



Navigating the healthcare system

Children and young people often struggle to understand how services connect and where to find accurate information about their condition

Sarena
● Aged 17
Felicity
● Aged 19
Tatiana
● Aged 23

Learning how to navigate the healthcare system can be just as tricky as learning how to manage a long-term condition.

How do services link up?

One of the biggest frustrations is how often young people have to repeat the same information at different appointments. Many hospitals, GP surgeries and specialist clinics still use different record systems that do not fully link together, meaning young people are often asked to explain their medical history again and again. For people with long-term conditions, this can be exhausting and stressful. It also creates the risk that key information could be missed if details are momentarily forgotten or misunderstood.

Discrepancies around young people's access to their own health information also exist across the UK. Some areas have one integrated platform that allows easy viewing of letters and appointments, but others have more disconnected systems that hinder access.

Giving children and young people a summary of their appointment to take

away would be a simple improvement, perhaps using AI/voice record tools to create accurate summaries quickly. This would make it easier for patients to attend future appointments without needing to remember or repeat everything. It would also help different healthcare professionals quickly understand a patient's situation.

How to find the right information

From my doctor... paediatricians are used to navigating the system, but they can forget that children and young people aren't taught how to do that. For example, we're told that we have a condition and that we have to learn how to manage it, but we're not told *how* to learn to manage it.

When talking to doctors, they may use full medical language or revert to talking as if to a young child. Both options can make us feel uncomfortable, particularly when conversations involve intimate personal details. Remembering that children and young people have very different developmental stages, and talking to us from the start in a developmentally appropriate manner, will immediately help us to feel more able to ask questions.

We might not know which symptoms are relevant to our appointment. We may have minimised symptoms, or there are so many that we forget them. Asking leading questions about possible symptoms can be really helpful, before talking us through what is going on.

From the internet... Sometimes, we've had to learn how to work out which websites have good information, and which ones are misleading. When doctors tell young people and their families which websites are good for advice, it makes life a lot easier.

Ensuring young people are familiar with information and support tools for their condition, as well as how services related to their condition link up, is fundamental. For example, DigiBete is an app for young people with Type 1 diabetes, with information about what to expect in check-ups and the different members of the diabetes multidisciplinary team. What apps are there for other conditions?

In summary, help us to understand who does what (and why), and where to find the right help. Don't assume we know how everything links up in a service, even if we've been using it for a long time – help us to help ourselves! 📱

ABOUT

RCPCH &Us: The Children and Young People's Engagement Team delivers projects and programmes across the UK to support patients, siblings, families and under 25s, and gives them a voice in shaping services, health policy and practice. RCPCH &Us is a network of young voices who work with the College, providing information and advice on children's rights and engagement.

 **RCPCH &Us**
The voice of children,
young people and families

KEEP IN TOUCH

✉ and_us@rcpch.ac.uk 🌐 rcpch.us 📺 @RCPCHandUs