

Young People and Their Parents Accessing Their Digital Health Data via a Patient Portal: The Ethical and Legal Implications

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Abstract : Background: With rapidly evolving digital health innovation, there is a need for digital health transformation that is accessible and sustainable, that demonstrates utility for all stakeholders while maintaining data safety. Great Ormond Street Hospital for Children aimed to future-proof the hospital by transitioning to an electronic patient record (EPR) system with a tethered patient portal (MyGOSH) in April 2019. MyGOSH patient portal enables patients 12 years or older (with their parent's consent) to access their digital health data. This includes access to results, documentation, and appointments that facilitate communication with their care team. As part of the Going Digital Study conducted between 2018-2021, data were collected from a sample of all relevant stakeholders before and after EPR and MyGOSH implementation. Data collection reach was wide and included the hospital legal and ethics teams. Aims: This study aims to understand the ethical and legal implications of young people and their parents accessing their digital health data. Methods: A focus group was conducted. Recruited participants were members of the Great Ormond Street Hospital Paediatric Bioethics Centre. Participants included expert and lay members from the Committee from a variety of professional or academic disciplines. Written informed consent was provided by all participants (n=7). The focus group was recorded, transcribed verbatim, and analyzed using thematic analysis. Results: Six themes were identified: access, competence and capacity - granting access to the system; inequalities in access resulting in inequities; burden, uncertainty and responding to change - managing expectations; documenting, risks and data safety; engagement, empowerment and understanding - how to use and manage personal information; legal considerations and obligations. Discussion: If healthcare professionals are to empower young people to be more engaged in their care, the importance of including them in decisions about their health is paramount, especially when they are approaching the age of becoming the consentor for treatment. Complexities exist in assessing competence or capacity when granting system access, when disclosing sensitive information, and maintaining confidentiality. Difficulties are also present in managing clinician burden, managing user expectations whilst providing an equitable service, and data management that meets professional and legal requirements. Conclusion: EPR and tethered-portal implementation at Great Ormond Street Hospital for Children was not only timely, due to the need for a rapid transition to remote consultations during the COVID-19 pandemic, which would not have been possible had EPR/MyGOSH not been implemented, but also integral to the digital health revolution required in healthcare today. This study is highly relevant in understanding the complexities around young people and their parents accessing their digital health data and, although the focus of this research related to portal use and access, the findings translate to young people in the wider digital health context. Ongoing support is required for all relevant stakeholders following MyGOSH patient portal implementation to navigate the ethical and legal complexities. Continued commitment is needed to balance the benefits and burdens, promote inclusion and equity, and ensure portal utility for patient benefit, whilst maintaining an individualized approach to care.

Keywords : patient portal, young people and their parents, ethical, legal

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