Embedding Co-Design in Digital Health: Responding to Gaps in Paediatric Neurorehabilitation

As healthcare moves increasingly toward digital solutions, it's vital that paediatric rehabilitation evolves alongside it (Chishtie et al., 2022). Around the world, technologies like artificial intelligence (AI) and machine learning are now helping doctors diagnose conditions earlier and offer more personalised treatments (Abbas et al., 2020). For children and young people (CYP) in rehabilitation, this could mean earlier and more targeted support, especially during key periods of brain development, when the brain is highly adaptable (Spear, 2013). But in reality, access to these early interventions remains limited.

Part of the problem is that healthcare systems are slow to adopt new technology, especially for paediatric care. Within the NHS, rolling out new digital tools faces hurdles like complex regulations and outdated infrastructure (Collins, 2018). Although the UK government has set goals to improve digital services across the NHS by 2025, backed by policy changes such as the NICE guidelines for best practice rehabilitation (UK Parliament, 2023), change is happening too slowly.

This is a missed opportunity. Technology has great potential to improve recovery, boost engagement, and increase consistency in therapy, especially for children and young people. Tools like virtual reality (VR), mobile apps, and gamified platforms offer engaging and easy-to-use alternatives to more traditional rehab (Wade et al., 2018; Arntz et al., 2023). These tools can also give real-time feedback, support family involvement, and provide more personalised care (Shin et al., 2023). As more care now takes place at home, rather than in hospitals, due to strain on the healthcare system (Arntz et al., 2023; Whitehead et al., 2024), this is becoming increasingly important.

But as promising as these tools are, we shouldn't adopt them uncritically. Experts warn that technology in rehab should support established therapy practices, not just offer flashy new features (Traficante & Antonietti, 2022). In other words, digital tools should help improve care, not distract from it.

A technology focused approach makes even more sense when we consider who these tools are for. Today's children are "digital natives" (Prensky, 2001), they've grown up using screens, games, and apps. Using technology in rehab can therefore make therapy more motivating and familiar for them (Howard & Davis, 2022; Glegg et al., 2024). Clinicians are beginning to see the

benefits too. Glegg et al. (2024) found that health professionals are increasingly recognising how digital tools can help personalise goals, show progress, and make therapy more engaging.

This is because digital platforms also support key psychological factors like motivation, confidence, and a sense of control, known to be crucial for successful rehabilitation (Gard, 2001). They are especially useful for children with additional needs, such as those with neurological conditions or learning differences. For these children, assistive technology can be tailored to suit their development and learning style (Wyeth et al., 2023; UNICEF, 2015). Yet despite all these benefits, many children who could benefit from this kind of technology don't have access to it. In many parts of the world, only a small number of CYP receive the assistive tools they need (UNICEF, 2015). Making sure all children have access to inclusive, adaptable digital support isn't just about fairness, it's essential to improving paediatric care overall.

As we develop new digital health tools, especially for something as personal as rehabilitation, involving the people who will use them is key. That's why co-design, a process that actively includes patients in the design of their own care tools, is so important. In paediatric rehabilitation, co-design makes sure that digital tools are actually useful, meaningful, and empowering for children. It also helps young people feel more in control of their care and ensures their voices are heard, something that often doesn't happen enough (N-ABLES, 2021). Research supports this: when people are involved in the design of their healthcare tools, they tend to feel more satisfied and have better health outcomes (Welsby et al., 2024). That's why co-design shouldn't be an afterthought, it should be a standard part of how we create new rehabilitation technologies. It's one of the best ways to make sure these tools are not only effective but also accessible and centred around the real needs of children and young people.

That's why co-design was embedded throughout the development of Kompass Kids, from the earliest ideas to the final refinements. We conducted two phases of interviews with children and young people who had experienced paediatric rehabilitation, as well as their parents. In the first phase, participants shared their general thoughts on technology and described what they would want from a patient portal. These insights directly informed the creation of the initial prototype wireframes. During the second phase, these wireframes were presented to participants, who provided detailed feedback on specific features and design elements. Their input was then used to refine the platform's functionality and ensure it met user needs. By involving patients and parents at every stage, we made sure the platform was grounded in the real experiences, priorities, and needs of those who understand rehabilitation best.

Participants expressed a strong desire to set their own individual goals within the system. In response, we integrated a child-friendly version of Goal Attainment Scaling (GAS), designed specifically for paediatric use. The goal-setting process was broken down into simple, easy-to-understand steps, each with clear explanations to guide users. This structure not only supports independent goal creation but also subtly introduces best practice standards, especially valuable in contexts where formal resources or professional guidance may be limited. To encourage motivation, each milestone or goal achievement is met with positive feedback and success messages, reflecting the importance CYP placed on feeling a sense of progress and accomplishment.

In addition to goal setting, we developed a patient passport, a central hub for organising rehabilitation-related information. This was created in direct response to feedback from participants, who often found it difficult to track and manage key documents and details. During the second phase of co-design, this feature was received particularly positively by parents, as it addressed a real-world problem they frequently experienced.

Other key features included accredited glossaries, targeted signposting, and information repositories tailored for CYP and their families following inpatient discharge. These were developed to address the poor continuity of care often reported during this transition period. Participants shared that in the absence of reliable information, they were left to search online, frequently encountering overwhelming or inaccurate content. These new tools aim to reduce that risk by offering trusted, accessible information in one place, helping users avoid the 'rabbit holes' of unfiltered internet searching.

Without the co-design involvement that we prioritised, the application would have looked very different, demonstrating the utility of allowing for lived experience viewpoints within research and development. Although developers and practitioners are experts in their own right, platforming those with a lived knowledge of the system and its effects provided us with the insights that made the patient portal the way that it was, and a much better and more useful application as a result. The two phases of co-design were instrumental for this, ensuring that the design of the application fit not only initial views and ideas but was refined and modified with participants further considerations.

Without the involvement of co-design, the application would have looked markedly different, highlighting the critical value of incorporating lived experience into research and development. While developers and practitioners bring essential expertise, it was the insights of those with direct experience of paediatric rehabilitation that shaped the platform into a more meaningful and practical tool. Their perspectives helped us move beyond assumptions to address real-world needs and challenges. The two phases of co-design were central to this process, ensuring that the initial ideas were not only grounded in user perspectives but also refined through ongoing feedback. This iterative approach resulted in a more responsive, relevant, and ultimately more effective application.

To conclude, this development approach and the resulting platform, directly responded to the growing call in the literature for more inclusive, innovative, and context-sensitive solutions in paediatric rehabilitation. As Johnson et al. (2022) highlight, children and young people remain chronically underserved, particularly in neurorehabilitation. Dodd et al. (2019) further emphasise the serious gaps during the healthcare-to-school transition, especially for children recovering from acquired brain injury (ABI), and point to the urgent need for cost-effective, evidence-based digital tools to support continuity of care.

Kompass Kids was developed to meet this need. Designed to function across settings, it bridges service gaps by offering tailored, developmentally appropriate support. Its core features align with evidence on the benefits of child- and family-friendly digital tools in improving adherence, motivation, and engagement (Wade et al., 2018; Glegg et al., 2024). These features were shaped and validated not only by the literature, but by the children, young people, and families who co-designed them, demonstrating their real-world relevance.

This project reinforces the value of co-design in healthcare innovation. While developers and clinicians bring essential expertise, it is those with lived experience who reveal what truly works in practice. Through co-design, Kompass Kids became not just a research product but a meaningful, user-informed solution to everyday challenges in paediatric rehabilitation. Moving forward, embedding co-design and user-centred development should be standard practice, ensuring that rehabilitation tools are not only technologically advanced, but genuinely empowering for the children and families who rely on them.