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Enhancing Transparency, Awareness, Accessibility of Healthcare Data Access for Research: the iCARE website redesign project

Sarindi Aryasinghe¹, Dimitri Papadimitriou¹, Ben Glampson¹, and Erik Mayer¹

¹Imperial Clinical Analytics, Research & Evaluation (iCARE), Digital Collaboration Space, NIHR Imperial Biomedical Research Centre, W2 6PY

Background

The iCARE (Imperial Clinical Analytics, Research and Evaluation) Secure Data Environment (SDE) is committed to further enhancing its website to improve awareness of processes and procedures for appropriately accessing the healthcare data it hosts for research. Our iCARE SDE is a cloud-based, big data analytics platform that offers clinicians, allied healthcare professionals, researchers, and data scientists access to large-scale, curated project-defined data for research via a HRA Research Ethics Committee compliant application and approval process, with lay partners embedded at each step to ensure that each project is of patient and public benefit.

By improving our website for researchers, patients, and the public, our ongoing work aims to further increase the awareness, accessibility, and transparency of the iCARE processes and use of healthcare data for research.

Introduction

By improving the iCARE website for researchers, patients and the public, our work aims to further increase the awareness, accessibility, and transparency of the iCARE processes and use of healthcare data for research. The primary objective was to review and enhance iCARE website, aligning with The Alliance Transparency Standards 2-6: Improve transparency of the application process and criteria, aligning with five safes framework (Standard 2); clearer and accessible website navigation (Standard 3); work with lay partners and researchers to ensure content is clear and transparent (Standard 4); comprehensive review of website content and FAQs, with ongoing review (Standard 5); transparency of data use and auditing, with accessible and user-friendly project lay summaries (Standard 6).

Methods

We began by reviewing existing materials and meeting with web developers to outline project requirements. We also co-developed with community partners a public guide on how data and artificial intelligence is used for research. Our website designer then built the website, integrating feedback from

the iCARE team, researchers, and community partners. To gather further feedback on the new website and co-develop the public-facing website content, including the FAQs, we held two workshops with a diverse panel of community partners in Northwest London.

Results

The updated iCARE website enhances accessibility, clarity, and transparency through feedback from community partners and researchers. The website now contains detailed steps streamlining the application process, reducing communication delays, and providing applicants with clearer expectations. Additionally, the website clarifies the analysis tools available in the iCARE SDE. For the public, the website more clearly describes the rigorous data access requirements and processes that researchers follow, and the measures taken to ensure the ethical and secure access and use of healthcare data for research in the iCARE SDE. We also integrated an educational guide on how data and artificial intelligence is used in healthcare and research, which was co-developed by lay partners for researchers and the public.

Conclusions

We anticipate that the redesigned iCARE website will improve awareness, clarity, and access to healthcare data for research by meeting The Alliance Transparency Standards and involving community partners and researchers in its redesign.

References

1. Macaulay Y, UK Health Data Research Alliance, Pan-UK Data Governance Steering Group, HDR UK Public Advisory Board, Five Safes Action Force. Pan-UK Data Governance Steering Group Data Access Transparency Standards. Zenodo 2023; <https://doi.org/10.5281/zenodo.8262453>