

Lay review of the South London and Maudsley NHS Foundation Trust’s Clinical Records Interactive Search (CRIS) system website to better meet UK Heath Data Research Alliance Transparency Standards

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Background and Aim

The South London and Maudsley NHS Foundation Trust (the Trust) is one of the largest providers of secondary mental healthcare in Europe. In 2007, the Trust developed the Clinical Record Interactive Search (CRIS) system which provides authorised researchers with regulated, secure access to anonymised information extracted from the Trust’s electronic clinical records system¹.

The CRIS website (www.maudsleybrc.nihr.ac.uk/cris) was developed to provide information to Trust service users, the general public, and prospective research users. It is the main source of information available to academic users prior to meeting with a member of the CRIS Team and is a large component of the wider CRIS communications plan which aims to ensure that all CRIS stakeholders can access relevant information about CRIS in several different formats.

We planned to conduct a lay review of the CRIS webpages designed to support with alignment against the following UK Heath Data Research Alliance (HDRA) Transparency Standards²:

- **Standard 1:** Open access application form and guidance
- **Standard 2:** Transparent application process and criteria
- **Standard 3:** Clear website navigation
- **Standard 4:** Consider Target Audience

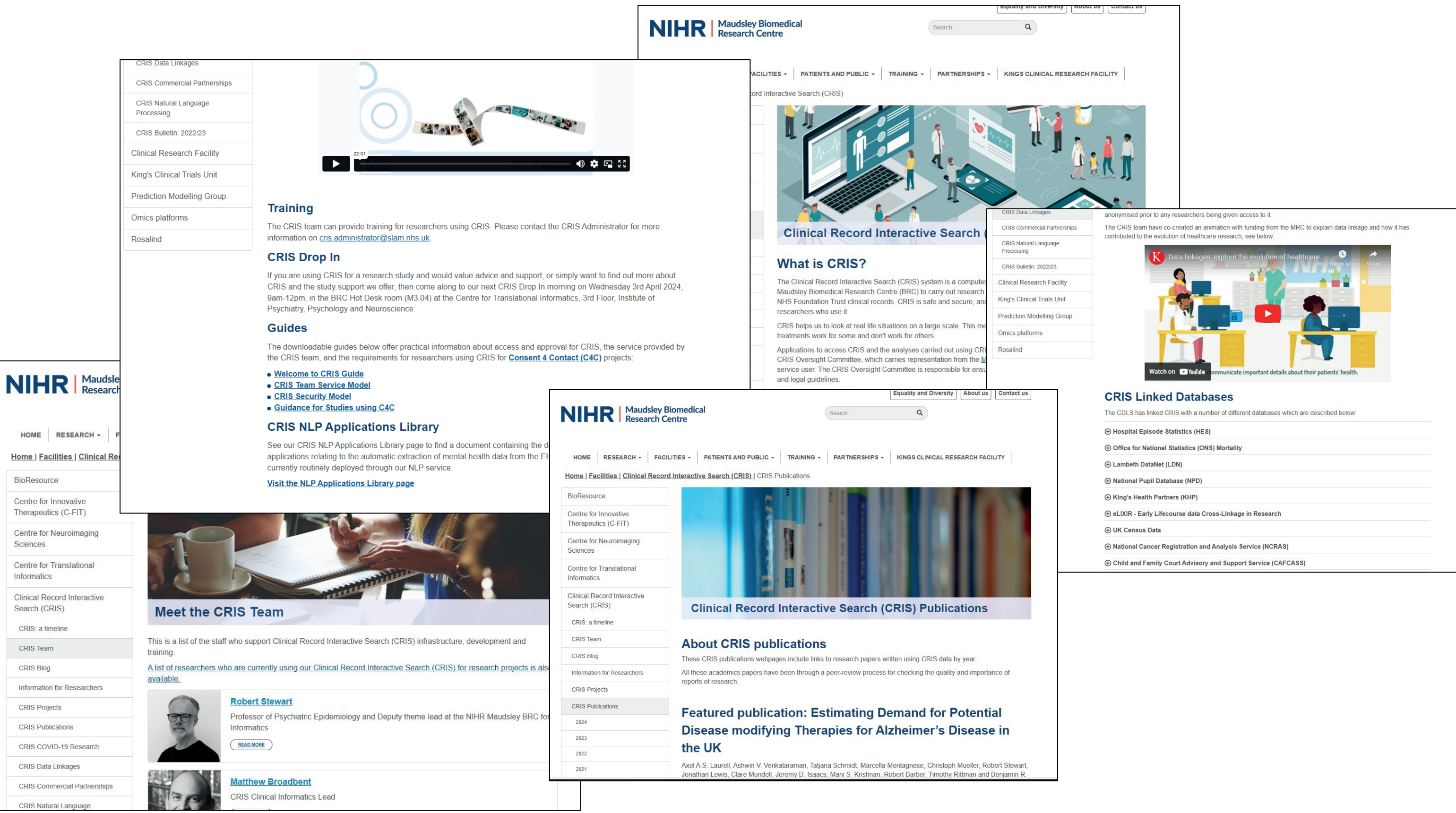


Fig 1. Screenshots of the CRIS website prior to the lay review.

Method

A lay review of the website was conducted with a group of five mental health service users and carers. The review was conducted in two stages: individual in-depth reviews with an online questionnaire followed by a focus group. An academic review by CRIS researchers was also conducted, this involved a review of the webpages and completion of an online questionnaire.

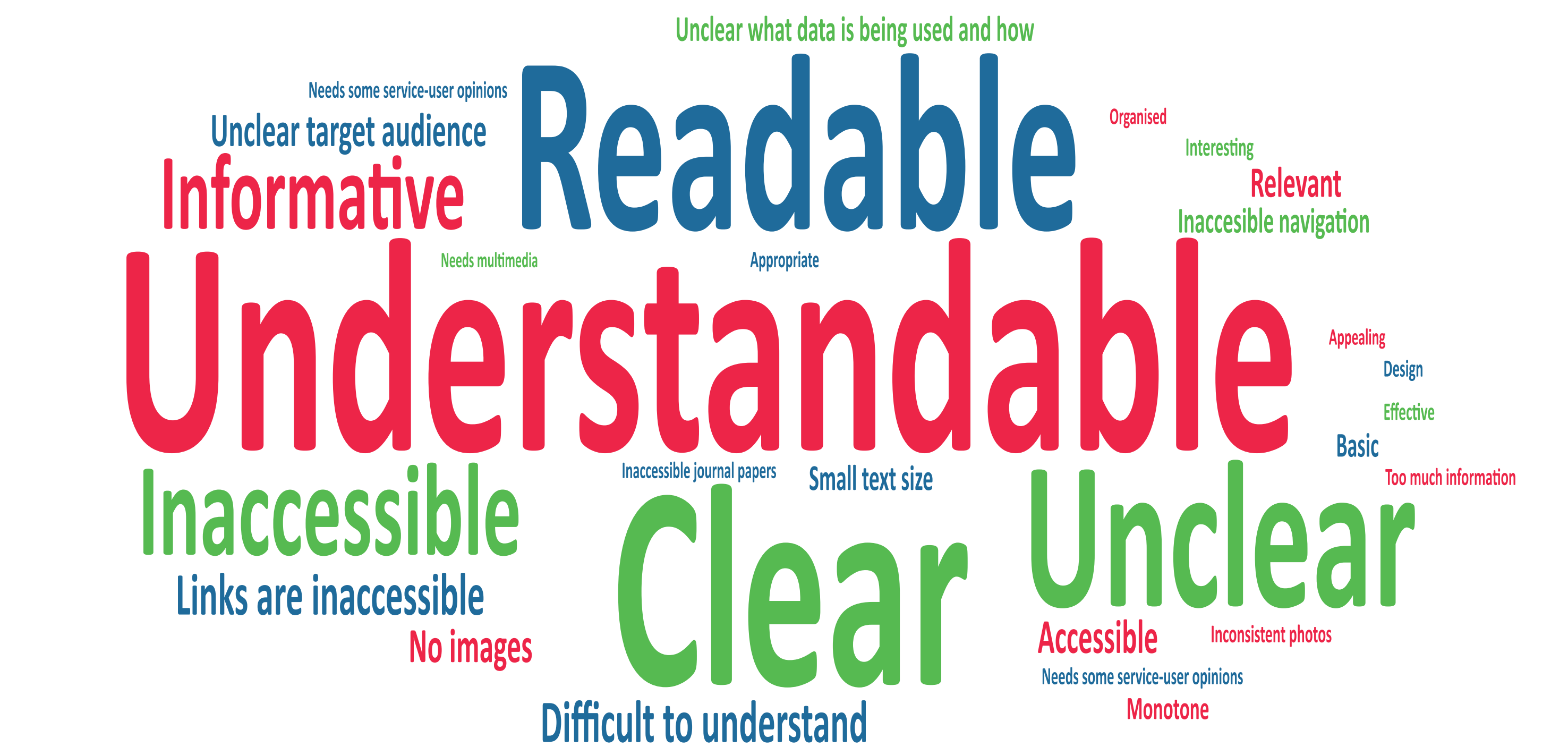


Fig 2. Word cloud illustrating feedback from the lay review.

Results

The lay review suggested several improvements to the website. Feedback was reviewed and compared against the UK HDRA Transparency Standards. Changes were drafted in consultation with communications colleagues, they included: updating images, adding additional information, making accessibility changes, and adding a new page aimed at service users and the public.



Fig 3. Screenshots of the CRIS website following implementation of the changes recommended in the lay review.

Lessons Learnt

- There are challenges in designing a website that is informative to both lay public readers and academic research users.
- Providing dedicated pages for patients and academic users can help to tailor relevant information to different stakeholders.
- Different people like to take in information in different formats, providing videos and pictures alongside text helps to support this.

References

1. Perera, G., et al. (2016) Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record-derived data resource. *BMJ Open*, 6:e00872.
2. Macaulay, Y., UK Health Data Research Alliance., Pan-UK Data Governance Steering Group., HDR UK Public Advisory Board., Five Safes Action Force. (2023) Pan-UK Data Governance Steering Group Data Access Transparency Standards. Available from: <https://zenodo.org/records/8262453>. [Accessed 23.04.2024]