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SUBMISSION #1 FROM THE Centre For Health Communication And Participation, La Trobe University TO "YOUR HEALTH. YOUR SAY: A CONSULTATION WITH THE AUSTRALIAN COMMUNITY TO CO-PRODUCE THE NATIONAL DIGITAL HEALTH STRATEGY" FROM THE AUSTRALIAN DIGITAL HEALTH AGENCY.

From: Sophie Hill, Centre for Health Communication and Participation, La Trobe University and Louisa Walsh, Centre for Health Communication and Participation, La Trobe University.

We are part of a national interdisciplinary research group[a], funded by the National Health and Medical Research Council (NHMRC), currently examining the use of the My Health Record for young adults with severe communication disability. In 2016 the research group examined the legal, ethical and health literacy demands of My Health Record, particularly for people with communication disabilities.

Here at the Centre for Communication and Participation, we have been examining issues with My Health Record have been identified in the areas of 1) consumer information and 2) usability. These issues have the potential to negatively impact the uptake and use of My Health Record, and are the focus of this submission.

1) Consumer Information

These issues were identified through a content analysis of all the online consumer-facing information about My Health Record. This included information produced by the Australian Government and from a range of other sources.

- The average readability of the consumer information available online at myhealthrecord.gov.au is currently above grade 11 level (as measured by Flesch-

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[a] NHMRC Project Grant 'Personally Controlled Electronic Health Records and Young Adults with Severe Communication Disability" A/Prof Hemsley, The University of Newcastle; A/Prof Andrew Georgiou, Macquarie University; Prof Susan Balandin, Deakin University; and Dr Sophie Hill, La Trobe University 2014-2017.

Kincaid Grade Level), with no resources having a reading level suitable for a 'low literacy audience' (below grade 6).

- The few translated resources available contain only basic registration information, and do not include detailed information about how to use the record either in an operational sense (e.g., navigation, adding information, setting access controls) or a strategic sense (e.g., encouraging health professionals to use the record, correcting mistakes in the record).

- The translated resources available cater only to opt-out areas, and there are no translated resources available for some of the most common languages in Australia, such as Vietnamese and Hindi.

- There is little use of pictures or video, and no use of audio or interactive tools, in presenting information about My Health Record which disadvantages people with low health literacy and those at risk of communication difficulties or disabilities.

- Few resources in our study were published by non-government sources. There may be opportunities for the Australian Digital Health Agency to work with organisations outside government to produce consumer information relevant and appropriate for specific consumer groups, especially those who are identified as priority groups for registration to My Health Record.

- Our examination showed that the information contained in the My Health Record consumer resources is detailed in relation to privacy and security, MyHR benefits, and registration instructions. However, there is currently little information about use of MyHR post-registration in healthcare contexts – either in an operational sense (e.g., navigation, trouble shooting, complaints/dispute resolution), or in a strategic sense (e.g., convincing or persuading one's health professionals to engage in using MyHR, user rights, knowing how MyHR fits in with other systems including the GP's own medical record system).

2) **Usability**

A range of usability issues were identified through a heuristic evaluation of the myhealthrecord.gov.au website and My Health Record. This evaluation, conducted in September and October 2016 used two checklists designed to assess the usability of online health information[1, 2] with a focus on usability issues which have been identified as particularly problematic for people with low health literacy. Through the heuristic evaluation the following issues were identified:

- Myhealthrecord.gov.au:
  - The key information not consistently included in first paragraph of each page and users often need to scroll down to access important instructions/information.

- o The language used throughout myhealthrecord.gov.au was measured as having a mean year 11 reading level (as measured by Flesch-Kincaid Grade Level testing) which is higher than the level considered to be 'plain English' (below Level 9) or suitable for a low literacy audience (below Level 6).
  - o Jargon is used heavily throughout and often not defined on the same webpage as it is used (users have to navigate to a glossary).
  - o There is a lack of lack of translated materials.
  - o There is a lack of images, multimedia and interactive elements to support learning.
  - o The links, buttons and other clickable elements are not always easily distinguishable from surrounding text and graphic elements.
  - o The image of doctor on homepage created impression that this information was for health professionals, not consumers.
  - o The search function not prominent enough.
  - o There is no ability for users to tailor information to their needs.
  - o There are no usability elements which facilitate social media sharing.
- My Health Record:
  - o The registration process and ongoing access through myGov is very complex.
  - o Instructions are not provided for all sections of the record and are not written in the active voice.
  - o There are no translated materials to facilitate use once users have accessed the Record.
  - o Navigation through the Record is complex, with navigation paths often poorly defined and links, buttons and other clickable elements are not always easily distinguishable from surrounding text and graphic elements.
  - o Users often have to scroll down the page to access key content.
  - o There is a lack of images to support learning and navigation.
  - o The accessibility modifications (e.g., access keys) did not work when tested by investigators.
  - o There is no search function.

Many of these problems could be identified and addressed with the inclusion of My Health Record user testing, especially with users from priority groups or who are at risk of low health literacy and/or communication difficulties/disability.

As My Health Record evolves and changes, there is an opportunity to include both user and usability testing as part of My Health Record development and quality improvement processes. This may help identify important barriers for consumers, and addressing these barriers may facilitate increased uptake and use of the system.

The next stage of this project will examine the negative and positive experiences people with communication disabilities have with using My Health Record. It is likely that this research will help to further develop and refine a list of recommendations for changes to My Health Record.

We would be pleased to further discuss the issues raised in this submission and the future plans for our research on My Health Record and/or share the manuscripts of our research with you.

Please contact Dr. Sophie Hill on 03 9479 1941 or via email: sophie.hill@latrobe.edu.au if you have any questions about this submission.

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1.   US Department of Health and Human Services and Office of Disease Prevention and Health Promotion. *Health Literacy Online: A guide to simplifying the user experience (2nd edition)*. 2015 2/8/16]; Available from: http://health.gov/healthliteracyonline/.
2.   Monkman, H., J. Griffith, and A.W. Kushniruk, *Evidence-based heuristics for evaluating demands on eHealth literacy and usability in a mobile consumer health application.* Studies in Health Technology and Informatics, 2015. **216**: p. 358-362.