

# Relationships of eHealth Literacy to Socio-Demographic Characteristics and Engagement in Online Learning: A Quantitative Study

A white paper published by the Flinders Research Centre for Palliative Care, Death and Dying

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# About this White Paper

This publication is a RePaDD White Paper and Research Report.

The RePaDD White Paper and Research Report Series provides researchers and policy makers with evidence-based data and recommendations. By organising, summarising, and disseminating previous and current studies, the series aims to inform ongoing and future research in palliative care, death, and dying.

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## Acknowledgement of Country

Flinders University was established on the lands of the Kurna nation, with the first University campus, Bedford Park, located on the ancestral body of Ngannu near Warriparinga.

Warriparinga is a significant site in the complex and multi-layered Dreaming of the Kurna ancestor, Tjilbruke. For the Kurna nation, Tjilbruke was a keeper of the fire and a peace maker/law maker. Tjilbruke is part of the living culture and traditions of the Kurna people. His spirit lives in the Land and Waters, in the Kurna people and in the glossy ibis (known as Tjilbruke for the Kurna). Through Tjilbruke, the Kurna people continue their creative relationship with their Country, its spirituality, and its stories.

Flinders University acknowledges the Traditional Owners and Custodians, both past and present, of the various locations the University operates on, and recognises their continued relationship and responsibility to these Lands and waters.

# About the RePaDD

Death and dying will affect all of us. The Research Centre for Palliative Care, Death, and Dying or RePaDD works to make a difference to the care of persons at the end of life.

We examine the universal experience of dying and create innovative solutions for people living with a life-limiting illness, their carers, and the clinicians caring for them. Our members lead major national palliative care projects in Australia. Our team of multidisciplinary researchers and experts work collaboratively with various organisations and funding agencies to deliver impact. We also strengthen research capacity by offering evidence-based resources, researcher education, and training and scholarships.

## Our research

We focus on the following research areas:

**Palliative care across the health system:** We conduct clinical and service studies and develop online palliative care resources and applications. Our work in this area contributes towards ensuring that quality palliative care can be delivered in all healthcare settings - whether in hospitals, aged care, homes, hospices, clinics, or the community.

**Death and dying across the community:** We examine and respond to community and consumer attitudes, views, and needs with respect to death and dying and palliative care. Our research in this area empowers the wider community to make informed decisions by raising awareness and building death literacy.

**Online evidence and practice translation:** We build, synthesise, and disseminate the evidence for palliative care. We also create innovative digital solutions to improve evidence translation and use. Our research in this area builds palliative care capacity of the health and aged care workforce, access and use of information by health consumers and the community.

Further information can be found at [flinders.edu.au/repadd](http://flinders.edu.au/repadd)

# About CareSearch

The CareSearch Project consolidates online palliative care knowledge for health professionals, people needing palliative care and their families, and for the general community. Our project is responsible for two major websites, the [CareSearch website](#) and the [palliAGED website](#). The CareSearch Project also works closely with a number of other projects to maximise impact within the sector.

Further information can be found at [caresearch.com.au](http://caresearch.com.au)

# About Dying2Learn

Developed by CareSearch, [Dying2Learn](#) was an innovative online course that aimed to help Australians feel more comfortable talking about death and dying. It did this by exploring different perspectives around death and dying, including how we engage with death and dying, the language we use in relation to death and dying and how we remember people who have died. Other topics discussed included representations of dying and the ways in which technology might be used to support those who are grieving.

As part of the new [CareSearch Portal](#) we are introducing the Dying2Learn Hub to help individuals and families explore different attitudes and practices around death and dying. This will be released in August 2021.

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# Executive Summary

Over the next two decades, population growth, chronic disease progression and an ageing population will see a growing number of people confront the difficulties that often accompany coming to the end of one's life. Online palliative care resources can provide valuable information to individuals, families, carers, and others. In order to be effective, however, such resources need to be readily found, understood, and applied by consumers.

eHealth literacy – the ability to find, understand, and apply online health resources – is becoming increasingly important in palliative care. While the body of literature pertaining to the way health information is provided to the community is growing, little is currently known about predictors of eHealth literacy in the context of death and dying, or how eHealth literacy is related to engagement with online health resources.

This White Paper reports on a study undertaken to examine relationships between eHealth literacy and socio-demographic and personal characteristics within a sample enrolled in an online course about death and dying. The Study on which this White Paper reports used a convenience sample of students who were participating in a MOOC (massive open online course) about death and dying.

Measures of socio-demographics and personal characteristics were

presented at course enrolment and in an optional survey. Participants completed the MOOC over 6 weeks and eHealth literacy was measured during the course. Participant engagement data was obtained from the online course platform.

The participants in the study demonstrated a high level of eHealth literacy driven by university level qualifications and health professional status. This confirmed the role of educational qualification as a strong predictor of eHealth literacy, as well as the influence of health professional status on eHealth literacy. However, while our data shows that education level influences the perception of the value of online health information, the importance of access to online health resources was not correlated with socioeconomic disadvantage, health-related quality of life, or self-rated health. This suggests that a broader range of community members recognise its importance and that it should be possible to recognise this perception of value to support initiatives to encourage effective access and use.

Ultimately, it is hoped that the information provided in this White Paper will help developers of online palliative health care resources and others create meaningful, usable content that encourages further uptake and effective utilisation by target audiences.

# Introduction

eHealth literacy (i.e., the ability to find, understand, and apply online health resources<sup>1</sup>) is important across health and aged care and is becoming increasingly important in palliative care given population ageing and associated projected increases in death rates.<sup>2, 3</sup> Access to online health resources could be vital in assisting carers, family members, community-based health professionals, and people undergoing palliative care to understand and plan in the face of a life limiting illness. Yet, little is currently known about predictors of eHealth literacy in the context of death and dying, or how eHealth literacy is related to engagement with online health resources. Such information could help developers of online palliative health resources create meaningful and usable content for their intended users. The purpose of this research was to examine relationships between eHealth literacy and socio-demographic and personal characteristics within a sample enrolled in an online course about death and dying. The association between engagement in the course and eHealth literacy was also investigated.

## **eHealth Literacy, Socio-Demographics characteristics, and Health in Palliative Care**

eHealth literacy encompasses skills enabling a person to search for, access, understand, and evaluate

online health resources and to address health problems by applying information gained in this way.<sup>1</sup> There are six skills underpinning eHealth literacy that are considered necessary to fully engage with online health resources. These skills can be divided into two categories: analytical (i.e., traditional, media, and information), and context-specific (i.e., computer, scientific, and health)<sup>1</sup>. This conceptualisation of eHealth literacy informed the development of the eHealth Literacy Scale (eHEALS)<sup>4</sup>, which has been commonly used in research.<sup>5, 6</sup> Palliative care affects not only the individual facing death but also friends and family who will support the person in the weeks and months before death. Online palliative care resources are an additional source of information and need to be readily found, understood, and applied by consumers. This necessitates an understanding of consumers' eHealth literacy.

Socio-demographic predictors of eHealth literacy in samples accessing information about death and dying have scarcely been addressed, with only two studies having been found that previously explored eHealth literacy in a palliative care context.<sup>7, 8</sup> Socio-demographic-specific information could be used to identify the types of people who may need support to access online health resources. The subject of access is critical; it is insufficient for resources to

merely be *available* online, they must also be *accessible* by those who need them in order for them to be effective. Information about socio-demographic predictors of eHealth literacy could be applied to the presentation of palliative care resources online (e.g., to assist in tailoring information to different groups), as well as within clinical practice (e.g., in deciding whether additional support should be given to a particular patient and their family).

Highest educational qualification and age are the socio-demographic characteristics that appear to be most relevant to eHealth literacy, based on research using the eHEALS in a variety of samples. A positive association between highest education and eHealth literacy has commonly been found<sup>6, 7, 9-13</sup>, although in some cases the relationship was not significant.<sup>14-16</sup> Likewise, evidence also largely suggests that eHealth literacy decreases with age<sup>6, 9-12, 15, 17</sup>, although again some null results have been reported<sup>7, 14, 18, 19</sup>, and in one study older people actually had generally higher eHealth literacy.<sup>16</sup>

There is little clarity regarding additional socio-demographic correlates of eHealth literacy. eHealth literacy in rural settings has received some attention recently, reflecting the potential that online health resources have to address the comparative lack of health providers and the ongoing training needs of health providers in rural areas.<sup>20-22</sup> Similarly, research has drawn attention to the potential deleterious impacts of socioeconomic disadvantage on eHealth literacy and

eHealth usage.<sup>18, 23, 24</sup> Indeed, some studies suggest that income and being employed are positively related to eHealth literacy<sup>9, 13, 16</sup>, although other evidence suggests no significant relationship between eHealth literacy and income, income-to-needs ratio, or home ownership.<sup>9, 10, 17, 25</sup> Research to date does not appear to have addressed the impact of either rurality or socioeconomic disadvantage on eHealth literacy in Australians. The evidence regarding the relationship between health status and eHealth literacy is also inconsistent. eHealth literacy has been found to have a positive relationship with one's own perceived health status<sup>9, 13</sup>, but also to have no relationship with one's own perceived health status<sup>6, 10</sup> or that of one's child<sup>7</sup>. Previous research has not addressed whether health-related quality of life might be relevant to eHealth literacy.

In the present study, we considered two additional personal characteristics that could impact on eHealth literacy. Health professionals might have better eHealth literacy than non-health professionals, due to the knowledge of health and use of health resources necessitated by their role. In the palliative care context, bereavement is also a relevant consideration with regards to eHealth literacy, because it may index the extent to which carers and family members are capable of accessing online resources to support themselves following the death of the person being cared for. Determining socio-demographic and personal characteristics that predict eHealth literacy will provide us with information

about the types of people who are broadly likely to be capable or incapable of using online health resources.

### **eHealth Literacy and Online Engagement**

There is some evidence that eHealth literacy is associated with engagement with eHealth technology, broadly defined. eHealth literacy has also been positively associated with favourable ratings and personal actions of an online HIV testing intervention<sup>26</sup>, reported “trialability” of a mobile health app<sup>27</sup>, use of online patient portals<sup>28, 29</sup>, and with use of social media and web-based support groups for health information.<sup>10</sup> These results suggest that people with higher eHealth literacy may be more likely to engage with, approve of, and apply eHealth technology.

Still, other research suggests a more indirect or null relationship between eHealth literacy and use of eHealth technology. eHealth literacy was indirectly associated with acceptance of occupational e-mental health<sup>30</sup>, and with extent of health app use, mediated by health app use efficacy.<sup>18</sup> Other studies found eHealth literacy was not related to patients’ acceptance of web-based aftercare<sup>31</sup>, older adults’ intention to engage with mobile health technology<sup>32</sup>, or electronic personal health record usage.<sup>33</sup> Therefore, the relationship between eHealth literacy and eHealth technology remains unclear. The present research aimed to address this by investigating

whether eHealth literacy impacts on online engagement in a MOOC (Massive Open Online Course) about death and dying.

A positive relationship between eHealth literacy and engagement might reflect that eHealth literacy can be a capacity developed in response to need; that is, engagement with health resources to help one manage one’s own health problems may provide the necessary experience to increase eHealth literacy. Studies have shown that people with chronic health conditions consume online health resources at a greater rate than those without chronic health conditions.<sup>34, 35</sup> This speaks to a motivational influence on eHealth literacy, which is further supported by the finding that this group is also more likely to work on or contribute to online discussions about health (e.g., blogs, group forums), and access health-related content produced by other online users (e.g., blog posts, hospital or doctor reviews, podcasts).<sup>34</sup> Such patients are also more likely to report that the health information they obtained online affected their treatment decisions, interactions with doctors, coping ability, and dieting and fitness regimen<sup>35</sup>. This level of engagement by the chronically ill is especially striking when one considers that membership of this group is associated with characteristics related to lower internet use (e.g., older age, lower education, lower income) and lack of regular computer use.<sup>34, 35</sup> So, people who may not usually engage with online resources are engaging,

apparently on the basis of need, highlighting the practical value of online information.

### **Methodology and Aims**

Participants in our study were enrollees in a MOOC called Dying2Learn.<sup>36</sup> Dying2Learn is delivered by CareSearch, an Australian website providing information and resources about palliative care.<sup>37</sup> Course content focusses on conceptualisations of death and dying and aims to promote discussion about, and acceptance of death as a normal part of life. It was developed in recognition that in Australia and other contemporary Western cultures, the capacity to discuss death and dying is inhibited by taboo, discomfort, or the appearance of insensitivity.<sup>3, 38-42</sup> Previous research has not addressed whether engagement in Dying2Learn, or in MOOCs generally, is influenced by participants' eHealth literacy.

Participants responded to questions at the time of enrolling in the course, after

which some also completed an additional, optional survey. They completed the Dying2Learn course over 6 weeks. The eHealth literacy measure was presented as a course activity during the fifth week. At the close of the course, information about participant engagement was obtained from the online course platform. Analyses were exploratory in nature, given that previously available information was limited and inconsistent, and aimed to address the following research questions:

1. What is the relationship between the socio-demographic characteristics and eHealth literacy of participants in a MOOC about death and dying?
2. Which socio-demographic characteristic holds the strongest unique association with eHealth literacy?
3. How is engagement with a MOOC about death and dying related to its participants' eHealth literacy?

# Methods

## **Participants**

Dying2Learn participants were recruited via advertisements posted to: CareSearch and related networks concerning palliative care, death, and dying; social media networks Facebook, Twitter, and LinkedIn; and online learning websites Open Learning and MOOC List.

Advertisements targeted the general Australian public, although participants outside Australia were not excluded.

Most non-Australian participants enrolled from Canada, the United States of America, the United Kingdom, and New Zealand.

Interested parties could register to be notified when course enrolment opened. Enrolees were invited to complete an optional survey prior to commencing Dying2Learn, the responses to which were used for the present research. Although there were 1960 enrolees, the present analyses used only those participants who gave complete responses to the eHealth literacy measure ( $N = 447$ ).

## **Materials**

### *Socio-Demographic Characteristics*

Five questions in the enrolment survey addressed socio-demographic characteristics: gender (male; female; trans; other; prefer not to disclose); age; Australian postcode if residing in Australia or country of residence if not; highest level of education (some high

school; completed high school; trade school or equivalent; university studies), adapted from a question in the Australian Bureau of Statistics (ABS) 2016 Census<sup>43</sup>; and whether the participant was, or had ever been, a health professional (yes; no).

Participants who reported that they were, or had been, a health professional also reported the type of health professional they were or had been (doctor; nurse; allied health; aged care worker; other). A dichotomised variable was created for analysis to distinguish participants located in Australia from those outside Australia.

Australian postcodes reported by participants residing in Australia were used to calculate socio-economic disadvantage with reference to the 2011 Census Socio-Economic Index for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage.<sup>44</sup> This index provides a ranking of relative disadvantage based on economic and social information about a given geographical postal area. Scores range from 506.3 to 1155.5, where lower scores indicate greater relative disadvantage and the average score is 1000.

Postcodes were also used to classify Australian participants as living in major cities or regional/remote areas based on the Australian Standard Geographical Classification (ASGC) Remoteness Structure (RA).<sup>45</sup> There



are five RA categories: RA1 is *Major Cities of Australia*; RA2 is *Inner Regional Australia*; RA3 is *Outer Regional Australia*; RA4 is *Remote Australia*; and RA5 is *Very Remote Australia*. Postcode classification was undertaken using an index matching 2012 postcodes to RA classifications.<sup>46</sup> A dichotomised variable was created for analysis, with area RA1 labelled a major city, and areas RA2 to RA5 labelled rural.

### *eHealth Literacy*

eHealth literacy was measured using the eHEALS<sup>4</sup>, an 8-item self-report scale measuring perceived knowledge, comfort, and skill at locating, evaluating, and using online health information (e.g., “I know how to find helpful health resources on the Internet”). This measure was presented as an activity in the fourth module of Dying2Learn. Responses are on a 5-point scale from 1 (*strongly disagree*) to 5 (*strongly agree*) such that the score range is 8 – 40, with higher scores indicating greater eHealth literacy. There are also two supplementary items that are recommended for gaining a broad understanding of respondents’ interest in eHealth, which are not a formal part of the scale. These are “How useful do you feel the Internet is in helping you in making decisions about your health?” (5-point scale from 1 *not useful at all* to 5 *very useful*) and “How important is it for you to be able to access health resources on the Internet?” (5-point scale from 1 *not important at all* to 5 *very important*).

The formal scale has been used in a range of samples, demonstrating good internal consistency and test-retest reliability<sup>4, 47-50</sup>. Internal consistency was also high in the present study (*Cronbach’s*  $\alpha = .90$ ). Scores have been found to relate positively with internet experience or usage<sup>6, 13, 14, 17, 25, 48</sup>, use of the internet to obtain health resources<sup>7, 9, 10, 47, 51</sup>, computer access<sup>6</sup>, computer knowledge<sup>48</sup>, information literacy<sup>11</sup>, health literacy<sup>52</sup>, health app use efficacy<sup>18</sup>, and healthy behaviours<sup>47, 51</sup> including physical exercise<sup>11, 53</sup> and eating a balanced diet.<sup>53</sup> Additionally, low scores have been associated with greater need for support to access online health information in adults with chronic health conditions.<sup>49</sup> Hence, the scale’s convergent validity is well established. Its single factor structure, as proposed by its authors, has been supported by research examining its psychometric properties.<sup>48, 50</sup>

### *Bereavement*

A single item in the optional pre-MOOC survey measured bereavement by asking participants “Has someone close to you died in the last 5 years?” (yes; no; not sure). The item was created for this research to provide a broad indication of bereavement, because previous experience with death may impact on the way people engage in a MOOC about death and dying. To simplify analysis, a dichotomised variable was created, whereby participants were considered bereaved if they responded ‘yes’, and not bereaved if they responded ‘no’ or ‘not sure’.

### *Health-Related Quality of Life*

The 12-item Assessment of Quality of Life (AQoL-4D)<sup>54</sup> measured health-related quality of life and was included in the optional pre-MOOC survey. Items suggest areas of life (e.g., “Thinking about how you sleep”) to which participants select a response that corresponds best to their experiences (e.g., “I am able to sleep without difficulty most of the time”). A weighted total utility score, designed to reflect the relative value respondents place on a given health status, was derived using the algorithm (version 8) available on the scale’s website.<sup>55</sup> Weighted scores can range from -0.04 (i.e., a state of health worse than death) to 1.00 (i.e., the best possible quality of life). Psychometric evaluation of the AQoL-4D supports its validity and reliability as a measure of health-related quality of life.<sup>54, 56-58</sup> This measure demonstrated adequate internal consistency in the present study (*Cronbach’s*  $\alpha = .67$ ).

### *Self-Rated Health*

Self-rated health was measured using a single item taken from the ABS National Health Survey, which was included in the optional pre-MOOC survey.<sup>43</sup> The item asks participants to rate their general health on a 5-point scale from 1 (*excellent*) to 5 (*poor*). Higher scores indicate poorer health.

### *Social Media Providing Perspectives on Death and Dying*

One item in the pre-enrolment survey asked participants to rate their

agreement with the statement: “Social media provides different perspectives to mainstream media on death and dying”. This item was created to measure death attitudes and was also used in evaluating the previous iteration of Dying2Learn.<sup>36</sup> Responses are on a 5-point scale from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*).

### *Online Course Engagement*

Online engagement in the MOOC was measured in three ways: the percentage of progress through the course reached by the time the course closed; number of comments posted throughout the course; and whether participants participated in the live chat activity, held during the third topic module. Percentage of course progress reflects the proportion of course content viewed or accessed and the proportion of activities that were set as essential to course completion that were actually completed. The live chat concerned the medicalisation of death and involved medical specialists responding to participants’ queries and comments on this topic. Participation in the live chat was included as a measure of engagement because it was the only activity requiring that participants be online and participating at a set time, which presumably requires more effort than completing an activity at one’s leisure. A participant was considered to have participated in the live chat if they posted a comment on that activity at any point between when it was officially opened (8:59pm ACDT) and



closed (11:18pm ACDT) by the facilitator hosting the chat (Christine Sanderson).

### *Procedure*

The Dying2Learn course was developed as a free platform for students to engage in social discourse, learning, and contemplation about death and dying. It was created by a team with clinical and academic experience in palliative care and related disciplines, and was hosted by the Open Learning website. The course contained an introductory module, four modules covering distinct topics relating to death and dying, and a reflections module. The course was delivered over 6 weeks from March to May 2017, with one module released each week. Participants were encouraged to participate in activities and interact with one another by engaging in commenting conversations. Course topics included how death and dying are expressed through humour, represented across different mediums, related to medicine, and implicated in digital technologies. Each module's content was curated by a different facilitator and contained a combination of text, images, videos, web links, and activities. Further information about the Dying2Learn course is available in other publications detailing its 2016 iteration.  
36, 42, 59, 60

When enrolling, participants completed a series of questions about socio-demographic characteristics (gender, age, Australian postcode, education level, occupation) and their attitudes toward and beliefs about death and

dying. Within approximately 24 hours of enrolling, participants were also emailed an invitation to participate in an optional research study. The email contained a unique web link to the pre-MOOC survey, which collected data pertaining to self-rated health, bereavement, country of birth, and quality of life. At the close of the course, data from the enrolment survey and modules were extracted from the Open Learning website. Data from the optional pre-MOOC survey was matched to the enrolment and module data, after which the file was fully de-identified for analysis. This project was approved by the Flinders University Social and Behavioural Research Ethics Committee (Project No. 7247).

### *Data Analysis*

Analyses were undertaken in IBM SPSS Statistics (version 25), unless otherwise indicated, with an alpha level of .05. Effect sizes were calculated using an online calculator<sup>61</sup> and interpreted with reference to the guidelines proposed by Cohen.<sup>62</sup> Descriptive statistics were calculated for each variable, including means and standard deviations for continuous and ordinal variables, and frequencies for categorical variables. Skewness and kurtosis of ordinal and continuous variables were found to generally be within normal ranges, with the exception of the engagement metrics reflecting course progress and number of comments made. Even though skewed distributions are common for count variables, to account for this, non-parametric tests were used for

these engagement indices. Group differences between participants who did and did not complete the eHealth literacy measure were tested using independent samples *t*-tests for ordinal and continuous variables, and chi-square tests of independence for categorical variables. Welch's unpaired *t*-tests were used to compare our eHealth literacy results to those of similar samples in the literature, which have different sample sizes and are drawn from different populations. The Welch unpaired *t*-tests tests were conducted online using GraphPad's *t*-test calculator.<sup>63</sup>

Relationships between eHealth literacy and other variables were tested using one-way ANOVAs for multi-level variables, bivariate correlations for continuous variables (Pearson and Spearman methods, as appropriate with regard to variable normality), and independent samples *t*-tests for dichotomous variables. Multiple linear regressions were also conducted to determine the strongest predictor of eHealth literacy, accounting for the contributions of other variables.

# Results

## Preliminary Analyses

Descriptive statistics for participants who did and did not complete the eHealth literacy measure are presented in Table 1. Participants who completed the eHealth literacy scale were significantly older ( $t(1954) = 5.00, P < .001$ ), more likely to be in Australia ( $\chi^2(1) = 28.50, P < .001$ ), and reported significantly better health-related quality of life ( $t(500.2) = 3.51, P < .001$ , unequal variances assumed) than those who did not. Effect sizes were small for differences in all three variables: age ( $d = 0.27$ ); likelihood of being in Australia ( $\Phi = .12$ ); and health-related quality of life ( $d = 0.31$ ). There were no other significant group differences.

**Table 1. Comparing participants who did and did not complete the eHealth Literacy Scale**

	<i>n</i> with data for this measure (did not, did complete eHEALS <sup>a</sup> )	Did not complete eHEALS <sup>a</sup> ( <i>n</i> = 1513) <i>M</i> ( <i>SD</i> ) or %, range	Completed eHEALS <sup>a</sup> ( <i>n</i> = 447) <i>M</i> ( <i>SD</i> ) or %, range
Gender (female)	1507, 442	92.0%	93.2%
Age	1509, 447	46.39 (12.33), 17 – 82	49.69 (11.95), 19 – 81
SEIFA disadvantage	1095, 378	1005.30 (63.13), 744.03 – 1132.10	998.84 (70.20), 662.71 – 1120.36
Located in Australia	1513, 447	71.1%	83.7%
Living in rural Australia <sup>b</sup>	1094, 378	37.5 %	39.4%
Identifies as a health professional	1511, 447	72.7%	74.7%
Health-related quality of life	353, 202	0.75 (0.18), 0.03 – 1.00	0.80 (0.14), 0.11 – 1.00
Self-rated health <sup>c</sup>	368, 208	2.35 (0.86), 1 – 5	2.23 (0.76), 1 – 4
Bereaved <sup>d</sup>	368, 208	67.9%	74.5%

<b>Highest education</b>		1511, 447		
	Some high school		3.9%	6.3%
	Completed high school		10.0%	8.5%
	Trade school or equivalent		17.7%	18.1%
	University studies		68.4%	67.1%

Note. Italicised statistics indicate significant group differences.

<sup>a</sup>The eHealth Literacy Scale<sup>4</sup>

<sup>b</sup>Living in an RA2 – RA5 area, per ASGC-RA index<sup>45</sup>

<sup>c</sup>Higher scores correspond to poorer health

<sup>d</sup>Someone close to them has died within the last five years

On average, our sample had high eHealth literacy ( $M = 30.76$ ,  $SD = 4.76$ , range = 15 – 40), using a previously suggested benchmark of  $\geq 26$  out of 40<sup>25</sup>. Our mean score indicates that participants were more likely to express agreement with scale items than disagreement or uncertainty. Response frequencies for the two supplementary eHealth literacy items indicated that 76.6% of participants felt that the internet is useful or very useful in helping them to make decisions about their health, and 84.9% thought it was important or very important for them to be able to access health resources on the internet. This indicates that our sample was generally interested in using eHealth resources.

Our eHealth literacy scores summing the 8 core scale items were compared to those of similar samples in the literature, with results presented in Table 2. Our sample scored significantly higher than that of Richtering, Hyun<sup>25</sup>, with a medium to large effect. This may be explained by differences in study methods; Richtering, Hyun's<sup>25</sup> participants completed the measure by face-to-face interview, whereas ours completed it online, within an online course. The online nature of our study may have attracted participants with greater eHealth literacy. In support of this, our sample also scored significantly higher than one where the scale was administered by telephone<sup>64</sup>, whereas our mean score did not differ from that of two samples where it was administered online.<sup>48, 50</sup> However, our sample did score significantly higher than one study in which the scale was presented online<sup>49</sup>, with a small effect. So, the relationship between presentation format and scores is not entirely clear.

**Table 2. Comparing eHealth literacy scores to other samples**

Authors	Sample (country)	Presentation format of eHEALS <sup>a</sup>	N	M age	M eHEALS <sup>a</sup> (SD)	t-test	Cohen's d
<i>Present Study</i>	<i>Participants in a MOOC about death and dying</i>	<i>Online</i>	447	49.69	30.76 (4.76)	-	-
Chung and Nahm <sup>48</sup>	Older adults aged 50 or over (USA)	Online	866	62.84	30.94 (6.00)	$t(1097) = 0.59, P = .55$	-
Lee, Hoti <sup>49</sup>	Adults with chronic health conditions who consume web-based health information (Australia)	Online	400	Not reported	29.5 (4.3)	$t(844) = 4.05, P < .0001$	0.28
Paige, Krieger <sup>50</sup>	Adults with a chronic disease who consume web-based health information (USA)	Online	648	47.24	30.34 (5.30)	$t(1020) = 1.37, P = .17$	-
Richtering, Hyun <sup>25</sup>	Adults with moderate-to-high cardiovascular risk (AUS)	Face-to-face interviews	453	67	27.2 (6.59)	$t(823) = 9.30, P < .0001$	0.62
Stellefson, Paige <sup>64</sup>	Older adults aged 50 or over (USA)	Telephone survey	283	67.46	29.05 (5.75)	$t(518) = 4.18, P < .0001$	0.32

Note. Information about the present study is italicised. Cohen's  $d$ <sup>62</sup> is only reported here for statistically significant group differences.

<sup>a</sup>The eHealth Literacy Scale<sup>4</sup>

### Socio-Demographic/Personal Characteristics and eHealth Literacy

Table 3 provides an overview of summed eHealth literacy scores across the levels of our categorical socio-demographic and personal characteristic variables. eHealth literacy was not significantly related to gender ( $t(440) = 0.12, P = .91$ ), Australian location ( $t(376) = 0.32, P = .75$ ), or bereavement ( $t(206) = 0.69, P = .49$ ). However, health professionals ( $M = 31.14, SD = 4.72$ ) had significantly higher eHealth literacy than non-health professionals ( $M = 29.61, SD = 4.72$ ) ( $t(445) = 2.99, P = .003$ ), with a small to medium effect size ( $d = 0.32$ ). A one-way ANOVA found that eHealth literacy did not differ between types of health professional ( $F(4, 333) = 1.33, P = .26$ ). Thus, health professionals had higher eHealth literacy than non-health professionals, and their eHealth literacy did not differ by type of health professional.

**Table 3. eHealth literacy by categorical socio-demographic/personal characteristics**

		<i>n</i> with data for this variable	<i>M</i> ( <i>SD</i> )	Observed range
Gender	Female	412	30.77 (4.70)	15 – 40
	Male/Trans/Other	30	30.67 (5.39)	18 – 40
Australian location	Rural <sup>a</sup>	149	30.69 (4.73)	15 – 40
	Major city <sup>b</sup>	229	30.85 (4.98)	15 – 40
Identifies as a health professional	Yes	334	31.14 (4.72)	15 – 40
	No	113	29.61 (4.72)	18 – 40
Type of health professional	Doctor	4	34.00 (4.00)	32 – 40
	Nurse	157	31.22 (4.53)	15 – 40
	Allied health	66	31.53 (4.36)	21 – 40
	Aged care worker	69	30.15 (5.12)	15 – 40
	Other	42	30.69 (5.00)	18 – 40

Highest education	Some high School	28	29.13 (5.34)	15 – 38
	Completed high School	38	28.73 (4.51)	17 – 36
	Trade school or equivalent	81	29.91 (4.44)	18 – 40
	University studies	300	31.39 (4.70)	15 – 40
Bereaved <sup>a</sup>	Yes	155	30.55 (4.91)	15 – 40
	No/not sure	53	31.09 (5.19)	19 – 40

Note. Scores are italicised where there was a significant difference.

<sup>a</sup>Living in an RA2 – 5 area, per ASGC-RA index<sup>45</sup>

<sup>b</sup>Living in an RA1 area, per ASGC-RA index<sup>45</sup>

<sup>c</sup>Someone close to them has died within the last five years

Highest educational qualification significantly impacted on eHealth literacy ( $F(3, 443) = 6.24$ ,  $P < .001$ ), with a small to medium effect size ( $\eta^2 = 0.04$ ). Post-hoc pairwise comparisons with a Bonferroni correction for multiple testing revealed that participants who had undertaken university studies scored significantly higher than those who had completed high school, at a significance level of  $P < .05$ . On average, participants who had undertaken university studies also scored higher than those who had completed some high school and those who had completed trade school or equivalent, although these differences did not reach statistical significance. These results provide evidence that education level is positively associated with eHealth literacy.

A series of bivariate Pearson correlations assessed the relationships between eHealth literacy and age, socioeconomic area disadvantage, health-related quality of life, and self-rated health (Table 4). Only age showed any relationship to eHealth literacy; there was a significant, although weak negative correlation between age and eHealth literacy ( $P = .02$ ). eHealth literacy was not correlated with the other measures.

**Table 4. Pearson correlations between eHealth literacy and ordinal or continuous variables**

	eHealth literacy	Age	SEIFA disadvantage	Health-related quality of life
Age	<i>-.11</i>	-		
SEIFA disadvantage	-0.03	-.01	-	
Health-related quality of life	-.02	-.06	.09	-
Self-rated health	.01	-.03	<i>-.15</i>	<i>-.40</i>

Note. Significant correlations are italicised.

Three multiple linear regressions were conducted to determine the strongest socio-demographic predictor of eHealth literacy. Given the reduced sample size with data on bereavement, self-assessed health, and health-related QOL, and that no bivariate associations were found, these variables were not examined in the multiple regressions.

The first model did not contain the variables specific to Australian participants (i.e., Australian location and SEIFA disadvantage score), so as not to exclude participants outside Australia. Age, gender (female/other), highest educational qualification, and health professional status (does/does not identify as a health professional) were entered into the first model in a single step. This model explained 5.8% of variance in eHealth literacy ( $R^2 = .058$ ) and was significant ( $F(4, 437) = 6.77, P < .001$ ). Highest educational qualification was the strongest predictor of eHealth literacy ( $B = 0.92, \beta = .17, P < .001, CI_{95} \text{ for } B = 0.42, 1.41$ ), followed by being a health professional ( $B = 1.37, \beta = .13, P = .008, CI_{95} \text{ for } B = 0.36, 2.37$ ). The remaining variables were not significant predictors, including age, which was significantly correlated to eHealth literacy when considered alone.

The second model contained all socio-demographic variables: age, gender, highest educational qualification, Australian location (major city/rural), SEIFA disadvantage score, and health professional status. These were entered in a single step. This model explained 5.9% of variance in eHealth literacy ( $R^2 = .059$ ), which was again significant ( $F(6, 367) = 3.84, P = .001$ ). Highest educational qualification ( $B = 0.92, \beta = .17, P = .001, CI_{95} \text{ for } B = 0.38, 1.46$ ) was the strongest predictor of eHealth literacy, followed once more by being a health professional ( $B = 1.33, \beta = .12, P = .02, CI_{95} \text{ for } B = 0.21, 2.44$ ). The other variables in the model did not predict eHealth literacy.



The final model contained only the two significant predictors from the previous models (i.e., highest educational qualification and being a health professional), both entered in one step. This model explained 5.3% of variance in eHealth literacy ( $R^2 = .053$ ), which was similar to the previous models, despite containing fewer variables. This model was also significant ( $F(2, 444) = 12.48, P < .001$ ), and highest educational qualification ( $B = 0.98, \beta = .18, P < .001, CI_{95} \text{ for } B = 0.49, 1.46$ ) remained the strongest predictor of eHealth literacy. Being a health professional ( $B = 1.44, \beta = .13, P = .005, CI_{95} \text{ for } B = 0.45, 2.43$ ) was a significant predictor as well.

Thus, all three models support that highest educational qualification was the strongest socio-demographic predictor of eHealth literacy. Moreover, the only other significant socio-demographic predictor, with the contributions of other variables taken into account, was being a health professional. We checked for multicollinearity in all three models, since health professionals are also likely to be highly educated, but found no strong evidence for multicollinearity of these or any other variables in any model, so they were retained.

### **Social Media, Online Engagement, and eHealth Literacy**

The social media item measured the extent of agreement with the statement: “Social media provides different perspectives to mainstream media on death and dying”. Online engagement variables included percentage of progress through the course, number of comments made during the course, and participation in the live chat activity. There was no significant relationship between eHealth literacy and agreement with the social media item ( $r = .03, P = .57$ ), course progress ( $\rho = .06, P = .18$ ), or number of comments made during the MOOC ( $\rho = .03, P = .48$ ). Likewise, an independent samples *t*-test revealed no significant difference in eHealth literacy between participants who did ( $M = 30.79, SD = 4.57$ ) and did not ( $M = 30.75, SD = 4.79$ ) participate in the live chat activity ( $t[445] = 0.05, P = .96$ ). Thus, the results do not suggest that eHealth literacy was related to online engagement.

### **Usefulness of the internet for health decisions**

The relationship of socio-demographic and personal characteristics to responses to the usefulness of the internet for making health decisions is summarised in Table 5. There were no significant differences in responses on the basis of gender ( $t(442) = 0.20, P = .85$ ), Australian location ( $t(378) = 0.53, P = .60$ ), being a health professional ( $t(226.46) = 1.31, P = .19$ , unequal variances assumed), or bereavement ( $t(124.18) = 1.20, P = .23$ , unequal variances assumed). Responses did not differ between types of health professional ( $F(4, 335) = 1.84, P = .12$ ) or highest educational qualification ( $F(3, 445) = 1.02, P = .39$ ). Responses were significantly, weakly, negatively correlated with age and health-related quality of life, but were not significantly correlated with socioeconomic disadvantage or self-rated

health. Younger people and people with poorer health-related quality of life found the internet slightly more useful in helping them make decisions about their health.

**Table 5. Relationships of socio-demographic and personal characteristics to usefulness of the internet for health decisions and importance of access to online health resources**

		<i>n</i> with data for this measure	Usefulness of the internet <sup>a</sup> , <i>M</i> ( <i>SD</i> ) or <i>r</i> ( <i>p</i> )	Importance of access <sup>b</sup> , <i>M</i> ( <i>SD</i> ) or <i>r</i> ( <i>p</i> )
Gender	Female	414	3.80 (0.82)	4.09 (0.86)
	Male/Trans/Other	30	3.77 (0.82)	3.80 (1.03)
Australian location	Rural <sup>c</sup>	230	3.74 (0.92)	3.99 (0.96)
	Major city <sup>d</sup>	150	3.79 (0.80)	4.13 (0.82)
Identifies as a health professional	Yes	336	3.77 (0.86)	4.10 (0.87)
	No	113	3.88 (0.72)	4.01 (0.90)
Bereaved <sup>e</sup>	Yes	157	3.75 (0.89)	4.01 (0.95)
	No/not sure	53	3.89 (0.64)	4.08 (0.76)
Type of health professional	Doctor	4	4.25 (0.5)	4.75 (0.5)
	Nurse	158	3.67 (0.91)	4.11 (0.85)
	Allied health	66	3.97 (0.72)	4.20 (0.75)
	Aged care worker	70	3.77 (0.85)	4.03 (0.98)
	Other	42	3.69 (0.81)	3.88 (0.94)
Highest education	Some high school	28	3.61 (1.07)	3.86 (1.01)
	Completed high school	39	3.69 (0.73)	3.85 (0.84)
	Trade school or equivalent	81	3.75 (0.78)	3.83 (1.03)

		<i>n</i> with data for this measure	Usefulness of the internet <sup>a</sup> , <i>M</i> ( <i>SD</i> ) or <i>r</i> ( <i>p</i> )	Importance of access <sup>b</sup> , <i>M</i> ( <i>SD</i> ) or <i>r</i> ( <i>p</i> )
	University studies	301	3.84 (0.82)	4.20 (0.80)
Age		449	<i>-.10</i> (.04)	<i>-.13</i> (.006)
SEIFA disadvantage		380	<i>-.01</i> (.79)	<i>.06</i> (.29)
Health-related quality of life		204	<i>-.17</i> (.01)	<i>-.10</i> (.17)
Self-rated health <sup>f</sup>		210	<i>.07</i> (.34)	<i>.01</i> (.85)

Note. Scores are italicised where there was a significant relationship.

<sup>a</sup>How useful do you feel the Internet is in helping you in making decisions about your health?" (5-point scale from 1 *not useful at all* to 5 *very useful*)

<sup>b</sup>"How important is it for you to be able to access health resources on the Internet?" (5-point scale from 1 *not important at all* to 5 *very important*)

<sup>c</sup>Living in an RA2 – 5 area, per ASGC-RA index<sup>45</sup>

<sup>d</sup>Living in an RA1 area, per ASGC-RA index<sup>45</sup>

<sup>e</sup>Someone close to them has died within the last five years

<sup>f</sup>Higher scores correspond to poorer health

There was no significant relationship between responses to the item measuring usefulness of the internet for health decisions and agreement with the statement: "Social media provides different perspectives to mainstream media on death and dying" ( $r = .03$ ,  $P = .47$ ), course progress ( $\rho = -.04$ ,  $P = .46$ ) or number of comments made during the MOOC ( $\rho = -.05$ ,  $P = .29$ ). Additionally, there was no significant difference in responses between participants who did ( $M = 3.84$ ,  $SD = 0.88$ ) and did not ( $M = 3.79$ ,  $SD = 0.82$ ) participate in the live chat activity ( $t(447) = 0.44$ ,  $P = .66$ ). So, online engagement was not related to perceived usefulness of the internet in making health decisions.

### **Importance of access to online health resources**

Information about how the importance of access to online health resources is related to socio-demographic and personal characteristics is presented in Table 5. There were no significant differences in responses on the basis of gender ( $t(442) = 1.76$ ,  $P = .08$ ), Australian location ( $t(378) = 1.52$ ,  $P = .13$ ), being a health professional ( $t(447) = 0.97$ ,  $P = .33$ ), or bereavement ( $t(208) = 0.48$ ,  $P = .63$ ). Responses also did not differ between types of health professional ( $F(4, 335) = 1.54$ ,  $P = .19$ ), but did differ

by highest educational qualification ( $F(3, 445) = 5.71, P = .001$ ). Post-hoc pairwise comparisons with a Bonferroni correction for multiple testing revealed that participants who had undertaken university studies scored significantly higher than those who had completed trade school or equivalent, at a significance level of  $P < .05$ . On average, participants who had undertaken university studies also scored higher than those who had completed some high school and those who had completed high school, although these differences were not statistically significant. These results suggest that education level is positively associated with perceived importance of access to the internet for health resources. Responses were significantly, weakly, negatively correlated with age, indicating that younger people ascribe slightly greater importance to access to online health resources. However, importance of access to online health resources was not correlated with socioeconomic disadvantage, health-related quality of life, or self-rated health.

There was no significant relationship between responses to the item addressing importance of access to online health resources and agreement with the statement: “Social media provides different perspectives to mainstream media on death and dying” ( $r = .05, P = .33$ ). Likewise, there was no relationship between responses and course progress ( $\rho = -.05, P = .30$ ) or number of comments made during the MOOC ( $\rho = -.001, P = .98$ ). Finally, responses did not differ between participants who did ( $M = 4.04, SD = 1.06$ ) and did not ( $M = 4.08, SD = 0.85$ ) participate in the live chat activity ( $t(447) = 0.34, P = .74$ ). Thus, importance of access to health resources on the internet was unrelated to online engagement.

## Discussion

This study adds to a growing body of evidence around eHealth literacy, which is a significant consideration of how we conceive and provide health information across the community.<sup>6</sup> The data confirms the role of educational qualification as a strong predictor of eHealth literacy and also the influence of health professional status on eHealth literacy. The study also highlights the self-selective nature of participation, with the cohort participating in this MOOC having a higher than average eHEALS score. Again this is perhaps not surprising given that MOOCs generally attract participants with university qualifications.<sup>65</sup>

While this study used a convenience sample of students who were participating in an online learning activity, it provided a unique opportunity to examine eHealth literacy in a context of death and dying. This is an under-researched area and one of growing importance given population ageing and chronic disease progression. The next two decades will see increasing numbers of families and communities having to address the reality of increasing numbers of people coming to the end of their life. Online information will be critical in meeting this demand. Even though our data shows that education level influences the perception of the value of online health information, the importance of access to online health resources was not correlated with socioeconomic disadvantage, health-related quality of life, or self-rated

health. This suggests that a broader range of community members recognise its importance and that it should be possible to recognise this perception of value to support initiatives to encourage effective access and use. The data also indicated that once involved in the online activity, eHEALS differences did not appear to express as differences in the context of online engagement. MOOCs may therefore offer a useful vehicle for interaction in issues around death, dying and bereavement. Creating relevant and engaging content is likely to be critical in supporting initial and continuing participation.

While attracting good numbers, the MOOC cohort represented more educated and knowledgeable community members. They also suggest that providing content to meet needs across the life course and across the community needs to be carefully considered to ensure inclusive provision and participation. It is unclear whether limited participation of those with lower eHealth literacy reflect a lack of interest in the topic, an inability to navigate the digital environment, or a lack of awareness of the learning opportunity. This will be an important area for further work. However, to provide meaningful digital resources, it is necessary to ensure that the nature of the medium, the formats and presentation as well as the characteristics and information needs of the knowledge seeker are addressed.<sup>66, 67</sup>

Researchers and health care professionals need to consider how to identify specific areas or elements such as awareness, skills, or ability to evaluate where competency is variable and target eHealth literacy improvement interventions accordingly. eHEALS appears to offer an accessible mechanism for identifying digital health literacy, which also provides indications of competency in different aspects of digital health literacy.<sup>68</sup> It could therefore assist web developers and health researchers to consider if improvement interventions are needed where competencies are low and to focus on targeted interventions relating to the area of need.

Given this course was designed for the general public as an open conversation around death and dying rather than palliative care education for health professionals, the findings also highlight the need to consider how people will find or become aware of resources as well as how they interact or engage with them. All people will die and populations are increasingly diverse, so web and digital developers will need to consider what is inclusive design and delivery in an online environment and what is appropriate marketing to build awareness across population diversity. This goes beyond thoughtfulness around image choice, accessibility considerations, and social media messages to a fundamental consideration of audience, digital access within the target audiences, and their likely comfort in being able to find and use information online.

The challenges in creating inclusive content for the palliative care field are beginning to be recognised.<sup>11, 69</sup>

Social determinants of digital health are likely to have a profound influence on potential users of online palliative care information, resources and courses.<sup>69-71</sup> This may further exacerbate a general reluctance to talk about death and dying or address end of life planning in a death-denying world. Without consideration of how to approach meaningfully inclusive offerings and mechanisms to support awareness and encourage participation, we risk creating resources that will potentially advantage those who already have greater capacity to navigate complex systems.

## Limitations

This was a convenience sample providing insight into a group expressing interest in palliative care, death, and dying. It was by nature a self-defining group rather than a representative sample of the community. The cohort was clearly skewed with respect to some socio-demographic characteristics, with a high proportion of females and health professionals. We note that the results may have been different if we got participants to complete the eHeals in the first week of the course rather than week 4.

The generalisability of the findings of this study to the larger community needs to be determined in future research. It is worth noting that health professionals themselves may have information needs relating to death and dying not only as clinicians but as individuals. In the absence longitudinal data, it was also not possible to gather evidence on the causal direction of effects between variables. The set of predictors we had did not explain a sizable proportion of the variance in eHeals scores (only 5.6%) – thus other factors we did not consider/measure are at play when determining what leads to e-health-literacy.

# Conclusions

The participants in a MOOC about death and dying demonstrated a high level of eHealth literacy driven by university level qualifications and health professional status. Given that death is a universal experience and death rates will increase over the next two decades, there is a need to consider how to ensure online resources such as MOOCs can support a whole of population approach to information access and use.



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