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

Amelia Jewell¹, Hannah Woods¹, Liz Morrow², Alex Booth², Franca Davenport², and Robert Stewart^{3,4}

¹South London and Maudsley NHS Foundation Trust

²Maudsley Biomedical Research Centre (BRC), King's College London

³Department of Psychological Medicine, King's College London

⁴South London and Maudsley NHS Foundation Trust

Background

The South London and Maudsley NHS Foundation Trust (SLaM) is one of the largest providers of secondary mental healthcare in Europe. In 2007, SLaM developed the Clinical Record Interactive Search (CRIS) system which provides authorised researchers with regulated, secure access to anonymised information extracted from SLaM's electronic clinical records system¹. CRIS has been very successful as a research data resource and has supported over 300 peer reviewed publications over its 15+ years of operation.

The CRIS website (www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris) was developed to provide information to SLaM service users, the general public, and prospective research users. The website includes information on what CRIS is, approved CRIS projects and publications resulting from CRIS projects, as well as detailed information on data linkages involving CRIS and on Natural Language Processing (NLP) algorithms as a resource.

The website 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 potential CRIS stakeholders can access relevant information about CRIS in several different formats.

Introduction

We planned to conduct a lay review of the CRIS webpages involving both SLaM service users, carers, and CRIS academic users. The lay review was 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

Methods

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, firstly, an individual in-depth review of two webpages per person with an online questionnaire, followed by a focus group. An academic review by two junior researchers was also conducted, this involved a review of the webpages and completion of an online questionnaire.

Results

The online questionnaires and focus group suggested several improvements to the website. Feedback on each page was reviewed and compared against the UK HDRA Transparency Standards. A list of changes was drafted in consultation with communications colleagues. Changes were made to pages, including updating images, adding additional information, making accessibility changes, and adding a new page specifically aimed at service users and the public. Service user consultees were sent a further online questionnaire to provide feedback on the updated pages. Feedback was positive.

Conclusions

There were challenges involved in designing a website that was informative to both lay public readers and potential research users. Following the lay review and subsequent changes to the CRIS website, the website better meets the UK HDRA Transparency Standards.

References

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