diseases. Our four new characters are:

- Nimesh – he suffers from severe allergies and his story explains the various symptoms, diagnosis methods and treatments available.
- Cassia – she has a form of cancer and helps explain the basics of the disease and how it can be fought. She also introduces all the different people involved in her treatment and recovery, from doctors to nurses, psychiatrists and family.
- Leo – is diabetic. Like the others, he explains the condition, the options for treatment, how to recognise the symptoms and the people there to help.
- Petra – dentistry. This story will concentrate on processes and procedures, much like the original stories, rather than condition. Helping to explain to children what to expect for standard visits and common procedures at the dentist can greatly reduce the anxiety a child, and their parent, will feel.

With regards to longer-term sustainability we, Becky, Ria and Global Initiative, plan to incorporate Hetty's Hospital into a limited company, which will make it easier and more manageable to fund. Our desire is very much to keep Hetty's Hospital as accessible as possible, and we have a real sense of responsibility in ensuring the project's longevity.

Relevance to Others

In order to market Hetty's Hospital, the launch onto the App Store coincided with National Play in Hospital Week and saw the team travel down to promote it at UCLH alongside other Play in Hospital initiatives. We've created business cards with the details of the app that have been handed out far and wide and Hetty's Hospital posters have also been scattered across Doctors' surgery waiting rooms throughout Oxfordshire.

Hetty is active on Twitter and Facebook and is becoming quite the sensation on Instagram.

- https://www. Facebook. com/ExploringHettysHospital/

- https://twitter. com/hettyshospital
- https://www. Instagram. com/hettyshospital/

Anyone involved with health care that has come across a problem and has a great idea for a solution but isn't sure what to do next can find inspiration in this project. The process that Dr Duncombe and Dr Evans went through – applying for funding from NHS 2023 Challenge, securing further funding from Global Initiative, and, most importantly, seeing the project through to the end – proves what can be done with tenacity and determination. Not only do we hope the project itself helps children across the UK, we also feel it holds enormous value in paving the way for similar initiatives. With regard to the project itself, we've received feedback that this would be a great platform for explaining issues to people with special needs, and even dementia. This is something we'd love to develop further, so we're excited and positive for the future of the project.

Standing Out

What makes Hetty's Hospital stand out is the incredibly positive sentiment that surrounds the project: from those that have worked on it, the medical professionals that are shouting about it, to the users that are playing it. The app is quirky and genuinely fun to play. What captivates people, however, is the enormity of the problem that it is trying to solve: every parent trying to console their young child before going into hospital or during a visit can appreciate the value that this app can have at making a hospital visit a little less daunting. The excitement around the project has been overwhelming, with so many new ideas about what it could do next. Besides developing more storylines to cover more medical conditions, the real potential lies in its ability to explain difficult topics to such a young audience.

Key Learning Points

The learning outcomes from the project I would highlight as follows:

- Test early and test well: We were very lucky to have direct access to an army of testers from the target audience via family members. The insights and misconceptions that they highlighted so early on in the project were invaluable and meant significant usability issues could be addressed before they became expensive to fix later on.
- User Experience: Despite our constant testing throughout the project, the ability for users to discover and feedback on better ways to interact was crucial. In the future, we'd recommend allowing for more time and budget to address finding and solving user experience issues earlier.
- Marketing: This is often the forgotten link for innovators and start-ups. Finding funding to invest in marketing is a far more difficult task than finding funding to invest in the building of the app itself. Again, allowing more time and budget for this I think would be a good learning point for any future projects like this.

Voice of Young People in Secure Mental Health Unit Helps to Shape Changes in Service
Healthwatch Essex
PENNA 2019
FINALIST – Engaging & Championing the Public

Organisation

Healthwatch Essex is an independent charity representing the voice of the people of Essex and their views in relation to health and social care. We gather and represent lived experience and use our findings to help shape health and care services in the county.
Our work covers all areas of health and social care. We undertake high-quality research and engagement to uncover lived experience of services. We also run an Information Service through which you can find out about services available in your area. We are based in Earls Colne in Essex and employ 10 full-time staff and 2 part-time staff.

General Summary

The SWEET! project (SWEET! stands for Services We Experience in Essex Today) was designed by Healthwatch Essex to engage with seldom-heard young people in Essex in order to understand their lived experience, their health and social care priorities, and their ideas and suggestions on how services could be improved.

Services are frequently commissioned or redesigned without feedback from young people, based on an assumption that they do not understand or use them. The SWEET!3 Report was the third in a trilogy of reports which allowed us to capture the voice and experience of young people who have not traditionally been heard in the creation of services, policies and strategies which fundamentally affect their daily lives.

SWEET!3 focussed on the experiences of young people living in a secure inpatient mental health unit in Essex. It is, to our knowledge, the first study of its kind in the county and our report provides powerful and compelling recommendations to commissioners and providers.

Rationale

Since 2014, Healthwatch Essex has gathered the health and social care lived experience of young people in Essex through the YEAH! and SWEET! projects. The SWEET! project has focussed on accessing the voices of seldom-heard groups who are not always engaged through traditional consultation platforms. We know that young people from these groups often have a poorer experience of the health and care services they use and therefore their lived experience is key to improving existing services or creating new ones.

To date, all projects Healthwatch Essex has undertaken with young people have identified a need in relation to mental health, so a targeted piece of work with young people with the highest need was a logical next step in our work.

Young people’s mental health has remained a local and national priority. Existing patient feedback in Essex has been conducted in mainstream education or community mental health services (such as CAMHS/EWMHS). Feedback tends to be gathered around specific services and is often carried out by service providers themselves to evaluate their own service.

The voices of young people accessing specialised mental health care in hospital settings are rarely heard, but most young people in these facilities have experienced a range of services and have often reached crisis on multiple occasions. Their experiences are therefore valuable in understanding how mental health services at all levels support young people, work together, and highlight where there are gaps. Both national (Future in Mind) and local (Open Up, Reach Out) guidelines place an emphasis on the need for effective early intervention and prevention. In particular, Healthwatch Essex wanted to understand how patients in a secure mental health facility felt their hospitalisation could have been prevented.

As commissioned Essex services such as EWMHS (The Emotional Wellbeing and Mental Health Service) and Reprezent mature into their contracts, this feedback would be timely in highlighting how mental health services are currently working and where there could be improvements.

Planning

Healthwatch Essex partnered with Poplar Adolescent Unit Education Centre, based in Rochford Community Hospital to carry out this work. While young people who are experiencing, or recovering from, severe mental illness clearly require a sensitive and responsible approach to discussing their experiences, this does not exclude them from safely participating in conversations about improving the services they use, or relating their needs to commissioners, professionals in charge of their care, and other decision makers. However, young inpatients of mental health units have not traditionally been engaged through the usual feedback platforms.

Our study took place over six months, in which time patients shared their lived experience within group discussions or one-to-one conversations. We worked closely with Poplar Adolescent Unit Education Centre staff to ensure our engagement would not be detrimental to patients' recovery and ensured compliance with safeguarding, confidentiality and patient safety procedures.

At the recommendation of staff, we devoted the first phase of the work to simply becoming familiar to patients, explaining the purpose of our engagement and how we hoped it could produce positive change. We welcomed questions about the study and made clear that participating was voluntary. We also explained that Healthwatch Essex was an independent charity and that talking to us would not impact on the care they received, although it could potentially change the care young people receive in future.

Patients were welcoming and became comfortable with our presence in the ward. This initial stage of our study involved joining patients in activities such as art and cooking or accompanying them on trips into the community, such as to the beach or the gym. Throughout the study we visited Poplar Adolescent Unit two days each week and were able to gain the trust of participants to discuss issues such as diagnosis, mental health services and stigma.

About halfway through our study it felt appropriate to offer the young people the option to self-select for a one-to-one discussion. These discussions would begin with us reminding participants they could opt out at any time and didn't have to talk about anything they didn't want to. One-to-ones were conducted in a quiet place where Healthwatch Essex staff and patients were in view of Education staff, who would be able to intervene if a patient became distressed (although this did not happen). We also made the young people aware of our safeguarding duties and, on one occasion, a hospital safeguarding form was completed and escalated. At the end of one-to-one discussions, we checked that patients felt well and able to return to the Education Centre.

After the six-month engagement period, we analysed our findings and presented them in a report, along with our recommendations.

Impact

In the report, young people being treated in a secure inpatient mental health setting share their lived experience of mental illness, the surrounding services, and the factors they believe could make the biggest difference to their recovery.

Forty-five patients and 11 professionals from the hospital, participated in the study. The professionals were able to provide insight into the overarching themes and commonalities across admissions. Twelve in-depth case studies were carried out with individual patients to provide a clearer picture of their journey through services from the moment they recognised they were unwell, to their admission to Poplar Adolescent Unit.

Key findings (available in full in the report) focussed on the barriers to accessing services, the impact of waiting times on mental health conditions, a lack of consistency (including a high turnover of workers), young people not feeling included in their care decisions, the impact of social factors as broader determinants of mental health and the complexity of some patients' cases.

Recommendations (available in full in the report) included: the value of lived experience, the importance of early intervention and prevention efforts, improving consistency of care, involving young people in decision making, embedding a holistic approach and system-wide collaboration (including the importance of a care navigation role).

Our innovative approach to engagement has enabled us to convey the experiences of these young people, which have not traditionally been heard. This has led to increased awareness of their needs, a better understanding of the importance of prevention and early intervention and other more general positive changes in the mental health landscape. We also hope that it has contributed to preserving the services or treatments that are currently working well.

To date, our impact includes the following:

- A commitment from CCG communications leads to use the findings to develop how they promote mental health services, including creating a film or audio recording from one of the case studies to use in training GPs.
- Essex Partnership University NHS Foundation Trust (EPUT) has embedded learning from this report into staff training events and found it useful to hear the lived experience of their patients in this level of detail.
- In response to the report's findings relating to awareness and reducing stigma, 150 Year 7 students from Colne Community School in Tendring participated in mental health Q&A sessions provided by Healthwatch Essex.
- The report is being used to directly inform the recommissioning of Essex County Council's EWMHS service and Healthwatch Essex has been commissioned to recruit a group of Young Mental Health Ambassadors who will be instrumental in co-producing the future mental health services available to young people in Essex.
- The report contributed to Mid Essex CCG's Pride in Practice work. Our findings also fed into the North East Essex CCG's IAPT survey.

SWEET!3 generated broad local and regional media interest which we hope contributed to raising awareness and reducing stigma, as well as improving understanding of the lived experience of young people in such services. We have also been able to influence other Healthwatch's from across the UK to consider taking this in-depth approach to gathering the lived experience of seldom-heard groups.

Relevance to Others

We believe the insight from this project is of value to anyone providing and commissioning mental health services or working more broadly within the field of mental health with young people. We have worked hard to share our findings across the NHS, local government and within the voluntary sector. In doing so, we have begun to influence CCGs to think differently about how they promote mental health services, encouraged changes to staff training and linked into schools as part of an effort to raise awareness and reduce the stigma surrounding young people's mental health.

Perhaps most significantly, the report has influenced how Essex County Council will recommission the EWMHS service, with young people with experiences of mental health having - for the first time - the opportunity to play a part in shaping that service for the future.

Standing Out

We have produced what is, to our knowledge, the first study of its kind in Essex.

This report undoubtedly makes for difficult reading at times, but we hope that conveying the experiences of these young people can lead to increased awareness of their needs, a better understanding of how prevention and early intervention can make the most difference, protection of the services or treatments that are working well and general positive changes in the mental health landscape.

Our approach to engagement with seldom heard groups of young people, has been helpful not only for the purpose of this study, but also to the young people themselves. We hope that patients who shared their experiences with us feel empowered by being heard – especially as many reported commonly feeling ignored or powerless in their journey through services.

The value of using lived experience is powerful. The SWEET! 3 report shows how high-quality engagement with young people, can not only provide valuable insight into the experiences of young people, but also contribute to an understanding of how these experiences can shape change.

The targeted dissemination approach has also contributed to the success of the project and its impact to date.

Key Learning Points

It is important to factor sufficient time and resource to fully get the benefit from this type of work. It is partially the investment of time and a dedicated resource that allows trust to develop – both with the organisation and with the participants of the study. It is crucial to spend time building trust as a foundation for the honest conversations you will need to have to create meaningful insight.

We also found it critical for the participants to understand what happened to the information and stories that they shared. Completing the feedback loop so that participants understood what happened with the insight they provided was important in thanking them for their contributions and seeing the impact that they had individually and collectively made.

Engaging with Children and Young People to Champion their Voice
Healthwatch Northamptonshire
PENNA 2016
FINALIST - Championing the Public

Organisation

Healthwatch Northamptonshire is a strong, resolute and independent community champion. We give local people a voice and work in partnership to influence the design and quality of health and social care provision in the county. Everything we say and do is informed by our connections to local people. Our sole focus is on understanding the needs, experiences and concerns of people of all ages who use services, to speak out on their behalf, and to give them a voice. We ensure that local decision makers and health and social care providers put the experiences of people at the heart of their work. We believe that asking people, including children and young people, about their views and experiences can identify issues that, if addressed, will make services better. We are a small team of dedicated staff supported by local volunteers, both young and old, in Northamptonshire. Resources are limited and we operate as a Community Interest Company (CIC).

General Summary

Engaging with children and young people (CYP) is not easy. It requires thought, planning, commitment and innovative ways of working to achieve outcomes that are meaningful. It is a journey of learning and if done well provides an organisation which is truly interested in what CYP think and experience an insight into better service provision for them and their families. For Healthwatch Northamptonshire that journey started in February 2015 when we held our first youth conference – which was designed and led by CYP of all abilities. It was a huge success and out of that came the focus and impetus to start “Young Healthwatch” and since then has led to some remarkable work with CYP. For example, Young Healthwatch have designed and produced a survey on eating disorders which was distributed through schools in the county and for which we received over 2000 responses – a survey “designed by young people, for young people”. The report and recommendations have been provided to commissioners to consider in the designing of their new eating disorder service. Other members of Young Healthwatch have conducted a visit to Kettering General Hospital to the Skylark children’s ward. The report was written in their own words and again the recommendations taken on by the Trust.

Rationale

One of the strategic priorities for Healthwatch Northamptonshire from its inception was to ensure that the voice of the child was heard in health and social care services design and provision. This aligns with a priority in the strategy of the county’s Health & Wellbeing Board and in 2014 we started to seriously think that we needed to lead on this area in Northamptonshire. As mentioned earlier, we started to prepare for a Youth Conference to be held in February 2015. We started the planning for this by setting up a steering group which included organisations already working directly with CYP and young people themselves e.g., Northampton Youth Forum, Shooting Stars and the children in care forum. The day was led by the Young Leaders who chaired the conference and facilitated on the tables. It was a huge success that led to the formation of Young Healthwatch and the work they have done since. It has helped ensure that the voice of CYP is heard by commissioners and providers in Northamptonshire and that their views and experiences are taken seriously.

Planning

Over 14 different organisations were involved in the initial steering group to set up the youth conference and Young Healthwatch. They were:

- Northamptonshire County Council
- Macmillan
- Young Leaders
- Northampton Youth Forum
- Connexions
- Children’s Rights Service
- Shooting Stars
- Shadow Board
- Children in Care

- Talk Out Loud
- East Northamptonshire District Council
- Nene and Corby CCG
- Kettering Borough Council
- Northamptonshire Association of Youth Councils
- Service Six

Since then, we have developed a Youth Engagement Forum with partners to ensure collaboration on youth engagement to avoid duplication and share good practice across the county.

Impact

Since working with children and young people as Young Healthwatch we have produced the following work and projects:

- A report on a survey of Young People's Wellbeing in Northamptonshire - February 2015
- A report on Healthwatch Northamptonshire's Young People's Health and Wellbeing Conference 18 February 2015 (Easy Read version also available)
- A report on the views of children and young people with SEND in Northamptonshire 2016
- Understanding Mental Health Easy Read Guide - Matthew's Story 2016
- Healthwatch Northamptonshire Understanding Mental Health Easy Read Guide 2016
- The views of Children and Young People in Northamptonshire about Eating Disorders 2016
- Eating Disorders and Body Image - Issues affecting LGBTQ Young People 2016
- Young Healthwatch Visit to Kettering General Hospital Report – June 2016

All the above include their findings and recommendations for commissioners and service providers. The eating disorder survey was completely designed by a group of young people at a workshop in January 2016. The initial aim was to get 300 - 400 surveys completed. The end result was that over 2000 surveys were completed. A huge success in itself. For the SEND report we engaged with children with disabilities as young as 2 years old by making the activity fun and engaging using nothing more than a paper tablecloth and coloured pens – and imagination!

Young Healthwatch has also developed their own Facebook and webpages as well as a Twitter account. They wrote and designed their own leaflet in July 2016 and in September 2016 made a short film about their work and achievements. https://youtu.be/yFTMDd-vTP4
On the 4th of October 2016 four of the young people helped present a Masterclass for the East Midlands Academic Health Science Network (EMAHSN). This was a potentially daunting presentation to professionals about how to engage with CYP and the work they have done to date – and the feedback from the EMAHSN has been terrific. The impact and achievements of Young Healthwatch over the past 2 years has been outstanding. For example, the Information and Advice Service for SEND (IASS) is going to use the findings about bullying to help design their next conference for young people with SEND. Commissioners are also going to use the views of over 2000 young people about eating disorders in service design.

All our reports and recommendations can be found at: www.healthwatchnorthamptonshire.co.uk

Relevance to Others

All the work that Healthwatch Northamptonshire and Young Healthwatch has done is relevant to all organisations that either commission or provide health and social care services for children, young people and their families. Organisations that are sincere about truly engaging and consulting with CYP to find out their views and experiences to improve service design and delivery can tailor what we do to meet their organisation's needs – or commission us to do it for them!

Standing Out

The key thing that makes this initiative special is that all the work of Young Healthwatch is driven by the young people themselves.

What has made it a success is that Healthwatch Northamptonshire staff and volunteers see engaging with CYP as a priority and have committed time and resources to make things happen. Without resources e.g., money for simple things - such as taxis ensuring access to and from events - the CYP would be unable to participate.

Key Learning Points

The key learning points have been:

1. Ensuring that engagement with CYP is a strategic priority to get own organisation buy-in to the work
2. Working with other organisations is essential as many already have the links with CYP
3. The importance that CYP see how their work is making a difference
4. The importance of having a lead officer/member of staff to oversee the work
5. The importance of reward and recognition for the CYP involved
6. Resources to enable access and participation are essential
7. To ensure that the CYP enjoy the experience – and benefit from it on a personal level

We have lots of tools and information to share:

- Questionnaires
- Reports
- Top 10 tips for engaging with CYP
- Easy Read reports
- Young Healthwatch film
- Facebook, Twitter and web pages
- Presentations
- Experience

NHS Go - An App for Young People, by Young People
Healthy London Partnership
PENNA 2016
FINALIST - Innovative Use of Technology

Organisation

Healthy London Partnership is a transformation partnership funded by NHS England London Office and the 32 CCGs across London. The NHS in London came together during 2015-16 to develop and agree a shared plan for the capital. The partnership was established in response to the Five Year Forward View and the London Health Commission. The aim is to take London from seventh in the global healthy city rankings, to the number one spot. The London Health Commission contained 10 aspirations for London. The work that we undertake is organised into transformational focus areas. Each programme aims to solve a different health and care challenge faced by the capital. All aim to make prevention of ill health and care more consistent across the city. The Children and Young People's programme aims to ensure consistent care for all the children and young people in London to ensure that all children have the best start in life. In the first year we engaged with over 600 children and young people who helped us to shape our programme and develop the programme's aims and outcomes. HLP employs around 50 staff to deliver the transformation programme with about 10 working solely on children's health.

General Summary

NHS Go is an app which pulls advice directly from NHS Choices in an engaging way for young people. The app was designed after engaging with young people that said they didn't know how, where or when to get health advice or what their rights were. Since its launch in July nearly 13,000 people have downloaded the app. We promote the app through Youtube to reach young people in their space. NHS Go is also promoted through pharmacies, GP surgeries and hospitals across London and feedback from health professionals has been very supportive. The app helps young people to access confidential advice, which ensures that they go to the right professional, if needed, for advice. This means that they will go to the right place for advice the first time.
The app pulls content from NHS Choices, which means that the information is up to date, validated and current. It is free, confidential and as the young people requested branded with the NHS logo. The app consists of three key sections:

- The health A-Z
- A service finder
- Your Health rights

The app can be downloaded on www.nhsgo.uk or on iTunes or Google play and is available to download anywhere in the world.

Rationale

The Healthy London Partnership's children and young people's programme was set up in 2015 in order to ensure that the population of London's children and young people were given the best start in life. A quarter of the population are under 18, 40% of 15-year-olds drink alcohol once a week and 20% of 13-year-olds drink alcohol once a week.
The aim of our programme is to reduce these figures and ensure that children and young people had an equal place at the table to other services in the NHS. We wanted young people from London to be at the heart of the Healthy London Children and Young People's Programme and held an engagement event for young people back in November 2015 asking young people about what they thought of the NHS and health service and what they thought could be improved. Around 100 young people attended the event. They came out with five key messages:

- They didn't know how to access health services
- They didn't know where to get health advice
- They didn't know when to get health advice
- They didn't know where their local health services were
- They didn't know what their health rights were when accessing services

Our aim was to find a way that young people could find out all these things in an easy and accessible format. The young people suggested that an app would be the best way to do this. Over the next few months, we worked with a focus group of young people to plan and deliver the app that they wanted.

Planning

After the initial engagement event with young people, we ran a series of workshops with young people to design the contents, feel, image and usability of the app. The young people were involved in every decision. We held focus groups with young people in Croydon and with the sexual health organisation Brook. From these sessions the app was developed. They determined:

- The name of the app
- The recognition that this was an NHS product
- The colour schemes
- The layout of the app
- The way the content was presented
- The confidentiality of the app

We also completed a survey where 500 young people responded to what information should be included in the app. This included the topics: sleep, LGBT, family health, long terms conditions, anxiety and depression, young people's health, puberty and growing up, allergies, colds, flu and pains, smoking, drugs and alcohol and eating healthily and exercise.

Young people were also involved in the tender process to select a company to develop the app and the marketing app. They were crucial and present at every key decision making point and as a result created an app which worked for them. Since the creation of the app, young people have been consulted on which you tubers they think we should use in developing the app and what topics they think we should refresh and promote. The next step will be to run another focus group with young people to start evaluating the app.

Impact

The app was released in July 2016 and so far, 13,000 people have downloaded the app. Given that the app has only recently been released we are still gathering some of the qualitative data on how the app has been received by young people. In the last week we have implemented an in-app rating which allows young people to rate the app and leave feedback after they have accessed a certain number of pages on the app. The results of this will be available shortly and will be collected on an on-going basis. In the next month we will be gathering some qualitative feedback from the young people on how the app feels and its usability so we can start to improve some of the aspects and develop it further. We have also gathered feedback from the YouTube videos which have been released, able to pick up on the aspects which aren't working and ensure that these errors are corrected.

We currently can collect data on the number of downloads and the impact of some of our marketing campaigns from YouTube.

- -So far, we have had 13,000 downloads
- We know how long a user would normally spend in the app when using it – this is above the average for all apps – about six minutes which indicates that users are engaging with the app more so than they would with other apps
- we have 220,000 visits to our landing page
- we have had 300,000 views of our YouTube video
- after a youtuber posts a video promoting NHS Go we can see a spike in downloads of anything between 100-400

We still have further work to do on the affect and impact of this app but the evaluation in the first few months is promising

Relevance to Others

The app is available to download anywhere in the world, we recently opened the market internationally to support international students who may be moving to the UK. This app can be promoted anywhere in the UK. Instead of all 32 CCGs in London developing their own app, we developed one which works everywhere and put together a strong marketing campaign to support it. Organisations that are interested in the app can download the promotional materials on www.nhsgo.uk and promote it in their local area, they can also use the YouTube video https://www.youtube.com/watch?v=mMBVW2lKtj0 and any of the supporting videos. We are sharing the app through social media, through presenting at conferences and through publishing our work on the Academy of Fab Stuff, we always welcome any feedback, and we are happy to help with any queries.

Standing Out

I think that this initiative does something completely unique in that it inhabits the space of the young person instead of asking the young person to come to the NHS. Traditionally, we ask young people to come to us to get health advice, to help us change services, to give us feedback, but the app inhabits a space they work in. However, what is even more innovative is the fact that we listened to young people, and we now market the app in their space. Using youtubers to promote the app has proved highly successful, it also has never before been done by the NHS. So often in the health service we create a brilliant resource, but we don't share it with the public in a way that engages them, this uses a completely new approach, engaging with the new technological age to promote a resource in a space that young people use and by people that young people listen to. Our creative approach to marketing has led to 13,000 downloads and the number is increasing. The fact that we listened and involved young people from the inception to the evaluation has meant that we have got it right for young people and they now have access to the health advice they need in a format they can engage with.

Key Learning Points

The success of our app was that the young person was at the heart of the process.

- Engage young people in everything you do which affects them and in every stage of the process, you will learn a lot and a lot of things they say are surprising
- Be prepared to take risks – using youtubers to talk about health issues was a risk, but it paid off and led to an innovative and successful campaign
- Don't stop promoting the product – just become something has been designed and promoted for a month doesn't mean people know about it
- Keep things relevant – young people are constantly picking up new trends and themes in the media, follow these trends and link your campaign up to them, so they can see its relevance
- Occupy the space of your target audience – don't get them to come to you.

NHS Go – An App for Young People, by Young People
Healthy London Partnership
PENNA 2018
FINALIST - Innovative Use of Technology

Organisation

Healthy London Partnership (HLP), a partnership of London's NHS, between all 32 London Clinical Commissioning Groups, and NHS England (London region), London Councils, Public Health England, Mayor of London with other organisations working together to make London the world's healthiest city. We work with our partners to improve Londoners' health and wellbeing so everyone can live healthier lives. We work to deliver changes best done once for London. Healthy London Partnership consists of eight overarching programmes and this submission is made on behalf of a piece of work within the Children and Young People's (CYP) programme.

General Summary

NHS Go is a free app for young Londoners designed by young people, for young people. It provides instant access to confidential NHS approved health and wellbeing information, supports young people to navigate NHS services and provides them with information on their rights when accessing services. NHS Go can also be accessed through the NHS Go website. NHS Go takes an innovative approach as to how young people interact with the NHS. It can provide them with instant access to health information and direct them to a relevant service without them needing to have had an initial point of contact with the NHS. NHS Go is maintained by the HLP CYP programme. It was co-produced with Young Londoners in 2016 based on the feedback of their experience with NHS information and services and to address what was identified as a solution to ensuring young people are better informed in relation to their health and wellbeing. The app has since gone through phases of re-development with young people continuing to be at the heart of this process. NHS Go has been downloaded over 75, 000 time and we are on target to reach 100, 000 downloads in the next quarter. We have seen over 939, 473 article views in app screen views in the app. We have run social media campaigns with reach of 1,077, 512. Our Facebook page has 16,381 followers. NHS Go was designed with sustainability in mind with a funding model that allows it to be available to all 32 CCGs in London. We know we have users outside of London and there are proposals for the app to be rolled out nationally. We are also in the final stages of obtaining NHS app store approval. A status of which will make the app more widely available to many other young people.

Rationale

NHS Go was the outcome of feedback from over 1000 young Londoners who told us about their experiences with the NHS and more specifically their awareness and interaction with information, advice and services are available to them. Young people specifically told us:

- They wanted a trusted place to find health information confidentially
- Navigating the NHS health services was a challenge for young people
- They didn't know when to access services, how to access services and where to access services. The NHS Go website/app covers a number of different topics with an emphasis on the key topics we know matter the most and are most relevant to young people aged 16-24 including.
- Sex and relationships
- Mental Health and wellbeing
- Eating healthily and exercise
- Sleep
- Long term condition, such as asthma and diabetes

The app is regularly updated to feature relevant health information in line with seasonal trends or health activity in the media. For example, information on festival health around the summertime or on self-care around the Christmas period which we know can be a challenge for young people and mental health. NHS Go further utilises Facebook as a platform to engage young people with the relevant NHS Go health information.

Planning

The idea for NHS Go was the outcome of a range of feedback obtained from over 1000 young people in London which included speaking directly to over 100 young people. Young people felt an app would be the best way to address the both the challenges they had in navigating the NHS and to ensure access to reliable health information. A young person's steering group was established to start developing NHS Go. The app was then tested on a different cohort of young people and shaped further. NHS Go was launched with a lot of energy in July 2016 and was promoted in an original way through using well-known young YouTube bloggers with an interest in health and wellbeing. The idea behind this was to move away from traditional methods of trying to engage with young people and to move into the digital space that young people occupy. We have continued this approach with youtubers with focus on events which affect the lives and health of young people for example, anti-bullying and fresher's week. Our most successful YouTube campaign has 296,000 views. We are fortunate to work with great app developers who are passionate about NHS Go and making a difference to young people. We are continually making updates and developing the app as well as responding to feedback from young people on user experience.

Impact

NHS Go has won awards in both 2016 and 2017 and the HLP CYP team have continued to develop the app with young people to build on its initial success and to ensure it continues to meet the needs of young Londoners. NHS Go has kept momentum with 75,644 installs to date and within the last year we have seen a rapid increase in page views on the NHS Go website (currently at 110,636 page views) which we attribute to using social media as a platform whereby we link through to content on the NHS Go website. We are approaching 1 million article views on the app alone (939, 473 article views in app). We have built our Facebook audience and interactions, with one of our most successful campaigns reaching XXX. NHS Go is endorsed and promoted widely by a range of health professionals including GP's and school nurses as well as, schools bust most importantly, young people themselves. The feedback we have received from young users really highlights the success of the app's rationale; to make trusted health information easily accessible in a confidential space. A few pieces of feedback below: "I think one of the things that is good is people who might find it difficult to talk about things... [NHSGo] allows you to answer your questions more discreetly sort of thing. Come to think about it there are certain things I'd like to look at on the app and I would look because I'd feel more comfortable" "I downloaded the NHS Go app and it's already helped me get in touch with a charity called "Beat". It helps people with eating disorders. If it wasn't for this video, I wouldn't have found help."

Relevance to Others

NHS Go is relevant to any young person aged 16-24. Healthy London partnership developed the NHS Go app once for London in order to prevent duplication of work across the 32 CCGs, but it has the potential to be available nationally. We have piloted an NHS Go local option, in Islington and if rolled out further, this would allow individual CCGs to have a local version of NHS Go, up to date with their own directory of services and feature locally relevant content for CYP. This could be rolled out nationally and would be set up in a way to allow local ownership of content featured.

Standing Out

NHS Go takes an innovative approach as to how young people interact with the NHS. It can provide them with health information and direct them to a relevant service without needing to have had an initial point of contact with the NHS. It allows young people to take greater control over their health, make healthier choices and have confidence that they have information from a trusted source when they don't know where to go. NHS Go social media is a really powerful tool for engaging young people with health information. Young people engage with loads of content online from various sources and have told us that when it comes to information online unsure if to trust or conflicting information or advice can be overwhelming. NHS Go social media shares the viral content on a health topic, such as a BBC news sexual health article but then links the young person to the relevant NHS, information standard approved information which if appropriate will direct to services. We are excited to be launching a young person's Digital Ambassadors scheme in the first part of 2019 in which young people can input into NHS Go in a way that is meaningful and rewarding to them. We are keen to support young people in producing content for social media, such as blogs and input into campaign ideas as well provide what we know will be meaningful promotion of the app through their peers and social media networks.

Key Learning Points

Ensure your end user / young person is at the heart of your initiative and look for ways to continually involve and engage with them -even if this is just a quick and informal ask for feedback at an event, you will get invaluable insights and ideas. Be bold and think outside the box when it comes to doing things for young people – our asthma rap challenge campaign is a great example of this. Not only was it effective in reaching our younger audience but it made an impression on our stakeholders. Work with developers who are genuinely passionate about improving health care and making a difference to young people – it brings energy to the project and work; they will have better development ideas and it will take it from strength to strength.

To Ascertain the views and experiences of patients aged between 16-24 years of age diagnosed with a cancer

Hull University Teaching Hospitals NHS Trust
PENNA 2020-21
FINALIST - CPES Award

Organisation

Hull University Teaching Hospitals NHS Trust (HUTH) is a large trust situated in Kingston upon Hull and the East Riding of Yorkshire. We have two main sites, The Hull Royal Infirmary (HRI) and Castle Hill Hospital (CHH). Our services include planned and unplanned general hospital services; a tertiary centre for Oncology and Haematology; centre for Cardiology and Cardiothoracic Surgery, Major Trauma Centre and a range of other specialist services.
We are also a partner in the Hull York Medical School providing comprehensive training placement and support to medical students.

The Trust's secondary care service portfolio is comprehensive, covering medical and surgical specialties, routine and specialist diagnostic services and clinical support services provided to a population of approx. 600.000 in the Hull and East Riding of Yorkshire area. The Trust provides specialist services to a catchment population of 1.5-1.8 million extending from York and Scarborough in North Yorkshire to Grimsby and Scunthorpe in North Lincolnshire and sits within the Humber Coast and Vale ICS.

As an organisation we value the contribution our patients, their families and carers can make to the improvement of our services. We have a Patient Experience Forum and a Patient Council to ensure their voices are heard.

The Teenage and Young Adult (TYA) Service is based within the Queens Centre at Castle Hill Hospital, which is part of Hull University Teaching Hospitals NHS Trust (HUTH). The TYA unit provides inpatient and outpatient services for 19-24 years old patients with a cancer diagnosis within the Cancer Alliance footprint and a shared care service for those patients aged 16-18 years having treatments at the Principal Treatment Centre in Leeds.

The TYA team at HUTH work closely all cancer site specific teams to enhance the care and support already given by the experts in their disease field. This collaborative approach aims to ensure the best possible clinical care with the advantage of expertise in Teenage and Young Adult care, including psychosocial and emotional wellbeing care.

The service has a bespoke 4 bedded ward with a dedicated outpatient area enabling care and treatment to be delivered as locally as possible. The TYA team consists of a Specialist Nurse, a staff nurse and a Youth Support worker who co-ordinate the patient pathway and deliver outreach care as required. This enables them to support our colleagues in other hospitals and community services who may have limited experience of caring for patients with a diagnosis of cancer within this age group.

General Summary

As part of their NHS Cancer Improvement Collaborative project, Hull University Teaching Hospitals NHS Trust developed a patient satisfaction survey to make sure the needs and experiences of patients' need accessing Teenagers and Young Adults service at Castle Hill Hospital were heard and understood.

Often underrepresented in wider surveys, this engagement exercise provided the TYA team with the much-needed opportunity to turn up the volume of the voices of TYA patients and helped to identify what parts of the service were working well, areas for improvement, and the impact of Covid-19.

A high response rate of 67% allowed the TYA team to better understand the views of patients and develop action plans that quickly saw improvements implemented.

The results of the survey also helped to raise awareness of the service across the Trust and Cancer Alliance, and this project has provided the team with a baseline for future engagement and improvement activities.

Rationale

The Cancer Improvement Collaborative (CIC) programme improves experience of care in NHS cancer care services by drawing on data from the annual national Cancer Patient Experience Survey (CPES) and other sources of insight and feedback.

Focusing on rare and less common cancers, Hull University Teaching Hospitals Trust (HUTH) decided to use the 2020/21 CIC project to focus on the experience of care for younger people.

By working collaboratively with patients, Humber, Coast and Vale Cancer Alliance, the Teenage and Young Adult (TYA) service team and wider Trust representatives, the project aimed to address how patients aged between 16-24 can often be underrepresented in wider engagement exercises whilst achieving a better understand of the views and experiences of patients living with cancer within this age range.

The National Patient Experience Survey results, which are used by HUTH to develop action plans for improvement of services, had 1,025 responses in 2019. Only two of these responses were from people aged 16-24 and as the results cannot be filtered by age range, it is difficult to establish individual feedback.

As well as understanding patient's views and experiences from diagnosis to living with and beyond cancer, the project also helped the TYA team to measure the impact of Covid-19 to teenage and young adults. How had the shielding and self-isolation impacted them when they are already isolated from their friends and normal activities due to their illness or treatment?

Planning

Representatives from the TYA service at HUTH worked with Humber, Coast and Vale Cancer Alliance (HCV CA) and a patient partner (Rachel*) worked collaboratively to develop the survey. Whilst some generic questions mirrored those used in the National Cancer Patient Experience Survey, to allow a comparison to wider Trust results, other questions were tailored to the intended audience and aimed to measure the impact of Covid-19.

Thanks to the input of the project's patient partner, the development of the survey could benefit from someone with lived experiences of the service and Rachel helped to ensure the questions where relevant and understandable by the intended participants.

The TYA patient survey was sent via to 65 patients on Monday 9th November 2020. Ensuring the survey was accessible to all those invited was extremely important and although the survey was sent out via a digital link, a follow up call was made to offer the survey in alternative format if required. Conducted by Charlene Kent, Youth Support Co-ordinator, these calls also provided an opportunity to encourage patients to complete the survey and/or answer any questions they had.

The survey closed on Sunday 22nd November and 44 responses were received, giving an overall response rate of 67.7%. The results were analysed by HCV CA and a report containing the results, key themes and recommendations was provided to HUTH in December 2020.

*Pseudonym used

Impact

This project provided an important opportunity for teenage and young adults to share personal experiences of living with and beyond cancer. The results of the survey have helped to shape improvements to the TYA service at Castle Hill Hospital and are also helping to raise awareness of the service within the Trust and across the Humber, Coast and Vale region.

Producing a report based on the results of the survey has helped to communicate the key findings with relevant stakeholders. It has also helped to put the patient voice at the centre of action plans which aim to improve the TYA service and patient experience.

Overall, the feedback received from this questionnaire is positive, with the majority of respondents speaking very highly of the Teenage and Young Adult services at Castle Hill Hospital. This positive feedback has helped the TYA service to gain recognition within the trust.

Key themes that emerged regarding areas for consideration and improvement include:

- Additional support needed - Patients expressed a desire for further support at home, including support for parents.
- Shorter waiting times - Respondents noted that chemotherapy appointments could be improved.
- Workforce capacity - Although patients rated TYA staff highly, respondents felt staff were often stretched and noted the need for additional capacity.
- Impact of COVID-19 and the importance of social activities - one third of respondents said Covid-19 has affected their experience during treatment and follow up, including levels of support. Respondents also noted that Covid-19 had resulted in restricted visitations, delayed and/or cancelled appointments and reduced social activities. Patients were appreciative of the social activities on offer prior to COVID-19 and noted the benefits of attending activities such as ‘Look Good, Feel Better’ and Alton Towers. There is a strong sense of urgency to restart face-to-face activities when possible.

Following the publication of the survey report, the TYA team acted quickly to develop an action plan and the Lead Cancer Nurse, TYA Cancer Nurse Specialist, Ward Sister and TYA Coordinator have already implemented some solutions to the feedback highlighted above.

The introduction of weekly ward handovers has resulted in shorter waiting times for chemotherapy and improved communication across the ward, pharmacy and teenage and young patients living with cancer.

Balancing measures were added to the process and further feedback obtained from staff on the ward has positively impacted on day-to-day business of the ward. For example, the TYA team have expressed how they now feel more of an extension to the ward, rather than separate.

Relevance to Others

As the views of teenage and young adults are often underrepresented in wider pieces of engagement activities, the results of this survey have been shared with internal and external colleagues that help to deliver cancer services locally. This includes:

- Humber, Coast and Vale Cancer Alliance (HCV CA) Collaborative Voices Network
- HCV CA Primary Care Strategy and Delivery Group
- Patient and Public Experience Leads from other Cancer Alliances
- Patient Experience Forum at HUTH

Standing Out

This project has helped to provide a voice to a previously underrepresented group at HUTH. The high response rate has supported the TYA team to make changes that are relevant to the needs of its patients and the results have helped to improve working relationships and processes within the trust.

Utilising individual skill sets and experiences ensured the survey receive a high response rate. Rachel, the patient partner, was key to ensuring the survey was understandable to its target audience. Charlene’s already established relationship with patients, as TYA Coordinator, helped to encourage participation, and the Lead Cancer Nurse and TYA CNS helped to ensure the results could support service improvements.

During a time that has been challenging for patients and staff, the survey provided an opportunity for reflection and an understanding of what matters to patients using TYA service. The positive feedback received helped to boost staff moral and promoted the services achievements within the Trust, and the opportunities for improvement have helped to provide clarity on what is needed moving forwards.

Key Learning Points

- Involve patients from the beginning. This can be key to success further down the line.
- Measure the impact of Covid-19 on patient experience. This can help shape plans for recovery.
- Collaboration is key to achieving success. It is important to utilise existing relationships and skillsets.

Practice Champions – Improving Child Health Across Northwest London
Imperial College Healthcare NHS Trust
PENNA 2016
RUNNER UP - Engaging and Championing the Public

Organisation

Connecting Care for Children (CC4C) is a Paediatric Integrated care model that has been operating whole systems change across North West London. It's an intervention that enables Primary, Secondary and Tertiary care to work cohesively, alongside the local population. At the core of this service is patient and practice engagement via co-design. To do so, CC4C and GP practices recruit Practice Champions (volunteers), to design and deliver support groups and health education events for children and families in their local community.

CC4C is small team, with two lead Paediatricians, a Programme Coordinator and a Practice Champion Manager, who leads on patient and public engagement.

General Summary

Connecting Care for Children (CC4C) is a Paediatric Integrated care model that has been operating whole systems change across North West London. It's an intervention that enables Primary, Secondary and Tertiary care to work cohesively, alongside the local population. At the core of this service is patient and practice engagement via co-design. To do so, CC4C and GP practices recruit Practice Champions (volunteers), to design and deliver support groups and health education events for children and families in their local community.

CC4C currently has over 30 Practice Champions, across Central and West London and Hammersmith and Fulham CCG, drawing on patient experience and facilitating change, at a local level. This means that patients feel more confident and supported with the care that they receive, whilst also knowing that their voice matters. This not only allows patients to be heard, but then enables them to bring about change, though education and understanding.

In 2015 we published an evaluation of the Child Health GP Hub, demonstrating its system-wide impact Child Health General Practice Hubs: a service evaluation archives of disease in childhood and in 2016, we published a broad umbrella approach to child health whole population integrated child health archives of disease in childhood.

Rationale

CC4C hopes to address child health inequalities across North West London by building relationships between Primary and Secondary care, whilst putting the child and families at the centre. Paediatricians at St Mary's Hospital realised that they could reduce the number of children being referred to outpatient appointments if there was a better case management and education of child conditions. However, to really make a difference to the local population CC4C understood the importance of championing patients to make change and educate.

Practice Champions are a way of understanding the actions of children and families, why they make certain decisions around their Child's healthcare, and how can we work together to make this a more positive experience. It's about finding out what really matters to a child. For example, it is important to acknowledge that a child has a condition, such as Asthma, but also how it impacts school, their sleep, and their relationships with friends. CC4C is championing patients to address all of these issues as healthcare has a big impact on a child long after they leave a hospital.

Planning

Enabling patients to share their experiences and facilitating change at a GP practice takes a lot of planning and careful consideration. All of the Practice Champions are assigned to a Child Health GP Hub so that they are fully integrated into the GP practice. Recruiting Practice Champions from within their GP practice It is essential that Practice Champions feel linked to the practice, as they will be giving up their time to help support local children and families.

The recruitment process takes approximately twelve weeks from initially meeting with the GP's to hosting the Practice Champion training event. Initially, the GP practice sends a text message to patients that are between 0-16 and 16-24 years old (0-16 years would reach parents of that GP practice).

All Practice Champions are offered training courses from the local authority and Public Health, giving them more confidence in their role. As the Practice Champion Manager, I ensure that they are given a space where they can express how they feel and plan with them how they want to make change. All feedback is welcome, the good and the bad, this will then make for a better outcome.

Impact

CC4C has recruited over 30 Practice Champions for GP practices, who have designed and delivered 5 support groups and two education events. The support groups include walking groups, mindfulness classes, adolescent sexual health drop in's and support groups for new fathers. All of the Practice Champions have received volunteer training and then 18 have gone on to do more specialised Public Health training. This has up skilled the Practice Champions and has even resulted in them finding employment. CC4C measures the number of Practice Champions that are at part of a Child Health Hub, how many hours a Practice Champion contributes and the number of sessions that are run. This can then also inform us how many patients are attending each event, if they are new or recurring. This data will allow us to access the impact that the Practice Champions are having on their patient population; we can share learning and create feedback loops for continuous development.

CC4C has developed clinical and patient networks, which have meant that this work is sustainable and continually growing. We measure the success of these networks by asking patients for feedback. CC4C currently uses PREM forms to ask patients about their experience of attending a Child Health Hub.

Relevance to Others

The Practice Champions at Parkview medical centre have developed a six-week health and wellbeing programme for 30 children, focusing on obesity. The Practice Champions said that the referral pathway for children that are overweight isn't straight forward and often leaves children feeling helpless, so they wanted to join up this programme with other activities. As they live locally, they know about existing organisations that work with children, so they have designed a collaborative programme that draws other expertise with the aim of creating a sustainable network. This network will not only ensure that organisations work better going forward, but that children and families will continually benefit. This is an example of how CC4C and GP Practices champion patients make change for the local patient population.

This model could easily be replicated across other specialities with Primary and Secondary care. The Practice Champions focus on improving the care of children by giving them and their parents an opportunity to have a voice. This is something that could equally help the elderly or patients with long term conditions.

Standing Out

Practice Champions are volunteers that want to improve child health for patients and families in their GP practice. CC4C is passionate about giving patients the opportunity to share their experiences, express their concerns and letting their voices be heard. However, this is more than just a platform to raise awareness; this model allows patients to lead change. We give patients education, support and the confidence to help other children and families.

The patients that attend an education event or support group are also gaining from peer-to-peer support. Patients have said that this has a very positive impact on their confidence and self-management of conditions. For example, there has been a recent outbreak of Measles and the Practice Champions wanted to run education sessions with Drs so that parents could ask what they might feel are 'silly' questions about the condition and the risks of immunising their children. We ran a session with two weeks and parents have asked for more sessions to be delivered at the GP practice and the local schools. We believe that listening to the patients and then mobilising our recourses can lead to positive outcomes for patients in Primary care.

Key Learning Points

CC4C has doubled the number of Practice Champions being recruited, training and delivering health education to their local population. This has taught us a lot about patient engagement and the importance of starting something with an aim of it becoming self-sufficient and sustainable.

- Firstly, for Practice Champions to be successful they must be integrated into the GP practice/ Child Health Hub. This means that the employees at the GP practice need to be helpful, accommodating and understand how the Practice Champions can add value and help their work.
- Secondly, the Practice Champions need to understand the commitment that they are signing up to, that they will need to attend meetings and training.
- Finally, the Practice Champions need to have clear communication throughout the process. It takes a long time to get from an idea to it becoming an event. It is important to communicate why this is and explain the barriers.

However, the most important thing is to not be worried about the information that the patients tell you. All feedback, good or bad is important. Patient will give bad feedback and CC4C has found that it’s important to create a space for patient to share and reflect and then to show them how collectively you can work with them to make change.

Type 1 Kidz - The Impact of Engaging Children and Young People with Type 1 Diabetes and Their Families to a Peer Support Project

Investing in Children

PENNA 2017

RUNNER UP - Support for Caregivers, Friends and Family, RUNNER UP - Access to Information

Organisation

Investing in Children (IiC) is a Community Interest Company based in Durham that works nationally and internationally. There are 10 employees. Using a children rights-based approach IiC works with children & young people from pre-school to 21 years old to help them to have a voice about things that affect them and make changes based on their suggestions and thoughts. For example, IiC facilitates the Children in Care Council, groups in a Secure Centre, health groups and Type 1 Kidz (children & young people with Type 1 Diabetes). IiC works closely with services and decision makers to make these changes happen.

General Summary

While working with CYP with T1D and their families in Co. Durham & Darlington and looking at improving the hospital service it became apparent that there was a need for opportunities for them to meet, learn together and support each other. For this reason, Type 1 Kidz (T1KZ) was formed and started running in Co. Durham and Darlington in 2012. The aim is to help families to have improved self-care, be more positive about the future and have greater self-belief, overall to become empowered to be healthy now and in the future. Following the success of the project in this area funding was achieved to spread the project to 4 other regions in 2014. Scoping work has been carried out in 2 other regions in the North East and Cumbria who would like to adopt the project in their region. An evaluation analysed by Sunderland University found that families that attended Type 1 Kidz for a longer period of time had more confidence and knowledge of 10 key areas than those that had attended fewer times. The project has already demonstrated that it has transferability, and the success has been disseminated through presenting at National Conferences, writing Journal Articles (in January and June 2017) and winning two awards at the Quality in Care Awards 2017.

Rationale

There are approximately 1800 children and young people living with T1D in North East England and Cumbria. T1D has devastating outcomes if not controlled well and there is a direct link between poor diabetes management and complications. T1D is a growing health crisis, with complications costing the NHS £1 million every hour. On average T1D reduces life expectancy by an average of 13 years and mortality is five times higher for young adults (under the age of 30 years old) with T1D than their peers. Many families reported that they did not have enough support and knowledge to be able to self-manage their diabetes effectively, leading to short and long-term complications. Because of this lack of knowledge and support families said they didn’t feel positive about the future, and they didn’t feel like they could try new things and go into new situations, such as going on day trips and starting new schools. Therefore, T1KZ was set up to give families opportunities to come together and get more support and knowledge which would hopefully give them more confidence resulting in better health outcomes (now and in the future) and more confidence.

Planning

A Young People’s Steering Group (SG) and Professional SG were created to work together to plan and deliver the project. This ensured that CYP’s voice was at the forefront of all decisions and that what was going to be delivered was exactly what CYP needed. The Professional SG consists of clinical teams, Universities and individuals from NHS England to ensure the project succeeds and meets its goals. After discussion was decided to have monthly sessions in two venues (covering 3 regions) and quarterly sessions in another venue (covering 2 regions). This would ensure that families could access a group session at least once every two weeks. There is also an active Facebook Group, Twitter account and website so families can access information and discussions regularly. The CYP and families set the agenda for discussion topics and Young Facilitators, who have been trained, facilitate the discussions and activities with their peers. Members of the Clinical Teams (Consultants, Specialist Nurses, Dieticians etc.) attend T1KZ monthly sessions informally to support discussions and activities and also to build a stronger relationship with families. As well as the support described above CYP wanted further opportunities to meet and raise awareness. This has been achieved via a two-day Peer Mentoring Course – ‘Swings and Roundabouts – Diabetes & Me’ as well as CYP developing and presenting an assembly to both Primary and Secondary Schools (approx. 30 in the last 2 years). The project also has an annual Fun Day and Christmas Party to bring all of the families from different regions together. The project is regularly asked to present their work and raise awareness of T1D in a range of places, and most recently to GPs in Co. Durham and Darlington. CYP are involved in the planning and delivery of all presentations and training.

Impact

At the beginning of project the YP's Steering Group identified areas that they were lacking in confidence and wanted more knowledge and support with, these were basic understanding of T1D, family support, different diabetes treatment options (injections, insulin types, insulin pump etc.), low BG, high BG, diabetes and illness, diabetes and exercise, diabetes and food/carb counting, self-management and overcoming future challenges. Everyone was asked to fill in a likert-scale survey when they joined and at 6 monthly intervals. An evaluation on the data carried out by Sunderland University showed that there was a significant improvement in the overall score by people who had attended more T1KZ sessions than those that had attended fewer sessions. There was especially a strong link with more confidence and knowledge of hypoglycaemia (low blood sugars) and different treatment options. Case studies and feedback are noted/collected from every session and include CYP having the confidence to try new injection sites (e. g. stomach and arms rather than only arms), having the confidence to stay at a friend's house for the first time and learning when to test for ketones (something you should do with high blood glucose levels). CYP said that these changes were a direct result from attending group sessions. We are currently working with NHS England to determine the financial impact of these results. In total the project has worked with around 180 CYP with T1D (20% of the patient population) as well as around 200 siblings, friends, parents and grandparents. NHS England said that this is around twice the average level of engagement.

Relevance to Others

This project is very relevant to other groups, within and outside of our organisation. Using this simple but unique approach could benefit any group that wants to help families to self-manage a condition and become confident to do so. The approach supports not only the individual but the whole family and other important people in their lives. We believe this approach could be relevant to groups both working with children and adults. Our current project has been successful in working with children and young people aged from 2-22 years old, as well as parents and other adults.

Standing Out

A unique approach focusing on the child's right to have a say in all matters affecting them and have this voice taken seriously ensures that children and young people really are at the forefront of all decisions. The CYP have had a say one all aspects of the project such as looking at the budget, volunteering, choosing venues, deciding on the project name, locations etc. as well as small (but important details) such as what refreshments should be at meetings, what resources should be bought and fundraising activities etc. Working as an independent organisation has contributed to the success of the project because it enables the project to have its own brand, goals etc. away from the hospital setting and clinical targets. This was something very important to the CYP. Being independent and delivering a project that CYP want/need has encouraged hard-to-reach families to engage in the project. Having Young Facilitators has also contributed to the success – CYP wanted to learn from each other and have discussions with other people who had similar experiences.

Key Learning Points

The main key learning point is to listen to CYP and take their suggestions seriously – let them take a lead on the planning and delivery of the project. Let the CYP have discussions to get the theoretical information and also have interactive activities, such as cookery sessions to learn about carbohydrate counting, doing exercise to learn about managing diabetes while doing sport … This will help to reinforce the information learned and allow the CYP to try new things in a safe environment.

Voices4Change - Children and Young People Making a Difference
Ipswich Hospital NHS Trust
PENNA 2016
FINALIST - Strengthening the Foundation

Organisation

Acute district general hospital + 3 community hospitals and some community health services
Catchment of more than 330,000 people living in and around urban Ipswich. Remainder of the population is rural and quite isolated.
500 beds + community beds
Annual turnover £200+ million.
3,500 whole time equivalent staff.
Typically, older catchment population than the England average with a greater proportion over 55.
Population served is an aging one (one of the fasted growth rates of very elderly people – over 80s – in the country), increasing levels of complexity of care including dementia, learning and other disabilities, co-morbidities; increasing population non-English reading/speaking; alongside older patients there are older family carers.

General Summary

Voice4Change (V4C) is the children and young people's group (CYP) at Ipswich Hospital (IHT) – more than a focus group
The group is innovative for its approach to targeting and engaging CYP and having a broader focus than just IHT patients; the group involves the wider community via schools and colleges. At the core of the group's ethos is a commitment to a two-way process – gathering feedback, influencing service change and development as well as volunteering to give something to the patients and carers, especially looking at inter-generational work. The work is directed by the CYP, supported by dedicated Children's Matron and Patient Experience Manager.
The outcomes demonstrate the group as being embedded now in the culture of IHT and its user involvement process through continued successful activities and a growing membership with 2 successful Takeover Challenge events under their belt as well as successful presentations to the Trust Board regarding transitional care. Successes have also been personal with members going on to become employees at IHT and entering medical/clinical training.
The group has created links to Ipswich Hospital User Group (IHUG – who have funded a number of their events) and externally with schools and colleges which will support its sustainability.
The model of engagement is easily transferable, and the group spoke about their achievements at a national patient experience conference in 2015.
It has been a real opportunity to engage the young people of Ipswich in the work being done at the hospital and also enabled us to involve them in developing services for young people.

Rationale

IHT identified that it received limited feedback from children and young people and that, whilst we had an extensive user group network it was clear that one group was not having its voice heard – children and young people.
We acknowledged we found it difficult to engage young patients in user forums – their format could be off-putting and boring! To counter this, the Children's Matron and Patient Experience Manager had tried different ways to engage via drop-ins, evening meetings and a Saturday session jointly run with Healthwatch Suffolk. To no avail!
We also recognised that there were lots of local young people who were applying to be volunteers at the hospital and saw an opportunity.
Regrouping and involving schools and college contacts a small group of teenagers was enticed and encouraged by the opportunity to share experiences, volunteer and eat cake.
This group, supported by the Children's Matron and Patient Experience Manager, formed the nucleus of Voice4Change – YCP group at IHT.
The aim of the group is twofold; to help IHT to get the views of young people in the hospital and community about services provided and service development, and to offer volunteer experience to young people hoping to have careers in health care.

Planning

Following the ‘re-group’ – our Children’s Matron and PE Manager pulled in our Volunteer Coordinator – identifying a handful of younger people already in his application pile they got together, after school and over food to plan a way forward. This core group identified that there are many young people in the community who want to share experiences, give feedback and also volunteer at the hospital as they wanted to pursue careers in healthcare.

The core group went to local schools and colleges, attending to talk to classes and at careers events, to promote the group and how it works. The initial group designed a twitter account, which both a group member and IHT have editor access to. They designed a logo for the group and set out the aims. They also requested lanyards with the logo on, to ensure they are recognised.

The group planned activities and events, including the first ever Takeover Challenge Day at IHT in November 2015. We have just held our 2nd this year.

Impact

Voice4Change now boasts over 20 members – one aspect that we have worked with is that the membership is fairly fluid unlike our other user groups, and this has to be accommodated if we are to engage with younger people.

The voice4change group has allowed local young people to experience how it is to work in a hospital. It has also given them confidence in communicating with people. They have also helped us to look into how we can improve services for young people at Ipswich Hospital and improve transitional care. Some of the things the group have been involved in are bingo on the elderly wards, a listening event around transitional services, a cinema night on the children’s ward, nail painting for carers. They also visit the wards on an adhoc basis to offer support. They were a big part of the hospitals ‘Take Over day’ in November 2015 and 2016. The group also take things back to their schools and colleges to get the views of the wider population.

Two of the initial members of the group have now joined the trust as Healthcare Assistants, one whilst awaiting medical school and one has recently started her midwifery studies.

Relevance to Others

Involving and engaging CYP is relevant to all health and social care (stat and vol sector) – the approach taken by IHT with V4C can be utilised elsewhere and is easily transferable.

We have worked closely with the Ipswich and East Suffolk Clinical Commissioning Group youth group and NHS England to give the views of Ipswich Hospital young people.

The group spoke about their achievements at a national patient experience conference in 2015.

Standing Out

It is more than a focus group – it is all about working together – to listen to CYP and ensure their voices are heard AND for them to have the opportunity to get involved directly through volunteering their time within the hospital gaining skills and experience.

It is an innovative way off engaging young people, before the group came along, we had held open days and open evenings and could not get any engagement from local young people.

I think one of the key elements to its success is the passion that the Children’s Matron and Patient Experience Manager have to make it a success. We meet the group outside of working hours, attending evenings in schools and colleges. It is also the commitment of the group members who attend regularly and are very engaged.

Key Learning Points

Visiting local schools and colleges to encourage people to join. Mutually beneficial relationship.

Leeds Children’s Hospital TV: A 21st Century Approach to Information Giving
Leeds Teaching Hospitals NHS Trust
PENNA 2016
FINALIST - Innovative Use of Technology, WINNER - Access to Information

Organisation

Leeds Teaching Hospitals NHS Trust (LTHT) is one of the largest Trusts in Europe and treats around 2 million patients a year. There are seven hospitals within the Trust; one of them, embedded within Leeds General Hospital is Leeds Children’s Hospital. LTHT is the tertiary centre for many childhoods long term conditions. Many specialities, i.e., cancer, renal, diabetes etc., will care for patients from Yorkshire and Humber and UK wide. In some instances, i.e., children’s liver transplantation, cardiac surgery, LTHT is one of the few tertiary centres in the UK, therefore taking referrals from many cities in the UK.
This project pertains to all children and young people treated in our hospital - but it is also transferrable to other centres.

General Summary

Children and young people in hospital (CYP) need to be informed in order to be involved in their care and treatment. This leads to better control for them, helps with self-management of care, allays fears and positively enhances their experience and improve health outcomes
In partnership with Leeds Hospitals Charitable Foundation and Mosaic North (a film company) we have developed the first online platform in the country called Leeds Children’s Hospital TV - www.lchtv.com This has been developed with and for, the CYP in Leeds Teaching Hospitals Trust (LTHT). Patient and professional short films introduce each ward and staff, show common procedures, patient stories and provide feedback in a way that is understood by the young people of today. It is a 21st Century approach to information giving.
This has been led by senior nurses within children’s services, and the Director of a film company, and has the views, input and work of CYP firmly embedded within it.
The site has had over 9000 hits since we first launched in June 2016 (June - Nov). The CQC recently rated it as ‘outstanding’, and recently won the Nursing Times Award in the Child and Adolescent category.
This project has just received further funding from the Charitable Trust to continue for a further two years and will continue to grow and keep up with the times.
This model has now been developed and, with funding, can be replicated to all children’s hospitals across the country

Rationale

The company ‘Mosaic North,’ already had the infrastructure in place in order to deliver this. For the last 10 years we have been involved in working with them whilst they develop a national platform for young people with cancer to share their experiences (www.jtvcancersupport.com). This model is highly successful and that this process helps CYP deal with their diagnosis, share their thoughts and feelings and help others in similar situations. We knew that we would be able to use the ‘build’ of this website and create a different model for children and young people who are in hospital. Rather than a support site, it would be an educational/information film site where CYP could share their views, show common procedures and give feedback about services. CYP have had full input into the project, helping to guide and lead it and to have a strong presence when making the films.

The project is overseen by Mosaic North under the leadership of Mark Wilkinson and guided by Senior Nurses and Play Specialists in Leeds Children’s Hospital (LCH) It is a CYP focussed development - providing a virtual, age-appropriate environment. Leeds Children’s Hospital TV (LCHTV) is the first Children’s Hospital in the UK to develop such an entity. It has developed user-driven, creative content for the web, in a safe and controlled environment, offering best practice in terms of safeguarding and signposting. It has involved children, young people, families, friends and professionals.

It helps to allay some of the unknowns of admission by showing them the personal faces of LCH - providing short films about how the wards look before they are admitted, and virtually meeting some of the staff.
It helps children and young people (CYP) who have been admitted to hospital, or who are receiving treatment, to share their personal experiences in a creative way though drama, documentary, procedural films, music or

animation. It gives the professionals who lead the services unprecedented access to feedback - helping to drive standards up.

It is providing the CYP treated in Leeds Children's Hospital and their families with a forum to share experiences and to learn from others. This is a therapeutic resource for CYP, and also generates content that is unique and a lasting testimony. It can help to pass the time whilst they are in hospital and can also give them a project to complete when they are at home.

Published research shows that CYP patients, undertaking a project developing a music video over three weeks, found that the group that made music videos reported feeling more resilient and better able to cope with their treatment than another group not offered music/video therapy.

The aims of the project are:

- To help to allay fears by providing information in an up-to-date way to aid better understanding of the diagnosis, treatment and facilities available
- Provide online peer group support by showing examples of the experiences of other CYP going through the same diagnosis/treatment/illness as them.
- To help allay anxieties by showing virtual tours of the ward areas and meeting the staff
- To aid staff training and create an ethos of young person friendly care
- Provide feedback about CYP experience in an innovative way - which will help to raise care standards and awareness of issue.
- To provide a forum where the CYP/families/staff can observe procedures explained by a professional and the CYP - to prepare and desensitise CYP prior to having tests/scans/procedures.
- To help support the process of transition from children to adult services**.**

Planning

After establishing a working partnership with the film company, we wrote a bid to the Leeds Hospitals Charitable Foundation for funding over two years to develop this project. This was awarded and we then began more planning discussions.

Those involved in the planning and delivery have been:
Children, young people and their families
The Leeds Hospital Youth Forum
Head of Nursing, Children
Consultant Nurse - teenagers and young adults with cancer
Lead Nurse Healthcare Transition
Communications team
Mosaic North
Youth Workers
Play Specialists
Ward Managers

Once funding was awarded, we then disseminated the information throughout children's services who then 'bid' for the films to be made. We started by making 'Welcome to the Ward' films and then moved on to other common procedure films.

Areas for filming identified by professionals are led by Senior Nurses - filming largely took place on the wards/clinical areas. This was then edited, checked by professionals and the CYP and then placed on the site.

The CYP can either make their own films via their own smartphones/tablets etc., or can be helped to do so by the Play Specialist/Youth Support Workers/professional from Mosaic North

Once the films have been recorded, they are then simply uploaded to the 'Edit Suite' on LCHTV. The films are then edited and sent back to the CYP/Professional who filmed it for approval. Once approved, they are put online for public viewing.

There is also a process for obtaining feedback using a portable 'video booth' placed in playrooms/day rooms and the CYP just needs to press a button and record feedback. This is then edited and placed on the site.

Full consent and safeguarding procedures are in place. Films can be taken down from the site immediately if warranted.

Impact

We have achieved an online website for children and young people, hosting a variety of self-made and professionally directed films. We have had verbal evidence from professionals, CYP and families who have stated that it has helped them in their experience and have placed these on the site, they have used our video booth, film and iPad films to present a dialogue of their experiences.

This project has exceeded expectations as it has:

- Produced high quality films
- It has had over 9000 hits (June - Nov) from cities all over the UK (the largest being from Leeds areas)
- Developed awareness of Leeds Children's Hospital, both in the local and national arena
- Created an awareness about CYP in LTHT and has aided the implementation of young person friendly care across the largest Trust in Europe
- Provided an unparalleled resource for CYP and for obtaining feedback from our service users
- The recent CQC Report 2016: Commended it as an 'area of outstanding practice' in LTHT
- There are currently have over 88 films, which is constantly growing, and we have just been given a further 2 years funding. Further films are under development. It is also being used by CYP in LTHT as well as with adults with learning disabilities; it is a visual tool, therefore accessible to the diverse group of CYP.
- LTHT Executive Board has used the films at the start of their Board meetings.

This IS the future of information given to ALL patients, not just children and young people. It is a blueprint for all other Children's Hospitals and has been collaboration with other individual departments within the Region – e.g., DigiBete (Diabetes), Cystic Fibrosis and Cardiac services, as well as a commissioned film explaining cardiac services by a young man with Down's Syndrome using Makaton.

Relevance to Others

We know that this site is used and as an education tool by many professionals and used in lectures. We have presented the project at University level where it can be used as an educational tool for learning for student nurses.

Promotional videos will also enhance the fundraising abilities of the Charity that has funded us
We are currently undertaking a large project to embed Transition services in out Trust (i.e., the movement of young people from Child to Adult services), there are films that describe the journey undertaken by young people, made by the young people in real time. These help professionals and CYP to understand more fully what this entails. Films have been produced of adult clinics and wards as the biggest fear is of the unknown, therefore seeing the environment before moving services helps to engage YP and reduces DNA rates

This model may also be used by other Children's Hospitals as the basis for developing the same process.

Standing Out

- Leeds Children's Hospital TV (LCHTV) is the first Children's Hospital in the UK to develop such an entity. It has developed user-driven, creative content for the web, in a safe and controlled environment, offering best practice in terms of safeguarding and signposting. It has involved children, young people, families, friends and professionals.

- It helps to allay some of the fears of admission before coming into hospital.

- It helps children and young people (CYP) who have been admitted to hospital, or who are receiving treatment, to share their personal experiences in a creative way though drama, documentary, procedural films, music or animation. It gives the professionals who lead the services unprecedented access to feedback - helping to drive standards up.

- It is providing the CYP treated in Leeds Children's Hospital and their families with a forum to share experiences and to learn from others. It is a site which teaches the CYP the skills with which to help them to self-manage their care as well as learning new skills with regard to media work.

- This is a therapeutic resource for CYP, and also generates content that is unique and a lasting testimony. It can help to pass the time whilst they are in hospital and can also give them a project to complete when they are at home. The therapeutic effects of sharing their experiences through film by creating a safe space for them to express their emotions, is well known.

- The key elements have been that we have ensured that the CYP have been at the centre of all developments and have helped to form the site. The views of the young people have been central to the initiative, and no decisions were made without their input.

- It is patient centred, aids the empowerment of CYP in taking control and helping with their self-management of care, particularly those with long term conditions.
- It has also been a true collaboration with many teams both within the NHS and externally

Key Learning Points

- Collaborate with other - garner expertise
- Identify and acknowledge funders
- Involve young people and families
- Engage management teams
- Disseminate continuously
- Safeguarding and consent with the ability to remove films if required
- Engage the Comms teams early on
- Prompt feedback and editing
- Robust systems for the checking of films
- Must be simple and easy to use - not too flash
- Have someone to coordinate the films/lead
- Accessibility - use on a number of devices
- Accessible to all patients regardless of ability
- Be proud and tell everyone about it!

Young Ambassadors Project
Liverpool University Hospitals NHS Foundation Trust
PENNA 2019
FINALIST - Using Insight for Improvement (Accessibility)

Organisation

Liverpool University Hospitals NHS Foundation Trust was formed on 1st October 2019 following the merger of Aintree University Hospitals NHS Foundation Trust and Royal Liverpool and Broadgreen University Hospitals NHS Trust. The Trust has 74 wards across 4 hospital sites in Liverpool and has over 12,500 staff, making it the largest employer in the city. The Rheumatology service for this submission is based at Aintree Hospital and cares for patients from young people to elderly.

General Summary

We did ask young patients attending the Aintree Rheumatology Young Adult Clinic what they thought about the service. While they were extremely happy with the clinic and transition experience, they felt the waiting area was not young person friendly as they didn't see young people represented in the displays. They also suggested that peer support to young patients during transition and before transfer to adult services could help anxiety and compliance during that complex period.

Their answers and suggestions were embraced by the team, and with the support of the Trust and its Dragon's Den initiative and funding, we asked a marketing "young academy" team to work with our patients in creating poster displays for the clinic waiting area and to produce videos showing our young ambassadors and their positive experiences on transition and life with chronic diseases. Those videos will be made available to younger patients starting the transition pathway. Our young people have become Ambassadors and they have already met as a focus group to further support the service and their peers.

Rationale

Transition to adult services is a complex process, and often is not well planned or even considered. Adult services have often been passive recipients of young patients with chronic conditions that are expected to attend regular appointments and adapt to an unfamiliar and unfriendly setting. This can impact in attendance, compliance to treatment and outcomes.

Our Trust has a proactive approach to transition of young people with rheumatic conditions. We run joint transition clinics with colleagues at Alder Hey Children's Trust and we facilitate and support those patients on their transfer to our sites, Broadgreen and Aintree Hospitals. In the Aintree site we did set up a Young Adult Clinic that has been running for few years to address many of the issues faced by adolescents and young patients. While we were happy with the feedback and complacent with the service, it was after directly asking our patients that we realised that we could improve a few areas. They were very complementary with the clinic itself and their transition experiences but agreed that the waiting room was not young people friendly, with information and displays directed to older population. They also volunteer that transition could be improved by peer support, especially with role models that have gone through the process and can reassure and advise younger patients about to start the process.

Planning

Under the leadership of the consultant specialised in transition, two trainees and a specialist nurse pitched the project to the Trust Dragon's den, obtaining funding for videos and displays. The marketing agency that was chosen had a young academy of apprentices of similar ages than our patients. We asked for volunteers amongst our patients to become Ambassadors, and of the ones that accepted, 3 had timing schedules that allowed them to work with the filming team and young marketing apprentices. We asked the young people to come up with their own ideas for the videos and displays, with little input from the clinical team until the editing time, to ensure a coherent and seamless message. The result was 3 professional high-quality videos representing the day-to-day life of 3 patients, talking about their experiences in transition, and the potential of living fulfilling lives even with a rheumatic disease. We also produced 3 banners with photos and quotes of our ambassadors to be displayed in the waiting areas, and we did contact multiple agencies to ensure information and leaflets appropriated to young people were available.

Impact

The Ambassadors and an extended group of young patients attended the presentation of the material and were invited to discuss as a focus group initiatives and ideas for the service. Their feedback was that the focus group had been very positive to start a network of young people and a feeling of belonging, as well as confirming their interest and willingness to continue to work with the Rheumatology team on any changes and developments, especially in the light of an imminent merger. We are planning to measure our service against transition NICE guidelines and work on changes with the young Ambassadors. The initiative is also considered in other specialities Trust wide. DNA rates and satisfaction will be monitored before and after the implementation of the project.

Relevance to Others

While the Ambassadors all had rheumatic conditions, the videos and quotes are universal, and would be applicable to any young patients transitioning with any chronic diseases. Similar focus groups can be adapted to different specialities. There is ongoing collaborative work with other providers, commissioners and third sector organisations (including Healthwatch and charities), and this initiative is being shared as a shining example of what can be achieved through effectively engaging with young people.

Standing Out

Transition is a hot topic and an area in development. This project was led and taken forward in close partnership with the patients. The starting point of improving the clinic did also bring additional innovative ideas from the young people, as peer support and role model need. This initiative can help other teams to work with young people and listen to their ideas and feedback in order to develop services that are user friendly and improve patient experience, and ultimately, clinical outcomes and user satisfaction.

- **Key Learning Points**
  1. Patient partnership and feedback can demonstrate areas for improvement that were not obvious to the clinical teams, even in services that consider themselves innovative and advanced.
- 2. Patients groups can offer peer support and fulfilling personal interaction as well as being essential to service development.
- 3. Transition and young people access to adult services is an area of special interest where patient support and partnership can help to change adult providers views on service delivery, as well as improving patient experience and satisfaction.

Little Journey: A Children's Healthcare Procedure Preparation and Support Tool
Little Journey
PENNA 2020-21
WINNER - Innovative Use of Technology, Digital and Social Media

Organisation

Little Journey is a Healthnet SME founded in 2019. It was created based off the clinical and research experiences of Dr Chris Evans. Initially Little Journey was focused on supporting children through day case surgery but has now grown to supporting children undergoing multiple healthcare procedures and those participating in clinical trials. The team has grown from two people in 2020 to up to ten in early 2021 and is looking to increase to twenty staff at the end of the 2021. Little Journey licences its solutions to healthcare organisations, life science and contract research organisations, providing a tailored version to their needs. We are providing the NHS with a low-cost solution focusing on the international healthcare and contract research market for ongoing company sustainability.

General Summary

Little Journey is an end-to-end digital psychological preparation and support tool for children and their families undergoing a healthcare procedure. Consisting of a patient-facing mobile application (app) and hospital-facing web application (portal) that enables organisations to control the app in real time, Little Journey provides engaging, interactive and age-tailored content to families from the safety of their own home.

Little Journey was founded by Dr Chris Evans – a peri-operative anxiety management expert and NHS England clinical entrepreneur - with the aim of democratising health information. Working closely with key stakeholders, the platform has grown and evolved based on his research and understanding of key stakeholder needs.

Little Journey has been configured to over 50 NHS organisations. A health economic analysis performed at five NHS organisations identified that 71% of patients verbally offered the app went on to use it, with 98% satisfaction. In addition, premedication rates, on-the-day cancellations, recovery times and fasting times were reduced providing cost-benefit to the hospital (£3.50 per pound invested) and society (£6.00 per pound invested).

Little Journey has since expanded to support families undergoing Endoscopy, phlebotomy and COVID swabs. It was accepted onto the NHS Innovation Accelerator program to increase adoption across the NHS.

Rationale

Each year, 600,000 children undergo day case surgery with research showing that 75% experience significant pre-operative anxiety. This anxiety is linked with worse physical and mental outcomes, and adverse financial implications for the NHS. Fifty percent of children experience bedwetting, nightmares and separation anxiety at two-weeks after a planned procedure, ongoing in 8% at one year.

For hospitals, especially during the pandemic, providing preparation for families before a procedure remotely is challenging. Information leaflets are the least effective form of psychological preparation but are the most common method of preparation due to time and cost pressures.

Little Journey, the concept, was created in 2014 when Dr Evans was working in a district general hospital. Witnessing the impact of pre-procedure anxiety and distress on patient outcomes, Dr Evans wanted to create a tool to increase patient preparation, moving the support away from hospital into families own homes before and after surgery - further reinforced by his experiences of his own child undergoing surgery.

In keeping with the NHS Long term plan and the Kings Fund, Little Journey have created a digital tool to improve the mental wellbeing of children (3.22) undergoing surgery. Our approach empowers families and improves patient experience (5.9) while capturing data as a by-product. Through reductions in anxiety and negative healthcare experiences in childhood, Little Journey provides upstream prevention (2.2) of negative health behaviours.

Planning

The first version of Little Journey was developed and launched in 2018 following an extensive double diamond co-development and design process through informal discussions, focus groups (both parent and Young Person advisory group (YPAGS)), as well as key stakeholder meetings. This version provided an age-tailored virtual reality tour of the rooms' children would visit on the day of an operation. The storylines, characters and technology itself were assessed through two separate YPAGs.

Following its successful launch, we performed a single-centre usability and acceptability study which identified that parents act as gate keepers of healthcare information. It also identified that parents were using the app independently of their child to enable discussions about what would happen. This led to a second version of the application being co-developed which delivered drip-fed information articles to parents before and after the procedure. After the second versions launch, we held focus with early adopters identifying their desire to:

1. create additional information pathways for common procedures such as MRI, Phlebotomy, etc
2. collect and report patient reported outcomes for service improvement
3. update information in real time

This has led to the significant expansion of our mobile- and web-facing applications to further benefit organisations and families. We have worked closely with organisations before and after launch to achieve ongoing customer success.

Impact

- Little Journey has been used over 35,000 times with over 350 app store reviews (4.7 rating). 97% of users rate the information provided as good or very good with an average use of 49 minutes and seven sessions.

- Our usability and acceptability study (IRAS number: 223644) surveyed parents of children undergoing ambulatory surgery to assess the usability and acceptability of the application and gain feedback, identifying that 100% of parents either agreed or strongly agreed it helped them talk to their child about the operation, that it helped prepare them for their child's operation and that they would recommend to a friend before an operation. A follow-on multi-centre randomised controlled trial is currently underway in 10 NHS hospitals (IRAS number: 251219, REC:19/LO/0255).

- An independent health economic analysis assessing the cost-benefit of Little Journey's introduction at five NHS Hospitals was performed. It identified a cost benefit to hospitals through lowering anxiety (reduction in premedication rates) and improving flow through the hospital (reduction in fasting times by one hour for liquids and two hours for solids, 30% reduction in the time spent in the recovery room and 42% reduction in on-the-day cancellations). Societal benefits were identified through an improvement in family's quality of life and reduction in missed days of work.

- Belfast children's hospital reported a 30% reduction in parent perceived anxiety levels in children with Autism and ADHD undergoing day case dental surgery.

Relevance to Others

The Little Journey solution can be applied to any healthcare procedure or interaction whether in primary, secondary or tertiary care. We are creating new content to support children undergoing an MRI and participating in a clinical trial. Our most recent requests from hospitals have been solutions to support children visiting the emergency department or fracture clinic and those undergoing vaccinations; similarly, adult versions for elective caesarean sections and surgery. Our new flexible modular architecture significantly reduces the cost of this.

New modules are assisting the transition of Little Journey from a short-term tool used over a number of weeks to a longer-term solution that supports children to better health. We achieve this through transforming current modules such as our medication tracking tool into public health interventions such as an oral hygiene tracker. These gamify and incentivise dental hygiene to modify behaviours. We are currently discussing how to evaluate such an intervention as a follow up study with Belfast Children's hospital.

We believe our solution is particularly relevant and required in high-risk populations. Health inequalities play an important role in the variation in outcomes surrounding surgery across the NHS. We are using data to better understand our users and modify content to specific patient subgroups. A key example is children with Autism and ADHD where Little Journey can help spread peer-to-peer information as well as healthcare provider created content.

Standing Out

Several patient-facing applications have been created with the aim of preparing children to come to hospital. Typically, they attempt to support children of a single age group over a wide range of procedures using generic, inflexible content with insufficient depth. Little Journey changes this.

Through provision of a solution designed for both children and their parents, Little Journey promotes discussion and learning across the child's social network, while provision of content over the whole peri-procedure period makes the information digestible and understandable. For children, the delivery of multi-faceted immersive, engaging and age-tailored content from virtual reality tours, therapeutic games and relaxation exercises promotes ongoing engagement and makes the preparation enjoyable.

A core component of Little Journey is the flexible, modular, hospital portal that puts hospitals directly in control. By enabling organisations to configure the mobile application to their local patient pathways, we create a personalised solution to increase engagement. The ability to update content in real time prevents incorrect and out of date information dissemination.

A key element contributing to the success of Little Journey has been its co-design with key stakeholders including children, families and healthcare professionals. Similarly, creating continual learning loops through formal research and real-world evidence has ensured the solution stays relevant and evidence driven. Finally, the pandemic has heightened the need for a digital solution that can be continually updated to support families from the comfort and safety of their own home.

Key Learning Points

- There are no one-size fits all solution and human behaviour requires variation to engage and satisfy everyone. This is particularly relevant when it comes to health behaviours and information preferences to better understand how people will respond to health information.

- Keep co-design at the core and listen

- Combine subject matter experts, healthcare professionals, children and families voice together to create the ideal solution but also identify how this solution should be implemented.

- Focus is often placed solely on the efficacy of the intervention rather than its ability – or the desire – for it to be implemented into routine care, resulting in a research-to-practice gap. Close this gap through implementation science focusing not only on the effectiveness of an intervention but the cost-effectiveness, security, implementation strategy and interoperability.

- Balance the need for accuracy and speed by generating data from both standard clinical trial methodologies and real-world evidence.

- Actively seek the unheard voice to address health inequalities. Young person advisory groups naturally self-select their participants with those with chronic illness, interests in healthcare or healthcare professional relatives. The voice of the person who needs the intervention most is often never heard.

- Continue to seek feedback and learn. Create continual learning loops to iterate and improve the solution. It is never finished.

Implementing Always Events during Covid-19 on a Children's Oncology Ward
Manchester University NHS Foundation Trust
PENNA 2020-21
FINALIST - Using Insight for Improvement (Innovation)

Organisation

Manchester University NHS Foundation Trust (MFT) was created in 2017 as part of the City of Manchester Single Hospital Service which involved the merger of Central Manchester University Hospitals NHS Foundation Trust (CMFT) and University Hospitals of South Manchester (UHSM). The second stage of this process involved the transfer of North Manchester General Hospital on 1st April 2021.

MFT now employs over 27,000 people, providing clinical services in ten hospitals across a number of sites in addition to community services across the city and providing a comprehensive range of functions from local district general hospital services through to highly specialised regional and national specialities. It is the principal provider of hospital care to a 'local' population of approximately 750,000 in Manchester and Trafford and to a much larger population requiring tertiary care and is the largest NHS hospital in the UK.

As an organisation, our purpose is to support patients, families and carers, making such people central to actions and decisions taken within the Trust. This reflects our vision to excel in patient experience and our values:

- working together to achieve an outcome
- sharing and valuing the views of all people involved because everyone matters
- respecting others by treating them with dignity and care
- creating a dialogue and establishing an open and honest channel of communication

The Trust is keen to strengthen the level of engagement and involvement of its users when developing services and improving patient experience. One way to do this is to implement Always Events® which is a NHSE initiative that offers a quality improvement methodology utilising co-production by seeking to understand what really matters to patients and their families.

In July 2019, the MFT Charitable Funds Committee supported a proposal to fund a new phase of the development of the WMTM Patient Experience Programme. The plan was to employ a programme lead for 12 months to pilot the integration of WMTM with the Always Events® Methodology within identified clinical areas of the Trust.

The initiative described within this entry was developed to deliver on our organisations visions and values whilst encouraging a cultural change to embrace co-production through utilisation of the Always Events® Methodology.

General Summary

Ward 84, Children's Oncology within Royal Manchester Children's Hospital (RMCH) participated in Always Events® and the programme lead has supported the clinical team throughout the process.
The ward team have successfully completed the implementation of their Always Event® during the Covid-19 pandemic despite pauses to the programme. This has resulted in the development of a co-produced daily communication tool for patients and families, identified as the Patient Information Update (PIU), designed to share key information about care and treatment. The Patient Information Update (PIU) tool includes daily blood count results and the name of the nurse in charge of their care for the day, which was identified as What Matters to them.
The feedback following implementation of the PIU communication tool from patients, families and staff members was extremely positive in improving experiences of care.
The Ward have now applied to NHS England (NHSE) to receive a recognition award and the Picker Institute (NHS Research organisation) have also identified Ward 84 as an area of good practice and will be utilising their case study in various promotional activities for Always Events® for both NHSE and on the Picker Institute website.

Rationale

MFT's Patient Experience framework is underpinned by the Trust vision and values and involves asking patients, service users and staff about 'What Matters to Me' (WMTM) and utilising this feedback to personalise care and to complement new and existing ideas for service improvement to ensure that 'people' are placed 'at the heart' of decision making.

The MFT Experience and Involvement Strategy: Our Commitments to Patients, Families and Carers 2020-2023 was co-designed with stakeholders and was launched in 2020. The Trust are keen to continue working in partnership with patients, families, and carers of services.

A commitment within the strategy is that Always Events® methodology is embedded across the organisation. To utilise this in everyday practice a step-by-step guide tool kit including resources has been developed for all staff to access to provide them with guidance and support.

The longer-term aim is for the improvement methodology to form part of the existing suite of MFT improvement tools that are accessible to staff through the Trust Improving Quality Programme (IQP) and to become part of everyday practice.

The process of co-design with patients and families provides an opportunity to increase service user involvement into the way services are delivered whilst identifying aspects of patient experience that matter to patients.

Planning

Ward 84 Children's Oncology within Royal Manchester Children's Hospital (RMCH) were the first team to participate in Always Events®.

Co-production enabled the ward to work with patients and their families to consider what improvements could be implemented that mattered to them, it also provided the ward with the opportunity to see this from a wider stakeholder perspective.

A range of feedback mechanisms were implemented which included promotional opportunities via social media utilising QR codes and survey links, information posters and written and verbal feedback with patients, families, and staff.

Following analysis of the feedback it was clear that communication was a key element that mattered and after consideration of further evidential data reflecting the themes it was identified that the provision of daily blood count results and having a written reminder of their Named Nurse for the day was important.

The Teenage bay within the ward aims to ensure young people who are admitted to hospital are accommodated in a bay with others of a similar age, to provide peer support. This bay was identified as a first pilot area for the Always Event® as this patient group and their families already had established relationships with the Teenage Cancer Youth Worker and regular engagement already took place, therefore following commencement of the programme it was felt that this patient cohort would be ideal to undertake the co-production with.

Following the process for the Always Events® methodology, a Vision statement in the voice of the patients was developed which states

"I will always receive written daily updates about my/my child's care plan, and this will include information about which Nurse is looking after me/my child".

This resulted in a written communication tool being developed in partnership with patients, families, and staff members, identified as the Patient Information Update (PIU).

As blood count results are available to staff on the night shift, the ward agreed that the communication tool (PIU) would be completed by them in readiness for distribution first thing in the morning, which provided patients and families with reassurance in respect of treatment progress schedules as soon as practically possible.

An 'Aim Statement' to support the process of the Always Event® occurring was developed with measures to sustain an agreed target.

Impact

Baseline data collected over a period of time highlighted that patients and families were not consistently receiving written daily blood count results (see Table 1 phase 1) in the agreed pilot area in the Teenage Bay. This resulted in patients and families not being informed of key information in a timely manner.

The Patient Information Update (PIU) was co-produced with patients and families and a PDSA (Plan Do Study Act) cycle was commenced in the pilot area to test its implementation. To monitor and evidence that the PIU was always being provided, staff carried out daily audits which evidenced that it did happen 100% of the time during the pilot (see Figure 1).
To test the Always Events® methodology in a second area of the ward (side rooms), additional baseline data was collected on the advice of the NHSE Always Events® team. This baseline data identified that patients in the side rooms were not receiving written blood count results (reflected in Table 1 phase 2). A further PDSA cycle was commenced to test the PIU with this group of patients to run alongside the PDSA in the Teenage Bay.
The PIU was adopted successfully in both the Teenage Bay and the side rooms therefore the next stage of the pilot was to roll out the Always Event® across the remaining ward areas. See Figure 1, highlighting improvements during the tests of change and implementation.
The PIU is now successfully embedded across all areas as part of everyday practice, which is evidenced by regular audits (see Figure 2).
Following successful roll out of the PIU across the ward, a short experience survey was circulated to all patients, families, and staff members to gain their feedback regarding the effectiveness of the tool. The survey results highlighted the following:

- 99% of patients' and their families and 84.5% of staff rated the PIU as excellent or good.
- 80% of patients' and their families and 69% of staff members said the tool was definitely useful.

Qualitative feedback regarding the PIU was extremely positive and is included in Table 2.

Relevance to Others

The MFT Always Events® pilot was designed to test the methodology in a range of patient groups. The clinical areas identified to test the Always Events® methodology included the Community Palliative Care Team, Maternity Services, and the Haematology Ward.

The Always Events® toolkit and resources are available to all staff to support quality patient and service improvements.

Always Events® methodology can be used to support our hospitals and community services to embed the Trust's Experience and Involvement Strategy commitment to co-produce services.

The PIU tool will be rolled out to other areas to support shared learning and the spread of good practice.

MFT have utilised key stakeholders for example, Healthwatch, who are members of the Always Events Oversight Group, to promote the learning from Always Events® on their external platforms.

Standing Out

- The implementation of Always Events® has improved the patient, parent and staff experience with positive qualitative experience feedback highlighted in Table 2. The outcomes of a patient, parent and staff survey highlighted that 99% of patient's families and 84.5% of staff rated the PIU as excellent or good. Similarly, 80% of patient's families and 69% of staff members reported that the PIU was definitely useful.

- Improved relationships with patients and families as the PIU has enabled staff members to provide timely, meaningful information regarding the patients scheduled day. The information recorded provides a reminder of the patient's blood count which subsequently impacts on treatment schedules for the day, ultimately improving their experience.

- Oncology patients' families often request a range of documents relating to care and treatment plans, to provide them with a visual reminder of planned treatment and for later reflection and recognition of treatment progress and diary recording. The PIU provides pertinent information in a timely, patient friendly format for their own safekeeping.

- The experience of staff members has improved since the Always Event® as it has proven to be an effective time management tool for staff. The key information is inputted on the PIU by the night staff before being distributed daily to the patients and families in the early morning. The PIU's are always distributed after the ward team huddle, pre-empting any queries or concerns from patients or their families. Subsequently the PIU circumvents the need for staff members to physically review the medical notes/systems to clarify information regarding blood count results.

- The name of the nurse looking after the patient each day is recorded on the PIU, this always allows first names to be used thus building relationships and improving experiences.

Key Learning Points

- Clear Senior Executive Sponsorship
- Oversight Group in place with key stakeholders to ensure progress, responsibility, and ownership
- Agree a formal process for reporting into existing organisational governance structures
- Clear benefits in regular NHSE Always Events® coaching calls
- Ensure Programme Leads develop the required knowledge & expertise to support teams with the implementation of the Always Events® methodology
- Ensure all measures are correct/accurate
- Advanced/strong analysis skills required to interpret the data to understand 'What Matters' to patients/families.
- Always Events® must always derive from the patients' vision.

The PACE Setter Award – The Primary Care Quality Mark for C&YP's NHS Services
NHS Coastal West Sussex CCG
PENNA 2016
WINNER - Strengthening the Foundation

Organisation

Pulborough Medical Group, Pulborough GP Surgery
(Part of NHS Coastal West Sussex Clinical Commissioning Group (CCG)) is delighted to be able to submit their application for consideration of a 2016 PENNA Award.
Our work was conducted as part of our application for a PACE SETTER Award which is the Quality Mark for Children and Young People's NHS Services (http://coastalwestsussexccg.nhs.uk/pacesetter)

General Summary

In terms of our local initiatives, we have decided to focus specifically on two areas for our PENNA Award application:

1. Receptionist (Non-Clinical Staff) Training (using a Red / Amber / Green (RAG) traffic light method) – (Slide set for energetic Receptionist Workshop attached)
2. Online video for young people – to improve patient experience and access for young people

Rationale

We saw the PACE SETTER Award as an opportunity to reassess and engage our services for young people and children so we can improve upon them in a patient-centred way.

At our practice, for our engagement with families, we undertook 5-hour session of telephone interviews comprising over 1.5% of population by the lead GP. This coupled with engagement with our staff lead us to focus on 2 initiatives:

- Ensuring our current appointment systems whilst timely were also robust and safe so that staff and patients could be confident that patients were being seen in the right time frame and in the right place. Therefore, we focused on training our non-clinical staff (receptionists) on the key features of patient contact that would raise concerns and led to a more prompt review or advise to call 999. To simplify this process symptoms were ranked into Red, Amber or Green categories by the receptionists (with the doctors only allowed to listen in) based on the risk of a severe problem. (See Workshop Slide set attached)

- On talking to our young people, it became clear that a significant proportion had been deterred from attending appointments due to unfamiliarity with the practice and process of having an appointment at the surgery. The message from young people was very clear that the preferred forum for sharing information regarding this was online. This led to the development of a 'walk through' video showing the practical and key aspects of attending an appointment, from what to do with a prescription to issues around confidentiality. This project led on to a dedicated sister site for young people with useful information available related to their concerns and needs. (Link to video is: https://coastalwestsussexccg.nhs.uk/pace-setter-pulborough-medical-group-pulborough)

The Panel letter received when we received the PACE SETTER Award states "Your application was particularly strong in the RAG Educational Receptionist Training Exercise (using the RAG status (similar to the high-volume condition pathways in use)). The way this was further corroborated by the thorough patient engagement exercise, which underpins this Award, is highly to be commended. This idea and the lessons learned in designing and implementing it will likely be of considerable interest to many other practices, so this is great and innovative too. "

Planning

1.Receptionist Training - Dr Nikki Tooley who undertook the telephone interviews with patients noted that "great feedback was received upon access as a result of triage system change. Therefore, we focused upon reinforcing the safety of this new system by planning receptionist training and development strategies."

Our new triage system allows receptionists to book more patients directly into appointments without an initial GP assessment. When we carried out an early assessment of the new system the staff identified a need for training in order that they can safely undertake the enhanced prioritisation process our new system requires. In particular, it had found that they were not all confident in their ability to recognise and distinguish the clinical features in a sick child that demand an immediate GP response. Patients and our patient group welcomed the proposal to provide the additional non-clinical training and the workshops for the receptionists were full of energy, lively discussion and were universally welcomed by the staff.

What did we plan to do?
We ran educational sessions exploring their beliefs and supporting nonclinical staff in making decisions on the urgency of clinical symptoms and the appropriate action. (GPs, GP trainees and nurses were allowed to attend in an Observer role but not input).

What did we do?
Two training sessions were undertaken with the reception staff that involved developing and introducing a Red/ Amber / Green (RAG) tool of urgency and group discussions on appropriate actions.

2. Accessing Services - Improve the online information aimed specifically at our young people as raised by the engagement exercise – prepared a video to inform patients with view to a sister website containing information specific to young people - The Panel was highly impressed with the online video produced and particularly with your comment that it was enlightening to see the building from a young person point of view. The PACE SETTER Award Panel stated, "It would be good to understand more about the talents and time needed to produce such a film piece to share with other practices as it would seem the script alone needs much work to fit so much information of relevance into a short slot."

Impact

The training project has had great impact on the working of the GP team in terms of patient safety as well as team working and communication.

Feedback regarding the website and video has been positive from our younger patients and is leading onto further project ideas.

Relevance to Others

Overall, Dr Nikki Tooley PACE SETTER Lead at Pulborough Medical Group stated that "our new PACE Setter Lens is allowing us to look at all the services we provide for Children and Young People and think differently about how we arrange and offer services for this important group."

Standing Out

- Many practices do not accept that their front line/ reception staff need to undertake a level of prioritisation in booking patients into appointments but the interest from our front-line staff and the confidence in their ability to undertake their work has been remarkable. Pulborough Medical Group may be ahead of their time in terms of seeking to boost the confidence of staff and their own fulfilment/ experience of working as part of our practice team.
- Our practice is all about Safety and we believe the whole patient experience should be as high quality as possible for the good of patients, their families and staff. This includes the first encounter that patients have with the practice team when they ring in or attend at the front desk.

Key Learning Points

Undertaking the PACE SETTER Award application around Children and Young People at our practice has been enjoyable and extremely rewarding and has helped to build up our practice team

Championing the Voice of Children and Young People in Southwark
NHS Southwark Clinical Commissioning Group
PENNA 2016
RUNNER UP - Commissioning for Patient Experience

Organisation

NHS Southwark Clinical Commissioning Group (SCCG) is one of 209 organisations nationally. SCCG is made up of 41 GP practices across Southwark. As members of the SCCG, they guide the organisation. They also make sure the CCG is getting the most from the money it is allocated from the Government.

Southwark GP practices have elected a Governing Body to lead the CCG work. The Governing Body is made up of local GPs and nurses, hospital doctors and NHS mangers. The CCG is also has around 50 members of staff that support the Governing Body.

General Summary

SCCG and Southwark Council worked together with children, young people (CYP) and families to develop priorities and solutions for health, education and social services in Southwark to make sure that children from 0 - 25 years, including maternity have the best health and wellbeing outcomes possible.
To engage with this group of people who are often considered to be seldom heard we designed a programme of innovative engagement methods which included;

- a pop-up graffiti wall in Peckham Square
- working with Southwark Youth Council to develop a survey
- developing a range of CYP personas
- text polling
- developing a forum theatre production
- commissioning a spoken work artist to perform a rap about mental health
- holding a solutions workshop with 20+ young people
- supporting a campaign led by young people

The programme of engagement was led by the CCG Engagement Manager and The CYP Project Manager and was supported by two clinical leads, two heads of service and the Director for Integrated Commissioning.

The rich information captured through this engagement process has been fed into commissioning intentions.

An engagement toolkit has been developed to ensure that methods from this programme of work can be replicated in other areas across the CCG.

Rationale

The health and wellbeing of CYP in Southwark is mixed compared to the England average and therefore we wanted to develop commissioning intentions that ensured CYP, and families have the best health and wellbeing outcomes possible.

We thought that it was extremely important to talk to CYP and families about what matters to them and what keeps them happy and healthy. We looked at all of the national and local evidence, mapped previous engagement and talked to professionals working with CYP to develop the following priorities:

1. Early years, better start, 0-5 years and being ready to start school
2. Emotional wellbeing and mental health
3. Long term physical conditions including diabetes, asthma, epilepsy, sickle cell and complex co-morbidity
4. Reduce the number of children and young people being admitted to hospital as emergencies
5. Young people's health (10-25 years old) including sexual health, drugs misuse, self-harm and gang violence
6. Vulnerable children and young people including
7. Children and young people who are very overweight

We wanted to test these priorities with CYP and families and begin developing solutions that CYP and families want and need.

Planning

The programme of engagement was led by the CCG Engagement Manager and The CYP Project Manager and was supported by two clinical leads, two heads of service and the Director for Integrated Commissioning.

We worked closely with Southwark Council and Healthwatch and held regular planning meetings were held to ensure everyone was clear of the objectives.

Our programme of engagement plans went to our Engagement Programme Board throughout 2015/2016 for advice and support in developing the methods we were going to use. The project was also assured by our Engagement and Patient Experience Committee (EPEC) – a subcommittee of our Governing Body.

A full report on the programme of engagement that was discussed and assured at EPEC has been submitted as supporting evidence.

Impact

The two main impact measurements included the number of young people who were actively engaged in this piece of work and how their feedback impacted decision making.

The CCG held workshops and focus groups, used art and theatre, undertaken surveys and supported campaigns – reaching out to over 280 young people in Southwark. We achieved this by working with voluntary organisations that worked with young people to promote our events, worked with Southwark Youth Council to develop and disseminate a survey and worked with the National Citizen's Service to run a solutions workshop with young people and a health and wellbeing campaign – designed and delivered by young people with support from the CCG.

By working with voluntary organisations, we were also able to reach out to 'seldom heard groups' including young people, who are LGBT, looked after children and families who have children with special education needs and disabilities.

The feedback collected from all of our activities has contributed to finalising the CYP Strategic Framework and commissioning intentions. We created a 'you said, we did / are doing' table to highlight the impact of their feedback. This can be located in the full report that has been submitted as supporting evidence on pages 30 and 31.

The participants from the National Citizen's Service gave excellent feedback regarding their involvement in this project and have expressed an interest in continuing to stay involved in the work of the CCG as advisors and story collectors (further details in section six).

Relevance to Others

We will continue working with Southwark Council, Healthwatch Southwark and local voluntary and community groups to build on this work and collect young people and families' stories to contribute to local decision making and commissioning intentions.

We will also continue to share the outcomes of this work with partners via our Engagement Newsletter.

Standing Out

Besides from running an extensive programme of engagement and reaching 280+ people from a population that is often seldom heard we also used novel methods for engagement that were relevant for that group including:

- working with Southwark Youth Council to develop and disseminate a survey to school children
- developing a range of CYP personas – case studies that are based on the lives of real people
- Text polling – a live, online poll that people can text anonymously for free to answer questions at workshops
- developing a forum theatre production

- commissioning a spoken work artist to perform a song about mental health
- holding a solutions workshop with 20+ young people
- supporting a campaign led by young people

We worked with Healthwatch and held a joint event ‘My Voice Counts’ in April 2016 where we used some of these methods. The event was planned and delivered jointly, and we commissioned the Bubble Theatre and a local rap artist to highlight health and wellbeing issues that are relevant to young people and then discussed solutions with the participants. The event was advertised via voluntary organisations, Southwark Youth Council and we ran a vibrant Twitter campaign. The report was disseminated to all Healthwatch members.

Key Learning Points

The key things that we learned from working on this project include:

- To reach seldom heard groups such as looked after children, young people who are LGBTQ and young people with special education needs and disabilities it is best to build up relationships with voluntary and community organisations who have access to this population and can support you to undertake workshops/ focus groups with this cohort.

- Have young people as champions to reach out to their peers. This worked really well for us, and we were only able to reach the high number of young people we did due to working with the Southwark Youth Council and participants from the National Citizen’s Service.

- One thing we would do differently is going to groups that already meet such as youth clubs and other after school groups. We found it quite difficult to get people to sign up to our ‘My Voice Counts’ event – although it did work out on the day as we did last minute promotion with the local school and got more people to attend.

- Young people have shorter attention spans then adults, so any engagement methods and activities have to be fun, quick and relevant to them.

NHS Child Health
NHS North of England Commissioning Support
PENNA 2016
FINALIST - Innovative Use of Technology

Organisation

North of England Commissioning Support (NECS) is one of the leading Commissioning Support suppliers in the country. The breadth and depth of our portfolio of services meet the end-to-end commissioning support needs of public sector organisations across the health and social care spectrum and beyond.

Our dedicated, expert, multi-disciplinary teams, supported by a broad range of specialist partners, apply their extensive knowledge and practice-based NHS experience to design and deliver creative solutions for our customers.

We employ more than 800 staff who have a wide range of skills and experience in designing and delivering innovative and high-quality healthcare commissioning solutions. NECS has offices in Newcastle, Durham, Teesside, Carlisle and Penrith. We work across the country, with customers in the North East, Cumbria, Lancashire, Yorkshire, Humber, Suffolk and London.

We deliver high quality, cost effective and innovative services locally, regionally and nationally to a range of customers including Clinical Commissioning Groups (CCGs), Commissioning Support Units, General Practices and GP Federations, Foundation Trusts, Local Authorities, NHS England and its Regional offices and Clinical Networks.

General Summary

The NHS child health project was developed by the North East Urgent and Emergency Care Network. It received funding from the NHS' New Models of Care programme for a range of pioneering projects.

As a result of researching patient perception, there was a significant opportunity to support parents of young children. This project focuses on producing a suite of material to support health care in the under-fives including an app, booklet and asset-based community engagement via the third sector to target key groups. The NHS child app project was developed and within eight weeks of its launch has nearly 3,000 downloads and 30,000 page views of the app.

The key benefit is giving parents more confidence in looking after their under five children and increased parent/carer satisfaction. The app gives easy to understand guidance on childhood illnesses, recognising when your child is unwell, and advice on when and where to seek further treatment.

The app is available on Google Play and the App Store by searching for NHS child health.

Rationale

Research shows that parents are becoming less confident about what to do over a range of common childhood illnesses, and intelligence suggests that parents are seeking more medical intervention earlier and attending Emergency Departments and walk-in centres/urgent care centres.

Societal changes have also had an impact on parents seeking help for their child as generally people live apart from support networks and tend to seek medical advice instead of advice from their parents/grandparents. Emergency Departments are seen as the safe choice, with individuals being more likely to attend with a third party, particularly with a child.

Children account for a high proportion of attendances (2015/16) but approximately 60% of 0–4-year-olds are discharged with no treatment. Added to this, attendances at Emergency Departments for under-fives in the North East region is 763.6 per 1,000 population, which is significantly higher than the England average of 540.5 per 1,000 population.

A fun day held in Sunderland created an opportunity to understand, from parents who had children under five, why and how they access certain services and the ways in which they would wish to receive information about health services in the future.

This helped to understand the gap in communications and the concepts people had about what each service was most appropriate for. Further intelligence was gathered using marketing analysis tools (Mosaic segmentation) and previous research to identify the key target group and how best to communicate with them. Families on low income, with young children and limited familial links were felt to be those needing support of the project. They have been identified as early adopters, key to embracing and spreading the messages of self-care wider.

This was tested further in focus groups targeted at parents and carers under five, mapped to the socio-economic groups of the North East. Some of the comments included:

- Parents would use both the app and booklet and would recommend to others
- More likely to be 'background' reading (learning about care before illness/accident occurs) rather than used in emergencies
- Would be read during nap time/feeding time or in the early onset of minor health/behavioural concerns (e.g., rashes, constipation, excessive crying, etc)
- Preference was therefore divided between smartphone (app), tablet (app), booklet or app and booklet e.g., some would use the app and direct grandparent carers to the booklet

A social marketing approach was implemented and an educational tool for parents and carers with children under five was developed.

Planning

Developing the NHS child health app and booklet

The NHS child health project was developed by the North East Urgent and Emergency Care Network. It received funding from the NHS' New Models of Care programme for a range of pioneering projects, such as improving the NHS 111 service through extra clinical support, and a new hi-tech 'flight deck' for more sophisticated management of urgent and emergency care capacity across the region.

A working group was developed which consisted of representatives from paediatrics, communications and engagement team, nurses, health visitors and pharmacists from across NHS organisations in the North East. This project is aimed at improving self-care and providing an education tool for parents and carers with children under five to give them advice and support. It was rolled out across the North East region to ensure that the same advice is given out consistently across the region.

The target audience was identified as:

- Parents and carers of children under five years old
    - Aimed specifically at the Mosaic Group M (family basics) which is a group that is over represented at Emergency Departments
- Healthcare professionals
- NHS organisations
- Local councils for children's centres

Using the intelligence gathered, the group developed a booklet and an app for the North East, targeted at parents and carers of under-fives to help to build confidence and encourage self-care. It is hoped that this will lead to:

- Better decisions made about common childhood illnesses and reduce inappropriate attendances at urgent and emergency care points of access
- Offering responsive, quality information and points of contact in primary and community services, it is hoped demand can be shifted towards this end of the health care system

The content of the booklet and app was written by the working group, and this undertook rigorous testing, including being independently reviewed by clinicians across the North East and reviewed by parents and carers of under five-year-olds.

The app also contains a feature that geo-targets NHS services to the user so that they can find the nearest NHS service to them, as from research showed that parents/carers were unsure where to go. Children centres were also added to this feature.

From the first focus groups that were undertaken, they have given clear guidelines about the tone of voice and the appearance of both the app and the booklet.

Once the app and booklet had been developed, further focus groups were undertaken in the North East (independently selected, within the target audience and socio-economically mapped). The feedback from the group was positive. The groups gave constructive feedback about how the app and booklet could be improved.

Examples included:
- Having an audio feature on the app so when they were taking care of their child, they could listen to the advice instead
- Ensuring that the search function within the app was more obvious
- Structuring the advice so that it always appeared in A-Z order
- Including additional advice such as bottle feeding, weening and how to put baby to sleep

These changes were implemented as a direct result of feedback from the target audience.

Changes were also incorporated from healthcare professionals including health visitors.

Materials that were developed
In order to support the app and booklet, further materials were developed including:
- Information card (A6 size) to be used by healthcare professionals to give to the target audience to enable them to download the app
- Interactive pdf that can be used and hosted by NHS organisations across the North East
- Toolkits which are used by partner organisations

Marketing campaign to promote
Once the education tools were developed, it was essential to make parents and carers of under-fives aware of these. Again, reviewing the insight and the Mosaic segmentation, a digitally led marketing campaign was developed.

This campaign was launched on 30 September and included the following activity:
- Launch in partnership with regional radio station
- Booklet distribution across the North East to NHS services. This meant that clinicians could hand them out as part of conversations about looking after the health of a child
- Information card distribution to pharmacies, children centres, play groups to encourage people to download the app
- Digital advertising via Mumsnet, online newspaper sites, Google AdWords, Facebook
- Digital content via social media includes production of video
- Insertions in the Primary Times and Raring2Go (magazines which are put into toddlers back packs at school)
- Asset based community engagement via the third sector to target key groups

The app has also been incorporated as part of the regional winter campaign for the North East, so further digital promotion is also taking place.

Impact
The NHS child health app and booklet has been available for eight weeks (on 25 November 2016) and is still in the early stages. However, given this short timescale, it has achieved the following:
- Positive comments from the target audience – examples given below
- Positive comments from healthcare professionals
- Nearly 3,000 downloads
- 30,500 page views of the app by individuals
- On average, users spend over two minutes on the app

- 61% of users of the app are under 35
- Social media reach of 273k, over 200 shares and 53k view of the video

The statistics on the app demonstrate that parents and carers of children under five are feeling more confident (number of uses and the average time spent). This is further demonstrated by a mid-review where the following comments were obtained.

Comment from target audience:

Jessica Bowen, new mum, Newcastle:
"I think we're pretty lucky that we have this kind of information. In past generations people didn't necessarily have such involvement from the health system – they relied on family. Nowadays we don't always have the time to spend with family, and relatives might live in different places, so this kind of information is a real help.

"As a new mum, I think it's aimed just right for me. It is clearly signposted, so you know how to find information easily, and I really like the advice from doctors and health visitors. I'd read the booklet when we first brought our baby home from hospital, then use the app to look up any symptoms or concerns later on."

App user: "Excellent – a must have app that has all the relevant information you should need for your child. A "must" that all parents should have on their phone."

Relevance to Others

- Already had other NHS organisations within other parts of the country ask for further information – content would be the same, the NHS services location finder would be the only element to be updated
- Provides basis and process for developing other apps
- This project would provide an evidence base to support similar initiates in the future as there is little available evidence readily available in other areas at the moment

Standing Out

- Part of national NHS drive to develop more apps to encourage self-care and help parents manage illness
- This project is built on evidence provided from pilots, from other schemes and using specialist knowledge and understanding of urgent and emergency care services
- The public influenced the development from start to finish - the app and booklet have been developed using insight and early results are showing that the target audience are using this
- Includes a location finder for NHS services
- Gives NHS health advice in people's homes via an app and increases confidence

Key Learning Points

- You need to understand your target audience
- These tools have been developed using a social marketing and research/insight

The Takeover Challenge
Northampton General Hospital, Kettering General Hospital, Young Healthwatch Northamptonshire
PENNA 2019
FINALIST – Engaging and Championing the Public

Organisation

Young Healthwatch Northamptonshire (YHWN) are a group of young people aged 11-24 who live in Northamptonshire. They make sure that children and young people have a voice in health and social care locally. The young people involved come from various backgrounds and have varied lived experience of health and social care. The role of Young Healthwatch Northamptonshire is to influence better health and wellbeing and improve the quality of services. The findings are reported to the decision makers so that they can improve services for other young people locally.

Northampton General Hospital NHS Trust is an 818 bedded (inc 128 mothers and babies) hospital providing general acute services for a population of 380,000 and hyper-acute stroke, vascular and renal services to people living throughout the whole of Northamptonshire, a population of 692,000. The Trust is also an accredited cancer centre and provides cancer services to a wider population of 880,000 who live in Northamptonshire and parts of Buckinghamshire. In addition to the main hospital site, which is located close to Northampton town centre, the Trust also provides outpatient and day surgery services at Danetre Hospital in Daventry. More than 5000 staff are employed by the hospital, including clinical and non-clinical.

General Summary

In November 2019 Northampton General Hospital (NGH) and Kettering General Hospital (KGH) worked collaboratively with Young Healthwatch Northamptonshire to use the ‘Takeover challenge’ as an effective means of involving children and young people in a mutually beneficial and positive way. The children and young people co-produced a fun packed, educational agenda which allowed for them to gain an insight into the workings of the hospital at the same time as providing their own feedback and insight into a number of areas. A day which ranged from attending Trust Board through to dressing in doctors’ scrubs and taking part in simulated activities has built a lasting relationship between the hospitals and the Young Healthwatch volunteers which will continue to flourish with many planned future activities. Feedback and insight provided from the children and young people has already been put into action by the hospitals with a new menu being designed on the children’s wards and a communication toolkit for staff.

Rationale

Conducting effective engagement with children and young people within the NHS can be challenging and many organisations fail to do it effectively. In November 2019 Northampton General Hospital (NGH) and Kettering General Hospital (KGH) worked collaboratively with Young Healthwatch Northamptonshire (YHWN) to use the ‘Takeover challenge’ as a means of involving children and young people in a mutually beneficial and positive way. The Takeover Challenge aims to puts children and young people into real-life decision-making positions within organisations and enable them to experience what it is like to ‘be on the other side’. Children gain a valuable insight and gain experience of a workplace, while organisations benefit from input into the everyday workings of their service. No other Healthwatch within the UK has previously undertaken this and the hospital and Young Healthwatch worked hard to make it work effectively and safely with extremely positive results.

Planning

It was important that the day worked for both the children and young people and the hospitals so the agenda for the day was coproduced between the hospitals and young people from the beginning. The children and young people identified areas of interest and the Heads of Patient Experience & Engagement/Involvement from the two hospitals spoke with key figures in the hospitals to see where the children and young people could make the most impact and influence. From this, a fun packed educational day was planned. In addition to this, safeguarding measures were put into place to ensure the children and young people were protected at all times as parents would not be attending- this is unusual in itself as most engagement activities would involve parents or guardians being present. This ensured we really heard the voice and the child or young person themselves.

At Northampton General Hospital, the day started at 10am with 3 Young Healthwatch volunteers ranging from 11 to 18, the Young Healthwatch Northamptonshire manager, the Head of Patient Experience & Engagement and the Patient Experience Coordinator. The day went as follows:

- Briefing between the team members and a welcome to the hospital from the Director of Nursing
- Meet and greet with the Clinical Director for Children's Services followed by a session with the children's matron and a member of the play team. The children and young people were able to learn more about the fantastic service the play team provide, in addition to giving their views on what it is like to be a patient. Some interesting conversations were had around the transition from children's services to adult services and the need for more support in this area. The children were also asked if they could support the hospital in future endeavours to collect feedback from children that have been patients, this was agreed, and further time together planned for in January.
- The children and young people were met at the ward by the volunteer train driver for the train that takes children to appointments and operations. The train was set up by the volunteer's service to ease children's anxiety. The children and young people had a ride on the train; there were definitely a lot of giggles and an agreement that the train was a positive experience.
- For lunch, the volunteers were joined by the Catering Department who provided a sample from the current menu and the proposed new menu for the children and young people to try. It was a resounding 'yes' to the new menu and the children and young people all agreed that the food was delicious. The catering department were grateful for the feedback.
- Following a short break, the children and young people spent the afternoon in the hospitals simulation suite where they were able to dress as doctors in scrubs and with the support of a hospital doctor and resus technician, take part in a number of simulated scenarios. This included drawing up drugs and anaesthetising the mannequin, carrying out the WHO checklist, taking consent to operate, bandaging the mannequin and many more educational and insightful activities.

At Kettering General Hospital, the day started at 9am with 4 Young Healthwatch (YHWN) volunteers ranging from 11 to 18, the Healthwatch Northamptonshire CEO and the Head of Patient Experience & Involvement.

- The day started with a welcome briefing with YHWN
- Following this was a meet and greet with the Chief Executive to talk about the workings of a hospital and the types of things a CEO does. There was a Q&A session where YHW could ask questions to understand more about NHS.
- YHWN attended Trust Board where they talked about the day ahead and any particular areas of interest; during the session with Trust Board a young person's patient story video was shown.
- There was a session with the communications team where YHWN designed public information to support the Trust on reaching a wider audience and ensuring the material it produces is engaging.
- YHWN reviewed how we collect patient experience from young people, help redesign this and provided feedback on other opportunities available to the Trust.
- For Lunch YHWN sampled the food that is server on Skylark, the Paediatric inpatient ward. Selecting from the lunch menu YHWN tried the same food that the patients were eating. After lunch we spent some time in the staff rest area where YHWN provided feedback and reflected on the day so far.
- YHWN then looked at the themes the Trust has received relating to Children and young people's services, they shared their thoughts on these themes and we discuss some case study's, following this, ways to improved were explored.
- We then visited the Radiology department to look at the types of equipment are use, why the hospital uses it and finished by looking at X-rays and taking a quiz.

Impact

Everyone that took part in the day across both NGH & KGH had a thoroughly enjoyable day. The feedback from YHW was extremely positive with the children and young praising the activities for how interesting they were, but also how they felt they were really listened to. Kia, a Young Healthwatch Northamptonshire Volunteer who visited Northampton General Hospital, said: "The environment is very friendly, all the staff are lovely, and they make you feel really welcome". Another Young Healthwatch Northamptonshire Volunteer, Anya, said: "We did a food tasting session of the food they give out on the children's ward, and we tried it all and gave our input on it and they said our input is very useful"

In response to the feedback the children and young people provided throughout the day, a number of changes are planned and have taken place as a result. This includes:

- Children and Young Peoples communication and involvement toolkit is being developed and rolled out to KGH staff with the support of the volunteers from Young Healthwatch Northamptonshire. (KGH)
- Planned change to the children's menu at NGH based on the feedback given. (NGH)
- Support from the volunteers in designing new feedback cards for children and young people in support of the changes to the Friends & Family Test taking place in April. (NGH & KGH)
- Discussions taking place around the transition between child and adult care and the problems this can cause. (KGH)

What is evident, is the lasting relationships that have been built between all involved. Both hospitals are eager to identify further coproduction pieces which can take place and ensure the voice of the child is heard throughout.

Relevance to Others

This is relevant to any organisation that is looking at ways to engage with children and young people in an interesting, educational and effective way. It didn't feel like the hospitals were just taking, it felt like they were also giving back.

Standing Out

This project stands out as no other Healthwatch participated with an NHS Trust in this way. Young Healthwatch coproduced this event in partnership with the trusts involved. This started from the very beginning with the design of the agenda and how the day would run, right through to identification of the projects which would be taken forward. In addition to this, the day was both educational and informative for the children and young people as well as providing useful input and feedback for the hospital. It is even hoped the hospitals may have encouraged a few more future employees for the NHS.

Key Learning Points

- Using the momentum of national activities such as Takeover Day can initiate effective engagement with Children & Young People and provide both educational and insightful days for all involved.
- You don't always have to involve parents in the day! Having Young Healthwatch volunteers meant we only heard the voice of the child.

Beads of Courage
Nottingham University Hospitals NHS Trust
PENNA 2020-21
FINALIST - Fiona Littledale Award, Personalisation of Care

Organisation

Nottingham University Hospitals NHS Trust provides services to over 2.5 million residents of Nottingham and its surrounding communities. We also provide specialist services for a further 3-4 million people from across the region.

We are one of the largest employers in the region, employing over 17,000 people at the Queen's Medical Centre (QMC), Nottingham City Hospital and Ropewalk House.

QMC is where our Emergency Department, Major Trauma Centre, Nottingham Treatment Centre and the Nottingham Children's Hospital are based. In 2020 the Children's Hospital was awarded Pathway to Excellence® accreditation in recognition of its outstanding work and commitment to paediatric care and treatment. QMC is also home to the University of Nottingham's School of Nursing and Medical School.

Nottingham City Hospital is our planned care site, where our Cancer Centre, Trent Cardiac Centre and stroke services are based. In 2020 Nottingham City Hospital was awarded Magnet® accreditation with 12 exemplars of outstanding practice.

Ropewalk House is where we provide a range of outpatient services, including stroke, renal, neurosciences, cancer services and trauma.

We are at the forefront of many research programmes and new surgical procedures. In partnership with the University of Nottingham we host a Biomedical Research Centre carrying out vital research into hearing, digestive diseases, respiratory, musculoskeletal disease, mental health and imaging.

As a teaching trust we have a strong relationship with our colleagues at the University of Nottingham and other universities across the East Midlands.

We play a vital role in the education and training of doctors, nurses and other healthcare professionals.

Beads of Courage UK was formerly known as Be Child Cancer Aware (BCCA). It was initially created to increase awareness of all childhood cancers. BCCA produced and distributed symptom awareness cards outlining the most common signs and symptoms of all childhood cancers. The response and awareness that was raised was phenomenal.

One of the families responsible for setting up the charity was disappointed when their son was given a cheap plastic medal when he finished his cancer treatment. It was a poor memento of the immense journey that he had completed.

Collaborating with Beads of Courage in the USA, the family, along with two other families launched the programme at The Royal Marsden, Basildon and Birmingham Children's Hospital.

Beads of Courage are now widely used in children's and young people's oncology settings across the UK. (www.beadsofcourageuk.org).

General Summary

Oncology Nurse Chloe, heard about Beads of Courage (BoC) from someone who had lost their young son to cancer.
In this innovative project young people are given coloured beads to mark a wide variety of therapies, treatments and experiences in recognition of their journey. They thread the beads on strings as a symbol of their courage in a difficult time.

Examples of beads include diagnostic biopsies, needle sticks, surgeries, chemotherapy and a range of other experiences.

Young people have a journal explaining what each bead represents and spaces for them to write dates and thoughts on the experience they have been through.

If the young person dies, their beads and journals become a precious memory for their loved ones.

Chloe was honoured with a DAISY Award for this initiative. This award recognises outstanding nursing care and practice. Through her tenacity and leadership Chloe has embedded this initiative into practice on our Teenage Cancer Trust (TCT) ward, empowering young people to feel in control of their treatment and help them make sense of their journey.

Healthcare professionals on the ward are engaged in this project, helping to promote and sustain it. Feedback from patients and families has been universally positive. The Teenage Cancer Trust has committed to funding the BoC programme, making it sustainable for the future.

The BoC programme offers beads for a number of other medical specialities, such as burns, neonatal intensive care, cardiology and chronic conditions. This makes the BoC a very transferable across our Trust

Rationale

Chloe, an Oncology Staff Nurse at Nottingham City Hospital, learned of Beads of Courage outside of work through a family that, on learning that she was a nurse, shared their child's cancer story with her. Unfortunately, their child passed away. Chloe was compelled by their story and the role that BoC played in their child's illness, and how BoC remain a vital source of comfort and an exceptionally precious memory of their child's journey. So inspired by what she had heard and motivated to transfer this initiative to her own place of work, she set out on an ambitious mission to deliver, and ultimately benefit and bring comfort to her patients and their families, during a hugely distressing time.

Chloe felt that the young people she cared for would benefit from this innovation, helping them to come to terms with their illness and the treatments.

She made enquiries and found that the kits were about £5000 to purchase. However, a phone call to the Paediatric Oncology Ward at our sister hospital revealed that they had kits that they were not using, and they very kindly donated them to her.

The beads are prescribed to the children and serve as a narrative of their medical care and tell the unique storey of their own journey.

The BoC are a symbol of their incredible bravery and is a way for them to track their treatment and also see how far they've come. They can be a means of starting difficult conversations and having open and honest discussions of their experience, helping them to become partners in their care and treatment, encouraging relationship-based care.

The goal of the programme:
- decrease illness-related distress
- increase the use of positive coping strategies
- restore a sense of self in children coping with serious illness
- provide something tangible the child can use to talk about their courage displayed during treatment and after.

Planning

Chloe shared her ambition for implementing the programme with colleagues. This included doctors, physiotherapists, phlebotomists, dieticians and many other health professionals. Through this support Chloe gained the buy-in and support to bring this vital initiative into our hospitals, in order to ultimately nurture and support the physical, emotional, and spiritual needs of Paediatric Oncology patients and their families.

Chloe contacted the paediatric oncology ward at our sister hospital (Queen's Medical Centre) to see if they had any insight into the Beads of Courage initiative. As it happened the ward had purchased the starter kit for BoC but did not have anyone to drive it and so it had been put away.

Chloe asked if they could be purchased from them, but they generously gave it to her.

With help and support from Sian, the Teenage Youth Support Worker, they started asking the young people coming to their ward if they would like to participate. This offer was enthusiastically taken up and one of the first recipients of the BoC, a young man called Lewis, used the beads to help him through his cancer journey. He and his family felt that they were a hugely helpful tool following a very difficult and traumatic start to his cancer journey.

Chloe contacted the BoC charity to register as an official ward, usually this would be accompanied by a great celebration, but COVID 19 restrictions have unfortunately prevented this. Chloe has also linked with the Teenage Cancer Trust (TCT), who have agreed to sponsor and fund the BoC initiative on Hogarth Ward.
Through word of mouth and via social media the BoC programme has grown, and word has spread. Patients and families have also been integral to spreading the word. One patient has a TikTok account and 500K followers. She has been documenting her journey through this medium and sharing her BoC along the way.
*Note: Lewis is his real name. Permission given by his mum.

Impact

Chloe has kindly shared, with permission, testimonials from two patients and their families to demonstrate how this initiative has helped those who have used it.
Lewis, who was mentioned earlier, had a traumatic start to his cancer journey, including misdiagnosis and surgery. However, when he arrived on the TCT ward, the staff went through his journey to date with him and immediately found that he had been through 167 procedures before he even got his first chemotherapy bead. His mum wrote that getting his beads helped to draw a line under his experience to that point and getting his silver acorn bead to show he was as resilient as a mighty oak was a turning point. The beads boosted Lewis' morale and gave him a voice.
All young people who access their service are offered BoC, and most do engage with the BoC programme and feel that it helps them through their journey and tells their story in a unique way.
It encompasses families too, so parents and siblings feel part of the narrative, bringing the family together in a shared experience.
Eden (real name, shared with permission), another young cancer patient, reports that it lightens up a hospital visit and shows what she has faced and overcome. She feels that the BoC programme could help many children and young people who have to face regular treatments and hospital visits and hopes that this will be expanded across different specialties.
The beads help children and young people to own, record, tell and share their story of their oncology treatment. They are a symbol of their bravery, courage and strength (Portnoy et al, (2016)).
With the help of the beads, even very young children can talk about their treatments, therapies and experiences.
There are 'Bumpies', which are glass beads with bumps all over them to symbolise a specific challenge they have faced, whether that relates to adverse reactions, side effects, or mobility changes. Beads are given for every single event, for example, they get one bead for each night they are in hospital, every single needle stick, every scan, medication, chemotherapy and surgery. The young people can end up with many thousands of beads and it is up to each child how they thread and display their collection.
A qualitative evaluation of the BoC programme was undertaken in 2010 (Baruch). The study evaluated the impact of BoC from the child's perspective. The conclusion was overwhelmingly positive, children spoke of them as rewards for their bravery, a method of making friends with other children with cancer, tracking their treatment and measuring their journey. They spoke about them with reflection and affection after treatment had ended, as a reminder of the challenges that they had been through and overcome. The conclusion of the study states "that the BOC Program, as an Arts-in-Health program, strengthens resilience and alleviates suffering in children and adolescents receiving treatment for cancer."
This is supported by Hall (2019) who confirms the positive impact of creative interventions to assist children and young people through oncology treatment.
The BoC programme has been running at NUH for just over a year now and the beads have been given to more than 20 young cancer patients during this time.

(Baruch, J.M. (2010). The Beads of Courage Program for Children Coping with Cancer. PhD Dissertation. The University of Arizona. Arizona. USA.
Hall, T., (2019). Creative, Culturally Sensitive Counselling for Paediatric Oncology Patients Undergoing Treatment. Journal of Creativity in Mental Health. Vol 14. (1). Pp. 70-80.
(Portnoy et al., (2016). Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach. Clin Child psychol psychiatry. Vol 21. (2). Pp. 255-67.

*Note: Stories and testimonials use the patients' real names and are shared with patient or family consent.

Relevance to Others

The Beads of Courage programme is an exemplar of personalisation of care and is not just for patients going through cancer treatment. There are programmes especially for a number of illnesses and conditions, including: refer to the category itself – ‘aimed at meeting individual needs’ – e.g., this programme of work is an exemplar of personalisation of care

- Cardiac
- Chronic Illness (Type 1 diabetes, autoimmune disorders, Epilepsy, Cystic Fibrosis, Cerebral Palsy etc.)
- NICU (gives parents a tangible way to record their baby’s journey)
- Burns
- Siblings

Parents and siblings also benefit from the BoC programme, prompting meaningful discussions and help form support networks with other families going through similar experiences.

Chloe would like to raise awareness with other departments and specialties to show how helpful BoC can be in supporting children, young people and families through their healthcare journeys.

Standing Out

This is not a commonly known programme in the UK. Through a serendipitous conversation with a bereaved mother, this fantastic initiative has been introduced into our Trust for our young cancer patients and we have been able to witness first hand, the amazing impact that it has had on our patients and their families.

It transforms children and young people from passive participants in their care into the true heroes that they are, it helps them to feel seen, heard and celebrated through their journey.

The full Beads of Courage program recognises the impact of serious illness on the whole family and endeavours to include everyone, parents and siblings, as well as clinicians as part of the shared experience.

The scope to share this programme across a variety of healthcare specialities is also a testament to how a simple concept can be used and adapted to help reduce anxiety and engage children and young people in their care and treatment.

Key Learning Points

For anyone who is thinking about initiating the Beads of Courage programme, we would strongly encourage them to go for it, following the advice below.

Although the set-up is expensive, the benefits are immeasurable.

Seek out charity support, we have been fortunate that the Teenage Cancer Trust fund our BoC programme.

Share, share, share. Spread the word, get clinicians involved, post on social media (if appropriate).

Encourage families to share their feedback and experiences in testimonials.

Invest in a wide variety of beads.

Make sure you register with the Beads of Courage organisation – you have to make it official, and there’s a big party to mark your registration (unfortunately currently affected by COVID-19 restrictions).

The Success of Takeover Day
Royal Cornwall Hospitals NHS Trust
PENNA 2018
WINNER - Communicating Effectively with Patients and Families, Using Insight for Improvement (Accessibility)

Organisation

Child Health spans health services across acute and community services for children and young people from birth to when they transition into adult services. The Child Health Directorate combines three Subspecialties, Acute Paediatrics, Community Paediatrics and Neonatology. Nursing staff and therapists work across all these services and are very proactive in breaking down barriers between different specialties and organisations to streamline care for children and families and deliver seamless care. Within acute paediatrics the majority of admissions are unplanned and come through our Paediatric Assessment Unit. The ward areas provide all paediatric inpatient, day case and assessment. This comprises 41 beds. The service offers age appropriate and same sex accommodation. There is a dedicated paediatric theatre and recovery area in Tower Block. Close working exists between paediatrics and ED and surgery/anaesthetics. The Child Health directorate is part of the Royal Cornwall Hospital Trust, Cornwall's only District General Hospital.

General Summary

On 24 November 2017 Child Health held their first ever National Takeover Day, to engage a group of 8–11-year-olds and hear their voices in relation to three specific areas we wanted to improve in direct response to findings from the CQC National Children's Survey. We wanted to make meaningful change in response to the survey that so many young people and parents had taken time to complete. Our aims for the Takeover Day were to make a radical difference in how we obtain feedback from this age group to ensure our service met with their specific needs. We also wanted to allow the children the freedom to express their opinions and have them heard and acted on by professionals. The success of this day has led to more opportunities for patient engagement and positive change within our directorate then we ever believed possible The changes made as a result of the project have not only been sustainable but have led to an ethos of constant patient engagement to further improve our service.

Rationale

The results of our 2016 CQC National Children's Survey highlighted that we needed to improve communication with children directly within the 8–11-year age group. The three areas we wanted to focus on with the children were-1. Inpatient and parental surveys2.Feedback display for real time feedback3.Hand hygiene- to improve staff compliance and to offer the children the opportunity to assess and feedback to professionals. We decided to approach a local school. Once the school had agreed to take part the response from the children was overwhelming leading the school to implement an application process, much like that of a job application. The head teacher chose ten successful candidates based on their ideas about the health sector and the changes they wanted to make which they later fed back to the school via assembly.

Planning

When the CQC Survey results were released the senior team in Acute Paediatrics met to formulate an action plan. We also liaised closely with the patient experience team to engage the whole Trust with what we were trying to achieve and how learning could be shared. We planned to have a Takeover Day as we felt this was an exciting and innovative way to engage with local children who use our services, and we designed a time table to ensure the day was well utilised and ran smoothly. We recognised the challenge having ten well children in an acute area could be, which is why the planning phase was key to the success of the day.
Services and activities involved in the day were-

- Practice Development Nurse- Put together the days' timetable, coordinated the day for the children, created resources, and collaborated results.
- Human Resources and ID services- each child had an official hospital ID badge, which for many was the best part of the day. They got to choose their job roles and have their pictures taken- jobs chosen ranged from nursing and medical staff to business and service leads
- Play team and volunteers - led the 'design a feedback Wonderwall' competition. The children took part in an art workshop with the initial plan to choose a winning design which would be made into our

Wonderwall, however; as the entries were of such a high standard the directorate voted to use all artwork to create an overall interactive design, which was achieved by working with a local design company.

- Senior Child Health team, parents and children-Tour of Child Health with question-and-answer session- children had the freedom to ask questions to all staff including the senior team. The children also interviewed parents and children on our inpatient wards.
- Survey design and a chance to share their views and ideas in a focus group with our Matron, Associate Director of Nursing and Service Lead as well as the Patient Experience Team.
- Catering staff-Lunch in the canteen with a VIP table!
- Medical staff- SIMs training with a Paediatric consultant, the children performed in hospital basic life support for infants with dummies and airway equipment.
- Infection control nurse- Hand hygiene teaching with Infection Control Nurse, Hand Hygiene audit on the wards.
- Senior team- Feedback and goody bag /certificate presentation given to the children as a thank you for their time and involvement.

Impact

The results from the day were compiled and presented across the Trust. Top trends and themes were identified. The results gave us clear direction and the outcomes to our aims; however, the impact has also made us all think about looking at our service from a child's perspective even more. The results showed us that what is important to a nine-year-old may not always be what adults perceive it to be. The children's focus was on comfort, companionship from staff, and communication at their level and not just with their parents. They asked parents on the ward directly 'are you frightened?' their communication was simple and focused. This learning may seem simple but has been shared throughout our directorate and made a real impact on assessing parent's ideas, concerns and expectations. This is now embedded within our medical admissions proforma. The impact of running this day has led to us installing an amazing feedback wall in our acute paediatrics corridor, this gives us instant real time feedback from children and families but also acts as an interactive play feature allowing children to move the magnets and design their own landscape, encouraging them to stop and take a minute to provide us with feedback. We have three different surveys for our admissions area and acute ward. One for children, one for parents and a new survey for adolescents. These surveys, having been designed by the children, allow us to keep focused on the basic needs they deem so important. The numbers of feedback we now receive have dramatically increased; this data is shared in our monthly newsletter. The Patient Experience team visit our Wonderwall and share the comments on social media on a weekly basis raising our profile and work within the Trust.

Relevance to Others

From the work we have carried out we have some extremely useful resources that can be shared with others either internally or externally. We have shared our surveys with the dietetics department and have also given advice to the scanning department re: making it more child friendly in response to feedback they had received. The design company who worked with the children on the Wonderwall shared the work and design with other NHS Trusts as an initiative idea. The video that is in production will be relevant to every child and family that comes to the paediatric service therefore the impact of this will be widespread and can be shared as a model for any paediatric unit.

Standing Out

Our entire project had children well and truly at its core. The result is a diverse, honest and colourful day that has led to fantastic end products, that we believe truly represents the input of our local children. The energy that children bring to our area is something we experience on a daily basis with our patients but embedding well children within our staff group for the day was such a positive and rewarding experience. We feel that if you are going to ask to hear the voice of the child it is vital to truly listen and act on their opinions without doubting or questioning their views. Having held our first Takeover Day, we are now planning another event to involve children in the design of our new build Woman and Children's Hospital, scheduled for completion within the next five years. The knowledge and experience we gained from this project will help us keep children at the centre of the new build to ensure we have the very best for the children of Cornwall.

Key Learning Points

Our main message is 'Be Brave'- by this we mean think outside of the box and be prepared for the feedback you may receive as it isn't always the feedback you may have been expecting! Planning is essential to keep both your patients and the visiting children safe and to ensure the day runs smoothly and is effective. Explicit written consent was obtained, and confidentiality was adhered to throughout the day. This was difficult but was managed well by the Child Health Team working closely with the teaching staff. Be prepared to really listen to the feedback you are getting and to respond appropriately- no question is off limits to children and sometimes they are brutally honest, however this is what made our day so special. Finally, the feedback from the children involved in the day was that they loved seeing the end result of their hard work, so it is vitally important to continue the work identified on the day. AND REMEMBER....'A child's voice, however how honest and true, is meaningless to those who've forgotten how to listen' Albus Dumbledore

Improving the 'Hospital to Home' Parent and Family Experience for Children on Long Term Ventilation via Tracheostomy
Royal Brompton and Harefield NHS Foundation Trust
PENNA 2015
FINALIST - Communicating Effectively with Patients and Families

Organisation

The Children's Long Term Ventilation (cLTV) service, at Royal Brompton & Harefield NHS Foundation Trust (RB&HFT) delivers a specialist respiratory outreach programme that sits within the multiprofessional Hospital to Home service. The cLTV team are specialists in paediatric intensive care, advanced respiratory and ventilatory management, and complex discharge planning. The outreach programme delivers a service to a network of neonatal and paediatric intensive care units (ICU), wards, local hospitals, children's centres and hospices throughout London and the South East region. The aim of the service is to move care closer to home for children on long term ventilation via tracheostomy (tr-LTV) by providing specialist clinical support, education and discharge pathway management, augmented by the development of an online pathway and workflow tool, across London and South East England using 'a hub and spoke' model. In addition, the Hospital to Home service delivers an actively managed web based integrated care pathway for LTV children that is now used by the majority of NHS England centres, and which has contributed to the development of a functional clinical network with shared purpose, best practice and standards.

General Summary

We evaluated family and professional experience of the hospital to home journey for children requiring tr-LTV using an adapted experience-based co-design (EBCD) approach. We conducted semi structured interviews with subsequent thematic analysis followed by co-design of identified service improvements with our sample. Technology dependent children require round the clock care from skilled carers, so families can find it difficult to travel away from home. Therefore, we adapted EBCD which traditionally involves face to face meetings by facilitating the co-design process via technology. We found this solution to provide an effective way of enabling our service users to contribute to service improvement which they may not otherwise have been able to do. We identified and implemented a number of practical and realistic service improvements in partnership with our participants. We are replicating our approach to investigate follow up services for our population. Furthermore, we have disseminated our experience with this approach nationally and internationally and are currently supporting our adult intensive care service to evaluate their stakeholder experience.

Rationale

The cLTV team aims to move care closer to home for children requiring tr-LTV. We have successfully demonstrated significant reductions in hospital length of stay (LOS) for this cohort from 9.8 months (baseline from historical controls) to an average of 2.7 months. The reduction in bed days correlates with financial savings (£915,000 per patient (baseline) to £251,000 (2012-14) based on an average bed cost of £1500 per patient). Whilst we have demonstrated significant efficiency gains, to further evaluate quality of our service we wanted to investigate if this correlated with improved experience for our service users. Our service underwent rapid growth, 2 people to a team of 20 within 5 years and delivers support in a unique, innovative way, crossing organisational boundaries to provide quaternary support via a hub and spoke approach. Many service users may not have experienced this model before therefore once reaching a steady state we wanted to evaluate their experience of this innovative model. We chose the user centric approach of EBCD because this methodology allowed us to not only evaluate service user experience but also work in partnership with them to make improvements. Whilst we had assumptions of what our service users experience may be, by enabling service users to tell the stories of experiences from their point of view, this method also offers opportunity to reveal unexpected areas for improvement. Alternative methods, such as questionnaires, would restrict the opportunity for this. Involving service users, not only in identifying improvements, but also in taking a role in implementing these, aimed to result in valuable long-lasting solutions.

Planning

The project was managed by a clinician with project management training (PRINCE2 Practitioner). We had not used EBCD previously therefore sought consultancy from the Head of Research in Nursing at RB&HFT throughout planning and implementation. Ethical approval was not required as this was a service evaluation and quality improvement project which allowed prompt initiation. Participants (10 family members and 10 professionals working in hospital and community environments) were identified by the service clinical nurse specialist and with administrative support, invited to take part via post and email. Written consent was obtained for semi-structured interviews which were conducted by an independent researcher recruited on a fixed-term basis, a psychotherapist. All interviews were audio recorded with subsequent thematic analysis. Interview data was pseudonymised and stored in line with local information governance policy. A Psychotherapist was selected as interviewer due to experience in listening and recognition and management of emotional distress. An escalation pathway to the RB&HFT Psychologist was defined for management of distressed methodology recommends family and professional events are held to check internal validity of results and identify service improvements. Families caring for children dependant on breathing support in the home can find it difficult to travel and find appropriate child care from skilled carers, therefore we adapted the approach, facilitating these via technology. Results were presented back to participants via private 'You Tube' videos to check validity then discussion and co-design meetings were facilitated using teleconferencing and web-based meeting technology. Invitations for meetings were sent via SMS text message as our participants are young, familiar with and informed us this is their preferred method of communication. Identified improvements were implemented internally and our participants consulted at key milestones of the process. Following completion an executive summary was produced and shared with all stakeholders followed by a full report. Throughout, the project team met on a fortnightly basis which ensured effective communication and review of progress against planned timescales. This maintained momentum and provided opportunity to identify and manage unexpected circumstances timely. Unexpected circumstances which required urgent action were escalated to the project manager between meetings.

Impact

Common themes identified through thematic analysis were similar for both groups of participants (families and professionals). Achievable improvements were identified for each theme and implemented as follows:

Communication - Both families and professionals requested written information about the service to clarify roles and responsibilities due to our innovative hub and spoke service model. Service standards were written which include communication standards. Business cards are distributed at the first visit of a new referral alongside family and professional information leaflets which are also posted to a newly developed public facing service website. The website also provides a central point for sharing resource for both families and professionals and offers a portal for direct communication with the service.www.hospitaltohome.nhs.uk

Welfare Support - All participants expressed frustration around difficulty of managing non-clinical aspects of the patient journey. Professionals felt ill equipped to resolve non-clinical issues and reported they would value support. A team of welfare advisors has been created. Professionals nationally can access advice from this team via a helpline. Since April 2015 total benefits and grants identified for families was £96,030.78. 28 enquires have come through the helpline from 8 different centres nationally and 344 pieces of information, advice and support have been provided to families. Multidisciplinary team meetings (MDT)Many families considered meetings “badly run”, “political” and felt excluded. Professionals reported difficulty in attending due to the time and travel required. We arranged a chairing meetings workshop for LTV specialists. We are now facilitating meetings using technology (teleconferencing and web-based technology) to reduce impact of travel time and increase attendance. An MDT module was developed for the online pathway which has been successfully adopted and nationally for LTV MDT meetings. This provides an agenda and prompts setting of SMART goals. MDT meeting minutes are being distributed securely to all families.

Key workers - An experienced key contact throughout the journey is highly regarded by both groups. The service structure has been realigned to ensure each family have a dedicated key worker. We have successfully achieved support from the WellChild charity to recruit a further clinical nurse specialist to support this. Discharge and follow up - Both parents and community professionals reported initial anxiety once home and requested more training at home. Families and community-based professionals thought communication about follow-up appointments is poor. Our service is not currently commissioned to support tr-LTV children post discharge. We are using our adapted EBCD approach again to further explore experience of follow up to inform future service design.

Relevance to Others

Many of the challenges faced by our service users are likely to be similar to those experienced elsewhere in the country and by patients with other long-term conditions. Other services may draw hypotheses about their own models from the themes highlighted. We have disseminated our results via our own national conference and internationally at the JIVD/ERCA Home Mechanical Ventilation Conference. Our adapted approach, using technology to facilitate co-design, makes this a viable option as a quality improvement approach when working with patients in remote areas or for patient populations for which it may be unsafe to attend group events (e.g., immunosuppressed patients) and also when working with young technically competent populations. We would recommend other services are not discouraged from using EBCD as we found taking a flexible approach enabled us to obtain rich experience data of a quality that we are likely to have not achieved via use of another method.

Standing Out

Our service model spans organisational boundaries giving us a unique opportunity to evaluate experience across the entire patient journey. Furthermore, our work goes further than evaluating experience but has made active changes and developments in partnership with our participants, which to our knowledge has not been done for the tr-LTV population before. The results of our project have supported the development of our website, a platform to support connections between health and social care professionals and patients and their families. Our service model provides a new innovative way of working, the EBCD approach was an effective way to support a cycle of continuous improvement for our team, allowing enhancements to our support provision through an iterative process. We found flexibility and adaptability was the key to the success of our project. Regular team meetings allowed a forum for discussing the challenges experienced and ideas generation around potential solutions. Although we could not follow the methodology as described, making modifications to the project plan enabled us to achieve our original aim.

Key Learning Points

We used technology as a solution to meeting with our service users who could not otherwise attend project events. Due to the complexity of the patient’s conditions, necessitating a dependence on technology, their families can struggle to travel from the home. Administration was required to set up this solution however this was no more labour intensive than organising a physical meeting would have been. We learnt that taking a flexible approach to EBCD for our project enabled us to continue to achieve our aim.

Personalisation of Care with Children and their Parents/Carers with Additional Needs
St Lawrence Surgery
PENNA 2016
FINALIST - Personalisation of Care

Organisation

St Lawrence Surgery team, Worthing (part of NHS Coastal West Sussex Clinical Commissioning Group (CWS CCG)) is delighted to be able to submit their application for consideration of a 2016 PENNA Award.

Our work was conducted as part of our application for a PACE SETTER Award which is the Quality Mark for Children and Young People's NHS Services (http://coastalwestsussexccg.nhs.uk/pacesetter

General Summary

Following some very exploratory and searching engagement and collaboration with local patients and families of children with additional needs we have enhanced the quality of our services for Children and Young People that delighted both staff and patients and families and is gaining recognition and interest nationwide. In addition, because of our local initiative the CQC has, in October 2016 awarded our Practice as overall 'outstanding' rating and they cited the "medical passport" as one of the reasons for innovation and responsiveness to our patients.

As part of our work, we have engaged with the West Sussex Family Network who has collaborated with us to generate ideas that have come to fruition e.g., the "Medical Passport" and "Hospital Diagnosis Pack" amongst other ingenious ideas for families with children with additional needs. These have improved the Continuity of Care for these families both in terms of their many interactions with their local GP surgery as well as with hospitals and in terms of supporting families to self-care and become more confident and resilient.

Rationale

We decided to apply for a PACE SETTER Award (see weblink above) as we would like to be known, as a local practice, for the high quality of our CYP Services. The critical part of the PACE SETTER Award is engagement undertaken with families/patients and staff. We decided to focus on children with Additional needs following a discussion with Lindsey Butterfield a parent at our practice. Lindsey has been an enormous help in giving us insight and a patient and/or carer perspective on what it's like for them to access our services.

We had many ideas initially including teenage health but decided this year to focus upon Children with Additional Needs and this has proved to be very successful.

Medical Passport – Why? Many anxious and frustrated parents who found attending the surgery a stressful time. All children with additional needs have individual stresses/triggers and ways they like to be handled by health care professionals. This helps the practice hold a bespoke service to get the best out of their consultations. It helps the patients, carers and the health care professionals.

Hospital Diagnosis Pack for newly diagnosed CYP with additional needs – Why? Parents said they feel isolated. When their child is given a diagnosis, they are discharged from hospital care without any further information on how to cope or what is available. We offer a 20-minute appointment with a GP and literature specific to the condition that child has been diagnosed with, together with offer of support groups here and within our area.

Planning

- Engagement – what we did? We worked with the West Sussex Parent Carers Forum and talked at length to Lindsey Butterfield, who is also our patient. We have run a search on all children under the age of 18 with physical and mental difficulties (see attached). Wrote out to this group to invite them to attend an evening meeting on 10.6.15 where Dr Catherine Joslin, Josiane Wadey, Debbie Elcome and Lindsey Butterfield with facilitate. The aim of this was to see what we can do to further support children with additional needs.

One example from Lindsey was that ‘my son gets very distressed when he comes to the surgery and cannot wait around long because he becomes so anxious that he faints, he also needs to lie down for injections and blood tests, but I don’t want to have to say that each time he comes’ We hope to have a bespoke system for this group of children where they will take priority and alerts will be put on the children’s records.

- Children with additional needs
- Establish a register of children with physical and mental difficulties
- Identify and engage by writing to the parents or carers.
- Run a search on EMIS Web and then write to the parents inviting them to a meeting in June.
- When we have a register of children and have a list of parents willing to attend.
- Also:
- Evening meeting with parents of children with additional learning needs (June)
- Establish their opinions on our service and what we can do to further support them
- Agree an action plan

- Hospital Diagnosis Pack – What? Solution: when we receive notification of a new diagnosis, we are to invite the child and parent in for an informal 20-minute appointment with the GP, included on the invite will be information about the Parent Forum we have at the surgery. Also send a New Diagnosis Pack- inside will include a leaflet about After Diagnosis, Local Offer, Parent Forum, Carers Support, STL Carers registration form and information about local support groups relevant to the diagnosis.

- Medical passport issued to all parents/carers with additional needs and pops up before GPs and Nurses see the children, so they are informed - As of 12.11.15 we have 25 completed medical passports. This information is added to the child’s medical records and prepares the clinician how to communicate with the child and parent, making the experience of the consultation much more positive and effective all round.

Email to Jo Wadey on 9.10.15
Positive feedback

Email 1

Just received this from a member of the tab school support group I run ...

Used my "I'm a parent carer" to book an appointment at GPs day before instead of on the day. Yay! Even better, just been and the doctor was brilliant. Took me a few weeks but finally done it. Had to go anyway as physio said I need to get stronger pain meds. Dr Stokes was really understanding and made me feel normal and not a fruit loop’

So, thank you for making a difference to a mum who is under loads of pressure in life...

Email 2.

Morning ladies,

We have been contacted by Brian O’Hagan who is the project manager for the local parent carer charity 'Reaching Families'. He is impressed with what we are doing at St Lawrence and would like to help support us by coming along to our next meeting. Brian was also the one who arranged for the herald to visit the ADHD group recently and he has just suggested that he gets Olivia Lerche the health editor from the herald to come and do a story with us as he feels what we are doing is very unique. I think it sounds like a good idea to get the word out there.... how do you feel about it Jo and Debbie? I’ve said I'll contact you first and let him know.

Impact

Regular parent support days now in place, alternating on a different day at a different day to try and accommodate as many parents.

Meeting held on 10.6.15 – notes attached below including 30 participants (including staff):

Register has 114 children with additional needs as patients. These are patients aged less than 18 years old with any of the following diagnosis: ADHD, Autism, Behavioural Problems, Cerebral Palsy, Developmental Delay, Down Syndrome, Epilepsy, Hearing Impairment, in a wheelchair, Learning Disabilities, Nervous System Abnormalities, Spina Bifida or Spinal Changes, Tourette's and Visual Impairment.
Some of the children will be on more than one register.
A general discussion between clinical, non-clinical and parents about previous struggles and how we as a surgery can learn from these experiences.

Agreed between Lindsey, Zoe, Rachel, Jo and Debbie the next Parent Support Group will be on Thursday 17th September 10-12am in the education room.

Actions made between 01.06.2015to 10.06.2015

- Waiting room slides have been updated with child friendly slides and information
- A new STL carers registration form
- My Medical Passport has now been approved and will be uploaded onto Emis soon

They met with the parents again in Sept 15 - and have agreed that they can have the premises to run regular support groups and hold role play groups for children, so they have seen a stethoscope or an auroscope before they come to the GP. This will be supported by our GP and HCA initially and then the parents will run it independently. This has not happened yet as there are mixed opinions from the parents whether it is still needed now that the children are more relaxed when they attend.

Relevance to Others

All practices will have similar groups of patients to St Lawrence Surgery, and we highly recommend that they adopt our ideas and/or apply for a PACE SETTER Award which provides a simple framework to improve the quality of local CYP Services. Not only are our patients and families delighted but so too are our staff who feel that the service we are providing is more joined up, compassionate and helpful to our local families. The out of hours service is also very grateful for the medical passports that are uploaded onto their system.

Standing Out

The PACE SETTER Award has helped us with quality improvement to galvanise our staff and patients to jointly produce initiatives that will make our services better all round. We've made a real difference to our children and parents and CQC awarded us outstanding with mention of the medical passport being very innovative.

Key Learning Points

Engagement – Lesson learned: There are some really simple solutions to create a friendlier and less stressed environment/experience.

These parents have a daily struggle, and we need to provide as much support as possible.

These children do not behave "badly" because of bad parenting – they just cannot help themselves.

Future plans:
Keep encouraging the parents to engage with us at the support groups and explain what they find difficult at the surgery.

The parents' meetings are now held monthly in a room at the surgery and proving to be a very effective support mechanism for parents. The continuity of care that they feel now is much better and joined up…

Medical Passport - Lesson learned: This has made a huge difference to the Health Care Professionals as well as the patients, as the Health Care Professionals are prepared for how to approach the consultation and gives them insight into the difficulties that the parents have when taking their children to the GP Practice.

Future plans: Keep going and aim to have a medical passport for each child.

Hospital Diagnosis Pack - Lesson learnt: We have learnt that after diagnosis the parents are then left with no support therefore, we feel it is our duty in primary care to provide the information they desperately need

More toys, quiet waiting room and more child friendly environment etc - Lesson Learnt:
Something so simple as toys, posters and books relaxes the child and helps them to wait without anxiety building up.

Staff photographs on the website – so the parents can show the child what their nurse or Doctor looks like, eases the child's anxiety.
Future plans:
Change the jokes on the waiting room screens monthly
Keep the toys and books in a suitable condition – if they are not then they will be replaced
WIFI to enable children to play games on iPad etc as requested by parents.
Spread to children with long term conditions
Support the CCG with roll out.

Quick Access Dental Pathway for Vulnerable Children
Surrey and Sussex Healthcare NHS Trust
PENNA 2018
FINALIST - Partnership Working to Improve the Experience

Organisation
Surrey and Sussex Healthcare NHS Trust (SASH) provides emergency and non-emergency services to the residents of east Surrey, north-east West Sussex, and South Croydon, including the major towns of Crawley, Horsham, Reigate and Redhill. At East Surrey Hospital, Redhill we have 697 beds and provide acute and complex services. In addition, we provide a range of outpatient, diagnostic and less complex planned services at The Earlswood Centre, Caterham Dene Hospital and Oxted Health Centre, in Surrey, and at Crawley Hospital and Horsham in West Sussex. SASH is a major local employer, with a diverse workforce of over 4,300 providing healthcare services to a growing population of around 535,000. On average each month during the last 12 months there were: •2,803 Ambulance arrivals at A&E•8,454 A&E attendance•3,107 Emergency Admissions•32,018 Outpatient Appointments•3,194 Day cases•437 Elective Inpatients SASH is part of the NHS partnership with Virginia Mason Institute to develop a 'lean' culture of continuous improvement which puts patients first. Through this partnership SASH pursues perfection in the delivery of safe, high-quality healthcare which puts the people of its community first. Jeremy Hunter, Secretary of State for Health and Social Care visited SASH in 2017 and stated: "They have fantastic values, but what sets them apart is their measurement of these values, which allows patients to see for themselves how the attitudes and ethos of staff directly improves the care they receive." The NHS National Staff Survey results place SASH in the top 20% nationally for the last three years and some scores ranked in the four organisations. Whilst the GMC (junior doctors) survey show that SASH has the best reported clinical supervision in the region. The Dental & Maxillofacial department offers comprehensive care for those from infancy to adulthood, covering a wide range of dental sub-specialities. The care is patient centred, and is delivered within an outpatient, inpatient, and day case general anaesthetic setting. Within the dept the paediatric dental unit is a high-profile consultant led service that has expanded to include a specialty training role and has developed an integrated care pathway for patients with special needs from childhood to maturity. Treatment is provided under local anaesthetic, conscious sedation, and regular general anaesthetic sessions for comprehensive care.

General Summary
This multi-disciplinary care pathway is the first in the south east which focuses on meeting the dental health needs of vulnerable children. It has resulted in a robust partnership with First Community Health and Care enabling us to fast track cases and to maintain anonymity for those children under protected care. Because of the shared commitment to improve the shocking dental health of this client group, The Dental and Homeless Teams have been able to jointly and dramatically improve this situation. We have shown that by working with partner agencies we can identify those in need quickly and address their dental needs.

Rationale
Dental decay in children has been on the decline in the general population, although there are those within the community who are seeing a rise in the rate of dental decay. This is further compounded when these children are at the periphery of society. Lack of appropriate dental access and care results in a great burden on their health. Within our catchment area we are encountering these children when they were at an advanced stage of dental decay due to lack of a clear care pathway and access to specialist care. Working with the homeless team – First Community Heath and Care, we soon developed an understanding of dental health needs of these vulnerable children. They fall in to the category of homeless children, including those from the Gypsy and Traveller communities, families fleeing Domestic abuse, families from war-torn countries such as Syria and those in our local homeless hostels. We quickly developed a multidisciplinary pathway for assessment and treatment of these children. Part of this work involves education of children and parents regarding oral health. This education is in the form of face-to-face discussions as well as appropriate literature.

Planning
Approximately 12 months ago, I approached the homeless team at First Community Health and Care to discuss the difficulty that homeless families had accessing both routine and emergency dental care. We were aware of

the poor dentition in this group and agreed to meet with the Homeless Team further to discuss ways of improving both access and outcomes. We quickly developed a referral pathway and agreed that we could accept and fast-track any referrals. Together with the partner agencies we have been dogged in pursuit of non-attenders and families who have changed addresses, which is frequent among homeless families. This also applied to families from other vulnerable groups as mentioned in section 3. We were also aware that a number of families needed their anonymity to be protected as they were in for example protected accommodation. For these families accessing care was a challenge as they felt their anonymity would be compromised. Together with our trust and the team at First Community Health and Care we developed strategies in order that anonymity was protected. This reassured these families and enabled them to access care without being worried.

Impact

Since this initiative started 12 months ago, the dental team have assessed and treated more than 50 homeless children, including those from the Gypsy and Traveller communities, families fleeing Domestic abuse, families from war-torn countries such as Syria and those in our local homeless hostels. In some cases, as many as 14 teeth have been removed per treatment but, more importantly preventative treatments and dental education and advice has been given and subsequent visits for both the children seen and younger siblings, has shown a significant improvement in the children's teeth. Unlike the usual process when non-attendance to a clinic result in referrals being cancelled, the dental team have put in protocols which has led to the team following up on these non-attenders and involving the safe guarding team where necessary. We have been exceptionally persistent and shown both empathy and commitment in order that vulnerable children get the dental care that they desperately need.

Relevance to Others

This initiative has been started by the paediatric dental team; however, the results show that it is about the individuals dental need and isn't necessarily limited to children, but that ALL patients who are vulnerable and need access to timely and appropriate dental care. We have demonstrated clearly that identifying deficiencies in health care delivery in itself is not the challenge. The challenge arises from working and bringing together all the allied professionals who are involved in the care of an individual or a family unit. We have demonstrated that through mutual respect and working as equal partners both primary and secondary care providers can overcome these challenges. The result is that we can demonstrate care that puts the child/families at the heart of a community health service.

Standing Out

This initiative is unique in that:

- This project puts the child and their families at the heart of the care they receive
- We have demonstrated an effective care pathway for delivery of care
- It has shown great multi agency collaboration within agencies
- It has demonstrated great partnership between primary and secondary care givers
- We have demonstrated an effective care pathway which ensures anonymity of patients and their families
- We have shown that through a rigorous process we make sure those who do not attend an appointment are followed up and where necessary safe guarding team are involved in order to address any welfare issues regarding the child

Key Learning Points

The key learning points came from the patients, the parents and allied health professionals and not just the clinicians. We listened to the concerns of patients and tailored their care as needed e.g., maintaining anonymity. Where there were hurdles such as families moving addresses frequently, these families were fast tracked to our assessment appointments. We made sure those who were refugees had a fixed member of staff who was also fluent in their language in order to streamline their care. Throughout this process we have liaised with allied professionals on a level playing field in order that both primary and secondary care providers are treated as equal partners. This has led to an open and more fruitful relationship which has ultimately benefited those who are in need of care.

The Introduction of Using Entonox in the Community for Children Facing Distressing and /or Painful Procedures

South Tyneside NHS Foundation Trust

PENNA 2015

RUNNER UP - Bringing Patient Experience Closer to Home

General Summary

When children experience pain or discomfort, during nursing interventions, cause distress for all involved. This may lead to fear, anxiety and potential long-term problems. We sought to reduce these issues by introducing the use of 50% Nitrous Oxide 50% Oxygen (Entonox) when undertaking invasive nursing procedures in children in the community. On investigation we found that this is not done by any other children's community nursing team in the country.

The initiatives objectives were therefore clearly identified from the start: Our aim was to find a solution which could be utilised in all invasive treatments, preventing pain, discomfort and distress for patients, families and team members. The outcome would be person centred, subjective and qualitative, with the experience of the child, family and team members determining if the initiative had been a success or not. It is envisioned that the initiative would make a sustainable difference as Entonox could be used for many children with varying nursing requirements on a long-term basis. All competencies, and guidelines developed are easily transferable to other teams and organisations and can be easily disseminated.

Rationale

The 'Eureka' moment in regard to the use of Entonox in the community was during the insertion of a nasogastric tube (NG) to one child known as Joe. Joe has undergone dialysis, he required twice weekly injections and found that the NG experience was one procedure too many. Joe is 5 years old. Joe became so upset and distressed, he was inconsolable. This caused mistrust towards the professional, breaking down an established relationship.

Following a staff supervision session, we analysed the situation and sought potential solutions. We considered sedation but felt this was too risky within the community. � We acknowledged we have the use of Entonox in the hospital therefore our initial plan was to meet Joe and his Mum in hospital. He self-administered Entonox and was given distraction whilst the tube was inserted much more easily. Joe was given 10 minutes to play following the procedure and was then allowed to go home. His mum commented she wished that could be done at home where he could watch his TV and feel more comfortable. Hospitals still scare Joe. This became the challenge for our team.

Planning

The process began by consulting the expertise of the pain control specialist nurse within the Trust. Through joint working and training we (the two teams) decided to look into the pros and cons of using Entonox on children in their own homes for any distressing procedure.

The use of Entonox is a universally established practice within community midwifery services and within our trust has been used for over 30 years. It has been found to be a safe and effective method of pain relief with a low incidence of adverse effects and a quick recovery time (Kanagasundaram S, Lane L, Cavalletto B, Keneally J and Cooper M 2001).

We carried out a risk analysis and the team underwent training and completed competencies, whilst being supervised and supported by our specialist colleagues. We contacted, by post, the entire directory of Community children's nurses in the United Kingdom to ask of their experiences, in this regard. 98% of respondents stated they did not routinely use Entonox in the Community but were greatly interested to learn from our experiences.

Practical problems we envisaged included:

- The cost of equipment
- Storage of equipment
- Car insurance & transportation
- Prescribing, patient group directives and consent
- Staff training
- On-going costs

The cost of the equipment was £400 which included 2 cylinders, the release valve, a carry bag and a box of disposable masks. The child keeps their own mask, and this can be reused, for on-going painful dressings or procedures. The cylinders are stored in our clean utility storage cupboard which is locked and accessed by the CCN team only.

All staff have business use for work on their car insurance and as long we notified our insurers of the potential of carriage of medical gases, no one incurred any additional cost. We were asked to display a sign in our cars when carrying medical gases.

The senior nurses within the team can all prescribe so this is prescribed as either a once only or as required dose; however, a Patient Group Directives (PGD) was also developed in collaboration with the pharmacy department to enable Staff Nurses to still use 111ntonox on the rare occasion a nurse prescriber is unavailable. Staff training was completed through multiagency working with the pain nurse specialists and the use of the medical representative. Hand-outs, written materials and competency sheets were undertaken by all staff. Consent of the family and\ or child is documented within the nursing notes.

On-going costs will be monitored but are felt to be minimal and cost effective in regard to patient comfort, compliance, prevention of re-admission/re-attendance at hospital and long-term outcomes of trust for the child. On-going audit will be more of a comparison of the child's previous experience and patient satisfaction is gauged both formally and informally. We observe comments made by the child and family and also issue patient satisfaction questionnaires on a rotational sequence. Since we have started this process, we have discussed this with the tissue viability team, and they are considering introducing this method of pain relief throughout their clinics and home calls for painful procedures. The population of CCN's are interested in using our experiences to inform their practice.

Our aim is for children not to ever experience pain, or distress!

The types of nursing action which will require consideration for the use of Entonox include but not exclusively limited to:

- The insertion of nasogastric tubes or gastrostomy button
- The insertion of a port-a-cath needle
- Painful burns, or dressing changes
- Injections or Venepuncture for a terrified child
- Removal of clips or sutures

If the child has a good experience, they are less likely to develop phobias or anxieties which can be carried through to adulthood.

Impact

Children do not have to experience any painful procedures without adequate pain relief and distraction. This should make the parents more relaxed and in turn the children may not have preconceived fears when faced with a nursing intervention in the future. The results are monitored formally by the use of patient and family satisfaction questionnaires and informally in verbal feedback from children and their families. So far, families have been very positive about the use of Entonox and children seen to be a lot less anxious about nurses visiting them at home.

Key Learning Points

- Collaborative working
- Reflecting upon experiences and identifying areas for improvement within our practice
- Identifying drawbacks
- Risk assessment
- Seeking solutions
- Sharing experiences
- Identifying a good practice
- Problem solving

If we change the beginning of the story, we change the whole story: Using Citizen and Workforce Insight to create and implement a Strategy for Children and Families
Surrey Heartlands Health and Care Partnership
PENNA 2020-21
WINNER - Using Insight for Improvement (Integrated)

Organisation

Surrey Heartlands is a partnership of health and care organisations working together – with staff, patients, their carers, families and members of the public – to transform local services and support people to live healthier lives. Together we are known as an 'Integrated Care System' – partnerships where health organisations, the local authorities and others take a collective responsibility for improving the health of the local population, managing resources (including money) and making sure services are high quality. Surrey Heartlands covers the majority of Surrey; those areas currently looked after by local partnerships covering the geographies of: East Surrey, Surrey Downs, North West Surrey and Guildford and Waverley but the partnership also encompasses all local NHS organisations and Surrey County Council.

General Summary

Based on evidence from UNICEF, the first 1,000 days of life – the time spanning conception until they are roughly two years old – is a unique period of opportunity where the foundations of health, growth and brain development are determined. This development is influenced by a wide range of factors such as the parents' physical health and mental wellbeing, child nutrition, early childhood experiences, the child's environment and their relationship with the family and caregivers.

This strategy development project aimed to commit to focusing on the First 1000 Days by creating a strategy that would shape how services would be delivered for the next five years, with the view to give every child in Surrey the best start in life. The purpose of the strategy document is to provide a vision for our First 1000 Days transformation programme that families and professionals can convene around.

This required partnership working across all sectors in Surrey to ensure that families are empowered and supported in a timely, informed and accessible manner. This project explored what children and parents need to flourish at home and in their local communities to inform how the system can be optimised to meet these needs.

Rationale

The Surrey Heartlands Executive Team recognises that there is an increasing gap between those families with the best outcomes and those with the worst outcomes, demonstrated by the fact that children born in the most deprived areas in Surrey will die six years earlier than children from the most affluent areas.

We know from child development and economics research that pregnancy and the first two years of life (the First 1000 Days) have a significant impact on a child's outcomes and the adult they become, more so than any other point in a child's life. To exemplify this, a child's development measured at age 22 months is an accurate predictor for educational attainment at 26 years old, showing the influence that the early years can have on later life outcomes. This creates a critical window of opportunity for health and social care services to improve outcomes for all children and close the gap between those with the best and worst outcomes. Surrey Heartlands has committed to a five year First 1000 days transformation programme, guided by a strategy, to give every child the best start in life.

For this transformation programme to have the intended impact, it needs to be beneficial to all of Surrey's families. We recognise that not every child has the same opportunities and that we must go further for those families who are vulnerable or at risk of health inequalities. In order to do this well, we aim to understand the needs of easy to ignore communities with protected characteristics, often referred to as 'harder to reach' groups, as well as the needs of the majority of the Surrey population.

The First 1000 Days strategy outlines insight from families and professionals and how we will act on this to improve outcomes for every child. The strategy also recognises that some families may need extra support, but this doesn't always have to come from the NHS or Surrey County Council. Enabling families to make connections and gain support from other families or enabling them to access community groups will help to avoid duplication, optimise existing resources and most importantly improve experiences and outcomes for families This means that our engagement/insight collection cannot focus on one service (such as maternity) or a theme e.g. mental health – we have to understand the family's holistic experience of their first 1000 days. This will enable us to improve our provision and provide impactful support.

The First 1000 Days strategy will be the foundation of a successful transformation programme. To ensure this strategy is able to guide us effectively, we will invest in understanding the needs of the youngest in our society, which will lead to a healthier and safer society overall. By working together with Surrey residents and workforce, we aim to ensure that our services and transformation plans are guided by evidence and lived experience. Furthermore, by involving these perspectives in the project from early on, we aim to develop credibility and trust in how our health and care services are planned and delivered.

Planning

In order to form the foundation of the strategy, initial workshops were externally commissioned in July 2019 involving families and members of workforce that were delivering and supporting care. The aim of these sessions were to: create a space where the experiences of parents in the first 1000 days could be really heard and explored; enable parents to tell their stories; enable practitioners to hear what is important to the parents they support.

This strategy was created with the initial insights gained from these engagements as well as input from stakeholders and local and national evidence. As the strategy was created with the ambition to shape the First 1000 Days programme priorities up until 2025, it was pertinent to test the draft strategy with families and professionals to ensure their priorities were reflected accurately. Shortly after the creation of the strategy, the Covid-19 outbreak took place, significantly affecting the strategy development. The outbreak and resulting profound changes to everyday life placed an extra pressure on families, leaving many families feeling more vulnerable.

This reinforced the need to offer support to families during this uncertain time, and to test the draft strategy in order to reassess whether needs and priorities had changed in light of the uncertain situation. We successfully conducted five focus groups with 16 citizens virtually, to ensure compliance with the government's Covid-19 social distancing restrictions.

We achieved a mix of perspectives including parents from a low socio-economic background, single parent families, parents of children with special educational needs or disabilities (SEND) and families from a Black, Asian and Minority Ethnic (BAME) background, all of which were recruited from a spread of geography across Surrey.

For the workforce perspective, healthcare, social care and third sector professionals were invited to attend interviews, which included a dedicated section of questions addressing their perspective of the strategy from their own professional opinion.

Impact

The Surrey Health and Wellbeing Strategy, published in 2020, identified three interconnected priorities to improve outcomes across the county, one of which was 'Starting Well.' This priority entails forming a good understanding of the needs of the children and families in Surrey, which the strategy has significantly contributed to.

Especially in light of the Covid-19 crisis and significant subsequent changes to the pregnancy and birthing experience, the day-to-day life of families and the amount of pressure and uncertainty they face, the strategy development helped to accurately frame the specific priorities of Surrey's families.

Having successfully created the Strategy using insight from families and the workforce, the First 1000 Days Programme can be confident that it meets the requirements of Surrey's families and that it fully acknowledges and addresses health inequalities, vulnerable families and families who have children with additional needs (e.g., SEND).

These insights have enabled the First 1000 Days Programme to allocate dedicated resources towards five workstreams that reflect the needs of Surrey's families and workforce. Without this insight, there is the risk that projects and transformation plans do not truly address the needs of Surrey's families.

Relevance to Others

As Surrey Heartlands Health and Care Partnership works with partner organisations from healthcare, social care and third sector backgrounds, the results of the research revealed a great amount of the changing needs and wants of the Surrey population. The research enabled our programme to look at a family's holistic experience of their first 1000 days, not just their experience of a particular service or theme area e.g., mental health. Families are the only people that experience the 'system' whereas services can take a more silo 'ed view. This research has enabled services to think about the 'system' and about how we can work more collaboratively as a collection of partners to make the journey easier for families.

For example, insight collected from members of workforce highlighted that more collaboration is needed to utilise existing resources such as third sector organisations, voluntary groups and faith groups, as they work closely with families and already know what their needs are.

The findings will have been shared with a wide range of partner organisations, with the view that this will promote more multi-agency working.

Standing Out

Traditionally, services conducting engagement activities do so out of obligation to meet their statutory requirements, rather than valuing the insights generated in themselves and the impact they will have. This tends to lead to tokenistic engagements that are less likely to match the needs of the local people who will be using services. This programme of research, however, follows principles of best practice by incorporating co-design from the start and throughout by using insight to generate both the original daft and the final versions.

In addition, this research looks at a family's holistic experience of pregnancy and the first 2 years of life, considering all the services they interact with and the non-service support they might need e.g., friendship networks, to have a positive and supported experience. Typically, organisations and services will only seek the views of their service and not how families move through the system of services. This is particularly pertinent to our vulnerable families that are likely to be supported by many services but struggling to navigate through the maze of support and know what is available.

Additionally, sufficient time and resources were dedicated in order to develop robust research using a range of different methodologies. Despite the challenges created by the Covid-19 crisis, this work was still considered a priority, with interviews focus groups for citizens taking place remotely throughout the crisis period.
This project successfully enabled mixed groups of health and social care staff, citizens, and stakeholders to work collaboratively to develop a strategy. There was a dedicated effort to involve minority groups and those with protected characteristics to ensure the needs of the minority, as well as of the majority, were taken into account.

This project was able to conduct meaningful and effective engagement by ensuring citizens and members of workforce that were regarded as 'experts by experience' are involved in the system's decision-making. This approach ensured that co-creation played a central role throughout, with the view that the insight will lead to greater quality, accountability, and relevance in the development of services.

Key Learning Points

- Take a holistic view of a patient's experience – patients experience the 'system' of support, so it is important to not engage with a silo 'ed mentality.
- Collaboration between the workforce and local people can improve the experience of services and the financial sustainability of our system.
- It is important that engagement is meaningful. It is the only way to ensure citizen and workforce engagement are built into 'business as usual' for service transformation

Virtual Youth Involvement Group
University Hospitals Bristol and Weston NHS Foundation Trust
PENNA 2020-21
WINNER - Communicating Effectively with Patients and Families

Organisation

University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) brings together a combined workforce of over 13,000 staff. The Trust delivers over 100 different clinical services across 10 different sites serving a core population of more than 500,000 people, which includes specialist services such as children's services based within Bristol Royal Hospital for Children.

The Bristol Royal Hospital for Children (BRHC) provides a local service for Bristol children and a referral service for specialist care for families across the South West and nationally.

General Summary

The UHBW Youth Involvement Group (YIG) was established in 2010 to encourage young people's voices to be heard more clearly in the hospital community, with the aim to create a two-way engagement space for the organisation to consult and for young people to raise issues. In order to keep this group actively involved in our hospital and Trust processes, during the pandemic we have taken our YIG sessions online. We wanted young people to still feel involved in the organisation and feel involved in the changes that were happening as well as provide us with feedback on the impact of these changes.

These sessions now run monthly and are a huge success and have proven to be an excellent way to communicate effectively with the young people involved in our hospital. The group has helped develop our Youth Voice programme, which looks at expanding opportunities for young people to be heard directly within our Trust; and has influenced the development of mental health support provision locally and within the Trust. This project is continuing to expand and are working to enable more activities as well as a combination of in-person and virtual sessions going forward.

Rationale

The UHBW Youth Involvement Group (YIG) was established in 2010 to encourage young people's voices to be heard more clearly in the hospital community, with the aim to create a two-way engagement space for the organisation to consult and for young people to raise issues. It also functions as a learning and development space for young people looking to pursue a career in health or social care. The group seeks to empower young people to participate and be open about their views and experiences to encourage reflection and learning within the organisation. The groups are supported by hospital charity, The Grand Appeal, who fund not only part of the salary for the Young Persons' Involvement Worker who coordinates the group, but the majority of activities.

Prior to March 2020, the group met face to face on a monthly basis with interim emails via the Young Persons' Involvement Worker. The attendance of these sessions was on average 8 -12 young people, and they were predominately from within a 20-mile radius of our site, despite Bristol Royal Hospital for Children covering the whole of the South West.

Like many were experiencing in 2020, Covid-19 called a halt to all meeting in person, but this was a key time for the Trust to understand what young people were experiencing and what was needed to support them; particularly given the impact of cancelled surgery and delayed appointments due to the need for social distancing. Our Trust was also using new techniques such as virtual and telephone clinics, so it was important to get a sense of how this felt for young people. We wanted young people to still feel involved in the organisation and feel involved in the changes that were happening as well as provide us with feedback on the impact of these changes.

Planning

In order to sustain the YIG, the process and sessions were moved online/virtual with collaboration from our IT services and Safeguarding, as well as support from divisional management. A risk assessment and a Standard

Operating Plan (SOP) of how the YIG could run safely and effectively during the pandemic was developed by the Young Persons' Involvement Worker.

As part of our regular email contact with the group, we announced that we will be holding virtual sessions and invited young people to let us know if they would like to come to the first session. Using our Trust's preferred and most secure platform at the time, we sent a video call invitation link to those who wanted to join along with the group agreement. The sessions are hosted and run by the Young Persons' Involvement Worker and the Communications and Engagement Coordinator. The first virtual session took place in February and was a big success with all who attended.

Sessions with the group have included activities on young people's rights. In addition, the group has helped develop the Youth Voice programme, which looks at expanding opportunities for young people to be heard directly within our Trust; and has influenced the development of mental health support provision both within the Trust and through links with the CCG (clinical commissioning group) in the BSSNG (Bristol, North Somerset and South Gloucestershire CCG) area.

The group's activities are regularly shared on social media (Bristol Royal Hospital for Children Facebook) and the group are currently working on a social media 'takeover week', with the aim of reaching a wider audience to encourage new members but also highlight the work that they have been doing to staff and families.

Impact

The impact and results we have achieved is primarily based on the feedback we have received from both young people and the wider staff group who have been involvement with elements of this work. Some of young people have become more and more involved with our hospital processes, and continue to do so, this is one of the biggest impacts we are proud of achieving from this initiative.

Key benefits of this change were not only that we continued to hear from young people about their thoughts and experiences at an important time in the history of the NHS, but also that we were able to more easily include young people from further afield within our tertiary setting. In addition to this, virtual sessions have also allowed young people who are immuno-compromised to attend, where previously we haven't been able to have more than one cystic fibrosis patient to keep everyone as safe as possible.

Whilst numbers of attendance are similar (8-12 young people), the mix of ethnicities, ages and localities within the group has significantly increased and attendance to the virtual sessions has been more consistent. The majority of attendees have been or are current patients of our Trust; some long term, across a range of specialities.

Young people have been able to maintain their profile and voice through our 'staff spotlight' feature with senior leaders and clinical staff. This is where we ask the YIG which staff they would like to hear from, give them the opportunity to ask the questions they are interested in, and we then link the process by identifying staff and collating their answers for our young people to read. Staff have benefitted from being able to hear from young people directly and have been impressed with the insight shown by the questions asked and comments made as part of this process. This has helped to challenge perceptions of how young people may be able to contribute to the strategic agenda, indirectly leading to the Youth Voice project. A member of the group has also been co-opted to the Equality and Diversity forum, participating in activities, which includes expanding the representation of BAME individuals in images and photographs within the organisation. Another has become an Ambassador to the NHSE Youth Forum and represents the group nationally. Three other members are currently working with support mentors to take on a regular role at our Divisional Board and Leadership as part of the Youth Voice Project. These opportunities have all been made possible by the ongoing effective running of the Youth Involvement Group the passion of the young people who are contributing. Some of the feedback we have received from young people as a result has very positive:

'Thank you for yesterday. I really enjoyed it and it was nice to feel a part of the group.'

'The work done by Youth Involvement Group has inspired me to keep doing more to make change. This is part of the reason why I applied to be a [GMC] Student Associate!'

‘Thank you for the email and organising the staff spotlight - I found R’s responses fascinating and very moving to read.’

Relevance to Others

As well as the increase in awareness with staff within our hospital and how the YIG is important and relevant to them. The Young Peoples’ Involvement Worker has also been involved with the National Youth Forum and the regular meetings which are held by a representative of the National NHS Youth Forum. It involves discussing and collaborating ideas and plans with other hospital youth leaders. This is where we have already shared the success of our virtual YIG sessions and communicated our learning and future plans.

Standing Out

Young People are the future. We believe this is a fantastic initiative to continue to support our youth hospital community as best we can and continue to provide a two-way engagement space for the organisation to consult and for young people to raise issues and ideas with us.

Key Learning Points

Our key learning points are to find ways to continue to make this group more accessible and more available to young people. And to identify which activities are desired by the young people, further find ways to support this and to increase the communication and awareness between or staff and young people.

Environments for Children
Wirral Community NHS Trust
PENNA 2015
FINALIST – Environment of Care

Organisation

As a community NHS trust provider our vision is to be the outstanding provider of high quality, integrated care to the communities we serve. We have a strong, clear vision and a set of values that were developed with our staff and stakeholders. The trust has reputation of providing high quality community health services that are safe, effective, caring, responsive and well led. Including Therapies, Community dental, Primary care and out of hours services, Cardia rehab Community Nursing and specialist nursing services. Our commitment is to provide the best possible standards of clinical care, show how we are listening to patients, staff and partners and how we have worked with them to deliver services that meet the needs and expectations of the people who use them. Our services are delivered by dedicated and innovative health professionals and supported by equally committed staff behind the scenes, around 1,463 in total. Our services are local and community-based, provided from around 50 sites across Wirral, including our main clinical bases, in Birkenhead and in Wallasey. We provide some therapeutic services in Liverpool and also the 0-19 service in East Cheshire Our three Walk-in Centres are located across the Wirral peninsular. We have no inpatient beds. We are now entering the final stages of our assessment for foundation trust (FT) status.

General Summary

The initiative is to improve the experience for children visiting our facilities, by creating a stimulating environment that is inspiring, engaging and supportive1.Innovation - The project aims to create a welcoming environment for children using services through the use of age-appropriate artwork, patient journey storybook, activities and participation in 4 settings. 2.Leadership –. The project group aimed to fully implement its objective within a six-month time frame. Progress is on target and has been regularly reported at Divisional level and also to Health watch3.Quality based outcomes were based on

- A literature review to appraise evidence from other similar initiatives.
- An appraisal of current facilities in the 4 main areas.
- Engagement events with local primary schools
- Delivery of a robust bespoke solution 4. Sustainability –Key touchpoints were identified with the patient journey identify opportunities for improvement in the experience of care for each step. Following initial costs, solutions will be low cost to ensure sustainability. 5.Transferability & Dissemination The organisation as developed an excellent partnership with the schools involved and it is hoped that this partnership can grow through collaboration. The project group intends to publish it work nationally The project group has developed a number of resources which can be shared with other services and organisations.

Rationale

The initiative aims to engage with young children to better understand their needs when receiving care at our walk-in centres and involve children in creating solutions to improving the care experience. The trust has 3 walk in centres and also a central clinic which runs a number of children's outpatient sessions. Our CQC inspection highlighted their little provision to occupy children in these areas and this increases anxiety for parents and carers. This was also reflected in patient feedback in these areas. The overall aim of the initiative is to improve the care environment in order provide a welcome for children and provide activities to engage and distract and reward children whilst waiting and onwardly through the care experience. The project group is a subgroup of the trust's Patient Experience Group (PEG), chaired by a non-executive trust Director who provides board visibility, effective support and challenge to the project group. Membership of the project group undertaking the initiative includes trust members (voluntary), and trust staff from different roles and services. The project group aimed to create a solution which is bespoke, sustainable and cost neutral to the organisation.

Planning

- The project group was formed to reflect the key skills required to achieve the objective. Trust members were seen as having a vital contribution to the project provide a broad range of ideas and solutions.

- An appraisal of current facilities and care environment was undertaken as each area required a unique solution. An engagement strategy was developed. 4 local schools were identified as they geographically close to the 4 improvement areas.
- Site visits to the local children's Emergency department and OPD at the local acute trust were visited to appraise their facilities.
- Patient and family shadowing was undertaken in all 4 settings to understand the needs of children and their families across all touchpoints in the care experience
- A literature review was undertaken to appraise similar initiatives
- Consultation was undertaken with a primary school teacher who supported the group to identify a target audience age range, themes children enjoy and assist with aligning the 'offer' to schools with the National curriculum
- Potential funding streams were identified
- Project progress was reported to the PEG and Divisional governance meetings
- A patient diary of a young child attending one of the walk-in centres was developed in pictorial form. This was developed in a presentation to be used during the engagement event. (See appendix)
- Four local schools were approached to participate in the initiative. A written offer was made to the schools inviting them to participate. This included a lesson plan of the activities children would participate in during the session; -a patient diary presentation showing a young child with her parent through their journey through the walk-in centre. Children were invited to explain what they could see in the photographs, describe how the young child was feeling, i.e., was she worried, was she brave? And guess what happens next? -Children were invited to participate in using clinical examination equipment, which was used in the patient's diary, e.g., a stethoscope, a pulse oximeter.- A session using animal flashcards to evoke themes around friendly animals, scary and animals and funny animals - A design task where children would develop illustrations of their own friendly animals. 3 schools responded and were happy to participate. The engagement t events were supported by the project team
- A judging panel was selected using trust staff and young children. 12 winning images were chosen.
- Procurement of large vinyl wall art images of the children's artwork is in progress
- Activity sheets, children's play equipment, mobiles and bravery stickers are in development based on the friendly animals theme
- Funding applications are in progress awaiting decision
- An awards event is planned with the 3 participating schools to recognise participation and children's achievements.
- Risk assessment re toys and activities is completed.
- An implementation plan with the estates team has been developed.

Impact

The project aims to improve the experience of children and their families across all touchpoints in their care experience journey. Key touchpoints were identified with the patient journey identifying opportunities for improvement in the experience of care for step. Collaboration with the children at engagement events revealed what makes children feel anxious whilst in the care environment. A friendly animal's theme has been developed in response to the children's feedback. The patient diary will be developed into a storybook available in the project areas. The trust currently uses patient experience questionnaires designed for adults and children and feedback kiosks in the 4 project areas. Current feedback shows that the care experience is a positive but that children could be better supported to have an improved experience through the environment and through play activity. Feedback via the questionnaire and feedback kiosk will be monitored to measure impact. Patient and family shadowing (an observation of care in action) will be repeated to assure the impact is maintained. Patient experience champions identified in the clinical areas will ensure the improvements are maintained.

Relevance to Others

The initiative has compelling relevance to all other providers of children's care services or services where children may be present.

Standing Out

This initiative has shown what can be achieved when we work together, with the community, to deliver improved services. By working with local schools, we have been able to share resources; they gave us their understanding and access to the minds of children so that our designs were led by the users. We, in return, supplied curriculum relevant workbooks that the schools can utilise to enhance their lesson plans. The initiative demonstrates the benefits that lay members/trust members have in quality improvement initiatives bringing a broader vision energy and support to the initiative. Trust members also participated in the engagement events with schools. By listening to the voices of the children, who were accurately able to articulate their experiences so far, we were able to demonstrate how settings are viewed differently by children. This insight has changed our pre conceived ideas of how a setting should appear, enabling us to focus on making the changes that actually make a difference to the children. Whilst the project has the full backing of the trust the implementation phase of the project will be funded by applications to the trust Charitable funds, the League of friends and the Arts Council.

Key Learning Points

- Project teams of mixed roles including lay members are innovative and creative and encourage participation.
- Creating an 'offer ' to schools aligned to the National curriculum increases the chances of participation
- Collaboration with very young children in a safe environment such as their school brings rich data
- Funding streams outside the NHS are available to support initiatives in improving care

The Young Carer Identification Card: Uncovering a Hidden Population
Whittington Health
PENNA 2018
WINNER - Partnership Working to Improve the Experience

Organisation

Whittington Health is an integrated care organisation providing general hospital and community care across North London. More than 4,000 staff work for the organisation to provide care to over 500,000 patients.

General Summary

Young carers are under 18s assisting in the care of a relative/friend who is ill, disabled or misuses drugs/alcohol. Despite their integral role within society, they remain a largely ‘hidden’ population and initiatives specific to their identification within healthcare are absent. Voices of young carers, healthcare professionals and voluntary organisations were acknowledged to improve young carer recognition. The co-creation of the young carer identification card was led by Colette Datt and Naheeda Rahman from Whittington Health in collaboration with Family Action, Healthy London Partnership and Together Creative. Multiple multidisciplinary team meetings, young carer workshops and presentations were executed to develop and disseminate this project.

By identifying themselves as young carers, users can open up much-needed channels of communication with professionals. This can lead to greater opportunities for young carers to positively contribute towards patient care and receive support. Supporting young carers, mentally and physically, will prevent future burden to the NHS, aligning with the five-year forward view. The identification card is being piloted by young carers across North London. Regular feedback will influence future prototypes and dissemination plans. Young carer identification is a universal issue–identification cards can be adapted and used across London to improve their access to healthcare.

Rationale

This is a quality improvement project initiated by Colette Datt, Nurse Consultant of Children and Young Person services at The Whittington Hospital, in response to engagement with young carers from two local boroughs. Young carers expressed concerns during a workshop held at Whittington Health in October 2017 about their experiences engaging with healthcare. Young carers highlighted their difficulty in accessing services and communicating with healthcare professionals; they were often not heard, engaged with nor respected by healthcare professionals because they did not know their rights as young people, and certainly not as young carers.

The primary outcome of this project is a cost-effective young carers card that empowers young carers to assert their rights within healthcare and increases their recognition among healthcare professionals. It was anticipated that an increased knowledge of their rights as young people and young carers within the NHS, supported by young carer identification cards, would encourage and empower young carers to confidently assert their rights to access support entitled to them.

Planning

This project was registered as a quality improvement project at The Whittington Hospital and was led by Colette Datt with considerable input from Naheeda Rahman, a UCL medical student as part of her iBSc in Paediatrics and Child Health. Voluntary organisations, Family Action Islington and Camden and Tottenham Early Help and Prevention Service, provided this project with indispensable insight into young carers’ needs; Healthy London Partnership funded and advised the development of identification cards; and Together Creative brought the young carers’ designs to life.

This initiative was only able to reach such levels of success within twelve months due to the communication and commitment offered by the team. A young carers rights workshop was held by Whittington Health in collaboration with Family Action in January 2018. This was in response to young carers who expressed a lack of knowledge of their rights as young people and young carers during the October 2017 engagement session. Naheeda carried out quantitative research during this workshop to elicit whether education on their rights within the NHS would increase their confidence to assert them. Naheeda then conducted semi-structured interviews to determine the awareness of young carers' rights and support within healthcare amongst young carers and healthcare professionals. Themes extracted from the interviews informed the design and dissemination of this initiative. In total, eight engagement events with twenty-one multi-ethnic young carers aged 11-19 were led in 2018 across North London via Family Action Islington and Camden and Tottenham Early Help and Prevention Service.

Young carer identification was discussed during the rights workshop and a unanimous decision was made to co-develop a young carers identification card. A small amount of funding was secured via Healthy London Partnership allowing the project to invite design company Together Creative to co-develop the identification cards with the young carers. Phase one of this pilot began in June 2018; engagement sessions provided young carers with opportunities to feedback on the usability and effectiveness of the cards. The final feedback session for phase one is in January 2019.

Impact

As a result of the rights workshop, young carers in Islington and Camden reported a 48% and 56% increase in their perceived knowledge and confidence to assert their rights in healthcare. These factors were assessed before and after the workshop via self-assigned 5-point Likert scores. Semi structured interviews were conducted with ten paediatric healthcare professionals, eight adult healthcare professionals and two young carers. Responses were thematically analysed and a lack of awareness and recognition of the young carer phenomenon by healthcare professionals was found to be the inevitable foundation of their poor healthcare experiences.

The young carer identification cards are being piloted via Family Action Islington and Camden and Tottenham Early Help and Prevention Service. Young carers provide feedback every three-months through workshops and questionnaires to establish where, how and why they used the cards and how they have been received by professionals. For example, a young carer in Islington used the card to access information about her mother's condition from a healthcare professional. Young carers also believe that the card will help them to collect prescriptions they have previously been denied.

Conversely, feedback from both young carer cohorts identified the following barriers: loss of card, misunderstanding of the card's purpose and limited interactions with healthcare professionals. Young carers have also expressed their desire for the card design to be similar to that of a more widely recognised identification card (i.e., a student identification card) as opposed to the current cardboard material. This initiative plans to re-design and print the cards onto recyclable plastic for phase two of the pilot.

Relevance to Others

The literature has demonstrated that young carer identification is a universal issue and therefore the associated problems will be equally applicable to other groups. While the young carer identification card has been co-created and piloted with young carers in North London, the concept and card can be adapted and used elsewhere. Once fully developed, the final young carer identification card can be implemented across all UK Trusts and services interacting with young carers.

Young carers are eager to use the identification cards across social, educational and recreational services as well as to access young carer discounts (i.e., cinema tickets, supermarkets). This initiative has been presented at external several conferences including: NHS England supporting carers in secondary care, Great Ormond Street Bioethics and Law Masterclass (1st prize) and the young carer quality improvement project has been accepted as an oral presentation for the Royal College of Paediatrics and Child Health conference in 2019. Professionals agree that young carers are a hidden population and that an identification card would not only raise awareness of the individual young carer but prompt them to consider who else may be a young carer.

Standing Out

This initiative worked in collaboration with young carers – a notoriously difficult population to engage with. Young carers communicated difficulties they face when interacting with healthcare services and their desire for change. Whittington Health partnered with Family Action, Tottenham Early Help and Prevention Services and Healthy London Partnership to use this information to educate young carers and provide them with rare opportunities to advocate for themselves within healthcare.

Working with voluntary organisations through several mixed multidisciplinary team meetings has allowed for enhanced communication between sectors and thus greater understanding of the barriers young carers face in healthcare. Moreover, this project has used the perspectives of young carers and healthcare professionals to create a cost-effective solution. Healthcare professionals acknowledged that they heavily relied on visual cues of caring to signpost them to consider the patient's wider caring network. It is anticipated that an identification card will encourage healthcare professionals to include young carers in conversations and that improving young carer experiences within healthcare will positively enhance their relationship with the NHS, as well as improve overall patient experience.

This could reduce the rates of mental and physical illness among young carers and therefore save the NHS money in the long-term. Above all, this initiative is exemplar of the work that can be achieved through partnering with several organisations, in addition to NHS users themselves. Young carers have consistently engaged with services to co-create a tool they believe can help them to access support. While there are challenges in partnering with multiple organisations, the commitment and passion shown by all parties is a true testament to this initiative's potential.

Key Learning Points

- Listening and understanding the views, opinions and feelings of young carers and using their experience to co-develop a resource has proven to be essential in the implementation of an initiative that excites them.
- Working with groups outside of the healthcare sector gave this project access to different knowledge bases and bridged the gap of miscommunication between service users and providers.
- While engagement with multiple organisations strengthened the project, it also made it difficult to schedule workshops. The project timeline was longer than anticipated to accommodate and maximise young carer engagement.
- Engagement with young people is notoriously difficult, but even more so with young carers who have additional responsibilities. This was demonstrated by the varying numbers of participants at each workshop. Similarly, it has been difficult to collect feedback from all young carers participating in the pilot due to their limited availability.
- Finally, it has been difficult to provide young carers with a card that they are satisfied with due to the lack of funding. Thus far, a fraction of the £13,000 required to create and disseminate the ideal young carers card has been accessed.