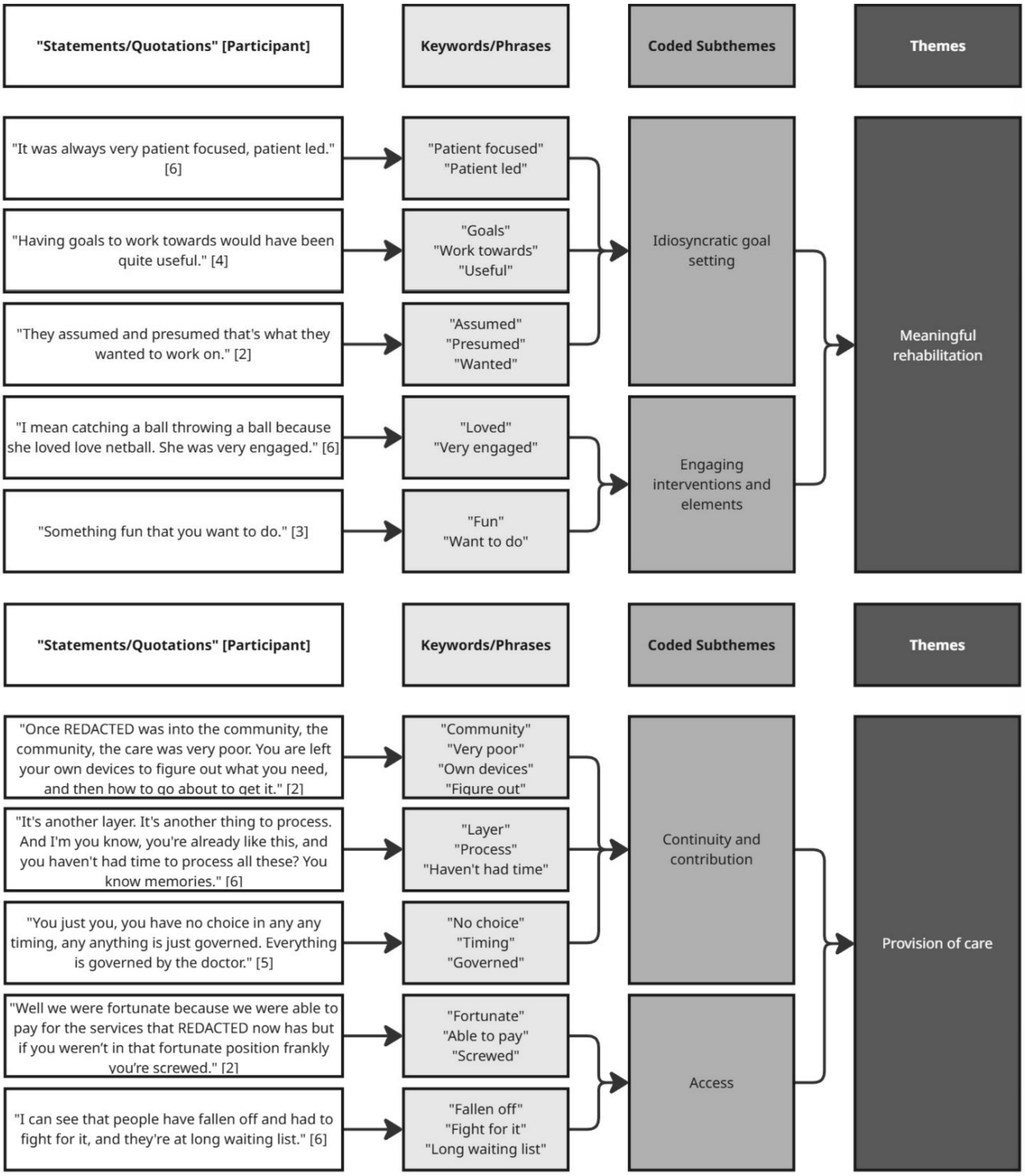
Designed With, Not For: Embedding Young People’s Voices in Paediatric Rehabilitation

Paediatric rehabilitation is key within healthcare, addressing the unique developmental needs of children and young people (CYP) with complex, chronic, or acquired conditions. Despite its importance, this area of healthcare remains both underfunded and under-researched (Chow et al., 2024). Globally, an estimated 162.3 million children need rehabilitation services (Cieza et al., 2020), highlighting the urgent need for new and creative approaches to deal with gaps in current care.

Studies show that rehabilitation services are not only limited but also unevenly spread, which can lead to poorer outcomes, especially after leaving hospital (Hayes et al., 2017; Jurgens et al., 2014; O’Connell et al., 2021; Treadgold et al., 2019). The situation is worse for children than for adults, with even greater inequalities in access and support (Johnson et al., 2022). In fact, NHS Providers (2023) reported that children and young people are regularly let down by the current system. Clearly, there's a strong need to improve paediatric rehabilitation so that it better meets the needs of young patients and reflects the high standards seen in other areas of child healthcare (Kerbl et al., 2016; Trabacca et al., 2016).

This need is especially pronounced as much of paediatric rehabilitation is modelled on adult care models, which haven’t been properly adapted for a younger population (Palanivel et al., 2025). But children are not just small adults. Their brains are still developing, undergoing important changes like synaptic pruning and myelination that shape how different areas of the brain communicate (Izadi-Najafabadi et al., 2019; Spear, 2013). As a result, adult-style rehabilitation strategies often fall short, or may even do harm, because they don’t match the developmental needs of children (Ghahramani et al., 2025).

To truly support children and young people, we need rehabilitation services designed specifically for them, ones that recognise their unique developmental journey and treat them as their own distinct group, not just smaller versions of adults. Therefore, Kompass held interviews with paediatric patients and parents to determine their experiences with and opinions on paediatric rehabilitation, to ascertain how it could be improved. From these interviews, 5 themes emerged. These were: Meaningful rehabilitation, Provision of care, Progress, Information, and Empowerment.



"Statements/Quotations" [Participant]	Keywords/Phrases	Coded Subthemes	Themes
"It was always very patient focused, patient led." [6]	"Patient focused" "Patient led"	Idiosyncratic goal setting	Meaningful rehabilitation
"Having goals to work towards would have been quite useful." [4]	"Goals" "Work towards" "Useful"		
"They assumed and presumed that's what they wanted to work on." [2]	"Assumed" "Presumed" "Wanted"		
"I mean catching a ball throwing a ball because she loved love netball. She was very engaged." [6]	"Loved" "Very engaged"	Engaging interventions and elements	
"Something fun that you want to do." [3]	"Fun" "Want to do"		

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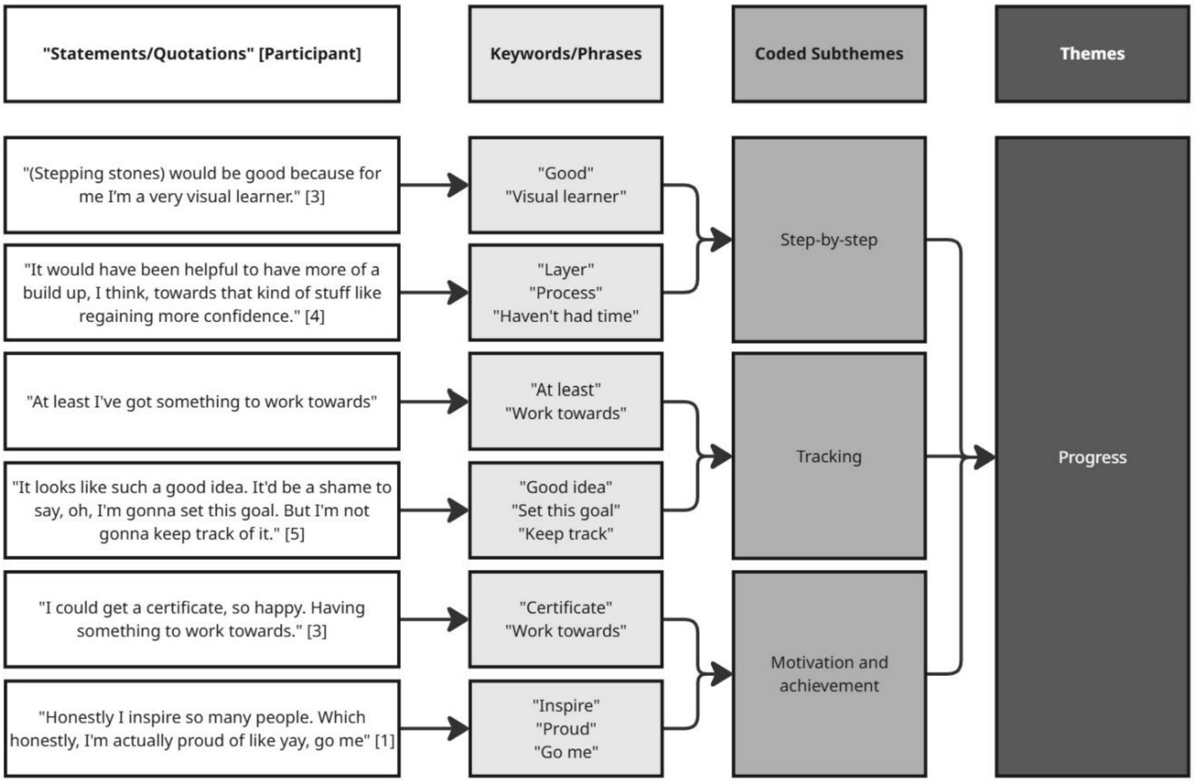
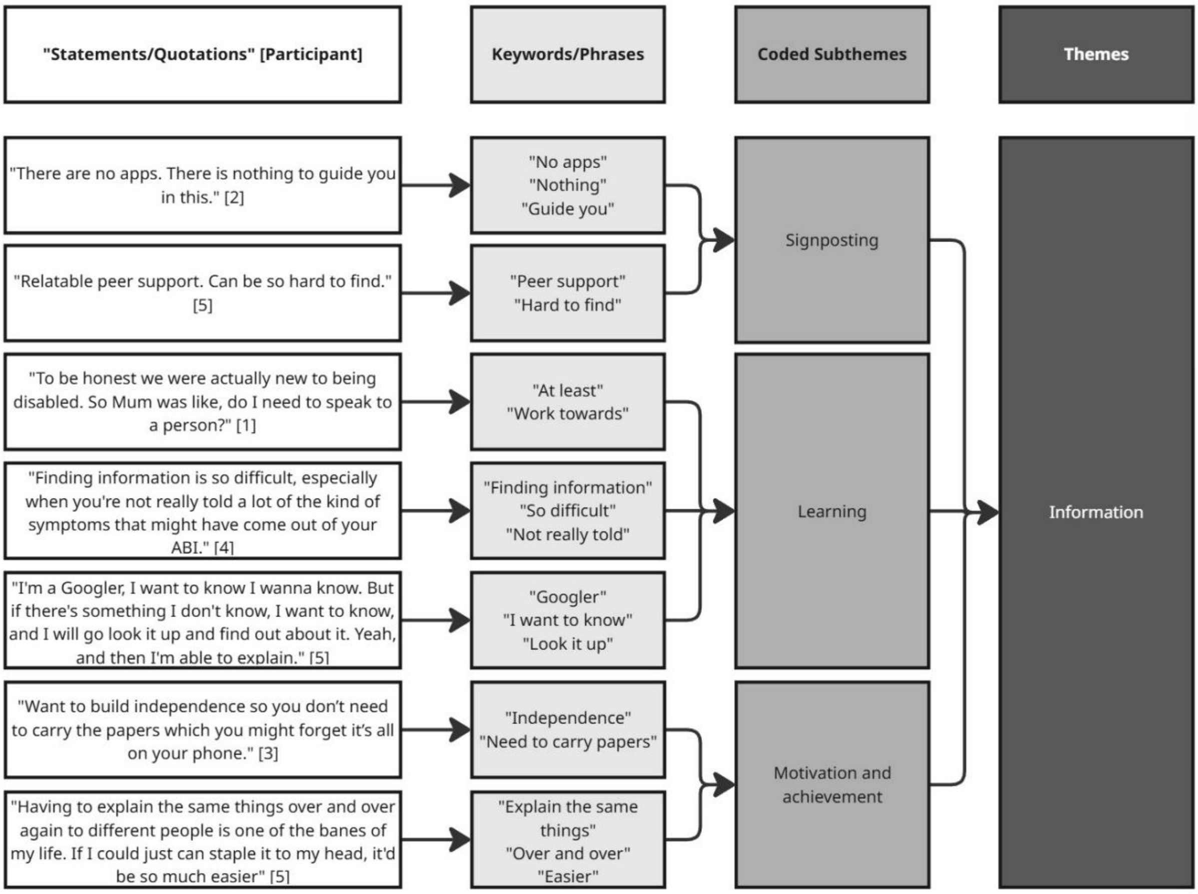
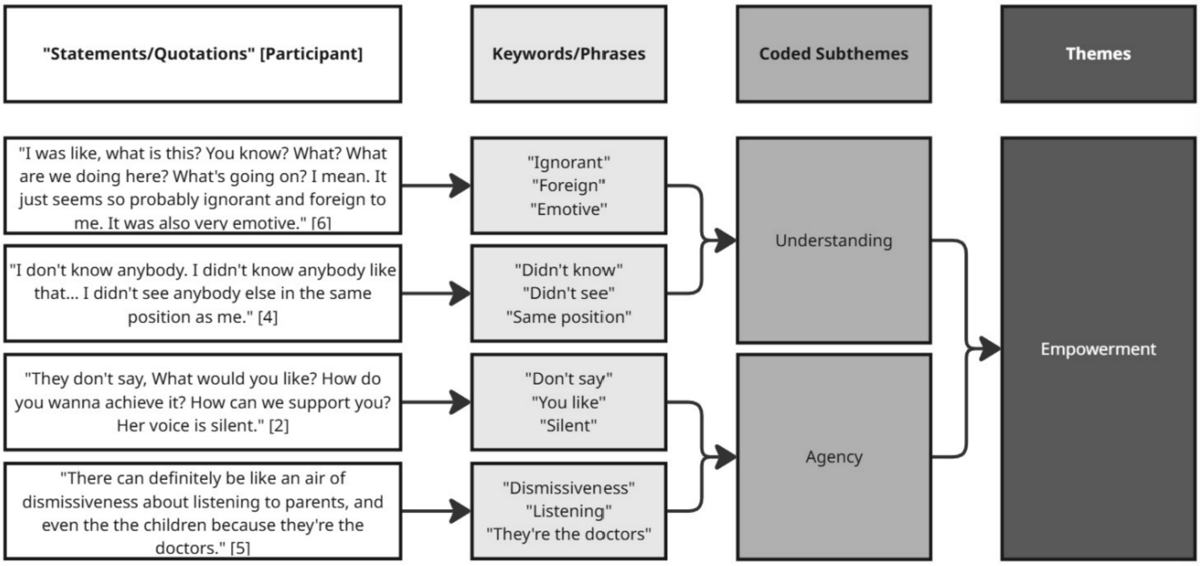
"Once REDACTED was into the community, the community, the care was very poor. You are left your own devices to figure out what you need, and then how to go about to get it." [2]	"Community" "Very poor" "Own devices" "Figure out"	Continuity and contribution	Provision of care
"It's another layer. It's another thing to process. And I'm you know, you're already like this, and you haven't had time to process all these? You know memories." [6]	"Layer" "Process" "Haven't had time"		
"You just you, you have no choice in any any timing, any anything is just governed. Everything is governed by the doctor." [5]	"No choice" "Timing" "Governed"		
"Well we were fortunate because we were able to pay for the services that REDACTED now has but if you weren’t in that fortunate position frankly you’re screwed." [2]	"Fortunate" "Able to pay" "Screwed"	Access	
"I can see that people have fallen off and had to fight for it, and they're at long waiting list." [6]	"Fallen off" "Fight for it" "Long waiting list"		



"Statements/Quotations" [Participant]	Keywords/Phrases	Coded Subthemes	Themes
"(Stepping stones) would be good because for me I'm a very visual learner." [3]	"Good" "Visual learner"	Step-by-step	Progress
"It would have been helpful to have more of a build up, I think, towards that kind of stuff like regaining more confidence." [4]	"Layer" "Process" "Haven't had time"		
"At least I've got something to work towards"	"At least" "Work towards"	Tracking	
"It looks like such a good idea. It'd be a shame to say, oh, I'm gonna set this goal. But I'm not gonna keep track of it." [5]	"Good idea" "Set this goal" "Keep track"		
"I could get a certificate, so happy. Having something to work towards." [3]	"Certificate" "Work towards"	Motivation and achievement	
"Honestly I inspire so many people. Which honestly, I'm actually proud of like yay, go me" [1]	"Inspire" "Proud" "Go me"		



"Statements/Quotations" [Participant]	Keywords/Phrases	Coded Subthemes	Themes
"There are no apps. There is nothing to guide you in this." [2]	"No apps" "Nothing" "Guide you"	Signposting	Information
"Relatable peer support. Can be so hard to find." [5]	"Peer support" "Hard to find"		
"To be honest we were actually new to being disabled. So Mum was like, do I need to speak to a person?" [1]	"At least" "Work towards"	Learning	
"Finding information is so difficult, especially when you're not really told a lot of the kind of symptoms that might have come out of your ABI." [4]	"Finding information" "So difficult" "Not really told"		
"I'm a Googler, I want to know I wanna know. But if there's something I don't know, I want to know, and I will go look it up and find out about it. Yeah, and then I'm able to explain." [5]	"Googler" "I want to know" "Look it up"		
"Want to build independence so you don't need to carry the papers which you might forget it's all on your phone." [3]	"Independence" "Need to carry papers"	Motivation and achievement	
"Having to explain the same things over and over again to different people is one of the banes of my life. If I could just can staple it to my head, it'd be so much easier" [5]	"Explain the same things" "Over and over" "Easier"		



"Statements/Quotations" [Participant]	Keywords/Phrases	Coded Subthemes	Themes
"I was like, what is this? You know? What? What are we doing here? What's going on? I mean. It just seems so probably ignorant and foreign to me. It was also very emotive." [6]	"Ignorant" "Foreign" "Emotive"	Understanding	Empowerment
"I don't know anybody. I didn't know anybody like that... I didn't see anybody else in the same position as me." [4]	"Didn't know" "Didn't see" "Same position"		
"They don't say, What would you like? How do you wanna achieve it? How can we support you? Her voice is silent." [2]	"Don't say" "You like" "Silent"	Agency	
"There can definitely be like an air of dismissiveness about listening to parents, and even the the children because they're the doctors." [5]	"Dismissiveness" "Listening" "They're the doctors"		

Meaningful rehabilitation

The first theme from our findings echoed what previous research has made clear: when rehabilitation is personalised and based on what truly matters to children and young people (CYP), it becomes much more effective (Jenerette & Mayer, 2016; Gard, 2001). Setting meaningful, personal goals helps CYP stay motivated and move forward in their recovery in ways that feel relevant to their own lives (Dekker et al., 2020; Wade, 2009). In fact, people are more likely to achieve goals that are meaningful to them personally (Alanko et al., 2019; Conrad et al., 2010). Yet, despite the known benefits, this kind of personalised goal setting is still not common in everyday healthcare. This gap in practice suggests an urgent need to prioritise meaningful, individualised goals within rehabilitation. When this isn't possible through traditional services, alternative ways to support this are needed.

Participants also highlighted how important it was that rehabilitation activities were engaging, something that is also often overlooked. What made activities engaging varied from person to person and was deeply tied to their own interests and preferences. Unfortunately, paediatric rehabilitation is often designed without considering what children find interesting or enjoyable (Palanivel et al., 2025), making it harder to keep them motivated and involved (Grünloh et al., 2018; Olszewski & Goldkind, 2018; Quaye et al., 2019; Teela et al., 2022). Children need to be active participants in their own care, and that means designing rehabilitation that suits their stage of development and their interests (Lieberman et al., 2009; Rennick et al., 2025). One promising way to achieve this is through digital tools, especially given that today’s young people are "digital natives" (Paulsen et al., 2021; Prensky, 2001).

Provision of care

The second theme that emerged from participants focused on how difficult it can be to access good rehabilitation care. Many described the services they received as a matter of luck, echoing what’s often called the “postcode lottery” in healthcare (Kettlewell et al., 2021; Lake et al., 2024; Murphy et al., 2024; Ridgway et al., 2012). Some children had access to great services, but others didn’t, depending largely on where they lived (Neuburder et al., 2014; Young et al., 2022). This problem is especially severe for children (Hayes et al., 2017; Treadgold et al., 2019), with long waiting times making it hard for children to get early, essential rehabilitation support (Gray et al., 2012; Grilli et al., 2007; Harding et al., 2022).

Continuity of care was another issue, particularly the transition from hospital to home. While this has been noted in adult care (Fowler et al., 2024; Pedrosa et al., 2022; Tennison et al., 2021), our discussions highlighted how it affects children too. This issue was compounded by cost, as financial resources particularly affected access to rehabilitation in this stage. Research confirms this is a problem in rehabilitation more generally (Ganesh et al., 2017; Knowlton et al., 2019). The UK government has long said that healthcare should be based on need, not finances or postcode, but this remains an unresolved issue nearly 25 years on.

Progress

Another insight from our discussions was that whilst progress was seen as incredibly motivating, tracking and discussing progress made with patients and parents was extremely limited. Where goals help break recovery into smaller, achievable steps (Evans et al., 2017; Wade, 2009), and tracking these steps can keep people going (Herbert et al., 1989), tracking progress should be easy and communicated.

Information

Participants also stressed the importance of having access to good information throughout their rehabilitation journey. However, they often found this information hard to get, leading them to search on their own and fall down negative ‘rabbit holes’. For over two decades, studies have shown that people, especially those with lower health literacy, struggle to find the information they need during rehabilitation (Clarke et al., 2020; Magasi et al., 2009; Röding et al., 2003; Tooth & Hoffmann, 2004). Without it, people can feel demotivated and overwhelmed (Maclean et al., 2000), demonstrating the need for its provision. Participants said they often felt lost in the healthcare system without access to this information. Because many were children, this burden often fell on their families (Ghazzawi et al., 2016; Graff et al., 2017). Poorly coordinated services don’t just frustrate people, they can negatively affect outcomes, especially for those with disabilities (Fowler et al., 2024; Timothy et al., 2024; Wicks, 2023).

Technology can help bridge this gap (Zhang & Yu, 2024). Having access to clear and accredited information was presented as invaluable in avoiding the ‘rabbit holes’ participants described. Participants also presented the need for signposting and access to peer support. While research on peer support in rehabilitation is still developing (Womba et al., 2016), early findings suggest it helps with motivation, self-belief, and connection (Clark et al., 2012; Gassaway et al., 2016; Magasi & Papadimitriou, 2022; Morris & Morris, 2011).

Empowerment

Finally, participants described how vital it was to understand their condition and the rehabilitation process. This kind of understanding helps build a sense of control, awareness, and empowerment (Clark et al., 2022; Wang et al., 2007), and is essential for speaking up and navigating the healthcare system (Graff et al., 2018). A key part of empowerment is agency, feeling like you have control and a say in your own care. While agency is a core value in rehabilitation (Blackburn et al., 2019), it's often missing in practice. Some research even describes how people feel invisible in their care journey (Melander Wikman & Fältholm, 2006; Röding et al., 2003). Recent literature hasn't focused much on agency, especially in children, so this research offers a new contribution.

Conclusion and outcome

Together, these findings highlight the pressing need to rethink how paediatric rehabilitation is designed and delivered. Children have unique developmental, emotional, and psychological needs that must be reflected in their care. Yet, across every theme explored, it's clear that current rehabilitation systems are falling short.

Participants spoke candidly about the barriers they face: inconsistent services, limited communication, a lack of agency, and care that often feels impersonal or irrelevant to their lives. These challenges not only limit progress but risk leaving children feeling disempowered at a time when support is most needed. However, they also provided a roadmap for change. They told us what makes rehabilitation meaningful, what helps them stay engaged, and what kinds of tools would empower them to take ownership of their recovery. Their insights offer a strong case for co-designing rehabilitation services with the very people who use them.

Kompass Kids was developed in response to these voices. It provides a platform that supports goal setting, tracks progress, shares reliable information, and gives children and families more control over their journey. But this is just one example of what's possible. If we are to create a rehabilitation system that truly meets the needs of CYP, we must continue listening to them, involving them in design, and investing in services that treat them as the experts in their own lives.