

“They talk over her, to her, through her and they don’t actually direct the questions to her”: Discussing the Need for a Patient Portal Application in Paediatric Rehabilitative Care

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Background Children and young people’s (CYP) perspectives are overlooked within rehabilitation (N-ABLES, 2021). Children are unique individuals, deserving products and services designed for their distinct needs. Goal Manager® is an application designed for clinicians to organise and track rehabilitation data and outcomes. This project worked with paediatric rehabilitation patients to codesign a Patient Portal application, allowing access to data they need to track their rehabilitation.

Methods Funding secured through a Innovate Biomedical Catalyst Grant supported the design of a Patient Portal. Virtual focus group discussions were held with young people who had previously experienced a brain injury and undergone rehabilitation, their parents and their clinicians, to gather insights and ensure co-design from the outset. Feedback was utilised in creation of wireframe designs, displayed during design refinement focus groups.

Results Focus group discussions illuminated the importance of accessibility, accountability co-design within healthcare technology development. Following discussion, key features were added to the design, including the ability to create meaningful goals, specify opinions surrounding rehabilitation, and colour-code appointment details.

Conclusions The patient portal addresses the growing need for resources to guide CYP through the rehabilitation journey and equip them with information to comprehend their rapidly changing circumstance. The innovative software solution encourages meaningful, patient led goal setting ensuring that rehabilitation remains value driven. Co-design was ensured through the use of focus groups to understand service users’ needs and establish key features for the development of the application, a principle that should be extrapolated to the development of other healthcare technologies.

Biography:

Dr Penny Trayner BSc (Hons), PGDip, DClinPsy, CPsychol, AFBPsS

Founder, CEO, Clinical Director, Clinical Neuropsychologist, Clinical Safety Officer

Dr Trayner has 15 years of clinical experience within neurorehabilitation, holding the UK’s highest and gold-standard qualification in paediatric clinical neuropsychology. She specialises in community-based work, predominantly for children and adolescents who have experienced catastrophic brain injuries. Dr Trayner’s passion for enhancing rehabilitative care, and recognition of a lack of infrastructure to set and manage rehabilitation goals, led to the development of Kompass. Under her leadership, Kompass has introduced innovative health tech solutions, including a quantitative data dashboard and a patient portal, to improve patient outcomes and streamline the rehabilitation process.