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Enhancing Transparency in Optimum Patient Care Research Database Access Procedures: A Multifaceted Approach Addressing Improvements in Transparency Standards

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Background

In healthcare research, leveraging data is vital for driving advancements in treatment, diagnosis, and healthcare delivery. However, transparency in data use is pivotal for credible, reproducible findings.

Introduction

Our initiative was designed to improve transparency in accessing the Optimum Patient Care Research Database (OPCRD: <https://doi.org/10.2147/POR.S39563>) and to highlight public benefits from utilising anonymised primary electronic medical record data. Our goal was to enhance user accessibility, transparency, and education about its use for research. Through new website content and case studies, we aimed to foster openness, accountability, and trust in research outcomes.

Methods

1. Researcher engagement to outline the data access process, to improve accessible formats with clear guidance. HDRUK Transparency Standard 2 (application process).
2. Stakeholder engagement to tailor our website content effectively by involving researchers, information governance professionals, and the public. HDRUK Transparency Standard 4 (audience).
3. Patient and Public Involvement (PPI) workshops were held to find out what the public had to say about their health data being used for research and how it could directly benefit the public and improve healthcare outcomes. HDRUK Transparency Standard 6 (data use).

Results

Enhanced Online Portal: our new online platform provides comprehensive information and educational guides on the

OPCRD data access and data transparency procedures. This portal serves as a crucial resource for healthcare researchers and the public, facilitating transparent and efficient data utilisation. (<https://www.opcrd.optimumpatientcare.org/health-data-for-research>)

Content Creation: we created new content and animated videos for the online portal. The additions ensured the accuracy of content on the platform, improved transparency and facilitated easier navigation of the data access protocols. The animated guides on general data transparency and accessing OPCRD data for research purposes resources significantly enhance the accessibility and understanding of health data for research initiatives.

Case Studies Repository: we curated a repository of case studies showcasing the tangible societal benefits and the real-world impact of utilising healthcare data, contributing to a deeper understanding of its broader implications. These were created following PPI engagement workshops where we explored the public benefits of data for healthcare research. This initiative provided invaluable insights into public perspectives to utilising health data transparently and effectively. The PPI engagement events were attended by a diverse participant demographic.

Conclusions

By applying HDRUK's Transparency Standards and implementing user-friendly resources, stakeholder engagement, and public involvement, Optimum Patient Care UK has developed an accessible online portal and a repository of animated guides and case studies relating to accessing and utilising data from the Optimum Patient Care Research Database. These efforts improve user accessibility and education on healthcare data use and foster openness, accountability, and trust in research outcomes. Our project contributes to the broader goal of ensuring transparency in data utilisation, thereby advancing healthcare research and promoting public health initiatives.

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