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UK Cystic Fibrosis Registry Website Enhancements: A User-Centred Approach to the Data Access Transparency

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Background

As a member of the HDR UK Alliance, Cystic Fibrosis Trust is committed to adopting and maintaining the transparency standards within the UK CF Registry (UKCFR). Our website is the primary source for providing information on UKCFR and data access processes. We aimed to review use and accessibility across all user groups to shape website enhancements.

This project aimed to improve transparency by conducting user experience (UX) research, and based on user feedback, enhance our website. For this project, we reviewed all of the HDR UK Transparency Standards. For this poster, we will focus on Standards 3 (Clear Website Navigation and 4 (Consider Target Audience).

Introduction

The primary objective was to enhance Transparency Standards by understanding audience needs and customise website improvements based on their needs. We envisaged that the outcome would be an improved and streamlined data access process to support transparency and trust among both data applicants and the public.

Methods

We employed a multi-method approach which incorporates public involvement throughout the whole process. We conducted on-site polls to intercept website visitors and gather quick feedback during their visit. Additionally, we created and distributed targeted surveys to various groups, including public and CF professionals, to delve deeper into their website experiences.

Results

1. The website's overall rating is high at 7.4/10.
2. UX research respondents: public 57% public and 43% CF Professionals.
3. The top reasons for visiting the website are accessing reports and statistics and finding out more about UK CF Registry.
4. Ease of finding information has fairly even spread, indicating room for improvement.

Conclusions

Based on user research, we're enhancing the website to make reports and statistics more prominent and informative. Furthermore, we are planning to improve data access guide, include more contents such as lay summaries and data use statistics.

We strongly encourage user experience (UX) research as a critical first step in website improvement projects. We have presented a sample of the results, but full outputs of the research provided valuable insights into the differing needs of our audience and also where we can make improvements to enhance our content and accessibility. Then results will feed into our ongoing work into improving our data access documentation and processes.

