

# BMJ Open Partnering with consumers to develop and evaluate a Vietnamese Dementia Talking-Book to support low health literacy: a qualitative study incorporating codesign and participatory action research

Dianne Goeman,<sup>1</sup> J Michael,<sup>1</sup> J King,<sup>1</sup> Huy Luu,<sup>2</sup> Claire Emmanuel,<sup>3</sup> S Koch<sup>1</sup>

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<sup>1</sup>RDNS Institute, Royal District Nursing Service Ltd, StKilda, Victoria, Australia

<sup>2</sup>Australian Vietnamese Women's Association, Richmond, Victoria, Australia

<sup>3</sup>Alzheimer's Australia Victoria, Parkville, Victoria, Australia

#### Correspondence to

Dr Dianne Goeman;  
dgoeman@rdns.com.au

#### ABSTRACT

**Objective:** The aim of the Vietnamese Dementia talking-book was to address low health literacy in older people of Vietnamese background living with dementia through the provision of an online resource to help individuals, their families and carers better understand and manage this condition and provide information about available dementia services.

**Design:** This qualitative study used codesign and participatory action research to develop and refine the talking-book in consultation with expert stakeholders, a consumer advocacy group and the Vietnamese community to assess its utility and ensure cultural and linguistic appropriateness and relevance.

**Participants:** 59 members of the Vietnamese community, 11 stakeholders from community health services and ethnic agencies, consumer advocacy groups and the research team participated in the codesign and refinement of the talking-book. 22 members of the Vietnamese community appraised the final product.

**Setting:** Vietnamese community planned activity groups in the Western, Northern and Southern suburbs of Melbourne, Australia.

**Results:** Our codesign study outlines the process required to develop a Vietnamese Dementia Talking-Book resource partnering with consumers and expert stakeholders to identify consumer need, selection of the content and appropriate language level, construction of the book, measuring acceptability of the talking-book, modification based on feedback and production and dissemination. Feedback on the final version of the talking-book revealed widespread consensus that the book enhanced the knowledge of members of the Vietnamese community in regard to understanding dementia and navigation and accessing of available services.

**Conclusions:** This free internationally available online Vietnamese Dementia Talking-Book facilitates improved dementia-related health literacy in the Vietnamese community. The book also serves as a tool to facilitate the provision of care to Vietnamese people living with

#### Strengths and limitations of this study

- Codesign and participatory action research principles ensured that the talking-book was user-friendly, relevant and culturally appropriate.
- This is the first online resource to provide members of the Vietnamese community with greater access to information about living with memory loss. Additionally, we have created a free nationally and internationally available online tool for Vietnamese people with dementia, their carers, family members and health professionals.
- The easy to access online Vietnamese Dementia Talking-Book provides an opportunity to build a positive professional relationship that will develop a culturally safe environment for the client, their family and carers. This increase in understanding of personal circumstances and needs enables the introduction and tailoring of services or care plans that may help address any concerns.
- Older migrants are less likely to use online information and communication technology; however, this barrier can be overcome through arranging for the hard copy bi-lingual versions of the content of the Vietnamese Dementia Talking-Book to be made available in local municipal libraries with high Vietnamese populations.

memory loss by assisting health professional staff to develop relationships with Vietnamese clients, their families and carers in a culturally appropriate manner.

#### INTRODUCTION

Older people from culturally and linguistically diverse (CALD) backgrounds are at higher risk of experiencing a health crisis.<sup>1 2</sup> Diagnosis of dementia in CALD communities

occurs mainly in the later stages of the disease, and contact with health professionals and access to dementia services usually happens at crisis point.<sup>2-4</sup> Although language is a primary barrier<sup>5</sup> issues affecting seeking assistance earlier include having little knowledge about the symptoms and care of people with dementia, where to seek help and stigma.<sup>6</sup> Factors affecting the uptake of dementia support services include lack of English, social isolation and access to culturally specific information and/or care.<sup>5</sup>

The Australian Vietnamese community is very diverse. To provide person-centred care to people of Vietnamese background, we need to understand the range of diversity characteristics that may be affecting on an individual to participate in their care.<sup>7</sup> After the war in Vietnam in 1975, many Vietnamese people fled their home country and sought refugee status in Australia. The migration of Vietnamese people to Australia again dramatically increased in the 1990s with the implementation of the Vietnamese Family Migration Programme. In 2015, the Australian Bureau of Statistics reported 223 180 (1.0%) of the Australian population were Vietnamese-born.<sup>8</sup> This represents the fifth largest migrant community in Australia.<sup>8</sup> Thirty-eight per cent (84 320) of this population were above 50 years of age<sup>8</sup> and 56% did not speak English well or not at all and due to living in a country at war often had no formal schooling in their own language.<sup>9</sup>

Health literacy refers to the characteristics and social resources needed for people to access, understand and use information to make decisions about health.<sup>10 11</sup> It also includes health professionals capacity to communicate and affect the way people access, understand and appraise health-related information and services.<sup>11-14</sup> New technologies have changed the way health information is disseminated by facilitating the promotion of health communication and self-management, the exchange of information and continuity of care beyond the face-to-face visit<sup>15</sup> leading to an increasing responsibility on individuals to acquire and use information to manage their health. Subsequently, there has been an increase in the number of new technologies; however, little research has assessed how individuals with limited health literacy interact with these new technologies.<sup>16</sup> To address the low literacy in older people of Vietnamese background living with cognitive impairment and provide an intergenerational tool that could be accessed through the internet, we developed an online Vietnamese Dementia 'talking-book' that covered aspects of dementia using simple information sheets and easy-to-understand, non-technical terminology. A 'talking-book' is a bi-lingual, multiple-media tool that can be viewed on a computer and accessed online. The talking-book can be used by an individual and/or their carer and families and as a teaching and learning resource to support health professional staff to provide health and care management education to Vietnamese clients. There is a choice of reading the information

on-screen or listening to it. Listening to the information especially benefits older Vietnamese people with reading and literacy difficulties. This paper reports on the development of the 'talking-book' tool and its acceptability to the Vietnamese community.

## METHODS

### Design

The theoretical basis of the development of the talking-book followed a codesign<sup>17</sup> Participatory Action Research (PAR) methodology to select content and language, refine content and to evaluate the acceptability and utility of the Vietnamese Dementia talking-book.<sup>18</sup> PAR is based on an iterative process that provides opportunity for communities to contribute to the research process by assisting researchers to gain an understanding of their lived experience and identifying and addressing the issues they face.<sup>18</sup> The talking-book was developed using existing help sheets developed by Alzheimer's Australia Vic (AAV). An appraisal of the content was undertaken in collaboration with expert stakeholders, AAV and the Australian Vietnamese Women's Association (AVWA). After translation the content of the talking-book was again presented to the advisory group and to Vietnamese community members to ensure that it was culturally appropriate and met the needs of the Vietnamese community.

RDNS Translation Standards guided the process on the cultural and linguistic appropriateness of the content of the talking-book.<sup>19</sup> The 10 components of the standards include:

- ▶ Develop the English text and/or text in consultation with the target community;
- ▶ Undertake a cultural and linguistic assessment of the English text prior to translation;
- ▶ Undertake a subject matter assessment of the English text as appropriate;
- ▶ Organise for the English text to be translated by a professional translator;
- ▶ Undertake a cultural and linguistic assessment of the translation (community consultation);
- ▶ Organise for the translation to be proofread by a professional translator;
- ▶ Include the title of the text in English on the translation;
- ▶ Include the name of the target language in English, on the English text and translation;
- ▶ Disseminate the translation in bilingual format (English and Vietnamese);
- ▶ Monitor, evaluate and update the English text and the translation as part of an ongoing review programme.

### Study setting

The study was conducted in Western, Northern and Southern suburbs of Melbourne, Victoria, Australia. We consulted with members of the AVWA and Springvale

Indochinese Mutual Assistance Association (SICMAA) Vietnamese seniors groups from both of these areas.

### Participants

A convenience sample of people who originated from Northern, Central and Southern areas of Vietnam and stakeholders from different sectors (Four Vietnamese Community Groups, a Dementia Consumer Advocacy Group and Home Nursing Service provider staff) participated in providing insight into understanding issues faced by Vietnamese people experiencing memory problems, their literacy levels, cultural beliefs and any stigma associated with dementia in the development phase of the talking-book. Members of the research team approached potential participants using community networks, telephone and face-to-face contact. Participant groups were again involved in the evaluation phase of the final product.

### Data collection

There were two main phases involved in the development of the talking-book. Selection and assessment of the English content and grade reading level prior to translation and production and then an evaluation of the finished product. Community consultation using focus groups to gain feedback on the content of the talking-book occurred in phase I. In phase II interviews and focus groups were used to evaluate the acceptability and utility of the final product. A semistructured interview guide was used to explore participants' experience of using the talking-book; whether it had assisted them; how the information was presented, how easy or difficult was it to use/access, if the information on dementia was useful and suggested changes.

#### Phase I

The purpose of phase I was to consult with the Vietnamese community in regard to the language and cultural appropriateness of the content selected for inclusion in the dementia talking-book. Focus groups were undertaken with two community groups to generate feedback on what aspects of the book needed modification. Interpreters were used to facilitate communication and two note takers, one English and one Vietnamese, recorded all feedback from the group on specifically designed information sheets.

#### Phase II

The purpose of phase II was to evaluate the acceptability and utility of the final version of the talking-book. An interview guide was used to promote discussion on the talking-book in regard to: language, content and structure, experience with using the book, ease of access and if it led to an increase in knowledge. Interviews or focus groups were undertaken with Vietnamese community members to explore their experience of using the talking-book and what aspects could be improved. Interpreters were used to facilitate communication.

Participants were selected from client records of a large home nursing organisation and from a large Vietnamese community activity group. Interviews and focus groups lasted between 30 and 60 min.

### Data analysis

Interviews were audio-recorded, transcribed, checked for accuracy and then imported into the NVivo10 qualitative software package (NVIVO10 Qualitative Software, Solutions and Research, Doncaster, Victoria, Australia.) to aid thematic analysis.<sup>20</sup> Coding of the data started with descriptive and topic codes, followed by identification of themes. The team met to ensure that there was agreement on the themes and all interpretations of the data were included. Interviews continued until data saturation was reached, that is, the point when no new themes are identified.

A descriptive analysis of participant demographics was undertaken using SPSS V.21 (IBM).

### Ethics approval

Ethics approval to conduct the study was obtained from the RDNS Human Research Ethics Committee (Project 155). Written informed consent was obtained from all study participants. Interpreters were used to facilitate this process.

## RESULTS

### Participants—phase I: development of the Vietnamese Dementia Talking-Book

The research team, members of the AAV the peak consumer advocacy body for dementia education advisory group and an expert Vietnamese linguist formed a working group to facilitate the selection of appropriate English content and its simplification to aid the translation of the final content into Vietnamese. Pre-translation assessments were undertaken by the AAV Learning and Development Advisory Group, the AAV cultural advisor and Vietnamese service providers to ensure that the information was culturally appropriate, non-offensive and covered topics that were important and relevant to the Vietnamese community in Australia and that the information was current and contact information accurate. Results from these assessments were that the standard of the information was very high and the working group was commended on having such a great outcome.

Overall the written material embraces AAVs philosophy and uses correct terminology that is, follows the person centred approach and encourages respect and dignity. (Learning and Development Advisory Group—AAV)

The content was then translated into Vietnamese by a professional translation company and presented to the Vietnamese community for consultation. The community consultations took place in December 2014 and January 2015. Fifty-nine participants (54 females and 5 males) ranging in age from 65 to 94 years with an

average age of 74 years participated in two community consultation sessions to provide feedback on the proposed content and language of the talking-book to ensure its acceptability. Twenty-three of the participants had arrived in Australia in the 1970s or 1980s with the remaining 36 having arrived in the 1990s. Eleven of the 59 participants had no schooling in Vietnamese and 30 had no schooling in the English language (see [table 1](#)).

Feedback from the two community consultations with the AVWA Vietnamese community was very positive. An example of the comments from the group included:

The terminology you have used is the best way to explain Dementia.

(Focus group participant 1)

I am so happy it is in Vietnamese and English, it means I can share the information with my family who do not understand Vietnamese.

(Focus group participant 20)

However, it was noted that some of the Vietnamese language used had a negative connotation attached to it and other participants noted grammatical errors in the Vietnamese. This information was identified, corrected and sent back to the translator for editing.

Once the suggested amendments were undertaken AVWA sourced a suitable narrator for the talking-book, a male employee of AVWA whose voice and accent was considered to be easily understood by all members of the Vietnamese community. A production company with experience in the development of the talking-book platform was employed to orchestrate the recording of the information sheets in the Vietnamese language and to construct the talking-book. Each page was recorded separately and electronically filed and catalogued to ensure the information would correspond to the correct information sheet.

**Table 1** Focus group participant demographics

Participants	n=59
Age (Mean and SD)	75.6±8.6
Gender	
Female	54 (91.5%)
Male	5 (8.5%)
Arrival in Australia	
1970–1980s	23 (9%)
1990s	36 (61.0%)
Education	
No formal education Vietnamese	11 (19%)
Education in Vietnamese <7 years	24 (41%)
Education in Vietnamese >7 years	24 (41%)
No education in English language	30 (51%)
Education in English <2 years	21 (36%)
Education in English >2–6 years	8 (13%)

During the recording process errors were revealed in several of the information sheets and these were marked for correction. These errors were able to be corrected immediately in the English information and the translated versions corrected soon after. The voice recordings, narrator photo and all written information was then provided to the production company for construction into an electronic ‘talking-book’. This process took 2 weeks. Once the electronic talking-book was received then the RDNS Information Technology Department organised the uploading of the program in readiness for the CEOs of AAV, AVWA and the Director of the RDNS Institute launching of the Vietnamese Talking-Book at Vietnamese Community Activity group on 24 April 2015.

### Talking-book production

The overall process in the development and the evaluation of the Vietnamese Dementia Talking-Book required the following steps: partnering with consumers and stakeholders, identification of consumer information needs, development of a project working group, development of outcomes, drafting of the talking-book content and grade reading level in English, professional translation of content into Vietnamese and construction of the talking-book, assessing acceptability of the content of the information in the talking-book, making modifications based on feedback, production and dissemination, evaluation of the talking-book and ongoing maintenance (see [figure 1](#)).

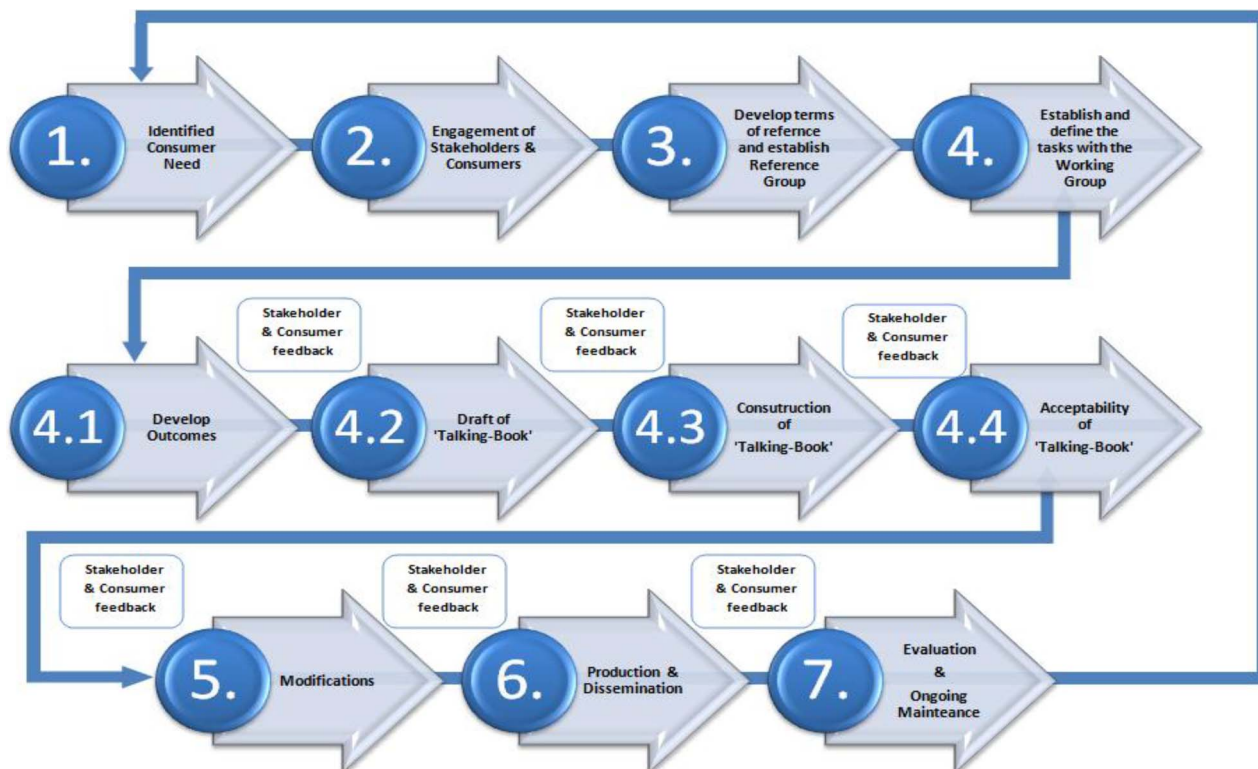
### Participants—phase II: evaluation of the acceptability and utility of the Vietnamese dementia talking-book

Twenty-two Vietnamese people (17 women and 5 men) participated in either a focus group or an individual interview to evaluate the final version of the talking-book. The average age of these participants was 61 years (range between 43 and 78 years). Approximately 50% of this group had arrived in Australia during 1970s and 1980s with the remaining having arrived between 1990 and 2013 (see [table 2](#)).

Feedback from the interviews with these Vietnamese community members demonstrated that participants were very satisfied with the content, and the format and structure of the talking-book and its cultural appropriateness. Participants also reported an increase in knowledge about dementia, how to assist/interact with people with dementia and where they could access information and services to assist people who are experiencing memory problems. There were mixed responses as to whether participants preferred to view the book online via the internet, access it using a USB, or actually print it off and read it as a hard copy (see [table 3](#)).

Although talking-book is available free on the RDNS, AAV and AVWA websites, several participants asked that the talking-book is made available through local municipal libraries. To facilitate this, an ISBN number has been obtained and hard copies of the book have been printed. Contact with local libraries in the South





**Figure 1** Steps in the development of a bi-lingual talking-book.

**Table 2** Evaluation participant demographics

Participants	n=22
Age (Mean and SD)	61±10.9
Gender	
Female	17 (77.0%)
Male	5 (23.0%)
Arrival in Australia	
1970–1980s	11 (50.0%)
Post 1990s	10 (45.0%)
Unknown	1 (5.0%)
Education	
No formal education Vietnamese/English	2 (9.0%)
Education in Vietnamese/English <7 years	3 (13.5%)
Education in Vietnamese/English >7 years	17 (77.5%)

Eastern, Northern and Western regions of Melbourne, areas with a high Vietnamese population, to facilitate the distribution of the book is in progress.

## DISCUSSION

The Vietnamese Dementia Talking-Book has been well received by the Vietnamese community. The book has enhanced the knowledge of members of the Vietnamese community who participated in focus groups in regard to understanding of dementia and navigating and accessing available services, thus enabling making decisions

about their care. It also serves as a tool that is able to facilitate the provision of care to Vietnamese people living with memory loss by assisting health professional staff to develop relationships with Vietnamese clients, their families and carers in a culturally appropriate manner.

In a recent report by the WHO, it was suggested that low health literacy ‘significantly drain(s) human and financial resources in the health system’.<sup>21</sup> For example, it is estimated that people with low individual health literacy are between one-and-a-half and three times more likely to experience adverse outcomes, higher rates of hospitalisation and emergency care.<sup>22</sup>

While there are commonalities across older Australians, many older Australians from culturally and linguistically diverse backgrounds (CALD) face circumstances that differ and that may affect not only their ageing experience due to different cultural beliefs, stigma and understandings about chronic illnesses but also their access to and use of aged care services.<sup>7 23 24</sup> With a rapidly ageing Australian population and a strong preference for older Australian’s to remain living in their own homes for, as long as possible, the development of strong systems of support for all community members are vital.<sup>23</sup> The aim of our project, therefore, was to provide a tool to address low dementia literacy in older Vietnamese people living with cognitive impairment, by developing an online ‘talking-book’ to help individuals, and their families and carers better understand and manage their condition. The talking-book

**Table 3** Key themes and illustrative quotes

Themes	Findings	Illustrative quotes
Dementia knowledge	The talking-book increases your knowledge about dementia and how to assist people with dementia	<p>'It helps improve understanding of these people and how to interact with them and how to help them' (Participant 3: male)</p> <p>'I think it's very good because if I know there are people with dementia and we don't know how to help them or we have to live with them, when don't know how to deal with this so this one is really good' (Focus Group 2: female)</p> <p>'So it's really very useful because everyone can understand about dementia. I find the information today is so helpful for me especially for my family because my mother in law has started having the problems, the symptoms of dementia so it's really good for me to understand that she's having to go through the symptoms.' (Focus Group 2: female)</p>
Accessing dementia services/information	The talking-book provided information on where to access information and services to assist people experiencing memory problems	<p>'this direct you to where you can get help. That mean the dementia hotline. You can read and you can follow the instructions, you can get help from your medical professional. You can see your family doctor, GP, or you can call up the interpreter service to help you if you have trouble with English' (Participant 1: male).</p>
Appropriateness and design of the book	<p>The narration of the book was found to be clear, easy to follow and the language used.</p> <p>Most participants found the book to be culturally appropriate; however, two participants commented on the level of the language and acceptability of the language being relevant to the region in Vietnam that one originates from</p>	<p>'The voice is very clear and he pronounces the words clearly, so it's good. It's a good choice of the person reading it' (Focus Group 3: male)</p> <p>'So a good thing about it is the pace of reading, it's slow. It's easy to understand' (Focus Group 2:female). (Focus Group 2:</p> <p>'I think the talking aspect is for the people who, with the English barrier, and some people, because in our country, lots of old people they don't have good education. Even in Vietnamese, they have problem with understand all the wording so lucky I finished Year 11. That means my Vietnamese is quite good. Other people only finish Year 7, Year 8 and because of the war, because of the poor condition of the country or where they grow up they have to work to make a living and to provide for the family'. (Participant 1: male)</p> <p>'...this is a very good one. People who don't understand in writing, they can understand in listen' (Participant 1: male).</p> <p>'When you use the word of having deteriorating mind, then it's a little bit difficult for Vietnamese to accept. If you say like, the memory, there is loss of memory or decreased memory or something, its probably easier to accept or understand...to say it shows the decrease in intellect, that makes it a little bit too academic'. (Participant 3: male)</p> <p>'Cuộc bộ is speaking for a joke or things like that like joking...đi bộ is easier to understand...and Cuộc bộ used for the person who lives in the north not for the south and the centre of Vietnam' (Focus Group 1: female)</p>

Continued

Table 3 Continued

Themes	Findings	Illustrative quotes
Accessibility/utility of the talking-book	There were mixed responses to whether participants preferred to view the talking-book online via the internet, access it on the computer using a USB or printing it off and reading it as a hard copy	<p>'I think the DVD more easy for the old person' (Participant 1: male);</p> <p>'No, no, the web address is good because we go on the internet and we can, I think that's good idea the website.' (Participant 2: female).</p> <p>'Now the government quite helpful, provide all the training so people will take in if they can learn something or can learn the new technology they will do that. A lot of people in the senior crowd, they enrol to learn how to use internet and this sort of thing. Like, I know how to use, I can go to Google and I can search for dementia if I want to' (Participant 2: female).</p> <p>'So after listening to the first topic, I found out this book is very useful for my family, especially because my husband has serious dementia and myself has slightly dementia as well, but because we have a computer but we rarely use it, I prefer to have the booklet, the hard copy, for me to read and understand more' (Focus Group 3: female).</p> <p>'I hoped that I could download it to the computer and then I could listen to it whenever I have time'. (Participant 3: male).</p> <p>'I think that it's necessary that someone in the family can help because not everybody can use the computer' (Participant 3: male).</p>

addresses the two components of health literacy as described by the Australian Commission on safety and quality in healthcare individual health literacy and the health literacy environment.<sup>25</sup>

### Strengths and weaknesses

While talking-books on diabetes in several languages have previously been developed by our group and the relevant ethnic communities, these earlier talking-books were not part of a research study that documented and described the processes involved in the production of such a tool or an evaluation of the acceptability of the final product. The Vietnamese Dementia Talking-Book used codesign and participatory action research principles to develop and appraise the final book to ensure that it was user-friendly, relevant and culturally appropriate.<sup>17 26</sup> This innovative tool is the first online resource to provide members of the Vietnamese community with greater access to information about living with memory loss, additionally a free nationally and internationally available online tool for Vietnamese people with dementia, their carers and family members and health professionals delivering care to this group has been created. Within the community, those delivering care to Vietnamese people in the home setting are able to access the Vietnamese Dementia Talking-Book online. In the clients home there is opportunity to build a positive professional relationship that will develop a culturally safe environment for the client, their family and carers to disclose further information to the nurse in order so that we can better understand their circumstances and needs<sup>7</sup> and adjust and introduce services or care plans that may help address their concerns.

Older migrants are less likely to use online information and communication technology,<sup>11 26 27</sup> however, this barrier can be overcome through accessing the hard copy bi-lingual versions of the content of the Vietnamese Dementia Talking-Book that is being made available in local municipal libraries with high Vietnamese populations and Alzheimer's Australia libraries. A/VWA have also stated that as the book is so effective and can be accessed online and off-line by all generations of Australian Vietnamese people that they will take action to introduce it to the Vietnamese community across Victoria.

### CONCLUSION

This freely internationally available online Vietnamese Dementia Talking-Book facilitates improved dementia-related health literacy in the Vietnamese community. The book also serves as a tool to facilitate the provision of care to Vietnamese people living with memory loss by assisting health professional staff to develop relationships with Vietnamese clients, their families and carers in a culturally appropriate manner. We recommend that further research using a randomised controlled trial design be undertaken to evaluate the full impact of the Vietnamese talking-book on health literacy outcomes.

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**Contributors** JM, SK and DG conceived and initiated the study. JK, SK, DG and JM developed the talking-book together with the project working group members from AVWA (HL) and AAV (CE). DG and JK undertook the data collection, DG and JK undertook the data analysis and the final drafting of the article and revised it for critical content. All authors contributed to and approved the final version of the paper and accept accountability for all aspects of the work.

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