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.

Aim

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).

Primary Objective & Outcome

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.

Approach

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.

Findings

First Impressions

Overall website rating
7.4/10

The quality of information is positively thought of by users

> The registry is a fantastic resource of information about people with CF in the UK. Long may it continue!

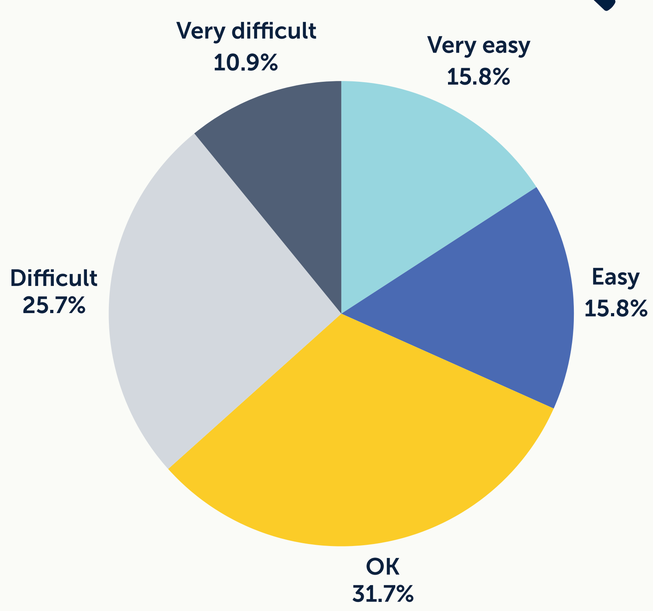
Quote from a user

What's important to users?

Public	CF Professionals
1. The latest at-a-glance report summary	1. The latest at-a-glance report summary
2. Latest CF statistics	2. The latest report
3. Information about the UK CF Registry	3. Information about the UK CF Registry
4. The latest report	4. Latest CF Statistics
5. Distribution of CF in the UK	5. Distribution of CF in the UK

CF Professionals: Our research reveals data access ranked lower than anticipated (#9 out of 13 priorities). This suggests our website may not be the primary place that requesters go to when planning a data access request. This could mean they are not using or accessing the correct forms, policies and application procedures.

Finding Information



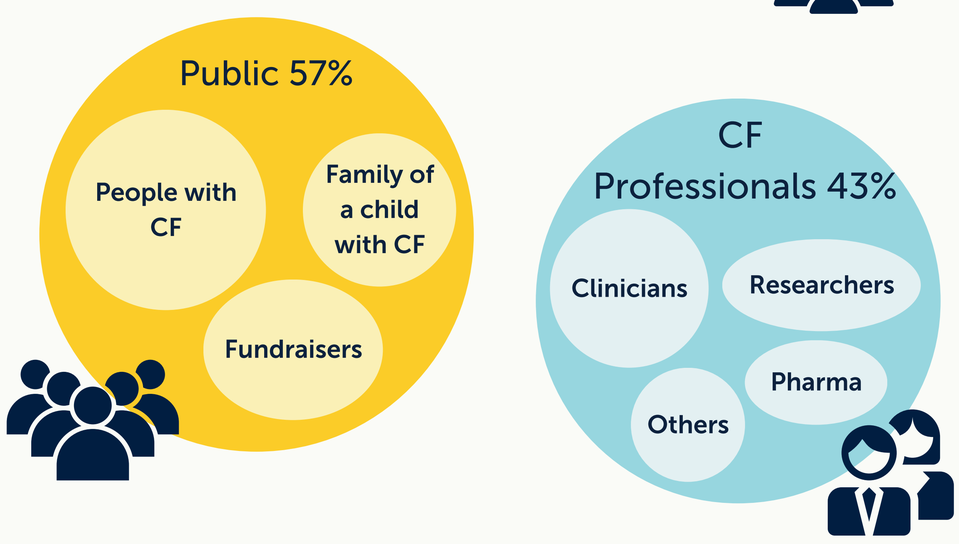
User feedback shows a mixed experience. We're revamping the website to make finding information easier for everyone.

User Feedback: Missing Information

Our research revealed user interest in additional website content:

- Lay summaries of past projects
- How people with CF are involved in UKCFR
- A clear list of available data for requests

UX Research Respondents



Survey respondents are primarily the public (57%), followed by CF Professionals (43%).

Project Outputs

Based on user research, we're enhancing the website to make reports and statistics more prominent and informative. Furthermore, we are planning to include more contents such as lay summaries, data use statistics, and improved data access guide. Visit our website for updates and explore the evolving improvements!

Scan me!

Benefits

CF Professionals can better access the information they need, while the public gains a clearer understanding of how their data is used. This fosters trust and transparency, benefiting both data access transparency and public engagement with the work of UKCFR. Such changes should additionally lead to improved quality of data access requests that meet UKCFR policies and streamline the application process.

Impact

Early user feedback indicates positive user experience across all target audiences. We anticipate continued enhancements through ongoing website review, ensuring alignment with HDR UK Transparency Standards.

Transferable Insights

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.

Cystic Fibrosis Trust — Since 1964 | We won't stop until CF does

HDRUK Health Data Research UK

UK Health Data Research Alliance

UKRI Medical Research Council

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