University of Wollongong

Research Online

Faculty of Engineering and Information
Sciences - Papers: Part B

Faculty of Engineering and Information
Sciences

2019

Evaluating the Managing Medicines for People With Dementia Website Version 2

Pippa Burns

University of Wollongong, pippa@uow.edu.au

Judy Mullan

University of Wollongong, jmullan@uow.edu.au

Robyn J. Gillespie

University of Wollongong, robyng@uow.edu.au

Lindsey Harrison

University of Wollongong, lharriso@uow.edu.au

Khin Than Win

University of Wollongong, win@uow.edu.au

See next page for additional authors

Follow this and additional works at: <https://ro.uow.edu.au/eispapers1>

Part of the [Engineering Commons](#), and the [Science and Technology Studies Commons](#)

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

Evaluating the Managing Medicines for People With Dementia Website Version 2

Abstract

The Managing Medicines for People With Dementia version 2 website was developed in three languages, English, Italian, and Macedonian, to assist informal caregivers in the task of managing medications. Medication management is a complex task with potentially high stakes health outcomes, including hospitalization and death. A mixed-methods evaluation was carried out. A survey was available to site users and Web log data were collected over a 3-month period. Subsequently, the quality and suitability of the information and readability and usability of the Web site were evaluated. Focus groups and interviews were conducted with end users from all three language groups. Data collected from the evaluation surveys during the pilot test showed that users were generally satisfied with site usability (77%). The results of the readability testing indicate that future versions could be improved. Feedback from the focus groups and interviews was generally positive. The use of multiple methodologies provided comprehensive testing that is likely to have identified the majority of usability issues. Ways in which the site can be maintained with up-to-date information and be promoted to the target population, informal carers, need to be explored.

Disciplines

Engineering | Science and Technology Studies

Publication Details

Burns, P., Mullan, J., Gillespie, R., Harrison, L., Win, K., Baker, A., Traynor, V., Kostovski, C., Thomas-Lee, R. Jay., Gleeson, H., Horne, F. & Velev, Z. (2019). Evaluating the Managing Medicines for People With Dementia Website Version 2. CIN: Computers, Informatics, Nursing, 37 (1), 47-54.

Authors

Pippa Burns, Judy Mullan, Robyn J. Gillespie, Lindsey Harrison, Khin Than Win, Amanda Ann Baker, Victoria Traynor, Catherine Kostovski, Rhett Jay Thomas-Lee, Holly Gleeson, Frances Horne, and Zoran Velev

Evaluating the *Managing Medicines for People with Dementia Website v2*

Pippa Burns BSc (Hons), MPH (Dist), PhD - (*Corresponding Author*)

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: pippa@uow.edu.au

Judy Mullan BPharm, BA, PhD

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: jmullan@uow.edu.au

Robyn Gillespie BN MPH PhD Candidate

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: robyng@uow.edu.au

Lindsey Harrison BA MSc PhD

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: lharriso@uow.edu.au

Khin Than Win MBBS DCS MSc PhD

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: win@uow.edu.au

Amanda Baker MA PhD

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: abaker@uow.edu.au

Victoria Traynor BSc (Hons), PhD, RGN, PGCHE, ILM,

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia.

Email: vtraynor@uow.edu.au

Catherine Kostovski

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia

Email: ck806@uowmail.edu.au

Rhett Jay Thomas-Lee

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia

Email: rhettthomaslee@uowmail.edu.au

Holly Gleeson

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia

Email: hlg774@uowmail.edu.au

Frances Horne

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia

Email: fmh95@uowmail.edu.au

Zoran Velez

University of Wollongong, Northfields Avenue, Wollongong, NSW 2522, Australia

Email: zv550@uowmail.edu.au

Acknowledgements

The evaluation reported here was funded by a seeding grant from the Global Challenges Program at the University of Wollongong.

Evaluating the Managing Medicines for People with Dementia Website Version 2

ABSTRACT

Introduction

The Managing Medicines for People with Dementia v2 website was developed in three languages: English, Italian and Macedonian, to assist informal caregivers in the task of managing medications. Medication management is a complex task with potentially high stakes health outcomes, including hospitalisation and death.

Methods

A mixed-methods evaluation was carried out. A survey was available to site users and web-log data were collected via Google Analytics, over a three month period. Subsequently, the quality and suitability of the information, readability and usability of the website was evaluated; and focus groups and interviews were conducted with end users from all three language groups.

Results

Data collected from the evaluation surveys, during the pilot, showed that users were generally satisfied with site usability (77%). The results of the readability testing indicate that future versions could be improved. Feedback from the focus groups and interviews was generally positive.

Discussion

The use of multiple methodologies provided comprehensive testing that is likely to have identified the majority of usability issues. Ways in which this site can maintain up-to-date information and be promoted to the target population, informal carers, needs to be explored.

INTRODUCTION

In 2015, it was estimated that 46.8 million people worldwide were living with dementia ¹ and this number is expected to nearly triple to 131.5 million by 2050 ¹. The current prevalence and expected increase in people living with dementia (PLWD) represents a significant concern, making dementia both a national and international health priority ^{2,3}. In many countries, PLWD are cared for by informal caregivers ⁴. In Australia, more than 70% of PLWD reside in the community ⁵ and most of them are cared for in family homes by informal caregivers; their spouse or adult children ⁶. In addition to their many other roles, these informal caregivers often need to understand how to manage their family members' medications appropriately, in order to prevent adverse drug events which may result in hospitalisations ⁷.

Complications with medicine management can easily occur due to the complexity of this task. It involves:

- being informed about what is prescribed
- maintaining continuous supplies of medications
- assisting with administration
- communicating with health care providers and care recipients
- monitoring medication adherence
- watching for medication-related side effects
- granting or refusing consent for medications where the care recipient is no longer able provide consent ^{8,9}.

The complexities of medication management further increase as the care recipient's cognitive abilities deteriorate, as the person no longer has the mental capacity to undertake all of the tasks required to safely manage their medicines ^{10,11}.

Despite these complexities, the role of informal caregivers in medication management remains an under researched topic area. Few studies have looked exclusively at informal caregivers of PLWD^{10–12}, and even fewer studies have looked at the experience of ethnic minority family caregivers^{13,14}. Unfortunately, there is currently little medication management support and information for informal caregivers, especially those from culturally and linguistically diverse backgrounds¹⁵. In an attempt to bridge this gap, a university research group, in partnership with the local health district, collaborated to develop a website, *Managing Medications for People with Dementia* (MMPD site).

Formative research

The original MMPD site was developed based on two years of extensive formative research^{15–17}. In 2012, participants from several ethnic minority groups (including Italian and Macedonian) participated in three focus groups and seven individual one-on-one interviews, which explored the informal caregivers' medication management experiences¹⁵.

Thematic analysis of the transcribed data identified four prominent concerns or issues among carers: 1) medication management was a source of stress for family caregivers; 2) medication management responsibility could be a point of conflict between the carer and the person living with dementia; 3) family support of this care-giving role was considered extremely important; and 4) family caregivers believed that they would benefit from external information and support regarding medication management. These themes were used to guide the development of an online medication management information resource for informal caregivers of PLWD. A pharmacist on the project team ensured that all of the information provided was both current and accurate. This website was the first version of the MMPD site. Health literacy guidelines were utilised to ensure that the information was easy to understand¹⁸. In addition, the content was pre-tested in English, with a small number of informal caregivers and health professionals to ensure clarity and usefulness, prior to having the material translated into Italian. The information, available online both as static written

pages and as audio recordings, was professionally translated by Multicultural Health Services; this service is responsible for ensuring that people from culturally and linguistically diverse backgrounds have access and equity within the public health system. Following this, the resource's content, usefulness, appeal, cultural relevance, readability, presentation, accessibility, credibility was assessed using an adapted version of the 'Quality checklist for reviewing health information' ¹⁹. Evaluation feedback was also sought through informal caregiver support groups. Results from this pre-testing informed the development and deployment of version two of the website, to ensure better content management and also to include material translated into Macedonian. Translations were provided in Italian and Macedonian as these are the most commonly spoken languages, other than English, in the region.²⁰ The website was designed by an external provider, in consultation with the project team. The project team was comprised of a group of cross-disciplinary researchers with backgrounds in: Education – specifically English as a second language; Information Technology; Pharmacy; Medicine; Nursing and Public Health. This paper describes the piloting and user testing of version 2 of the *Managing Medicines for People with Dementia* (MMPD v2 - www.dementiameds.com).

METHODS

The MMPD v2 site went live at the start of June 2015 and was publicised through personal contacts and articles in relevant professional newsletters^{21–24}. The MMPD v2 site underwent a series of evaluation and user testing, which included: a user survey, usability testing, and assessment of readability and quality of information provided. Approval for this study was granted through the University's Human Research Ethics Committee (HE11/436). The following sections outline the various approaches and tools utilised to evaluate the site.

Internet Self-Management Uniform Reporting Framework

The Internet Self-Management Uniform Reporting Framework (iSMURF) was designed as a minimum reporting set to allow the easy reporting of internet interventions supporting self-management of chronic diseases²⁵. The Internet Self-Management Uniform Reporting Framework (iSMURF) has six domains: web site design; support; study design; web site use; user characteristics and reporting outcomes. The iSMURF tool has been used here to capture the specific components of the MMPD v2 evaluation (Figure 1).

Figure 1: The internet Self-Management Uniform Reporting Framework (iSMURF)

Website design	
Technological platform	WordPress
Use of evidence based guidelines in site design	Yes/no – Name of guidelines
Support	
Provision of computer/ technical equipment to participants	No
Provision of technical support	No
Use of clinicians/moderators	No
I. Frequency of contact	N/A
II. Mode of contact e.g. phone, email etc	N/A
Provision of peer support e.g. forums	No
Was intervention incorporated into usual care	N/A
Study design	
Date of study	1 st June 2015
Length of study	31 st August 2015
Recruitment methods	Online/offline
Potential reach of intervention	Open to everyone
Use of incentives	No
Use of reminders	No
Website use (from Google Analytics)	
Engagement	Total number of visits: 3,117
	Returning visitors: 9.7%; n=302
	Most viewed page: Introduction
Exposure	Pages per session: 4.05
	Average viewing time by participants: 2.13 mins
Attrition	Over time e.g. baseline and post intervention as minimum: N/A
User characteristics (from Survey Monkey data)	
Age	55-64 yrs: 41%; n=26
Sex	Female: 84%; n=54
Ethnicity	Spoke English at home: 81%; n=51
Computer confidence/internet experience	5+ yrs: 97%; n=61
Level of education	Tertiary educated: 97%; n=62
Health literacy	Measured using “Confident with Forms” ²⁸ Inadequate health literacy: 7.8%; n=5
Number of co-morbid conditions	N/A
Reporting Outcomes	
Inclusion of costs/ cost effectiveness data	No
Participant satisfaction	Qualitative & quantitative

Google Analytics

Google Analytics (Google, Mountain View, California, USA <https://analytics.google.com/>) was set up to collect web-log data from all visitors to the website during the pilot phase. This included information on: number of site visitors; country of origin; visit duration and the device used by participants.

Survey Monkey Evaluation

An online evaluation survey was available on the site between June and September 2015. Visitors to the website could access the survey through an icon on the bottom left-hand navigation bar. This icon was visible on all site pages. The survey was hosted by SurveyMonkey Inc. (San Mateo, California, USA, www.surveymonkey.com) and contained 26 items which included demographic questions; and a modified version of the Perceived Health Web Site Usability Questionnaire for Older Adults (PHWSUQ) ²⁶. The PHWSUQ comprised of ten questions across three domains: satisfaction, ease of use and usefulness. The third domain, usefulness, had three questions, which were modified to reflect the website content: 'using this website will help me to understand more about managing medicines'; 'using this website helped improve my knowledge about managing medicines'; and 'using this website will help me to look after medicines for a person living with a dementia'. The generic questions were modified in keeping with the findings of previous research ²⁷. The validity and reliability of this tool have been previously reported ²⁶.

User Testing

Summative user testing was undertaken to ensure that the MMPD v2 site met the needs of the end-users. User testing is the process of observing, and learning from end-users as they perform tasks on

a site under development. This is important because even experienced web users become confused on an unfamiliar site by small problems²⁸. User testing is often part of a larger, iterative process, used to create a well-refined product. The software program Morae Recorder (TechSmith, Okemos, Michigan) was used to conduct the user testing. This software records participant's visual, audio and mouse movements.

A convenience sample, of participants who care for someone living with dementia, was recruited. Prior to user testing, participants were asked to complete a short demographic survey, including questions about age, gender, employment status, education levels and experience using the internet. Subsequently, participants were asked to complete five tasks on the MMPD v2 site to ensure different aspects of the usability of the website usability were evaluated (Figure 2). A think-aloud method was utilised with participants to understand their thought processes, personal opinions and reactions whilst completing each task. The two researchers who undertook the user testing did not engage or help the participants unless the participant became very frustrated. Both researchers wrote field notes based on their own observations after each testing session.

Figure 2: Usability Tasks

Task	
Task 1	Please change the language settings from English to Italian. Once completed please change the language settings back to English?
Task 2	Locate the "Site Map" for the Website. Once located, please navigate to the page titled "Generic Medicines"?
Task 3	Please find the phone number for the Independent Living Centres, located on the website?
Task 4	Please find the area where you can subscribe for email updates about "Managing Medicine For People With Dementia"?
Task 5	Name aloud one benefit of the Blister Pack medicine system?

Focus Groups and Interviews

The usefulness of the website was evaluated qualitatively, with caregivers from English, Macedonian and Italian speaking backgrounds. Participants were recruited through advertising in local community facilities (e.g. libraries), and via word-of-mouth. Focus group discussions were held with both English (three focus groups; n=16) and Italian speaking caregivers (one focus group; n=6), while individual interviews were conducted with Macedonian caregivers (n=9). Interviews were conducted with the Macedonian participants as it proved hard to recruit interested participants within a confined geographic location. Participants were asked to share their viewpoint on the suitability, presentation, understandability, accessibility and credibility of content and were invited to suggest improvements or additions to the site. Italian and Macedonian participants were also asked to comment on the suitability of the in-language versions, including the written and audio versions.

Quality and Suitability of Information

Three website rating tools were used to assess the MMPD v2 site for accessibility, quality and reliability.

Suitability Assessment of Materials³⁰ assessed six areas: content, literacy demand, graphics, layout and type, learning stimulation and motivation and cultural appropriateness. For each factor, the materials were categorised by the researchers and rated as not suitable (0), adequate (1) and superior (2) based on the objective criteria.

Health-Related Web Site Evaluation Form³¹ has 36 questions, under the headings of: content, accuracy, author, currency, audience, navigation, external links and structure. Each criteria was defined as poor (<75%), adequate (75% - 89%) or excellent (>90%).

Health on the Net³² provides a code of ethics for medical and health information on the internet.

The HONcode has eight principles: authority, complementary, confidentiality, attribution, justification, transparency, financial disclosure and advertising. The HONcode Evaluation Checklist consisted of fifteen items, across eight principles.

Evaluation of Readability Levels

The readability levels of the English content of the MMPD v2 site was evaluated by the researchers using four readability level tools: Flesch Kincaid, Gunning Fog, Simple Measure of Gobbledygook (SMOG) and Dale-Chall. Four measures were used to ensure a comprehensive evaluation because not all readability tools assess the same criteria.

The readability of the Italian information was evaluated using the Italian Read-IT Dylan Text Tools³³ and the Italian Translated Readability Analyser³⁴. The researchers were unable to locate a tool to evaluate readability in Macedonian. Text from each page of the website was copied and pasted into an appropriate tool, which provided the readability scores. All the identified tools are widely available, quick and easy to administer

RESULTS

This section provides a summary of the results obtained from each test and evaluation.

Google Analytics

During the pilot web-log data were collected through Google Analytics. There were 12,616 page views across 3,117 sessions. Approximately 10% of these visits were attributed to return visitors

(n=302). The average visitor viewed 4.05 pages and stayed on the site for 2.13 min. While the majority of site visitors came from Australia (n=1,155; 37.05%), there were also visitors from other countries, including the USA (n=622; 20%), China (n=124; 4%), Japan (n=66; 2%) and South Korea (n=52; 2%), the UK (n=50) and Italy (n=34). The majority of visitors accessed the site through a desktop computer (94%; n=2,928) using the internet browser Chrome (67%; n=2,082).

Survey Monkey Evaluation

The online evaluation survey was completed by 70 site users; however, as respondents were not required to complete every question, individual response rates for questions varied. Most participants were between 45 and 64 years old (77%; n=49), female (84%; n=54), employed either full-time (67%; n=43) or part-time (22%; n=14), had completed tertiary studies (97%; n=62), and lived in Australia (100%; n=64). The respondents were mainly service providers and not informal carers of someone living with dementia.

The majority of participants were experienced internet users, having used the internet for more than five years (97%; n=61), rated themselves as “very comfortable” using the internet (73%; n=46), and used the internet or email for more than 15 hours each week (60%; n=38).

The majority found the information on the website trustworthy (94%; n=61). Nearly one-fifth of the sample spoke a language other than English at home (19%; n=12) and most of these participants felt that the information on the website would be useful to people from their cultural background (97%; n=62).

The total mean-converted score for the usability questionnaire (PHWSUQ) was 77% (Table 1).

Ranking of individual domains were similar, with ‘satisfaction’ scoring highest (78%) and ‘usefulness’ scoring lowest (76%).

Table 1: Perceived Health Website Usability Questionnaire Total and Subscale Mean Scores

	Range	Mean (SD)	Mean * Converted
Satisfaction	5 – 35	27.3 (7.15)	78%
Ease of Use	3 – 21	16.1 (3.73)	77%
Usefulness	3 – 21	15.9 (4.73)	76%
Total	11 - 77	59.2 (13.42)	77%

* Mean value/highest possible score x 100 = total percent

User Testing

A convenience sample of ten participants (age range: 26 - 79 years; mean age 51.8 years) completed the user testing which is a sufficient number to detect 85% of usability problems³⁵. Participants were informal carers of people diagnosed with a dementia; all spoke English at home; the majority were born in Australia (90%); and four were male (40%). Nine participants had used the internet for more than five years and just over half the participants reported using the internet more than 10-15 hours a week (60%). All participants were willing to be recorded during the user testing process.

The first task required the language settings on the website to be changed, which was only successfully completed by 60% of participants. The second task required participants to locate the site map, and then navigate to the page titles 'Generic Medications'. This task was completed by 90% of participants, all within a relatively short time. Task 3 required participants to use the 'Site Map' or 'About Us' pages to try and find a contact number. This task was only completed by two participants, giving the task a total successful completion rate of 20%. For Task 4, most participants (90%) were unable to locate where to subscribe for email updates. The final task – 'name one benefit of the Blister Pack medicine system?' had a 50% completion rate.

It should be noted that numerous variables affected task completion time, and no doubt impacted the successful completion of the tasks. These variables included the presence of children, phones

ringing, and the telling of personal stories. One participant failed to successfully complete any of the tasks. It was noticeable that participants who reported over 10 hours of internet usage per week were more successful in completing the tasks.

User Testing was facilitated by use of dedicated software which recorded each session. However, the software appears as a pop-up window, on top of the website and this confused some participants. Future research using this software should include a short task prior to beginning the user testing to help overcome this confusion. Further, the research was undertaken on the researchers' computers which the participants were not familiar with. This may have hindered their ability and confidence in performing the set tasks.

Focus Groups and Interviews

A number of focus groups and interviews were conducted with carers from diverse backgrounds: English (three focus groups; n=16; females=15/94%), Italian (one focus group; n=6; females=5/83%) and Macedonian (nine interviews; females=2/22%). Data from the interviews and focus groups were combined and analysed, in response to the question prompts.

Participants found the site content to be useful and comprehensive. Experienced informal caregivers stated they knew most of the information already but thought that new caregivers would benefit from the content. They also reported that people in the early stages of dementia could use the site to maintain independence.

- ❖ *“Look, it’s great, I think that it will be useful for the older generation, and especially the Macedonian community...”* (Macedonian language group)

- ❖ *“This is extremely useful for people that haven’t been through it (looking after a PLWD)) and don’t know it (how to deal with it), (the resource) has got good points and good information, it is extremely useful.”* (Macedonian language group)
- ❖ *“Content is familiar to us as experienced caregivers, we knew it all, but it would be very helpful for new carers. Some things were new however like the crushing tool so we can find out about that now when the time comes.”* (Italian language group)

Several participants commended that the font size, contrast and the use of ‘plain language’, aided their reading and understanding. Participants suggested using images showing greater diversity with regards to gender, age and cultural differences.

- ❖ *“And more visual I don’t think [there] is enough visuals, I don’t think [there] is enough graphics, like pictures, or even like cartoonish sort of things explaining a little bit more than words.”* (Macedonian language group)
- ❖ *“People seem to be getting younger and younger developing it [dementia]... So I feel that slanting a picture like that is assuming that you have to be old to get dementia...”* (English language group)

Overall, participants from an English speaking background found the language and wording of the website clear, succinct and acceptable but some participants commented that the content was repetitive and that the site contained too much information.

- ❖ *“There’s plenty of details there; I probably think that we need to sort of cut it down a little bit, well people with, people that are looking after people with dementia or sufferers I think that they need something that is clear and short.”* (Macedonian language group)
- ❖ *“I found that it was really good plain English, and because you know I have always been aware of vision problems,... audio is just fantastic, a big tick in my eyes....”* (English language group)

There were mixed responses regarding the understandability of the Italian and Macedonian text and audio information. Younger, second generation caregivers found the Italian hard to understand or spoke a different dialect so were not familiar with some words used.

- ❖ *“The Italian was hard with the long words.”* (Italian language group)
- ❖ *“I’m from Calabria so I couldn’t understand half the words (in Italian) but I could follow it in the English so it was ok.”* (Italian language group)

Older participants, however, liked the translations and could understand it easily. They pointed out that many older Italian women, especially those from the south of Italy, did not attend school so cannot read or write. They felt the audio version would be helpful for these groups.

Macedonian participants mostly found the translation to be too formal and suggested the language be amended to reflect a more colloquial style to improve understanding.

- ❖ *“Just what I said before the way is written and formatted, maybe a little bit clearer, more dot points, and I think a lot less jargon.”* (Macedonian language group)

- ❖ *“For me, because of that very literal Macedonian translation was very difficult to understand, but I did understand it but took some thinking about what was being said.”* (Macedonian language group)

Italian and Macedonian participants were concerned that, in the current online format older people would not be able to access the site as they did not know how to use computers or access the internet.

- ❖ *“Not sure how well used the resource will be for the older carers who I suspect may not be well versed in using this sort of media however I think having things online is the way to go in the future.”* (Italian language group).

Macedonian caregivers also wondered how caregivers would find out about the site. Additionally they were concerned that the ongoing stigma around dementia would result in few Macedonian people accessing the site. English speaking participants suggested an app version be developed for use on mobile devices to increase accessibility.

- ❖ *“I was wondering about an app because so many people are on their smart phones everywhere they go...”* (English language group)

Quality and Suitability of Information

Analysis by researchers of the MMPD v2 site for quality and suitability of information, found it to be both very reliable and provide superior materials (Table 2). Some minor discrepancies in site design

were identified through the review process. This included the following missing items: date the website was created, date the page was updated, contact information and some missing developers credentials.

Evaluation of Readability Levels

The results of readability levels ranged from grade six to college level (Table 2).

Table 2: Readability Scores and Evaluation Scores and Ratings of the *Managing Medicines for People with Dementia v.2*

	Score	Interpretation
Readability Tools - English		
Flesch Kincaid	8.7	Grade 8 level
Gunning Fog	15.4	College junior level
Simple Measure of Gobbledygook (SMOG)	20.9	Grade 8 level
Dale-Chall	6.8	Grade 7/8 level
Flesch Kincaid Reading Ease	44.0	College level
Readability Tools - Italian		
Italian Read-It	59.4	Difficult to read for those with middle school education
Italian Translated Readability Analyser	Average	Scale ranges from easy – average - hard
Evaluation Tools		
Health-Related Web Site Evaluation Form	93%	>90% Excellent 75-89% Adequate <75% Poor
Suitability Assessment of Materials (SAM)	Superior	70-100% Superior 40-60% Adequate 0-39% Not Adequate
Health on the Net Foundation Checklist (HONcode)	Very Reliable	Very Reliable Reliable Unreliable

DISCUSSION

Data collected from the evaluation surveys during the pilot showed that site users were generally satisfied with the MMPD v2 site. While respondents were primarily service providers their feedback is valid as they are likely to refer carers to support tools that they themselves find useful. Findings from the focus groups and interviews were also generally positive. After careful consideration of all of the results obtained through the evaluation process, it is recommended that the following changes should be considered and addressed where possible:

- inclusion of a search tool;
- use of larger navigation icons;
- use of subheadings;
- a dedicated contact page;
- use of more diverse images;
- addition of the date the page was last updated;
- information on the site authors;
- improving readability through reducing the use of long sentences;
- review of Italian and Macedonian translations

The low readability results are consistent with other research looking at health and educational materials on dementia which found that most are written at high reading levels ^{36–39}. Research shows there is increasing concern about the inconsistency between scores when evaluating the same text using different readability tools ^{38,40}. This problem is compounded by different formulas based on syllables, words and sentences. In addition, font size, font type, illustrations, and pictures, as well as word length and sentences also influence readability levels ^{36,37}. Inevitably, some of the medical terms, such as ‘Alzheimer’s’, will have affected the readability scores. Although the

readability levels were relatively high it is worth noting that audio versions of the information are available in each language, making the information more accessible to people with limited literacy.

The use of multiple methodologies provided comprehensive site testing that is likely to have identified the majority of usability issues. While convenience samples were frequently used, which would normally limit generalisability, it is likely that the number of different evaluations conducted will have ensured that the majority of issues were picked up. Ideally, these methods would have been employed sequentially, with the user testing being conducted prior to site evaluation. However, their use here reflects research in a real world setting with tight deadlines and limited available funding.

Many of the evaluation tools employed throughout the testing are freely available and easy to deploy. For instance, Google Analytics was easy to set up and provided information pertaining to site usage during the pilot period and provided some understanding of user characteristics. Similarly the readability tools are all freely available online.

Participants from both the Italian focus group and Macedonian interviews raised a few concerns about the translation of the materials. This was unexpected as all translations had been undertaken by professional interpreters employed by the local health service and thus warrants further investigation. It is possible that the interpreters used a more formal form of the languages, more characteristic of older generations, than what the younger participants were accustomed to.

Once the recommendations put forward here have been addressed, it is suggested that the future sustainability and promotion of the site needs to be explored. Future iterations of the MMPD site should seek to include materials in other prevalent community languages. It is most likely that this will only be successfully achieved through partnership with other national and international organisations. Finally, the need and appropriateness of providing this information on a mobile app platform, for this audience, should be explored.

CONCLUSION

This paper reported the findings from an evaluation process, which was operationalised to assess the MMPD v2 site. The evaluation methods used in this study explored both the information content, usability and website design features of the site. The use of multiple methodologies provided robust testing that is likely to have identified not only the majority of usability issues but also the strengths of this web-based information platform. Addressing the issues identified by the analytical tools will serve to enhance the accessibility of a website designed to ensure that carers from diverse backgrounds receive appropriate information and support to care for their family members. This innovative use of multiple methodologies provides an assessment template that can be used to evaluate the design of future health care-related websites, including those intending to reach people from non-English speaking backgrounds.

This process has demonstrated the feasibility and usefulness of providing an online information resource for informal caregivers of PLWD, including those from diverse backgrounds. Similar resources could be developed using the same process, to address other identified needs of carers such as decision aids regarding driving with dementia.

REFERENCES

1. Prince M, Wimo A, Guerchet M, Gemma-Claire A, Wu Y-T, Prina M. *World Alzheimer Report 2015: The Global Impact of Dementia - An Analysis of Prevalence, Incidence, Cost and Trends.*; 2015. doi:10.1111/j.0963-7214.2004.00293.x.
2. Australian Institute of Health and Welfare (AIHW). Dementia. Ageing, disability & carers,. <http://www.aihw.gov.au/dementia/>. Published 2016. Accessed December 5, 2016.
3. World Health Organization. Dementia: a public health priority. *Dementia*. 2012;112. doi:978 92 4 156445 8.
4. World Health Organisation. Supporting Informal Caregivers of People Living With Dementia Supporting Informal Caregivers of People Living. 2015:1-4.
5. Australian Institute of Health and Welfare. *Dementia in Australia. Cat. No. AGE 70*. Canberra; 2012.
6. Australian Institute of Health and Welfare. *Australia's Health 2012*. Australia'. Canberra, ACT: AIHW; 2012.
7. Arlt S, Lindner R, Roesler A, von Renteln-Kruse W, Rosler A, von Renteln-Kruse W. Adherence to medication in patients with dementia: predictors and strategies for improvement. *Drugs and Aging*. 2008;25(12):1033-1047.
<http://elib.tcd.ie/login?url=http://search.proquest.com/professional/docview/616895557?accountid=14404%25Cnhttp://linksource.ebsco.com/linking.aspx?sid=ProQ%253Aipab&fmt=journal&genre=unknown&issn=1170229X&volume=25&issue=12&date=2008-01-01&spage=1033&ti>.
8. Smith F, Francis S, Gray N, Denham M, Graffy J. A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services. *Health Soc Care Community*. 2003;11(2):138-145.
<http://www.ncbi.nlm.nih.gov/pubmed/14629216>.
9. Brodaty H, Green A. Defining the Role of the Caregiver in Alzheimer ' s Disease Treatment.

- 2002;19(12):891-898.
10. Cotrell V, Wild K, Ms TB, Cotrell V. Medication Management and Adherence Among Cognitively Impaired Older Adults Medication Management and Adherence Among Cognitively Impaired Older Adults. *J Gerontol Soc Work*. 2015;4372(3-4):31-46. doi:10.1300/J083v47n03.
 11. Kaasalainen S, Dolovich L, Papaioannou A, et al. The process of medication management for older adults with dementia. *J Nurs Healthc Chronic Illn*. 2011;3(4):407-418. doi:10.1111/j.1752-9824.2011.01114.x.
 12. While C, Duane F, Beanland C, Koch S. Medication management: The perspectives of people with dementia and family carers. *Dementia*. 2013;12(6):734-750. doi:10.1177/1471301212444056.
 13. Cultural and Indigenous Research Centre Australia (CIRCA). *CALD Dementia Strategic Model: Literature Review, Report, Model*. Sydney, Australia; 2008.
 14. Gillespie RJ, Mullan JR, Harrison L. Developing a Medication Management Resource for Ethnic Minority Informal Caregivers of People Living with Dementia. In: Emerging Researchers in Ageing, ed. *Enabling Active Ageing - The 12th National Conference of Emerging Researchers in Ageing*,. Sydney, Australia; 2013:83-87. <http://www.era.edu.au/ERA+2013>.
 15. Gillespie R, Harrison L, Mullan J. Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia*. 2013;14(1):47-62. doi:10.1177/1471301213488900.
 16. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *J Clin Nurs*. 2013;23:3296-3308. doi:10.1111/jocn.12519.
 17. Mullan J, Gillespie R. Developing a medication management information guide for ethnic minority family caregivers of people living with dementia. 2013.
 18. U.S. Department of Health and Human Services. *Simply Put: A Guide to Creating Easy-to-*

- Understand Materials*. Atlanta, Georgia; 2009.
19. Government of South Australia. *Evaluating Health Information with Consumers. Sample Questions for Consumers. Children.*; 2006.
 20. Wollongong City Council. Language spoken at home - Ranked by size. Wollongong City. <https://profile.id.com.au/wollongong/language>. Published 2016. Accessed May 23, 2018.
 21. Primary Health Care Research and Information Service. Managing your medicines when you're living with a dementia - website evaluation. This Week in PHC. <http://www.phcris.org.au/news/community-notice/item.php?id=16373&spindex=5&promoid=771&mid=39&style=twiphc&linkid=51637>. Published 2015. Accessed May 31, 2016.
 22. World's First Medication Management Website. *Aust J Dement Care*. 2015:5.
 23. Gillespie R. Managing Medicine for People with Dementia. intouch. https://issuu.com/intouch_phaa2015/docs/150730_august_intouch_2015. Published 2015. Accessed May 31, 2016.
 24. Illawarra Health and Medical Research Institute. Managing medication when you have dementia. *Res Matters*. 2015:13. <http://ihmri.uow.edu.au/content/groups/public/@web/@ihmri/documents/doc/uow199730.pdf>.
 25. Burns P, Jones S, Iverson D, Caputi P. Internet Self-Management Uniform Reporting Framework: the need for uniform reporting criteria when reporting Internet interventions. *Comput Informatics, Nurs*. 2013;31(11):554-565. doi:10.1097/01.NCN.0000432129.84397.a8.
 26. Nahm E-S, Resnick B, Mills ME. Development and pilot-testing of the perceived health web site usability questionnaire (PHWSUQ) for older adults. In: Park HA, Murray P, Delaney C, eds. *Consumer-Centred Computer-Supported Care for Healthy People: Proceedings of NI2006*. Lansdale, PA, USA: IOS Press; 2006:38-44.
 27. Burns P, Jones S, Iverson D, Caputi P. Usability testing of AsthmaWise with Older Adults.

- Comput Informatics Nurs.* 2013;31(5):219-226.
28. Barnum CM. *Usability Testing Essentials: Ready, Set ... Test!* Burlington, MA, USA: Elsevier Inc.; 2011.
 29. Chew L, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med.* 2008;23(5):561-566. doi:10.1007/s11606-008-0520-5.
 30. Doak CC, Doak LG, Root JH. SAM: Suitability assessment of materials for evaluation of health-related information for adults. *Teach Patients with Low Lit Ski.* 1996:1-2.
 31. Teach L. Health-Related Website Evaluation Form. <http://terpconnect.umd.edu/~kbedon/webeval3.html>. Published 1998. Accessed May 31, 2016.
 32. The Health on the Net Foundation. HON. <http://www.hon.ch/HONcode/Conduct.html>. Published 2017. Accessed June 20, 2017.
 33. Orletta FD, Montemagni S, Venturi G, et al. READ – IT : Assessing Readability of Italian Texts with a View to Text Simplification. 2011:73-83.
 34. Translated Net Labs. Readability analyser: Italian. <http://labs.translated.net/text-readability/>. Published 2015. Accessed March 9, 2016.
 35. Nielsen J. Usability testing with five users. <http://www.useit.com/alertbox/20000319.html>. Published 2000. Accessed March 1, 2012.
 36. Walsh TM, Volsko T a. Readability assessment of internet-based consumer health information. *Respir Care.* 2008;53(10):1310-1315.
 37. Weih M, Reinhold A, Klein H, Kornhuber J. Unsuitable readability levels of patient information pertaining to dementia and related diseases : a comparative analysis. 2008;(june):1116-1123. doi:10.1017/S1041610208007576.
 38. Sabharwal S, Mbbs SB. Readability of Online Patient Education Materials From the AAOS Web Site. 2008:1245-1250. doi:10.1007/s11999-008-0193-8.

39. Keselman A, Logan R, Arnott Smith C, Leroy G, Zeng-Treitler Q. Developing informatics tools and strategies for consumer-centred health communication. *J Am Med Informatics Assoc.* 2008;15(4):473-483. doi:10.1197/jamia.M2744.Introduction.
40. Shedlosky-Shoemaker R, Sturm AC, Saleem M, Kelly KM. Tools for assessing readability and quality of health-related web sites. *J Genet Couns.* 2009;18(1):49-59. doi:10.1007/s10897-008-9181-0.