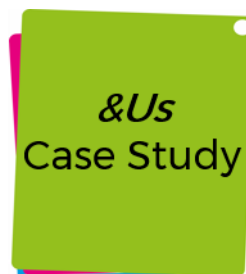




Educate, collaborate,
engage and change!



As part of our refresh of Not Just a Phase (2010), we are profiling different examples of child health engagement.

These snapshot case studies will give you a sense of the type of engagement activity, who is involved, what takes place and the impact of the activity. You can download the theory behind participation and engagement in health services at www.rcpch.ac.uk/and_us by searching for Not Just A Phase.

For more information on the programmes and case studies featured, please contact each organisation directly. To submit your case study, please contact and_us@rcpch.ac.uk



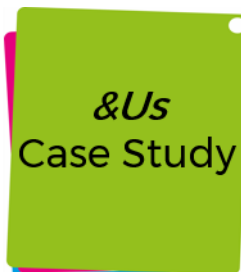
A Guide to the Participation
of Children and Young People
in Health Services



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Registered Charity in England and Wales (1057744) and in Scotland (SC038299).



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The Fruit Fly Collective

www.fruitflycollective.com

Twitter @FruitflyC

Facebook FruitFlyC



Tell me about your project in one sentence...

Giving families the tools to understand and communicate about cancer to improve how children cope and build resilience during a challenging uncertain time.

What does your project do?

Our project promotes education, understanding and communication between a parent/carer and their child when the parent has been diagnosed with cancer.

Where does your project take place?

Multiple sites. Within homes, schools, hospitals and cancer support organisations.

Who does your project help?

Children affected by parental cancer, families, and adults who need support talking to children about cancer.

Who is involved in your project?

Children, young people, parents, carers, healthcare professionals, teachers, and charity support staff.

When does your project happen?

When a child/parent/family requires support at the sites where the project is running.

What is your top success or achievement for your project?

Recognition amongst healthcare professionals that the resources created are needed to support families affected by cancer, winning two BMA awards for Children Information and Innovation, and receiving feedback from a clinical psychologist who reported the positive impact of our project on a self-harming young person.

Anything else you would like to tell us about your child health engagement project?

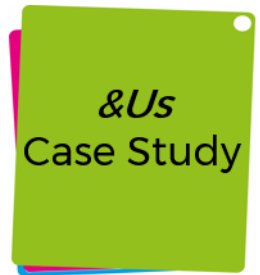
Next year we are embedding our project within Guy's and St Thomas' Cancer Centre where we will be training cancer nurses in how to use our resources as well as designing a new method to give consistent support for a patient's who has dependent children.



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Victoria's Voice

<http://www.bfwh.nhs.uk/childrens/say.shtml>

Twitter @voice_victoria



Tell me about your project in one sentence...

Young people share their expertise with hospital staff in training sessions to improve communication with young patients and improve healthcare for young people

What does your project do?

Empowers young people to train healthcare staff in areas of their expertise- communicating with young people, caring for young people with additional needs etc.

Where does your project take place?

Blackpool Victoria Hospital

Who does your project help?

Blackpool Victoria Hospital

Who is involved in your project?

Young people, local school teachers, staff at the hospital- from a wide range of disciplines

When does your project happen?

Approx. every 4-6 months. Done several sessions so far

What is your top success or achievement for your project?

Staff have made pledges to show how they will work differently to involve young people in their care and treat each person as an individual to cater for their needs

Anything else you would like to tell us about your child health engagement project?

More information at:

- <http://www.bfwh.nhs.uk/pupils-show-nhs-staff-how-people-with-additional-needs-would-like-to-be-treated-in-hospital/>
- <http://www.bfwh.nhs.uk/group-gives-young-fylde-coast-patients-a-powerful-voice/>

The projects began as one-off sessions, but due to their success have now become a regular piece of work.



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Alder Hey's Children and Young People's Forum

julie.sellers@alderhey.nhs.uk



Tell me about your project in one sentence...

Peer Clinical Reference project via '&US' facilitating training for young people to engage with patients and parents of young children thus representing 'patient voices' in a quality project

What does your project do?

Works towards engaging patients and families 'voice' giving a platform for patients to express views and for young people to work as partners in care.

Where does your project take place?

Alder Hey Children's Hospital Liverpool

Who does your project help?

Primarily patients and families and staff awareness

Who is involved in your project?

Young people's patient forum, children, parents, & young people

When does your project happen?

The groups meet every 6-8 weeks.

What is your top success or achievement for your project?

Peer Clinical Reference project via '&US' facilitating training for young people to engage with patients and parents of young children thus representing 'patient voices' in a quality project

Anything else you would like to tell us about your child health engagement project?

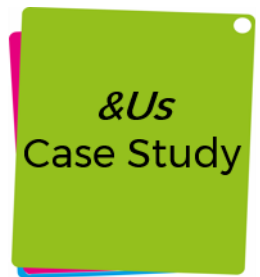
The patient forums consist of 3 groups: Parents; Young People; Children all groups have been engaged in quality projects to enhance patient experience. The groups have also participated in PLACE inspections. The young people and Children's groups have regularly participated in focus groups for senior management and consultants interviews with the young people directly feeding views back to panel toward formal interviews thus involved in decision making. The forum has also been involved in the design of the new hospital building and now involved in interior design and technology projects.



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RAiISE UK

Twitter @raaiseuk
Facebook Raaise



Tell me about your project in one sentence...

RAiISE is a project which aims to Raise Awareness of Invisible Illnesses in Schools and Education by highlighting that not all illnesses are visible and providing information for education professionals so they can give adequate support for their students.

What does your project do?

Raise awareness of invisible illnesses in schools and promote methods for educational professionals to provide better care.

Where does your project take place?

The project is aimed at schools and all meetings so far have been held at Alder Hey Children's Hospital

Who does your project help?

Young people in education with invisible illnesses and their teachers

Who is involved in your project?

Young people from primary school to post-university age, their parents, education and health professionals and charity representative

When does your project happen?

We host meetings every few months with young people which inform the development of the information pack we are creating.

What is your top success or achievement for your project?

North West Coast Research and Innovation Award for Contribution to Patient and Public Involvement in Research

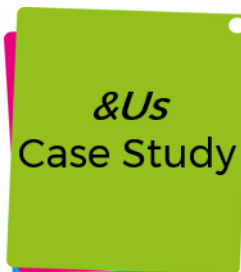
Anything else you would like to tell us about your child health engagement project?

RAiISE has been a great success since it began last year and momentum for the project has been growing even more so in the last few months. I have had the opportunity to present at several international conferences including the European Medicines Agency and Paediatric Rheumatology European Society. Throughout my research it has become evident that there is a great need for a project such as this due to the high proportion of young people with 'invisible' conditions who are unable to get the support they need in school.





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Great Ormond Street Hospital Young People's Forum

<http://www.gosh.nhs.uk/teenagers/teengosh-community/young-peoples-forum>



Tell me about your project in one sentence...

Food for young people, chosen and tested by young people

What does your project do?

Improves the mealtime experience for patients and their families

Where does your project take place?

Great Ormond Street Hospital

Who does your project help?

Patients and their families

Who is involved in your project?

Young People's Forum - ex and current patients from 11-25

When does your project happen?

6 times a year

What is your top success or achievement for your project?

Improved comments about food

Anything else you would like to tell us about your child health engagement project?

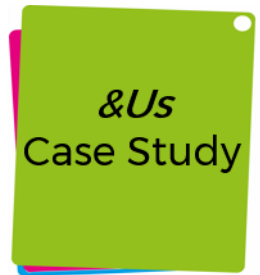
Providing healthy, tasty meals that patients want to eat is a challenge for all hospitals. Here at Great Ormond Street the challenges are even greater to the wide variety of needs our patients have due to their complex needs. We have therefore enlisted the help of patients to do food tasting, suggest items for the menu and even tour the kitchens to help us improve the mealtime experience for patients. Results have included changing a 1 week rotating menu to a 3 week rotating menu, the introduction of meal boxes decorated for animals for smaller children, more child friendly cutlery and plates/ bowls and many others.



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Lister Young Voices

Twitter @ListerYouth
Facebook Lister Young Voices
YouTube Lister Young Voices



Tell me about your project in one sentence...

Inspiring young people giving their time, imagination and creativity to improve public services

What does your project do?

Connects local young people to the Lister hospital to give insight and add value

Where does your project take place?

Lister hospital

Who does your project help?

Hospital - understand needs and aspirations of CYP, CYP - learning and personal development through involvement

Who is involved in your project?

A core group of a dozen or so 14-18 CYP - a youth forum collectively known as Lister Young Voices

When does your project happen?

Regularly through meetings, web, social media, group chat...

What is your top success or achievement for your project?

About to launch a film commissioned and designed by Lister Young Voices showing CYP it's not so scary to come into hospital

Anything else you would like to tell us about your child health engagement project?

LYV hosted a Christmas party for inpatients on our paediatric ward on 28 December - a big success!



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Healthwatch Dorset - Be Yourself Everybody Else is Taken

www.healthwatchdorset.co.uk

Twitter @HwatchDorset #BeYourself

Facebook HealthwatchDorset



Tell me about your project in one sentence...

Gathering children & young people's creative feedback on their health, identity and emotional wellbeing to improve children's services

What does your project do?

Our project called "Be Yourself Everybody Else is Taken" was designed by young people to gather creative feedback about health & care services from children & young people

Where does your project take place?

Bournemouth, Poole & Dorset - the area Healthwatch Dorset covers

Who does your project help?

Our project helps children & young people share their feedback about health and care services in a way that suits them and provides NHS and Council commissioners and providers with creative feedback

Who is involved in your project?

Children & young people, local schools, colleges, youth clubs, young carer groups and other voluntary sector organisations

When does your project happen?

Our project was launched in January 2016 and we're holding a celebration event on 25/4/17 to share the project with NHS and social care commissioners and providers. At the event we'll be making some recommendations about how children & young people's views can influence the future design of health & care services across Dorset.

What is your top success or achievement for your project?

Gaining the support of our local premier league football club, AFC Bournemouth, has really helped promote the project to more children & young people.

Anything else you would like to tell us about your child health engagement project?

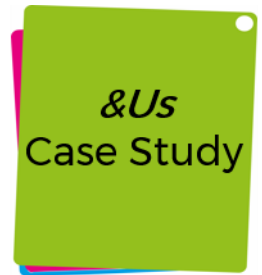
There's a collection of the amazing contributions we've received from children and young people on Pinterest: <https://uk.pinterest.com/hwatchdorset/be-yourself-everybody-else-is-taken/>



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Your Rheum

www.yourrheum.org

Twitter @YourRheum



Tell me about your project in one sentence...

It is a new UK-wide advisory group for young people aged 11-24 years to get involved with rheumatology research

What does your project do?

It is a new UK-wide advisory group for young people aged 11-24 years to get involved with rheumatology research

Where does your project take place?

Across the UK and online

Who does your project help?

11-24 year olds with diagnosed rheumatic conditions and rheumatology researchers

Who is involved in your project?

Young people aged 11-24 years, Clinical Researchers, Public Programmes Team

When does your project happen?

Regular activities happen across the year.

What is your top success or achievement for your project?

Establishing the first UK-wide rheumatology specific advisory group.



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Aparito

www.aparito.com

Twitter @aparitohealth



Tell me about your project in one sentence...

An app for young people to report the issues that are important to them

What does your project do?

Our project provides a disease specific app co designed with young people from the Gaucher Association Empowerment project to allow young people to report their own symptoms

Where does your project take place?

In people's home via an app on their phone

Who does your project help?

Helps young people be giving them a platform to report the issues that are important to them while helping them remember to take their medication

Who is involved in your project?

Leading physician and patient group supporting the young people

When does your project happen?

Started in Dec 2016

What is your top success or achievement for your project?

Engagement of the app by the young people themselves to better inform Doctors about their needs

Anything else you would like to tell us about your child health engagement project?

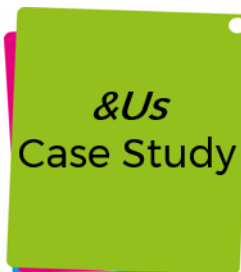
Working in partnership with the Gaucher Association, aparito hosted two workshops to co-develop the app with the young people.



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Future Pulse

www.futurepulsenottingham.wordpress.com

Twitter @futurePulse

Facebook @futurepulsenottingham



Tell me about your project in one sentence...

Empowering young people to have a voice in the community

What does your project do?

Improve access to health services for under 25's

Where does your project take place?

Nottingham

Who does your project help?

Ensures children, young people and young adults have their say about the health services they access. Supports health services to make changes based on the recommendations of young people. Provides positive, diverse and exciting volunteering opportunities for under 25's

Who is involved in your project?

Children, young people, young adults, health professionals

When does your project happen?

On going

What is your top success or achievement for your project?

NHS Expo, interviewing Simon Stevens, seeing positive changes being made in services across the city



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