



State of Child Health &Us

Views from the
RCPCH &Us network

Background

The RCPCH State of Child Health (2017) is our snapshot of infant, children and young people's health across the UK, physical and mental, as well as the determinants of health.

In 2016, over 300 children, young people and families took part in sessions looking at issues and challenges faced by children and young people that stop them from staying happy, healthy and well. These views were shared in the 2017 The State of Child Health report, highlighting 4 areas of importance for under 25s – poverty, communication between children and young people and their healthcare workers, mental health and having high quality PSHE (personal, social and health education) in schools.

As part of the *State of Child Health – One Year On* report launched in 2018, children, young people and families shared their views, comments and project ideas on the 2017 four topic areas, as well as noting emerging topics including LGBT+ health and increasing awareness of children's rights with healthcare professionals.

This latest *State of Child Health – Two Years On* report for 2019 looks at these topics plus new areas of interest for the RCPCH &Us Network for children, young people and family members – Youth Friendly Services and Hidden Health Needs. This report shares their views on these topics, their suggestions and projects to support change led by children, young people and families supported by RCPCH.

The State of Child Health &Us

The RCPCH &Us Network delivers engagement, involvement and participation activities to support children, young people and families in sharing voices, views and solutions on child health topics. During 2018, children, young people and family members took part in sessions, challenge days, projects, consultations and events focused on key topics within the State of Child Health report.

Stats box for 2018	
Children, young people and families involved	1,004
Project / workshop sessions with children, young people and families	43
UK towns, cities and villages visited	28
Nations covered	4
Workers involved in children's rights and participation awareness sessions	1077

Over the last 12 months... RCPCH &Us Network members priorities were:

Hidden Health (new for 2019)

Throughout 2018, children, young people and families worked with RCPCH &Us on topics relating to Hidden Health needs including having long term conditions such as epilepsy or asthma, the impact this has on the carer's health (sibling carer or parent/carer) and about the hidden conditions such as mental health needs or heart conditions.

Challenges identified include:

- A lack of peer support groups for children, young people or their families where they can meet other people with similar, hidden conditions (Greater Manchester 2018)
- More consistent support and awareness raising in schools of

hidden health needs with students, families and school staff (Surrey 2018)

- Increasing awareness within healthcare settings from reception to clinical teams of the hidden health needs of children and young people, particularly where there are a range of professionals supporting them (Liverpool 2018)

The primary request is that healthcare workers become more aware of the child as a whole, rather than just their medical condition or illness and can signpost for holistic support both for the patient and their family.

#HIDDENHEALTH



Hidden Health (new for 2019)

Case Study: #HiddenHealth #ThisIsMe

Throughout 2018, parents from Alder Hey Children's Hospital have been working with RCPCH &Us to develop a project on hidden health. The project has been thinking about three different elements of being "hidden"

- Children and young people with a hidden condition or illness
- Hidden family carers providing support
- Hidden support services such as parent carer forums that are not always signposted by staff.

Project members have shared their hopes and wishes, collected the experiences of others and looked at what would help them and their children to feel visible again.

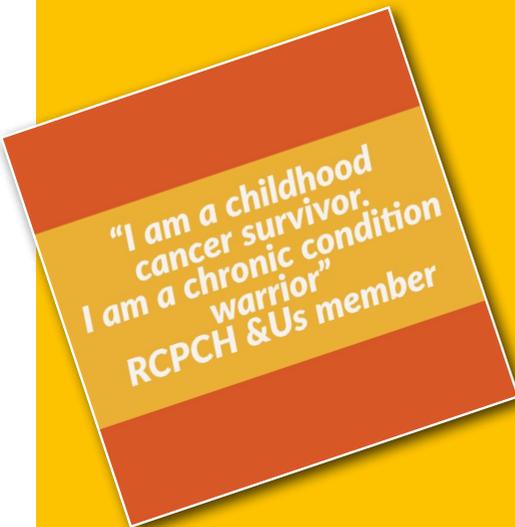
Project members said that hidden health to them means:

“

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Something that makes me a warrior, where I need notes sharing between departments, links to be made between symptoms, where I gain strength and empowerment through supporting my child with a hidden health issue” (Liverpool 2018)

“

.....
Conditions that the world and people just don't understand – mental health, blood disorders, autism, bowel issues, breathing issues (no tubes or gadgets to see), something that isn't relatable to you (Liverpool 2018)



"I am a childhood cancer survivor. I am a chronic condition warrior"
RCPCH &Us member



Project members created a #HiddenHealth #ThisIsMe card which they are testing locally to help raise awareness of conditions, support services and what makes them or their child a warrior. The cards will be available for free download in May 2019:

www.rcpch.ac.uk/and_us

Hidden Health (new for 2019)

Case Study: Clinic Chats for Long Term Conditions

As part of project work funded by the Healthcare Quality Improvement Partnership to look at children and young people's experiences of care in epilepsy and asthma services, RCPCH &Us members have been sharing their views on living with invisible illnesses and what they need to be different.

Over 130 children, young people and their families took part in clinic chats and family event days in 2018 to share what it is like living with a hidden health need, with youth advocates reviewing the responses and identifying what would make the most difference if improved. Topics included;

- Schools providing more support, having good care plans, awareness training visits from specialist nurses
- Support for worries and anxieties such as “why me?”, help with transition, mental health, giving positive messages of hope
- Practical help about lifestyle tips, independence, sleep and how to explain epilepsy to friends and family

The youth advocates created a 75-minute presentation for over 160 epilepsy specialists about the findings and what everyone could do to make a difference



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Some times living with an invisible illness, it can seem that seizures are unstoppable. But looking at the results of the clinic chats, the children and the young people are the ones who are unstoppable

which they shared in June 2018. Their next steps included creating a report about their findings and a video of their presentation to keep sharing the learning. In 2019, they will be working with epilepsy units to create and test solutions to the challenges raised in their clinic chats. You can find out more at

www.rcpch.ac.uk/epilepsy12

At the Asthma Patient Panel and clinic chats in 2018, similar views were shared with young people and families commenting on the need to improve awareness and support in schools about asthma. Young people mentioned the link to experiencing poor mental health due to the condition and its impact on everyday life. The need to improve communications between general teams and specialist clinicians was also raised, so that everyone has access to the same information about treatment and care.

In 2019, there will be more clinic chats to be reviewed and shared by the Asthma Youth Advocates in the summer – keep an eye on www.rcplondon.ac.uk/projects/national-asthma-and-copd-audit-programme-nacap

ASTHMA AND ME

Hacks and coughs
Breathing smoke,
Frozen throat,
Asthma, not cold.

Don't need drops,
Meds are pipes,
Brown, blue or purple.
I keep on choking.

Chest hurts a lot,
Hard to even walk,
I can't talk
Breath has stopped.

Can't breathe now,
Ice stuck in throat.
Inhaler helps,
But my Asthma still
sticks to my throat
Like barnacles to a
boat.

(RCPCH &Us Member)

Youth Friendly Services (new for 2019)

Across sessions in 2018, young people shared their ideas and views on how to create youth friendly services that met their needs in the way they are involved in their care, in the environment that clinics take place and in how they are spoken with. In clinic chats, workshops or project sessions, young people said the key features of youth friendly services are;

- Being with people of a similar age when getting health support, including creating wards and clinics for 16-25-year olds (Bedfordshire 2018)
- Having a one stop shop approach to increase young people's use of health services and their regular appointments where they can ask private questions about sexual health, get careers advice, find out about money and get their condition reviewed (London 2018)
- Think about the needs of those with complex health conditions or ongoing health needs, so that they have access to see clinicians at the same time and to have consistent staff like specialist nurses (Mansfield 2018)
- Have a choice of when and how you can see health professionals so that you don't have to miss school, college or work (Southampton 2018)

Views from young people were also collected to inform the NHS England Long Term Plan in partnership with other youth focused organisations. Over 300 young people took part with 31% saying that creating youth friendly services is vital to keeping young people healthy, happy and well over the next 10 years.



Case study: Feedback on your service

In summer 2018, a group of young people visited RCPCH to take part in a Digital Takeover Challenge, reviewing content from across our online platforms and identifying where there were gaps for young people. Joseph had previously found it difficult to know how or when to give feedback to services when you are a young person and worked with RCPCH & Us to create a new resource.

“Want to give feedback about an experience at your hospital or clinic and not sure where to start? Maybe you have had bad treatment, or didn’t understand what was said to you or didn’t feel right?”

This short 90 second video explains how to give feedback, who to share your views with and what to expect. There is even an example letter drafted as part of the Takeover Challenge that shows young people how to create a formal letter and what to include. You can find out more at:

www.rcpch.ac.uk/cyp-feedback

Youth Friendly Services (new for 2019) Case Study: A youth friendly RCPCH

In 2018, children and young people helped in creating youth friendly services within RCPCH by being involved in three big projects – voice in paediatric training, exams and assessments, recruiting staff including the Chief Executive and supporting the development of guidance on children and young people’s representatives in committees.

Voice in recruitment

Young Recruiters have training, plan their interview tasks and questions, review the job description and run their interview process with candidates independently of the worker or trustee panels. They are supported with note takers and provide written feedback on answers given in the same way as other parts of the process and have an agreed part of the overall score. In 2018, 12 young recruiters interviewed over 3 days, ensuring that the ethos and values of children and young people’s involvement was clear throughout the process.

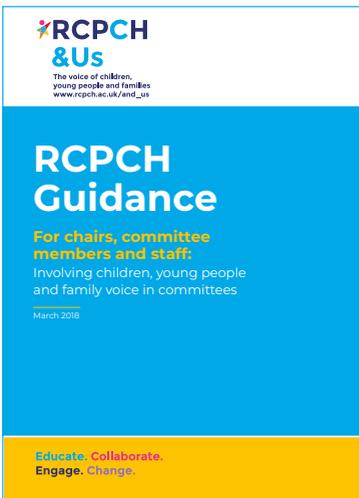
Voice in governance

To support the development of friendly governance structures within the RCPCH, young people and their families have been involved in reviewing how children, young people and family voice can be part of formal meetings such as College committees. As part of the review, members of The RCPCH Infants, Children and Young People’s Engagement Committee along with voice representatives from other committees, created guidance which showcased different models of involvement in formal meetings and checklists to support everyone involved. This can be downloaded at:

www.rcpch.ac.uk/CYP-voice-committees

Voice in paediatric training

Pilots, workshops and sessions have been taking place to think about what children, young people and families are looking for in a paediatrician, and how this can be developed into scenarios, questions and assessments through the career of a paediatrician. Top priority for children, young people and families is how healthcare workers speak with them and explain what is going on during their appointments and treatment. Pilots in 2018 developed how to capture this feedback during the paediatric exam process - watch out for developments in 2019!



VERY GOOD



GOOD



VERY BAD



BAD

LGBT+ Young People (2018 emerging priority)

Following on from LGBT+ young people's health being raised as an emerging priority in the 2018 State of Child Health &Us report, we have been working with an exciting new initiative spreading across Twitter and the NHS.

Case study: Rainbow NHS badge

The Rainbow NHS Badge Project was developed at Evelina London to make a positive difference by promoting a

message of inclusion. Many young LGBT+ people say that they do not have an adult they can turn to or confide in. The Rainbow NHS Badge Project believes that people who work in health-care can play a key role in making things better. If you see someone wearing a badge, you can talk to staff about who you are and how you feel, knowing they are a good person to talk to about issues relating to sexuality and/or gender, who will signpost towards further help and resources if needed, aiming to break down barriers faced by LGBT+ people when accessing healthcare.



LGBT+ Young People (2018 emerging priority)

Case study: Rainbow NHS Badge &Us

In 2018 we started working with the Rainbow NHS Badge Project and Central Bedfordshire Youth Voice to explore what it would mean to young people to see health workers wearing the Rainbow NHS Badge, to develop youth led materials to help raise awareness and to empower young people to speak to health services locally about the project.

So far, the RCPCH &Us project has worked with young people to:

- Share their views on how to promote the badge and how to support workers wearing the badge to understand their role
- Attend Herts Pride in Sept 2018 to consult with young people on what the badge means to them and how it could make a difference to the LGBT+ youth community. "The badge means that I am included" Herts Pride young person, Hertfordshire

- Create materials to help young people lead a grass roots campaign in their local area to raise money for the badges and to raise awareness with health workers about why they are needed in all health services – from school nurses to GPs to emergency departments to dentists to physios to...the list is endless!
- Identify barriers to LGBT+ young people feeling included and welcome in health settings

The next steps for this project will be to launch their youth toolkit in 2019. Keep an eye for details!

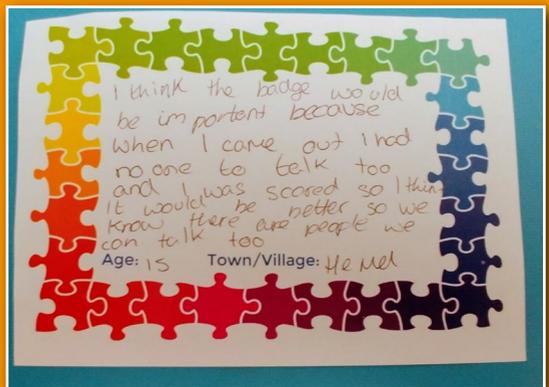
www.twitter.com/rainbownhsbadge



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The badge makes me think.... the NHS is supporting it (LGBT+ issues) and understanding of the situation faced by the LGBT+ community

Central Bedfordshire Youth Voice member



Children's Rights (2018 emerging priority) Case study: The Science of Engagement

In October 2018, over 100 workers in Cardiff, London, Belfast and Glasgow took part in sessions looking at The Art and Science of Effective Engagement with Children and Young People, coordinated by the Children and Young People's Engagement Team at RCPCH with trainers from the Kaizen Partnership.

Workers explored themes including children's rights, levels of engagement, developing an engagement plan, common barriers to successful engagement and how to overcome these. As part of the interactive training sessions, attendees also shared ideas about how to keep building an engagement movement amongst their peers and colleagues, so that as many staff as possible can learn about why we involve children and young people in shaping services, how to do it and what difference it can make.

We hope to run more training sessions in the future – keep checking www.rcpch.ac.uk/news-events/events

The Art and Science of Effective Engagement with Children and Young People

15 October, Cardiff
16 October, London
29 October, Belfast
30 October, Glasgow



The 2017 State of Child Health voice priorities are still important too!

Personal, social and health education (PSHE):

Having access to high quality lessons at schools or sessions in health/youth settings about skills for life continues to feature, with children and young people (London 2018) wanting to know more about:

- Finances and budgeting
- Domestic literacy
- Careers
- Relationships
- Mental health first aid
- Healthy lifestyles
- Accessing health services
- Being safe online
- Living with health conditions

Young people also said that parents and carers need to be involved so that they also have the knowledge and that it needs to be open, honest and adapted for each person and their needs. The RCPCH &Us Network contributed to the Government consultation on PSHE in 2018.

Mental Health

Having access to support with emotional health and wellbeing is vital for children, young people and families to be able to develop and thrive. Sessions continue to highlight the need for increasing support at all levels:

- How to support friends who are struggling, or knowing where to go for help with stress or anxiety about everyday things like relationships, exams and growing up (London 2018)
- Help when diagnosed with a long-term condition for the whole family (Kent 2018)
- Having quick access to support when you need it, so that you don't wait and get worse (Greater Manchester 2018)
- Having more staff from all sectors trained to spot, signpost and support children and young people's mental health (Northamptonshire 2018)
- Young people with a long-term condition need support with their mental health – there is a lack of help for young adults in adult's services following transition out of child and adolescent mental health services (London 2018)



Mental health is as equally important as physical health. It is fundamental to epilepsy treatment. In the UK one fifth of people suffer from depression. For people living with epilepsy this is a third

RCPCH &Us Member

RCPCH &Us Network contributed their views on mental health services as part of the NHS England Long-Term Plan consultation in 2018.

Communications:

Children and young people want to be involved in the discussions and decisions that affect their health, using a range of communication approaches to improve dialogue between health professionals and patients.

During 2018, sessions focused on how to improve sharing health messages and reducing the frustration caused when it doesn't work well:

- We need to have access to someone we can trust to talk to who knows about our life (Edinburgh 2018)
- Using pictures, drawing on scans and letting me take it home and using child friendly sheets really helps (Greater Manchester 2018)
- Having professionals who are open minded, aware and respectful that talk to you and not at you really helps (Swansea 2018)
- We need doctors who understand what we are trying to say and who can pick up what we are trying to say when we can't quite say it ourselves (Northamptonshire 2018)

Children and young people's views on communication skills for doctors has started to inform the RCPCH Shape of Paediatric Training Programme, with views being shared with committee members in 2018.

Poverty:

Discussions with children and young people continue to focus on the need for support with accessing services due to transport costs, or having healthy food to eat that is affordable or not being able to access sports to be able to live an active life.

During Takeover Challenges in 2018, young people looked at the impact on poverty on staying healthy, happy and well:

- Young people need to know how to cook a healthy meal for a fiver that is nutritious especially if they have a long-term condition (Swansea 2018)
- We need to help parents and give them advice to make the right choices that can make a good difference in a child's diet and life (Edinburgh 2018)
- People in poverty still need to be active and they need free or cheap sports clubs for primary and high school students (Edinburgh 2018)

Young people in Swansea are working with RCPCH & Us to develop a "How2Adult" guide, helping young people to live healthily on a budget along with other practical advice and tips for young adults. It will be available in Spring 2019, keep an eye on www.twitter.com/RCPCH_and_us for more information

Resources

- The State of Child Health – full report (2017), one year on scorecards (2018), State of Child Health &Us views from young people report (2018)
www.rcpch.ac.uk/resources/state-child-health
- RCPCH &Us – project updates, news and views from children and young people
www.rcpch.ac.uk/and_us
- Epilepsy12 Audit Programme
www.rcpch.ac.uk/epilepsy12
- National Asthma and COPD Audit Programme
www.rcplondon.ac.uk/projects/national-asthma-and-copd-audit-programme-nacap
- Young people's feedback resource designed by RCPCH &Us members
www.rcpch.ac.uk/cyp-feedback
- Guidance on involving children, young people and family voice in committees
www.rcpch.ac.uk/resources/involving-children-young-people-family-voice-committees
- Guidance for health professionals and families on screen time use
www.rcpch.ac.uk/screen-time
- Facing the Future - standards for children and young people in emergency care settings
www.rcpch.ac.uk/facing-the-future
- Addressing child to adult transition in national clinical audit A guide
www.hqip.org.uk/resource/addressing-child-to-adult-transition-in-national-clinical-audit-a-guide/
- Rainbow NHS Badge Project information
www.twitter.com/rainbownhsbadge
- United Nations Convention on the Rights of the Child
www.unicef.org.uk/what-we-do/un-convention-child-rights/
- RCPCH Courses and Events
www.rcpch.ac.uk/news-events/events
- RCPCH &Us Voice Bank – for access to responses, please contact:
and_us@rcpch.ac.uk



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