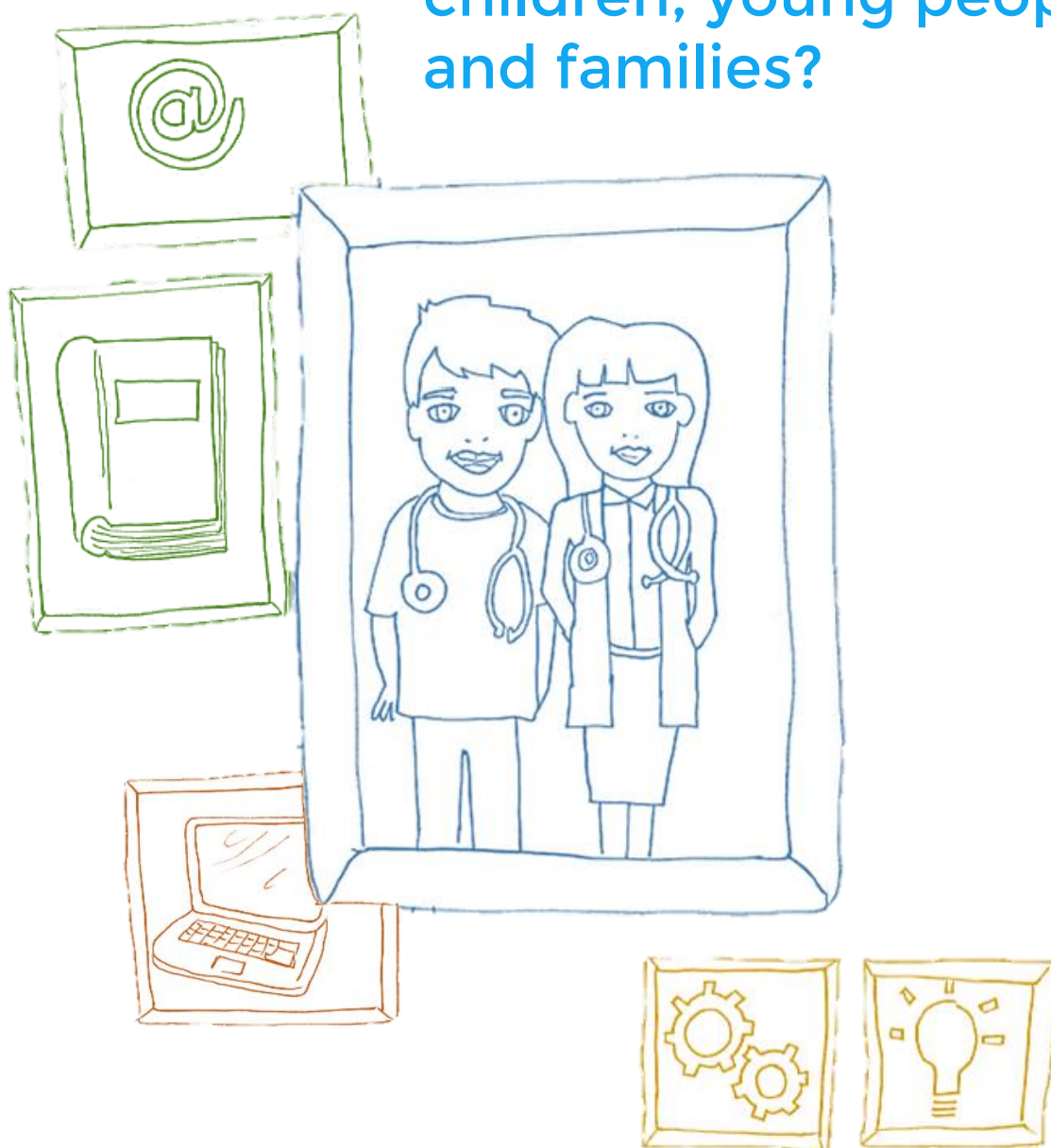


RCPCH Progress

What do the RCPCH
Progress domains mean to
children, young people
and families?



RCPCH Progress and children, young people & their families

This booklet brings together voices, views, ideas and experiences from children, young people and their families in relation to the RCPCH Progress domains. Please use these to help inform and shape your services, practice and reflections.

For more information about children, young people, family voice and engagement, please contact and_us@rcpch.ac.uk

RCPCH Progress
Paediatric curriculum for excellence

RCPCH Progress
is the new curriculum
for training doctors
in paediatrics.

**What makes
a great doctor?**

Did you know?
More than 200
children, young people
and their parents and carers
helped develop the curriculum,
to ensure we train doctors who
understand the needs and
interests of their patients.
They told us what matters
most to them, and what
makes a great doctor.

Making children's voices heard
Content written by some of these young people
is indicated within the syllabus documents.

Find out more at www.rcpch.ac.uk/progress

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RCPCH &Us
The voice of children, young people and families
The RCPCH &Us group ensure patient voices are heard in all aspects of the RCPCH's work. Find out how you can get involved in future projects at www.rcpch.ac.uk/and_us

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

What does the domain “Professional values and behaviours” mean to children and young people from RCPCH &Us?



Don't be afraid to talk to us about the future. Don't speak to me just about my condition but speak to me about my life.



RCPCH &Us Member



Over 200 children, young people and families told RCPCH &Us what makes the best paediatrician.

Watch their video:

<https://youtu.be/jkKSPT4CnhQ>



The best doctor is...

informed about national & local services support for children and young people, signposting and engaging with them.

Young person, RCPCH &Us



Children, young people and families said that professional values and behaviours to them includes paediatricians who are:

- professional at work
- open minded
- aware of their own actions
- respectful
- following “good medical practice”
- friendly and approachable
- age appropriate
- talking to you not at you
- knowledgeable.



The best doctor is...

someone who can change your feelings of health and can help you on the worst day possible.

RCPCH &Us Voice Bank



What does the domain “Leadership and team working” mean to children and young people from RCPCH &Us?



Over 200 children, young people and families told RCPCH &Us that team working is important for the best healthcare possible.

Watch their video:
<https://youtu.be/E3303esR3Js>

“

“Remember to coordinate between teams with an awareness of the impact on the life of the family with a long term condition having lots of appointments and tests”

Parent - RCPCH &Us

“

“Everyone working together when it is time for transition is important. Having an appointment with my childrens hospital doctor with the one from the new adult hospital helps ”

Young person - RCPCH &Us

”

Children, young people and families said that “leadership and team working” to them includes paediatricians who are:

- Know who your team is and how to get in touch with them
- Helping others to understand what is going on and why
- Includes other people too like schools, nan’s and friends – not all medical people
- Find the right person who can help you and get them to see you quickly
- Making me feel confident that you know what needs to happen next

“

“My wish for child health is that children and young people are given the power and tools to make decisions that affect their lives. The only way to know what we want is to ask us and talk to us”

Young person - RCPCH &Us

”

What does the domain “Research” mean to children and young people from RCPCH &Us?



“

“Paediatricians need to be clear with children and young people about what research is, what will happen and how they can get involved. Stop using jargon or words that might mean something different for children and young people”

Young people - RCPCH &Us

”

Over 130 children, young people and families helped to create the Research &Us Charter to support involvement of children and young people in child health research.

Watch the video:

<https://youtu.be/xrNGG9HlzyC>

and download your full A4 Charter:

www.rcpch.ac.uk/cyp-research-charter

We asked children and young people how they want to get involved in research with paediatricians and they said by;

- Raising awareness of research with children and young people
- Encouraging children and young people to get involved in child health research from the start
- Developing the research design – from the question, to choosing how to do the research and who is involved
- Helping children and young people to be able to give informed consent
- Helping to do the research and checking it is doing what it is meant to be doing

Research &Us

Infants', Children's and Young People's Child Health Research Charter



The voice of children, young people and families
www.rcpch.ac.uk/and_us

Remember it's about me; involve and support me at every stage and keep me safe from harm.

Empower me, my family, and the people caring for me; help us to understand and feel more confident about research.

Support me, my family, and the people caring for me; give us time to understand research processes, how to assess risks and benefits, and what it will mean to be involved.

Engage with me and my family; listen to our questions and ideas, so we can help you to help us benefit from research.

Actively gain my consent or assent and explain my right to change my mind and withdraw at any time.

Rights are important to me; my right to understand research, be involved in decisions, be respected, and to help others benefit from research.

Communicate with me directly and clearly; make it easy for me to talk to someone about the research when I have questions or ideas.

Help others by sharing our stories; the things that worked and the things that didn't.



Contact your local engagement lead for information:

Go to www.rcpch.ac.uk/cyp-research-charter for more information about external resources and useful links to support child health research.

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Royal College of Paediatrics and Child Health
Leading the way in Children's Health

What does the domain “health promotion & illness prevention” mean to children and young people from RCPCH &Us?



30 children age 7 & 8 took part in a Takeover Challenge in the College where they learnt about child health past, present and thought about what they need in the future. They created a video for us about why health promotion around hidden sugars in food is important for keeping children healthy, happy and well.

Watch the video: <https://youtu.be/4Qk0eAtv4js>

Over 300 young people told RCPCH and partners what they thought was important for the next 10 years of the NHS. They said:

We asked children and young people what keeps them healthy, happy and well and they said;

WHAT DO YOUNG PEOPLE WANT TO BE IMPROVED AS PART OF THE NHS LONG TERM PLAN? OVER 300 YOUNG PEOPLE SHARED THEIR VIEWS...

GIVE US SKILLS FOR HEALTH

21% SAID

MORE TIME GIVEN TO SHOW US HOW TO STAY HEALTHY, SUPPORT TO LEARN ABOUT BUYING AND COOKING HEALTHY FOOD, SHOW US HOW TO DO SELF CARE WELL TO HELP PREVENT PROBLEMS HAPPENING, BETTER HEALTH EDUCATION

- Health information which is more interactive and memorable
- Having annual checks for vulnerable groups and introduce health checks in secondary school
- All doctors to have a good understanding of how to support good mental health for children and young people
- More education and awareness sessions on mental and physical health from a younger age
- Have more opportunities for parents and patients to talk to each other and get advice/support from people with lived experiences of conditions – tips to prevent crisis

What does the domain “patient safety including safe prescribing” mean to families from Medicines for Children?



Parents and nurses from the children's charity WellChild helped to create instructional videos designed to be an accurate source of practical information for parents and carers giving medicines at home to their child. **Watch the videos:** www.medicinesforchildren.org.uk/types-of-medicines

We asked 225 parents of children and young people with complex health needs what their biggest concerns were in relation to patient safety and safe prescribing and they said:

1. Communicating with other carers and healthcare professionals about their child's medication
2. Remembering which medication to give and when
3. Their child's response to receiving the medication
4. How to administer the medicine and how much to give

“Thinking about the last 24 hrs only - how much time would you estimate you have spent on providing care for your child/children?”

On average, respondents spent:
17.9 hours providing care, including
3.4 hour administering medicine

How Medicines for Children can help trainees:

- www.medicinesforchildren.org.uk has 200+ patient information leaflets, developed by experts in paediatric medicines.
- The information is written to a reading age of 12 to be accessible for all. The leaflets can be viewed online or printed in clinic to read at home
- Contact us for more information: medicines.leaflets@rcpch.org.uk

“What a fabulous resource!
We're five years into complex need parenting and this has helped us many a time over the years!”

Parent and Medicine for Children user

Medicines for Children mobile app



Following calls from parents and carers, a mobile app is being developed to help to manage children's medication needs. The app will enable easier access to medicines information whenever and wherever parents need it.

The medicines management app will:

- Provide guidance on how to administer medicines safely
- Offer reminders when doses are due
- Aid communication with professionals

What does the domain “education and training” mean to children and young people from RCPCH &Us?



VERY GOOD



GOOD



VERY BAD



BAD

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 have been featured in the BMJ and have helped us to develop how to capture formative feedback from children and young people during the paediatric exam process - watch out for developments in 2019!

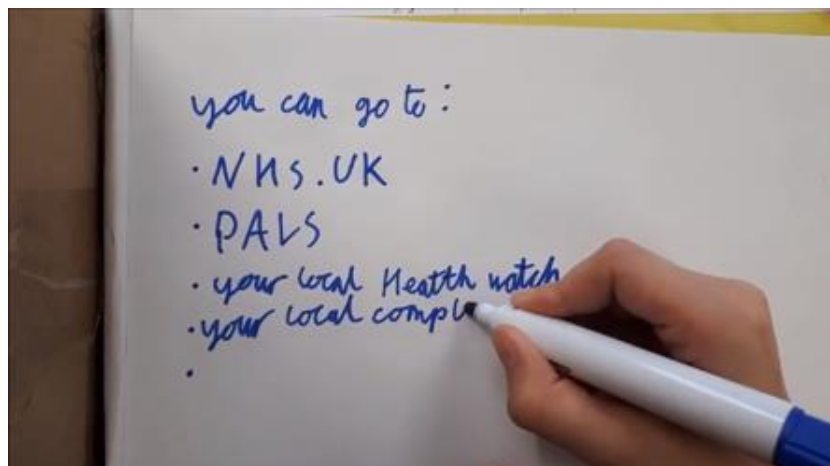
In 2017, young people created a learning tool to help doctors to stay child & young person focused. This was included in the Facing the Future: Standards for children in emergency care:

U	Us – who is the patient? Talk to Us and not just our parents or carers
N	Numbers matter – missed opportunities to find out more or to actively listen to Us
D	Disclosure – we want to know who has to know, who needs to know and ask Us who do I want to know
E	Environment – is it a child/youth friendly waiting area/ consultation space so that I feel comfortable to talk with you about what has happened?
R	Reassure Us that you have listened, heard and acted on what we have said
S	Signposting – do you know your local child/youth support services? Help Us to get support once you have gone
T	Transition - within hospitals / GPs and other services should include Us in the conversation and planning
A	Attitude - a smile costs nothing but makes Us feel like we matter
N	Needs – find out what matters to Us this could be how or where we are treated, who we want to be with Us .
D	Decisions – need to involve Us . Article 12 from the United Nations Convention on the Rights of the Child helps Us to have access to best healthcare possible, Article 24.

We asked children and young people about training paediatricians and they said:

- Children and young people have to be involved!
- We want to help you to learn as well as you teaching us about our condition
- It’s not only doctors that need to learn new things, we wish that all school staff understood more about our conditions like epilepsy and asthma. Maybe doctors or nurses could visit the schools?
- The most important thing for us is that doctors are taught how to understand what I am not saying, especially as a teenager!
- We need all doctors to be taught about mental health so that if we see them in the hospital or in A&E or in our school they know how to help us or who is the best person that can help quickly

What does the domain “communication” mean to children and young people from RCPCH &Us?



Feedback resource by young people for young people

Joseph (11) spotted a gap in young people's knowledge around how to provide feedback on services and to communicate their concerns, wishes and needs. He created a short video guide along with a template letter to show young people what to do. You can view both at www.rcpch.ac.uk/cyp-feedback

Over 300 young people told RCPCH and partners what they thought was important for the next 10 years of the NHS. They said:

WHAT DO YOUNG PEOPLE WANT TO BE IMPROVED AS PART OF THE NHS LONG TERM PLAN? OVER 300 YOUNG PEOPLE SHARED THEIR VIEWS...

LISTEN TO OUR VOICE

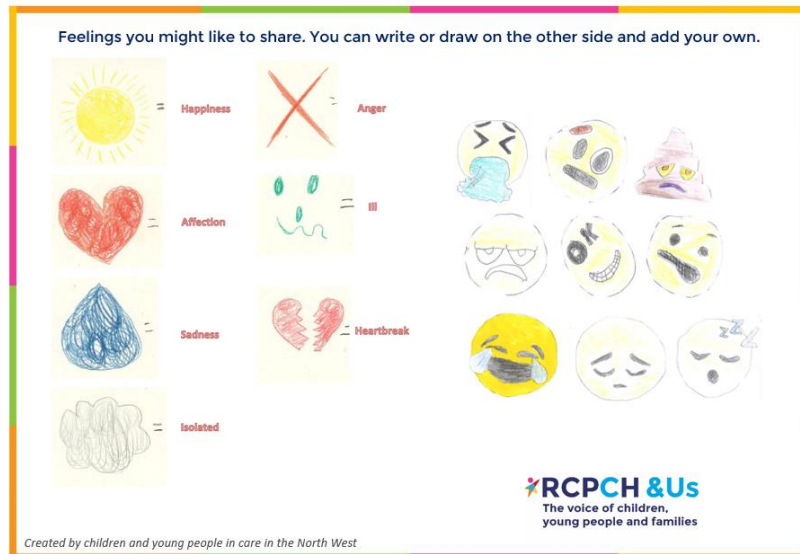


UNDERSTAND, LISTEN, VALUE & INCLUDE OUR VOICE & OUR RIGHTS IN OUR HEALTHCARE, INCLUDE US IN SHAPING SERVICES, RESPECT OUR NEEDS THAT ARE DIFFERENT TO WHEN YOU WERE OUR AGE

We asked children and young people what good communication with services means to them and they said:

- It needs to be easy to tell you what I need or what I think
- It would be good if we could email or message you our questions before the appointment in case we forget or aren't brave enough to ask
- We are the future. Services need us to be part of them to help them be what we need and this means you need to ask us and then do something with what we say
- I want to feel that I understand my doctor and what he is saying, so that I don't have to ask mum afterwards
- Communication is about building up trust, it's nice when the doctor knows I like cadets and asks me at the start. It makes me feel comfortable.

What does the domain “patient management” mean to children and young people from RCPCH &Us?



Patient management for Looked After Children

Children and young people in care are working with RCPCH to develop an understanding of what patient management and support means to them. Over the course of their project, they have looked at how appointments should be tailored to meet their needs, whether that means using iPads or feelings cards, or using activities to help find them explain what is wrong and understand a treatment plan.

You can find out more about this project in their presentation at the RCPCH Annual Conference.

We asked young people what they think creates a good transition process for young patients between services and they said:

- Recognise and **discuss individual needs in young people friendly terms**
- **Look at transition holistically**, to include advice on: social, emotional, educational, geographical, employment, relationships and physical health
- Adult services to make social connections and have a long term relationship with young people, to **provide continuity of care**
- **Multidisciplinary teams are important** and should meet regularly to prepare the young person for transition
- Signpost to **local services, resources and knowledge**
- Support young people with their **mental health**

“You have come to the doctors today and we would like to know why. Tell us your feelings. Don’t keep them inside. We can get you fixed up in no time. Just tell us how you are”

Children and Young People
Looked After Voices Project, 2019

What does the domain “safeguarding” mean to children and young people from RCPCH &Us?



"Don't miss the chance to help us and our families before it gets too bad"



Child - RCPCH &Us

Children aged 10 and 11 in Scotland have been sharing what the impact of living in poverty has on their physical health, mental health, wellbeing and aspirations for the future. They wanted everyone involved in the child's life to be part of supporting them to stay healthy and safe and to make sure that living in poverty didn't lead to things getting worse with deteriorating health, feeling judged or not being able to stay with their families.

The voices and views of the 90 children that took part are informing the work of the State of Child Health 2020 project stream.



We asked children & young people what they think keeps them safe and they said:

- Adults that we know and trust to speak with about things that are going on in our lives
- Safe places to go in our local area which helps us to see friends, do things together and not be out on the street
- An environment that is safe, clean, fixed up and doesn't encourage bad things to happen
- Not being judged by services or staff – just because we have a social worker or need a bit of help doesn't make us a bad person
- To give us access to support when we need it, so we don't have to wait or be worse to qualify for help



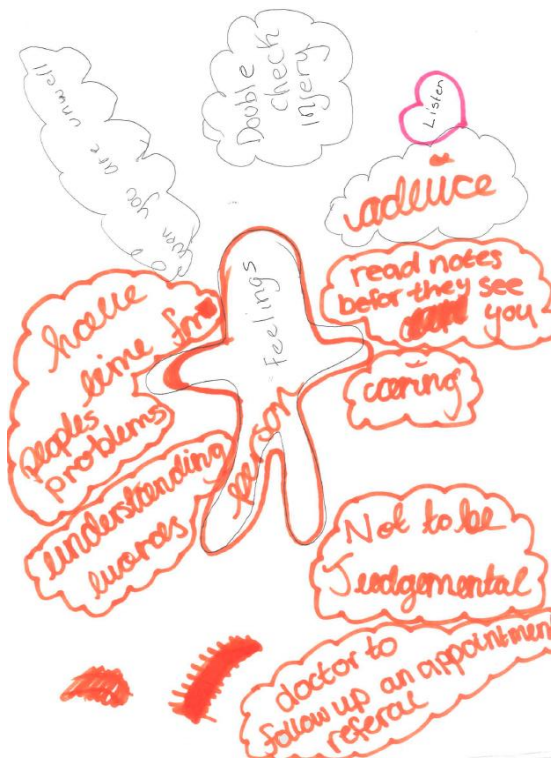
"Doctors need to know that sometimes children's hearts are broken and we are not always happy"



Looked After Child - RCPCH &Us

What does the domain “procedures” mean to children and young people from RCPCH &Us?

Children, young people and families told us what helps them when they are being seen by a doctor:



“

"Remember the things that can't be seen like anxiety, being scared of needles, having learning disabilities, being in chronic pain and our feelings. This might change how we respond to what you are doing"

”

Young people- RCPCH &Us

We asked for examples of when doctors have changed what they are doing to meet the needs of the patient. Children, young people and families shared their experiences:

- A young person with cerebral palsy and limited speech likes it when they are talked to directly and when the consultant emails before with questions and information
- A child with epilepsy liked it when they got a copy of the brain scan which was drawn all over by the doctor to explain what happens
- A young person said about how the doctor used easier words and did a drawing to explain what was going to happen
- A parent shared how the doctor works with play specialists to use play, activities and role play to explain what will happen with the needle and when they have their procedure

“

"There needs to be emotional support for parents, especially when they has been medical emergency with their child"

”

Parent - RCPCH &Us

#Resources

Useful resources shared with each domain

Professional values and behaviours

- Consultation activities at www.rcpch.ac.uk/recipesforengagement
- How to write an engagement plan www.rcpch.ac.uk/write-engagement-plan

Leadership and team working

- Involving children and young people in leadership and governance
- www.rcpch.ac.uk/resources/involving-children-young-people-family-voice-committees

Research

- ADC article “Advancing child health research”
<https://adc.bmj.com/content/102/4/299>
- Webinar on involving children and young people in research
<https://youtu.be/xbjKaYZiHVg>
- Guidance on involving children and young people in research
<https://www.rcpch.ac.uk/resources/research-charter-resources>

Health promotion and illness prevention

- Emoji cards to help speak with children and young people about their mental health
<https://www.rcpch.ac.uk/resources/emoji-card-game>
- Chatterbox game to talk about staying healthy, happy and well
<https://www.rcpch.ac.uk/resources/chatterbox-game-five-ways-healthy-wellbeing>
- Read what is important to children and young people for good health
<https://www.rcpch.ac.uk/resources/state-child-health-us-views-rcpch-us-network>

Patient safety including safe prescribing

- Medicines for Children flyers for parents and professionals:
<https://www.medicinesforchildren.org.uk/resources-health-care-professionals>
- Medicines for Children website:
<https://www.medicinesforchildren.org.uk/>

#Resources

Useful resources shared with each domain

Education and training

- RCPCH Facing the Future: Standards for children in emergency care settings
https://www.rcpch.ac.uk/sites/default/files/2018-06/ftf_emergency_standards_digital_-_website_version.pdf
- The patients who decide what makes a good doctor (BMJ article featuring RCPCH &Us) <https://www.bmj.com/content/361/bmj.k1829>

Communication

- Find out what patients & families with epilepsy have said about communicating with services
<https://www.rcpch.ac.uk/resources/epilepsy12-us-voices-rcpch-us-network>
- Read what is important to children and young people for good health & services in 2019
<https://www.rcpch.ac.uk/resources/state-child-health-us-2019>

Patient management

- New transition resources have been published including hopes, wishes and needs from young people -
<https://www.rcpch.ac.uk/resources/young-peoples-experiences-health-transition>
- What do children and young people need from the Long Term Plan?
<https://www.rcpch.ac.uk/resources/what-do-young-people-want-nhs-long-term-plan>

Safeguarding

- RCPCH &Us members are supporting the @RainbowNHSBadge project (check twitter for more details!)
- New resources by children and young people in care
www.rcpch.ac.uk/being-me

Procedures

- New toolkit by parents on hidden health needs
www.rcpch.ac.uk/hiddenhealth

You can access resources from trainees, clinical leads, RCPCH staff and other key stakeholders on each of the domains at www.rcpch.ac.uk/progress and on involving children and young people in your work at www.rcpch.ac.uk/and_us



#Notes

Discuss with my team/peers

Discuss with my supervisor

Domain areas to consult on locally with children and young people



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