Research Article

Health Information Management Journal
2021, Vol. 50(1-2) 13–25

DOI: 10.1177/1833358319864734
journals.sagepub.com/home/himj
SAGE

Assessing the information quality and usability of *My Health Record* within a health literacy framework: What's changed since 2016?

Louisa Walsh, *BPhysio (Hons), MstratComm*[1],
Bronwyn Hemsley, *BAppSc(Speech Path), PhD*[2,3],
Meredith Allan, *BA, BEc*[4],
Maria R Dahm, *MA, PhD*[5],
Susan Balandin, *PhD*[4],
Andrew Georgiou, *DipArts, BA, MSc, FCHSM, FACHI, FSc (Research), RCPA, PhD*[5],
Isabel Higgins, *RN, MN, PhD*[3],
Shaun McCarthy, *BA, LLB, Diploma Legal Practice*[3],
Sophie Hill, *BA (Hons), MA, PhD*[1]

Abstract

Background: This study examined the health literacy demands of My Health Record (MyHR) in the context of preparing for a government-announced opt-out system by repeating two studies of health information and usability conducted in 2016. **Objective:** To examine whether Australia's MyHR meets the information and usability needs of people at risk of low health literacy and changes since 2016. **Method:** *Content analysis*: Informed by the 2016 methods and findings, measures of information quality, themes and target audiences were recorded and reported for each online consumer-facing health information resource. *Heuristic evaluation*: An evaluation of the MyHR and supporting information website was conducted using a predetermined checklist of usability criteria. A list of usability violations for both websites was identified. **Results:** Total number of resources grew from 80 in 2016 to 233 in 2018. There was little change since 2016 to average readability levels, target audiences, presentation style, links between resources and usability of MyHR. Compared to 2016, this study demonstrated increases in resources from non-government organisations; video resources; translated resources; and resources with themes of privacy, security and post-registration use. **Conclusion:** This study identified some improvements in information quality since 2016, but gaps remain in information quality and usability which may negatively impact the ability for people with low health literacy to access and use MyHR. **Implications:** This study provides a framework for ongoing monitoring and evaluation of the suitability of MyHR for people at risk of low health literacy.

Keywords (MeSH)
electronic health record; health literacy; consumer health information; ehealth; personal health record; health information management

Introduction

In 2017, our group published two research papers on the health literacy demands of My Health Record (MyHR) using data collected in 2016 (Walsh et al., 2017a, 2017b). The first was a content analysis using a health literacy framework to analyse 80 online resources, which supported the uptake and use of MyHR (Walsh et al., 2017b). The second was a heuristic analysis of usability of the MyHR information website (www.myhealthrecord.gov.au) and the

---

[1] La Trobe University, Australia
[2] University of Technology Sydney, Australia
[3] The University of Newcastle, Australia
[4] Deakin University, Australia
[5] Macquarie University, Australia

Accepted for publication July 1, 2019.

Corresponding author:
Louisa Walsh, Centre for Health Communication and Participation, School of Science, Health and Engineering, La Trobe University, Bundoora, Victoria 3086, Australia.
E-mail: louisa.walsh@latrobe.edu.au

Record, using heuristic sets designed to assess online health information and its suitability for a low health literacy audience (Walsh et al., 2017a). The findings demonstrated that information content and design of online resources about MyHR catered poorly to audiences at risk of low health literacy, with the potential to adversely affect uptake and use of MyHR (Walsh et al., 2017a, 2017b).

The data collection for the original studies occurred during a period of transition for the MyHR in 2016. The formerly named "Personally Controlled Electronic Health Record" (PCEHR) was transitioning to the current "My Health Record," and responsibility for the management of the Record was shifting from the Australian Department of Health and the National E-Health Transition Authority to the newly created Australian Digital Health Agency (ADHA, n.d.-a). The MyHR is recognised as providing potential benefit to healthcare consumers because it provides an electronic (online) mechanism for sharing summary health information across multiple healthcare providers, potentially increasing healthcare quality and safety (Hemsley et al., 2016). In 2016, in order to increase uptake and use of MyHR, there was a successful trial of the opt-out system of registration in two regions in Australia (Siggins Miller, 2016) leading to another period of transition for MyHR with the introduction of an opt-out system of registration for MyHR across Australia (Ministerial Office of Greg Hunt, 2018). Between 16 July 2018 and 31 January 2019, Australians without a MyHR had the opportunity to opt out of the system ahead of the national roll-out (Australian Digital Health Agency, 2018c). After this date, all Australians registered on the Medicare system who had not chosen to opt out had a MyHR created for them (Australian Digital Health Agency, 2018c). After this date, if people no longer wanted a MyHR they could cancel or suspend their MyHR at any time (Australian Digital Health Agency, 2018c). Such a decision is an important one, considering both the potential risks and potential benefits of either opting out or staying in the system in terms of both healthcare quality and safety and any privacy or legal issues. Considering that many members of the public are at risk of low health literacy, for a variety of reasons (e.g. having low literacy, disability, or health conditions affecting access to written materials) (see Walsh et al., 2017a, 2017b) it is important to maintain research attention on the accessibility of information about MyHR. Research on the information accessibility and usability of MyHR could be used to inform efforts of both government and non-government organisations (NGOs) towards inclusion and participation in MyHR by all Australians who wish to participate in using the system.

The aims of the current study were to (a) update the MyHR search for and content analysis of consumer-facing information online and (b) conduct a heuristic analysis of usability of the information website (www.myhealthrecord.gov.au) and MyHR, within the initial 2018 phase of the opt-out period. This information could be used to determine whether the several changes recommended in our prior publications (Walsh et al., 2017a, 2017b) or other improvements had been made to the information content of the main sources of online consumer-facing information about MyHR, or to design elements of MyHR, to better support people at risk of low health literacy in their ability to access and use the national personally controlled electronic health system.

Method

Content analysis

Between 25 July and 5 September 2018, an online search was conducted by two authors (LW and SH) for consumer-facing information relating to MyHR. The term "My Health Record" was used to search Google and Bing search engines; the YouTube search function; the search function on each National, State and Territory Health and Human Services Department website; and the search function on each Primary Health Network page. The first 20 pages of results from each search were examined for eligible resources (Walsh et al., 2017b). In addition to the search, any hyperlinks on the retrieved consumer-facing information were used to locate the linked web pages and check these for relevance and inclusion in the study.

Inclusion criteria: Only Australian MyHR information resources available online and aimed at healthcare recipients (including consumers or carers), developed by any government department or any NGOs, were included in the study.

Exclusion criteria: Any information about other e-Health programs or platforms (i.e. with no MyHR content) or materials that were about MyHR that were aimed at healthcare providers or MyHR program implementers (e.g. research reports, media releases, media resources, legislation, submissions, reviews, opinion pieces, videos of lectures, presentations or webinars) was excluded. As in the original study replicated here, these sources were excluded as the primary audience for these materials is either healthcare providers, who are not at risk of having low health literacy, or implementers who have other insider knowledge of MyHR systems.

The search strategy was largely unchanged since the 2016 search. The only change was the use of "My Health Record" as sole search term, a decision taken as the name "My Health Record" had been in use since the period of the last search (Walsh et al., 2017b) and the original additional search terms ("PCEHR," "personally controlled electronic health record" and "eHealth") would not necessarily reflect how consumers would currently search for information about MyHR and would potentially only retrieve material that was no longer relevant.

The measures of resource quality have remained the same since the original research, and detailed justification for the choice of measures can be found in the original publication (Walsh et al., 2017b). The target audience codes (e.g. General Public, Carers, People with Chronic Conditions, Aboriginal and Torres Strait Islanders) are unchanged from the original publication (Walsh et al., 2017b) and the full list is included in the results section in the "Target audience" row of Table 1. The theme categories have largely remained the same; however, the "Opt-out trials" theme was slightly altered to "Opt-out," and an additional theme of "Risk" was evident in this analysis. These subtle changes to themes developed throughout the period of data collection and analysis. LW conducted the same inductive content analysis method (Elo and Kyngäs, 2008) as was conducted in the original paper (Walsh et al., 2017b).

Heuristic evaluation

The heuristic evaluation method conducted in the original paper (Walsh et al., 2017a) was repeated for this analysis. Heuristic evaluation seeks to present a list of usability violations that can be used to inform design changes to enhance usability (Nielsen, 1994), in this study for healthcare consumers using MyHR. Repeating an analysis to monitor changes over time is in accordance with the principles of heuristic evaluation (Nielsen, 1994). As with the first study, violations were not assigned severity levels due to known poor interrater reliability when using this method (Nielsen, 1994). Instead, the total number of violations are presented in the results, compared to the findings from the original study, and differences indicated where they occur. "Improvement" in the context of this heuristic analysis method would be a decrease in the number of violations (Nielsen, 1994).

Three evaluators (LW, MA, MRD) employed Nielsen's method of heuristic evaluation (Nielsen, 1994) using a set of heuristics, which considered the usability need of people with low health literacy when looking for health information online. The only difference between this and the evaluation method used in our earlier research in 2016 was that we added two items to the heuristic set. In our original research, the evaluators found that the Health Literacy Online (HLO) heuristic set (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015) was easier to use and returned more specific results than the second heuristic set under examination (Monkman et al., 2015), except across two domains – "avoid registration" and "offer content in multiple languages" (Walsh et al., 2017a). Based on this finding, and to ensure a comprehensive analysis, in the present study, the two domains from the Monkman heuristics (Monkman et al., 2015) were added to the HLO heuristic set (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015) to create a new heuristic set which better met the aims of the current project. The heuristic set can be seen in the results section, within Tables 2 and 3.

The evaluation was conducted between 31 August and 17 September 2018. As in the original project, the heuristic evaluation was conducted on the MyHR information website (www.myhealthrecord.gov.au) and on the MyHR. In accordance with the principles of heuristic evaluation (Nielsen, 1994), the findings from this study could inform both future user testing to comprehensively identify improvements that could increase the usability of MyHR and future monitoring using this heuristic analysis method to detect changes over time.

Results

The results are presented in two sections. The "*Content analysis*" section presents the findings from the content analysis of the consumer-facing information available online found during the 2018 search and compares the 2018 results to the results from the 2016 search (Walsh et al., 2017b). Full results are presented in Table 1, with a brief commentary of most important differences between 2016 and 2018 presented under subheadings in the text. The "*Heuristic evaluation*" section presents the usability analysis. Two heuristic analyses was conducted separately on the MyHR information website (www.myhealthrecord.gov.au) and the MyHR itself. The full results of the 2018 heuristic evaluation, along with the results of the original study (Walsh et al., 2017a), are presented in Table 2 (information website) and Table 3 (MyHR). Following each table is a short commentary outlining the number and type of violations and a comparison to the original study results.

Content analysis

Table 1 presents the full analysis results from the 2018 content analysis of consumer-facing information alongside the results from the analysis of the 2016 search results. A number of differences can be seen between the 2016 and 2018 search and analysis results, the most noteworthy of these being highlighted in the commentary following the table. The subheadings presented in the content analysis commentary section correspond to the measures analysed in Table 1.

Commentary on comparisons of content analyses

Total resources. Overall there was growth in the number of total resources found in the search and included in the analysis, from 80 in 2016 to 233 in 2018 (Table 1).

Readability. In 2018, the level of literacy required to read MyHR resources remains high, at a mean Flesch–Kincaid grade level (Flesch, 1979) of 10.9 across all resources. For comparison, a grade level of 7 or 8 is considered to be "Plain English" and would be accessible to a majority of readers, a grade level of 6 and below is considered to be "Easy English" and accessible to readers with low literacy (Flesch, 1979). Although the overall number of Plain English resources increased almost threefold from 11 in 2016 to 32 in 2018, the proportion of Plain English (Flesch, 1979) resources available in the sample is relatively stable, dropping only 1% from 17% in 2016 to 16% in 2018. Indeed, despite a tripling in the number of resources available, as in 2016, there was only one Easy English (Flesch, 1979) resource found in the 2018 search, and the 2018 resource was not the same resource or from the same organisation as the Easy English resource found in the 2016 search. These

Table 1. A comparison of measures of information quality, target audiences and key themes within online consumer-facing MyHR information between 2016 and 2018.

Criteria	March 2016 (*n* = 80) (Walsh et al., 2017b)	September 2018 results (*n* = 233)
Readability	• 64 resources included in testing • Mean Flesch–Kincaid grade level = 11.8 (SD 2.6) • 11 resources (17%) rated between 7 and 9 ("Plain English") • 1 resource rated <6 ("Low Literacy")	• 199 resources included • Mean Flesch–Kincaid grade level = 10.9 (SD 2.0) • 32 resources (16%) rated between 7 and 9 ("Plain English") • 1 resource rated <6 ("Low Literacy")
Currency	• 2011: 3 (4%) • 2012: 6 (8%) • 2013: 7 (9%) • 2014: 17 (21%) • 2015: 8 (10%) • 2016: 33 (41%) • Unstated: 6 (8%)	• 2014: 1 (0.4%) • 2017: 6 (3%) • 12018: 83 (36%) • Unstated: 143 (61%)
Information source	• MyHR: 23 (29%) • Australian government (non MyHR): 22 (28%) • Primary Health Network: 12 (15%) • State and Territory government: 8 (10%) • Non-government organisation: 6 (8%) • Medicare local: 3 (4%) • Credentialing organisation: 2 (3%) • Health consortia: 2 (3%) • Industry peak body: 1 (1%) • Private health provider: 1 (1%)	• MyHR (ADHA): 157 (67%) • Non-government organisation: 22 (9%) • Australian government (non-MyHR/ADHA): 20 (9%) • Primary Health Network: 18 (8%) • State and Territory government: 7 (3%) • Public hospital/health service: 3 (1%) • Financial services comparison website: 3 (1%) • Private health provider: 1 (0.4%) • Professional body: 1 (0.4%) • Independent online content creator: 1 (0.4%)
Target audience[a]	• General public: 65 (81%) • Health providers: 18 (23%) • Parents of infants/toddlers: 15 (19%) • Parents: 13 (16%) • Authorised/nominated representatives: 11 (14%) • Older people: 7 (9%) • People with chronic conditions: 6 (8%) • People from CALD backgrounds: 6 (8%) • Opt-out trial sites: 5 (6%) • People with mental health conditions: 4 (5%) • Adolescents: 2 (3%) • Carers: 2 (3%) • Aboriginal and Torres Strait Islanders: 1 (1%) • Veterans: 1 (1%) • Other: 7 (9%)	• General public: 164 (70%) • Parents of children under 18: 43 (18%) • Authorised/nominated representatives: 22 (9%) • People with chronic conditions: 21 (9%) • Health providers: 18 (8%) • Aboriginal and Torres Strait Islanders: 11 (4%) (plus uncounted resources in community languages) • Older people: 14 (6%) • Carers: 9 (4%) • Adolescents: 8 (3%) • People from CALD backgrounds: 4 (1%) (plus uncounted resources in community languages) • Veterans: 5 (2%) • People with mental health conditions: 3 (1%) • Opt-out trial sites: 1 (0.4%) • Other: 17 (7%) (including people who inject drugs, members of the LGBTIQ+ community, clients of particular health services, working age adults)
Themes[a]	• Registration: 51 (64%) • Privacy/security: 49 (61%) • Benefits: 46 (58%) • Post-registration use: 41 (51%) • Use of representatives: 23 (29%) • Relationships with health providers in relation to MyHR: 16 (20%) • Dispute resolution: 9 (11%) • Opt-out trials: 5 (6%)	• Privacy/security: 134 (58%) • Post-registration use: 131 (56%) • Benefits: 112 (48%) • Registration: 91 (40%) • Use of representatives: 86 (37%) • Opt-out: 76 (33%) • Risks: 16 (7%) • Relationships with health providers in relation to MyHR: 13 (6%) • Dispute resolution: 13 (6%)
Presentation style	• 64 text-based (80%) • 16 videos (20%)	• 204 text-based (88%) • 29 videos (12%)
Links between resources	5 MyHR resources link to external websites (all Australian government sites). All external resources link to MyHR.	All external resources link back to MyHR. 15 MyHR pages link to external websites (all Australian government sites) which house supporting resources (including Department of Human Services, Office of the Australian Information Commissioner, Scamwatch, relevant legislation). 4 external resources link to a range of media and opinion pieces about MyHR.

MyHR: My Health Record; SD: standard deviation; ADHA: Australian Digital Health Agency; CALD: culturally and linguistically diverse; LGBTQI+: lesbian, gay, bisexual, transgender, queer, intersex, +.

[a] Note that most resources have multiple target audiences and resource themes, which accounts for the discrepancy between the number of resources included in the analysis and the numbers/percentages reported in the table against target audience and themes criteria.

Table 2. Heuristic evaluation of MyHR information website (www.myhealthrecord.gov.au) – Comparison of 2016 and 2018 results.

Heuristic checklist criteria	October 2016 results	September 2018 results
Identify user motivations and goals	Y	Y
Put the most important information first	N – sometimes key information is not in first paragraph.	Y
Describe the health behaviour – basics	Y	Y
Positive tone	Y	Y
Provide action steps	Y	Y
Plain language	N – readability issues as per first paper, long sentences, jargon used without explanation in places.	N – readability issues as per analysis, poor use of active voice.
Check content for accuracy	Y	N – no version/update date or name of content reviewer, only ©ADHA
Limit paragraph size (use bullets/lists)	Y	N – inconsistent. Technical pages and privacy/security pages particularly dense.
Meaningful headings	Y	Y
Readable font (min 16 pixels/12 point)	Y	Y
White space/avoid clutter	Y	Y
Most important content above the fold	N – key information sometimes below the fold	N – inconsistent, especially on mobile devices.
Use links effectively	Y	Y – however the position of links on some pages may lead users to exit before they can read the key information.
Colour or underline to identify links	Y	Y
Images to assist learning	N – few images used on site.	N – use of images is limited but includes some videos
Appropriate contrast	Y	Y
Printer friendly content	Y	Y – however no still image is printed in place of videos
Disability accessible	N – https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/accessibility claims accessibility, but unable to get access keys to work.	N – access keys work, and there is a read speaker, however many navigation elements are required to access the read speaker if user is unable to use mouse.
Responsive website	Y	Y
Mobile content to meet user needs	Y	Y
Simple and engaging homepage	N – some of the links would be better represented by clickable buttons. Image of health professional used makes the page appear designed for a health professional rather than consumer.	N – the “You and your family” homepage has too much written information with video and images only after the fold.
Label and organise content	Y	Y
Create linear information paths	Y	N – inconsistent – linear information paths are available for some headings but not consistently throughout (for e.g. in the how to guides).
Buttons have meaningful labels	Y	Y
Clickable elements are recognisable	N – only when the user skims across some headings with their mouse do they change and become active clickable buttons, which may not be obvious to the average user.	Y
Browser “back” button works	Y	Y
Easy access to home and menu pages	Y	Y
Users have options to browse	Y	Y

(continued)

Table 2. (continued)

Heuristic checklist criteria	October 2016 results	September 2018 results
Simple search function	N – search function not obvious. No heading such as "search My Health Record" or "Go" button.	N – health professionals information seems to be prioritised on search, even when search initiated from the 'For me and my family' site; no permanent search bar; magnifying glass icon might not be easy for user to associate with search functions; search doesn't allow for common typos.
Display search results clearly	Y	Y
Share information through multimedia	N – text only, few pictures, no multimedia used.	Y
Intuitive interactive graphics and tools	N – no use of interactive graphics or tools.	N – no interactive tools.
Tailored information	N – no ability for user to enter personal details to tailor and guide their information gathering.	N –- no ability for user to enter personal details to tailor and guide their information gathering.
User-friendly forms and quizzes	N – no forms or quizzes.	N – no forms of quizzes.
Social media sharing options	N	N
Avoid registration. If unavoidable, make registration and logging in simple and obvious.	Y	Y
Offer content in multiple languages	N – all content not provided in multiple languages.	Y – basic info offered in 19 languages other than English, all web pages translated into 17 community languages.

MyHR: My Health Record; ADHA: Australian Digital Health Agency.

Table 3. Heuristic evaluation of MyHR: Comparison of 2016 and 2018 results.

Heuristic checklist criteria	October 2016 results	September 2018 results
Identify user motivations and goals	N – no introductory statements on home page.	N – no introductory statements on home page.
Put the most important information first	N – no introductory statements on home page.	N – no introductory statements on home page, often need to click link to reveal important information.
Describe the health behaviour – basics	N – inconsistent instructions throughout.	N – inconsistent instructions.
Positive tone	Y	Y
Provide action steps	N – inconsistent action steps throughout.	N – inconsistent use of action steps.
Plain language	N – poor use of active voice. Readability untested.	N – poor use of active voice.
Check content for accuracy	Y	Y
Limit paragraph size (use bullets/lists)	Y	Y
Meaningful headings	N – too many headings, with layering of key information under other headings which makes navigation to some parts of the record difficult.	Y
Readable font (min 16 pixels/12 point)	Y	Y
White space/avoid clutter	Y	Y
Most important content above the fold	N – important content on home page falls below the fold.	N – many headings, clickable elements to key sections and important information on the Record fall beneath the fold on the home page.
Use links effectively	N – links not clearly differentiated from surrounding text.	Y

(continued)

Table 3. (continued)

Heuristic checklist criteria	October 2016 results	September 2018 results
Colour or underline to identify links	N – links not clearly differentiated from surrounding text.	N – headings are often links but not distinguished with colour or underline.
Images to assist learning	N – no images.	N
Appropriate contrast	Y	Y
Printer friendly content	Y	N – long records cannot be printed in full as display is limited to the last five entries.
Disability accessible	N – https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/accessibility claims accessibility, but unable to get access keys to work.	N – screen reader issue, when using access keys the relevant section is not always highlighted, so it is sometimes difficult for the user to see where they are on the page.
Responsive website	Y	Y
Mobile content to meet user needs	Y	Y
Simple and engaging homepage	Y	N – the home page lacks Plain English or low literacy information, images, colour and large button links that facilitate engagement and navigation for a low health literacy audience.
Label and organise content	Y	Y
Create linear information paths	Y	N – linear navigation paths not available.
Buttons have meaningful labels	Y	N – buttons and hyperlinks poorly distinguished from surrounding text, no use of colour or images to assist navigation.
Clickable elements are recognisable	N – links not clearly differentiated from surrounding text.	N – headings are often links but not distinguished with colour or underline
Browser "back" button works	Y	Y
Easy access to home and menu pages	Y	Y
Users have options to browse	Y	Y
Simple search function	N – no search function.	N – search doesn't allow for common typos.
Display search results clearly	N – no search function.	Y
Share information through multimedia	N	N
Intuitive interactive graphics and tools	N – however a number of interactive quizzes about child health are available through parent's section.	N – no interactive tools.
Tailored information	Y	Y
User-friendly forms and quizzes	N – forms can be challenging to find in the record and not intuitive to use.	Y
Social media sharing options	N	N
Avoid registration. If unavoidable, make registration and logging in simple and obvious.	N – registration not simple, multiple step process involving MyGov.	N – registration not simple, multiple step process involving MyGov.
Offer content in multiple languages	N – available in English only.	N – available in English only.

results suggest that the provision of either written Plain English or Easy English resources are not a priority in relation to the development of new information sources aimed at consumers in relation to MyHR.

Currency. The majority (61%) of resources from the 2018 search were undated. This is largely because most web pages on the MyHR website did not include a date of publication, which accounted for the majority of the undated resources. Given that the content of many of these undated pages refers to opt-out registration and opt-out deadlines, and these changes to MyHR were made public in 2018 (Australian Digital Health Agency, 2018b), it can be inferred that these pages were last updated in 2018. Nonetheless, best practice recommends that the year of publication or update of a web page should be made public on the web pages (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015) as both health consumers and health professionals use date of update to determine the currency of information and help judge information quality (Marton, 2010; Roberts, 2010).

It is worth noting that coinciding with the announcement of the change to an opt-out model in 2018 (Australian Digital Health Agency, 2018c), a large proportion (36%) of dated resources were published in 2018.

Information source. The MyHR website has grown substantially in size, increasing from 23 pages in 2016 to 157 pages in 2018. The number of resources provided by NGOs has also grown in this time. Many of the NGO resources found in the search provided tailored information specific to their consumer-base, often focused on privacy and security concerns and advised on decision-making around opting out of MyHR (Duck-Chong, n.d; Hepatitis NSW, 2018; Queensland Council of Social Service, n.d; Robertson-Dunn, 2018).

Target audience. Target audiences have remained similar to the 2016 search, with the general public, parents and authorised/nominated representatives being the top three consumer audiences identified in both 2016 and 2018.

Themes. Given the change in MyHR to an opt-out system of registration, the most common theme in 2018 resources relating to MyHR addressed consumer privacy and security concerns. There was also an increase in available resources on how to use the Record after registration, a topic identified as a gap in 2016 resources (Walsh et al., 2017b).

Presentation style. In 2018, the presentation format and style of information provided to the public remains largely text-based, however there has been an increase in the number of videos available. As in 2016, no interactive, or audio-only resources were found in the 2018 data.

Links between resources. Reflecting the prominence of the government websites in providing the information, all external resources located in the search link back to the MyHR information website; and all resources from the MyHR information website that provide external links to other sites link only to other government websites.

Other notes. While some resources found in the search – particularly those from the Office of the Australian Information Commissioner and some pages from the MyHR website (www.myhealthrecord.gov.au) – were updates of web pages originally found in the 2016 search, the majority of resources were new. Of those pages that were updates, the only important change from 2016 to 2018 was the inclusion of information about the opt-out model and dates for transition to opt out.

Heuristic evaluation

Commentary on comparisons of heuristic evaluation of the MyHR information website (Table 2)

Total violations. Of the 37 heuristic criteria for evaluating the MyHR information website, there were 14 violations in 2016 and 13 in 2018.

Changes in violations. In total, 4 (28%) of the 14 criteria which were violations in 2016 were no longer considered violations in 2018: "put the most important information first," "offer content in multiple languages," "clickable elements are recognisable" and "share information through multimedia." Overall, there were three new violations. The lack of version numbers and/or publication or review dates on the information website violates the "check content for accuracy" criterion. The density of text on technical pages and privacy/security information violated the "limit paragraph size" criterion. The violated criteria of "create linear navigation paths" may reflect the growth in size of the MyHR website with substantially more pages aimed at consumers.

Other notes. The use of a "read speaker" (i.e. a website plugin that provides text-to-speech capability) and working access keys (i.e. the ability to navigate throughout the website without using the mouse) were noted as an improvement against the "disability accessible" criterion. However, navigation using keys to enable use of the read speaker was considered burdensome by one evaluator in this study, and therefore the criteria violation remained.

Commentary on the comparisons of heuristic evaluation of MyHR

Total violations. Out of 37 heuristic criteria for evaluating the MyHR, in 2016 we noted 20 violated criteria in the Record. In 2018 remained at 20 violations, with some changes in the criteria violated (Table 3).

Changes in violations. Four criteria which were violations in 2016 were no longer considered violations in 2018. These were "meaningful headings," "use links effectively," "display search results clearly" and "user friendly-forms and quizzes."

The fact that long records cannot be printed in full created a new violation against the "printer friendly content" criterion.

The lack of Easy English, images, colours and large buttons on the home page created a new violation against the "simple and engaging home page" criterion.

The lack of linear navigation paths and buttons and hyperlinks being poorly differentiated from surrounding text created violations in the "create linear information paths" and "buttons have meaningful labels" criteria.

Other notes. While the inclusion of a search function was noted as an improvement by the evaluators, the fact that it does not correct for common typing errors means that the "simple search function" criterion remains a violation.

We also note that despite the improvements to disability accessibility and access to information in multiple languages about the MyHR, the Record itself purportedly does not comply with Web Content Accessibility Guidelines (Community Affairs Legislation Committee, 2018), access key navigation is inconsistent and the Record is offered only in English.

Discussion

In the 2016 content analysis of the consumer-facing information, we identified a number of gaps in the provision of MyHR resources to people at risk of low health literacy. These were:

- Lack of Plain English, Easy English or low literacy resources;
- Lack of resources in community languages;
- Lack of diversity in presentation styles;
- Lack of resources from non-government sources (e.g. consumer groups, self-advocacy groups or condition-specific peak bodies);
- Lack of targeted resources for the target audiences named in the Concept of Operations (Australian Department of Health and Ageing, 2011): older people, veterans, people with chronic conditions, people with mental health conditions, Aboriginal and Torres Strait Islanders, adolescents, people with disabilities and people living in rural and remote areas; and
- Lack of information about post-registration use MyHR in an operational ("how to use") sense, to assist negotiation with health professionals around use and to support integration of MyHR in self-management or person-centred care approaches (Walsh et al., 2017b).

Our research shows that some of these information gaps have been addressed in the 2-year period since our last studies (Walsh et al., 2017a, 2017b). At the time of this 2018 data collection, all pages on the MyHR information website could be displayed in 17 community languages: Arabic, Chinese, Croatian, Greek, Hindi, Italian, Japanese, Korean, Macedonian, Persian (Farsi), Punjabi, Russian, Serbian, Spanish, Thai, Turkish and Vietnamese (Australian Digital Health Agency, n.d.-b). These languages largely correspond with the top languages spoken in Australia identified through the 2016 Census (Australian Bureau of Statistics, 2016; idcommunity, n.d.). Although this was not captured through the content analysis method used, it is worth noting as the development of more translated resources in a wider variety of community languages was a key recommendation in our prior report (Walsh et al., 2017b). In addition, basic written information about the record is now also provided in two Aboriginal and Torres Strait Islander languages – Yumplatok and Kriol (Australian Digital Health Agency, n.d.-b).

There are now more resources available in video format and more diversity in the government and NGOs producing online consumer-facing information to cater to the communities they service. Presentation styles are now more diverse, with more videos available about MyHR including consumer stories and videos in languages other than English. There are also more resources providing details on how to use MyHR once registered. Increasing the amount of information provided in a variety of languages (McInnes and Haglund, 2011), providing information in a variety of formats (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015) and developing and sharing information from a variety of trusted sources (Diviani et al., 2015) are all evidence-based strategies for increasing accessibility of information for people with, or at risk of, low health literacy.

However, some gaps present in 2016 still remain. The average readability of online MyHR resources remains high at a mean Flesch–Kincaid grade level of 10.9, and while there has been an increase in the number of resources in the Plain English range, there has not been any increase in low literacy resources since 2016, with only one resource being considered appropriate for people with low literacy based on Flesch–Kincaid grade level (Flesch, 1979). It is very common for the readability levels of health information to be too high for people who experience difficulty in understanding written English (McInnes and Haglund, 2011). Producing written health information in a language or linguistic level that is easier for the reader to understand increases both accessibility of the information (McInnes and Haglund, 2011; Patient Information Forum, n.d.) and trust by the reader in the organisation that produces it (Diviani et al., 2015). However, it is also possible that the higher number of resources now available about MyHR online might also increase redundancy of information for some readers who are helped by receiving information in a variety of formats (e.g. video resources supplementing written materials).

A large number of resources included in the analysis did not include dates of update and/or review. The majority of these undated resources came from the MyHR information website. According to best practice in online information provision, the year of publication or update of a web page should be made public (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015). This allows users to judge information currency, which is an important marker of information quality for users (Marton, 2010; Roberts, 2010). Being transparent with publication and review dates is a way that organisations who produce information about MyHR can easily increase the quality of their information.

Since the first study, the target audiences named by the MyHR developers have changed. In the original Concept of Operations, the target audiences were named as adolescents, older people, Aboriginal and Torres Strait Islanders, veterans, people living in rural and remote areas, people with chronic conditions, people with mental health conditions and people with disabilities (Australian Department of Health and Ageing, 2011). In 2017, the ADHA outlined the target audiences for information about MyHR as all individuals (14–18 years+); senior Australians; parents and their children (newborn to under 14); carers and representatives; Aboriginal and/or Torres Strait Islanders; people with a non-English speaking background; and people living in rural, regional and remote locations (Australian Digital Health Agency, 2017).

This shift in nominated audiences has been reflected in increased numbers of targeted resources identified through this study for the general public, Aboriginal and Torres

Strait Islanders (through the provision of English-language and translated resources), parents, representatives and culturally and linguistically diverse communities (through the provision of full MyHR website translation for 17 community languages and other translated resources). While there are some additional resources for carers and senior Australians in 2018 compared with 2016, people living in rural, regional and remote locations have not been well-served with targeted resources in either search, despite being named as target audiences for information about MyHR in 2017 (Australian Digital Health Agency, 2017).

Additionally, some of the original target audiences from the concept of operations – such as people with chronic conditions, people with mental illness, veterans and people with disability (Australian Department of Health and Ageing, 2011) – are no longer specifically named as target audiences for MyHR information provided through the website. Given that these audiences are members of groups identified as being at high risk of having low health literacy (Greenhalgh, 2015; Nutbeam, 2008), and being at risk of exclusion from use of the MyHR (Hemsley et al., 2018), removing their "target audience" status may shift focus away from providing high quality, targeted online resources which address the specific needs of these groups. This, in turn, may disadvantage people from these groups when using MyHR or when they are making decisions around opting in or out of MyHR during the opt-out period. Furthermore, removing people with disability as a target audience might in fact reduce the imperative for further improvements to the MyHR and websites hosting consumer-facing information about the record being made accessible to this audience.

In regards to usability, while there are improvements in some areas, there have been new violations in others, resulting in a net result of largely unchanged numbers of usability violations across the information website and MyHR. Ease of use is a well-established barrier to the uptake of PCEHRs (Bush et al., 2015; Hanna et al., 2016; Irizarry et al., 2015; Otte-Trojel et al., 2016; Zahabi et al., 2015). Given that a lack of "user focus"' has been an identified issue with the MyHR information website (Australian Digital Health Agency, 2017), usability for people at risk of low health literacy and those with disability must be addressed to support consumers' ongoing use of MyHR.

Identified in the heuristic evaluation are both violations that could be viewed as simple to resolve (e.g. making hyperlinks distinct from surrounding text or putting an introductory statement on the home page of the Record) and violations that may prove challenging to change (e.g. deprioritising health professional-targeted search results made on the MyHR information website). There are also violations that may not be feasible to change under current use or legislative requirements associated with MyHR, such as simplifying registration processes or including social media sharing options. It is important to understand that the heuristic set used is based on best practice recommendations for online health resources for low health literacy audiences (US Department of Health and Human Services and Office of Disease Prevention and Health Promotion, 2015; Monkman et al., 2015) but is not tailored to the PCEHR context. This limitation in the present study reinforces the need for regular user testing with a range of stakeholders (Nielsen, 1994), including consumers with, or at risk of, low health literacy to ensure usability elements of MyHR are meeting the needs of all users.

Overall, this analysis has demonstrated that while there have been some improvements in the quality of information about MyHR since 2016, the information and usability needs of people with, or at risk of, low health literacy are still not being adequately met, and issues identified in the previous research remain unresolved. As identified by Hemsley et al. (2018),

> the very nature of 'personal control' in the record means that some people will be advantaged and others disadvantaged in using MyHR because of multiple factors affecting an individual's choice and control in many areas of life, including (a) health literacy (b) cognitive capacity, and (c) inequity in relation to *exercising* choice or in the *direct supports or assistance* available to make decisions. (Hemsley et al., 2018, p 508)

If MyHR doesn't provide relevant information or usable systems for people at risk of low health literacy, then MyHR is not providing equitable support and assistance for all users to access the Record. This may mean that people at risk of low health literacy are less likely to make full use of the system and receive the potential benefits of using MyHR. This in turn could increase health disparities between users and non-users if the promoted potential benefits of use – such as improved continuity of care, communication between treating health professionals and ease of access in an emergency (Australian Digital Health Agency, n.d.) – are realised.

In addition, inequity of information and system access across stakeholder groups raises questions in regard to the provision of informed consent during the opt-out period for people with low health literacy. People with low health literacy experience barriers to providing informed consent and require extra support to sufficiently comprehend the health information presented (Lorenzen et al., 2008). As MyHR is now an opt-out system, not providing adequate accessible information to support those with low health literacy to make an informed choice (i.e. either to be registered into or opt out of MyHR) and, if registered, thereafter to understand and use the system safely, is inequitable (Hemsley et al., 2016). Being registered into or opting out of a system without knowledge of its use, including information about its safety or privacy and what to do in the event of a breach, is a particular concern because of extensive public discussion (Grattan, 2018) and parliamentary debate (Community Affairs Legislation Committee, 2018) surrounding privacy and security concerns related to MyHR.

MyHR is a system undergoing transition and with that has come a rapid update of information available to users. For example, in the short time between the search ending, and this article being written, videos in 13 Aboriginal and Torres Strait Islander languages were added to the MyHR information website and the YouTube site (Australian Digital Health Agency, 2018a). Additional information has also been added about changes in opt-out period (Australian Digital Health Agency, 2018c). The responsiveness that the ADHA has demonstrated during this period of transition could be applied to addressing the gaps in information and usability identified in this article and the provision of information targeting people at risk of low health literacy, including people with disability and/or mental health conditions. This period of transition could provide an opportunity for changes to information and usability which improve access to, and better support decision making around, MyHR. At this critical time in the evolution of MyHR and its use in Australia, NGOs and consumer advocacy groups or peak bodies could also do more to increase the provision of information about MyHR on their websites and to ensure their target audiences include people at risk of low health literacy.

Limitations and directions for further research

As a search and analysis of an evolving system at a period of transition, the data collected in this cross-sectional study were limited and can only be considered a snapshot in time, so should be interpreted with caution. Through repeating the content analysis and heuristic evaluation, we aim to document changes over time and also establish a method for ongoing monitoring and evaluation of MyHR and other similar portals in the future. The authors acknowledge that while the MyHR website is a primary, authoritative and credible source of information about MyHR online, it and the other sources included in this research are not the only sources of information about MyHR and that a variety of other information sources of varying degrees of authority, credibility and trustworthiness exist in mainstream and social media (e.g. Palmer and Hemsley, 2018). While including such sources was beyond the aim or scope of this study, future research could examine both mainstream (e.g. televised) and social media (e.g. YouTube, Twitter and Facebook) publications for their information quality and accessibility to populations at risk of low health literacy. Considering that only three healthcare consumers who were not at risk of low health literacy evaluated the usability of MyHR in this study, further research could include a larger number of consumers with diverse healthcare needs and different risk factors for low health literacy (e.g. people with intellectual and developmental disability or communication disability) who potentially benefit by use of MyHR for exchanging information about their health with multiple healthcare providers (Hemsley et al., 2018). Further research could also examine the information aimed at healthcare providers for its coverage on ways for providers to explain the MyHR operations, risks and benefits to populations at risk of low health literacy so that they may make informed decisions about their engagement with the system.

Additionally, as noted in the original research, content analysis and heuristic evaluation methods are an adjunct to but do not replace user testing (Nielsen, 1994). It is essential that user testing is conducted with every new iteration of the information website or the MyHR, including with the many diverse groups at risk of low health literacy in Australia.

Conclusion

In this study, we present an analysis of some important aspects of MyHR's information quality and usability at a single point in its evolution. While there has been some improvement in the quality of MyHR health information since 2016 for people at risk of low health literacy, particularly in the areas of information for culturally and linguistically diverse audiences and the development of information by NGOs, gaps in information and issues with usability remain. In addition, the opt-out model potentially presents additional challenges in ensuring people at risk of low health literacy are receiving adequate information about, and support to use, MyHR and are able to make informed decisions about opting in or out of the system.

The ADHA has demonstrated an ability to rapidly respond to changes in legislation and community information needs around MyHR in the lead up to the opt-out deadline. The results and analysis presented here could help guide future changes to MyHR, as well as form part of ongoing monitoring and evaluation of the suitability of MyHR for people with, or at risk of, low health literacy.

Author contributions

LW conducted the search and content analysis, conducted the heuristic evaluation and was a major contributor in writing the manuscript. SH assisted with the search and content analysis and was a major contributor in writing the manuscript. BH was a major contributor in writing the manuscript. MA and MRD conducted the heuristic evaluation and reviewed and commented on multiple drafts of the manuscript. AG, SB, IH and SM reviewed and commented on multiple drafts of the manuscript. All authors read and approved the final manuscript.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Louisa Walsh, BPhysio (Hons), MstratComm https://orcid.org/0000-0001-6712-3011

References

Australian Bureau of Statistics (2016) B.13 Language spoken at home by sex. Available at: http://stat.abs.gov.au/Index.aspx?DataSetCode=ABS_CENSUS2011_B13 (accessed 12 February 2019).

Australian Department of Health and Ageing (2011) Concept of operations: relating to the introduction of a personally controlled electronic health record system, Report. Canberra: Commonwealth of Australia.

Australian Digital Health Agency (2017) My Health Record website redevelopment. Available at: https://marketplace.service.gov.au/digital-marketplace/opportunities/647 (accessed 9 October 2018).

Australian Digital Health Agency (2018a) Information in Aboriginal and Torres Strait Islander languages. Available at: https://www.myhealthrecord.gov.au/information-in-aboriginal-and-torres-strait-islander-languages (accessed 16 October 2018).

Australian Digital Health Agency (2018b) My Health Record opt out date announced. Available at: https://www.myhealthrecord.gov.au/news-and-media/media-releases/my-health-record-opt-out-date-announced (accessed 12 February 2019).

Australian Digital Health Agency (2018c) Opt out of My Health Record. Available at: https://www.myhealthrecord.gov.au/for-you-your-family/opt-out-my-health-record (accessed 26 September 2018).

Australian Digital Health Agency (n.d.) How My Health Record benefits you. Available at: https://www.myhealthrecord.gov.au/for-you-your-family/my-health-record-benefits (accessed 12 February 2019).

Australian Digital Health Agency (n.d.-a) About the agency. Available at: https://www.digitalhealth.gov.au/about-the-agency (accessed 26 September 2018).

Australian Digital Health Agency (n.d.-b) Information in your language. Available at: https://www.myhealthrecord.gov.au/for-you-your-family/howtos/information-in-your-language (accessed 16 October 2018).

Bush RA, Connelly CD, Fuller M, et al. (2015) Implementation of the integrated electronic patient portal in the pediatric population: a systematic review. *Telemedicine and e-Health* 22(2): 144–152.

Community Affairs Legislation Committee (2018) *My Health Records Amendment (Strengthening Privacy) Bill 2018 [Provisions]*. Canberra: Commonwealth of Australia.

Diviani N, van den Putte B, Giani S, et al. (2015) Low health literacy and evaluation of online health information: a systematic review of the literature. *Journal of Medical Internet Research* 17(5): e112.

Duck-Chong L (n.d.) *Navigating My Health Record for trans and gender diverse communites*. Available at: https://www.aconhealth.org.au/navigating_my_health_record_for_trans_and_gender_diverse_communites (accessed 12 December 2018).

Elo S and Kyngäs H (2008) The qualitative content analysis process. *Journal of Advanced Nursing* 62(1): 107.

Flesch R (1979) *How to Write Plain English: A Book for Lawyers and Consumers*. New York: Harper and Row.

Grattan M (2018) Opt-out period for My Health Record extended. The Conversation, 21 November.

Greenhalgh T (2015) Health literacy: towards system level solutions. *British Medical Journal* 350: h1026.

Hanna L, Gill SD, Newstead L, et al. (2016) Patient perspectives on a personally controlled electronic health record used in regional Australia: 'I can be like my own doctor'. *Health Information Management Journal* 46(1): 42–48.

Hemsley B, Georgiou A, Carter R, et al. (2016) Use of the My Health Record by people with communication disability in Australia: a review to inform the design and direction of future research. *Health Information Management Journal* 45(3): 107–115.

Hemsley B, McCarthy S, Adams N, et al. (2018) Legal, ethical, and rights issues in the adoption and use of the "My Health Record" by people with communication disability in Australia. *Journal of Intellectual & Developmental Disability* 43(4): 506–514.

Hepatitis NSW (2018) *My Health Record: information about your options*. Available at: https://www.hep.org.au/my-health-record-information-about-your-options/ (accessed 12 December 2018).

idcommunity (n.d.) *Australia Language spoken at home*. Available at: https://profile.id.com.au/australia/language (accessed 12 February 2019).

Irizarry T, Dabbs AD and Curran CR (2015) Patient portals and patient engagement: a state of the science review. *Journal of Medical Internet Research* 17(6): e148.

Lorenzen B, Melby CE and Earles B (2008) Using principles of health literacy to enhance the informed consent process. *AORN Journal* 88(1): 23–29.

Marton C (2010) How women with mental health conditions evaluate the quality of information on mental health web sites: a qualitative approach. *Journal of Hospital Librarianship* 10(3): 235.

McInnes N and Haglund BJA (2011) Readability of online health information: implications for health literacy. *Informatics for health & social care* 36(4): 173–189.

Ministerial Office of Greg Hunt (2018) My Health Record opt out period extended. Available at: https://www.greghunt.com.au/my-health-record-opt-out-period-extended/ (accessed 10 August 2018).

Monkman H, Griffith J and Kushniruk AW (2015) Evidence-based heuristics for evaluating demands on eHealth literacy and usability in a mobile consumer health application. *Studies in Health Technology and Informatics* 216: 358–362.

Nielsen J (1994) Heuristic evaluation. In: Nielsen J and Mack R (eds) *Usability Inspection Methods*. New York: John Wiley & Sons, pp. 25–62.

Nutbeam D (2008) The evolving concept of health literacy. *Social Science & Medicine* 67(12): 2072–2078.

Otte-Trojel T, de Bont A, Rundall TG, et al. (2016) What do we know about developing patient portals? A systematic literature review. *Journal of the American Medical Informatics Association* 23(e1): e162–e168.

Palmer S and Hemsley B (2018) Analysis of three Twitter hashtags for discussion of personal electronic health records. In: *ECSM 2018: Proceedings of the 5th European Conference on Social Media* (ed Cunnane V and Corcoran N), Reading, UK, 21–22 June 2018, pp.236–245. Reading, UK: Academic Conferences and Publishing International Limited.

Patient Information Forum (n.d.) Patient information toolkit. Available at: https://www.pifonline.org.uk/toolkit (accessed 12 February 2019).

Queensland Council of Social Service (n.d.) My Health Record information. Available at: https://www.qcoss.org.au/my-health-record-information (accessed on 12 December 2018).

Roberts L (2010) Health information and the internet: the 5 Cs website evaluation tool. *British Journal of Nursing* 19(5): 322–325.

Robertson-Dunn B (2018) My Health Record. Available at: https://privacy.org.au/campaigns/myhr/ (accessed on 12 December 2018).

Siggins Miller (2016) *Evaluation of the Participation Trials for the My Health Record*. Australia: Siggins Miller.

US Department of Health and Human Services and Office of Disease Prevention and Health Promotion (2015) *Health Literacy Online: A Guide to Simplifying the User Experience*. 2nd ed. Available at: http://health.gov/healthliteracyonline/ (accessed on 12 February 2019).

Walsh L, Hemsley B, Allan M, et al. (2017a) The e-health literacy demands of Australia's My Health Record: a heuristic evaluation of usability. *Perspectives in Health Information Management* 14(Fall): 1f. PMCID: PMC5653954.

Walsh L, Hill S, Allan M, et al. (2017b) A content analysis of the consumer-facing online information about My Health Record: implications for increasing knowledge and awareness to facilitate uptake and use. *Health Information Management Journal* 47(3): 106–115.

Zahabi M, Kaber DB and Swangnetr M (2015) Usability and safety in electronic medical records interface design: a review of recent literature and guideline formulation. *Human Factors: The Journal of the Human Factors and Ergonomics Society* 57(5): 805–834.