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Breathing not wheezing: the development & piloting of an online asthma education intervention for older Australians

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**This thesis is presented in fulfilment of the requirements for the
award of the degree of Doctor of Philosophy
from the University of Wollongong**

**Breathing not Wheezing: the Development &
Piloting of an Online Asthma Education
Intervention for Older Australians**

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2013

CERTIFICATION

I, Pippa Burns, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Nursing, Midwifery and Indigenous Health, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Pippa Burns

15 October 2013

ABSTRACT

This doctoral thesis has been prepared in Type 2 - Journal Article Style, and addresses the development and piloting of an online asthma self-management education tool for use by older adults, consists of a literature review and five empirical papers. The Introduction provides the background to the research, which was part of a larger project funded by an Australian Research Council (ARC) Linkage Grant in partnership with Asthma Foundation NSW.

The burden of asthma mortality and morbidity currently lies with older adults and is likely to increase as the population ages, placing further pressure on the primary healthcare system. However, active self-management can improve symptom control, leading to fewer attacks and resulting in quality of life gains.

A user-centred design process was utilised to develop an intervention that met the needs of older adults. The first step in this process was the development of a paper-based survey. Data from the survey pilot is presented exploring the impact of various demographic variables on Internet use. While a surprising number of respondents were online (62%), this was more likely if they had a higher income (> \$40,000) or had completed tertiary education. Data from the main survey, completed by 4,060 people was explored in relation to health information sources used by older adults. The Internet was found to be the third most frequently used source of health information after doctors (96%) and pharmacists (60%) suggesting that the Internet has a role in providing education in the self-management of asthma.

The literature review, aimed to identify the “active ingredients” present in online interventions targeting older adults with chronic diseases, using Ritterband’s model of Internet Interventions. However, the diversity of interventions coupled with differences in reporting methods made it difficult to identify the “active ingredients”. As such, the candidate proposed the iSMURF (Internet Self-Management Uniform Reporting Framework) as a means of standardising the information reported. iSMURF consists of six domains: website design, support, study design, website use, user characteristics and reporting outcomes.

Data from both the paper-based survey and the focus groups is brought together to identify the types of asthma information older adults were interested in learning about and the types of technology with which they were happy to engage. It was found that the main topics of interest included the identification and avoidance of triggers, dealing with attacks, and the latest information about asthma. Despite huge advancements in interactive web-technologies such as blogs and forums, older adults expressed little interest in using such technology to learn about asthma. These findings informed the development of AsthmaWise.

User-centred testing was undertaken and is reported, this included usability testing using a sample of end users (older adults with asthma), a cognitive walk through by an independent researcher, and assessment of content readability. The issues identified through the usability testing were reported to the developer and AsthmaWise was subsequently refined. Finally, the piloting of the refined version of AsthmaWise over a three month period is reported. Matched data were obtained from 51 participants and showed significant improvements in asthma knowledge, asthma control, and asthma quality of life. Results from this pilot study suggest that this online asthma self-management education program is acceptable to older Australians with asthma.

This doctoral thesis provides a number of contributions to the literature. Primarily it shows that online asthma self-management education is acceptable to older adults and can result in improved self-reported outcomes. No evidence has been found to indicate that previous online asthma education programs have targeted older adults. Secondly, the thesis proposes the Internet Self-Management Uniform Reporting Framework (iSMURF) as a standardised reporting framework, which can be utilised in the future by researchers reporting Internet interventions targeting chronic diseases, enabling comparisons between studies.

STATEMENT OF VERIFICATION

This statement verifies that the greater part of the work in the above-named manuscripts is attributed to the candidate. Pippa Burns, under the guidance of her supervisors, took primary responsibility for the study design, all data collection and analysis and prepared the first draft of each manuscript. She then responded to editorial suggestions of co-authors (supervisors) and prepared the articles for submission to the relevant journals.

Pippa Burns (PhD Candidate)

Professor Sandra C Jones (Primary Supervisor)

PUBLICATIONS CONSTITUTING THIS THESIS

The chapters of this thesis have been prepared for publication.

Published

Burns P, Jones SC, Iverson D and Caputi P. (2012). Riding the wave or paddling in the shallows? Understanding older Australians' use of the Internet. *Health Promotion Journal of Australia*; 23 (2): 145-8; (Chapter 2).

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Burns, P, Jones, SC, Iverson, D, & Caputi, P. (In press). Internet Self-Management Uniform Reporting Framework: the need for uniform reporting criteria when reporting Internet interventions. *Computers, Informatics, Nursing*; (Chapter 4).

Burns, P, Jones, SC, Iverson, D, & Caputi, P. (2013). The devil is in the detail: determining the content of an Internet intervention for older adults with asthma. *Journal of Asthma & Allergy Educators, Early Online*, doi:10.1177/2150129713495057; (Chapter 5).

Burns, P, Jones, SC, Iverson, D, & Caputi, P. (2013). Usability testing of AsthmaWise with older adults. *Computers, Informatics, Nursing*, 31(5), 219–226; (Chapter 6).

Burns, P, Jones, SC, Iverson, D, & Caputi, P. (2013). AsthmaWise - a field of dreams? The results of an online education program targeting older adults with asthma. *Journal of Asthma, Early Online*, 1–8. doi:10.3109/02770903.2013.799688. (Chapter 7).

OTHER PUBLICATIONS AND PRESENTATIONS FROM THIS THESIS

The following publications and presentations resulted from work carried out for the thesis, but do not constitute the main body of this work.

Publications

Burns P. (2012). AsthmaWise: helping older adults manage their asthma. *Australian Nursing Journal*; 19 (9): 45; (Appendix E).

Jones SC, Iverson D, Burns P, Evers U, Caputi P, Morgan S. (2011). Asthma and ageing: an end user's perspective - the perception and problems with the management of asthma in the elderly. *Clinical and Experimental Allergy*; 41 (4): 471–81.

Conference Presentations

Jones SC, Burns P, Evers U, Iverson D, Caputi P, Andrews K, Morgan S & Goldman M. Breathing better: a multi component intervention to improve asthma awareness and outcomes in the elderly. Paper presented at: Tackling Asthma in Australia – the next 5 years; 2013 19-20 March; Canberra, Australia.

Jones SC, Burns P & Evers U. This is not normal - it's asthma. Paper presented at: International Conference on Communication in healthcare; 2012 4-7 September; St Andrews, Scotland; (Appendix F).

Burns P, Jones SC & Iverson D. Breathing not wheezing: developing an Internet intervention for older Australians with asthma. Presented at: Positive 2012; 2012 22-25 March; Wollongong, Australia; (Appendix G).

Burns P, Jones SC & Iverson D. The impact of self-efficacy on asthma management amongst older Australian adults. Presented at: Emerging Researchers in Ageing (ERA) 2011. 24-25 November; Sydney, Australia; (Appendix H).

Burns P, Jones SC & Iverson D. Profiling the silver surfers: which older Australians are using the Internet? Presented at: Emerging Researchers in Ageing (ERA) 2011. 24-25 November; Sydney, Australia; (Appendix I).

Burns P, Jones SC & Iverson D. Health Literacy and older adults with asthma. Presented at: Primary Health Care Conference 2011; 2011 13-15 July; Brisbane, Australia; (Appendix J).

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This thesis is dedicated to the memory of Frank Birch (my Uncle) and Janette Ellis (former colleague, PhD student and friend) who both passed away the week this thesis was submitted.

The electoral roll data was supplied by the Australian Electoral Commission in conformity with sections 91(4 A)(e) and 91(2 A)(c) of the Commonwealth Electoral Act 1918 and regulation 10 of the Electoral and Referendum Regulations.

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CHAPTER 1

INTRODUCTION

1.1 Asthma

In 2007-08, the prevalence of current asthma (that is a diagnosis of asthma by a health professional and still having asthma) in Australia was 8.9% for males of all ages and 10.9% for females, which equates to over two million people¹. Australian asthma rates are high by international standards and are only surpassed by those in New Zealand and the UK^{1,2}. The impact of asthma on sufferers is significant as people with an asthma diagnosis report lower quality of life and poorer self-rated health than those without asthma¹. Further, a study of older adults showed that those with asthma not only reported poorer health status, but worse psychological and physical morbidity than those without asthma³. As might be expected, having asthma leads to a higher proportion of days off work, school or study¹, which is further evidenced by 57% of respondents to a New South Wales (NSW) survey, of adults with asthma reporting that the condition interfered with their daily activities⁴.

1.2 The Cost of Asthma

Although the number of asthma deaths in Australia has decreased by 35% during the last decade, the risk of dying from asthma increases with age, as most deaths (76.7%) occur in people over 65 years of age^{1,5}. While asthma is not a major cause of death in Australia, its high prevalence rate is responsible for large health care expenditures⁶. The most recently available data estimate that \$606 million was spent on asthma in Australia in 2004/05, which equates to 1.2% of the total health budget¹.

1.3 Older People with Asthma

The prevalence of current asthma amongst women increases with age, while prevalence rates amongst males peak between 65 – 74 years (Figure 1-1)¹.

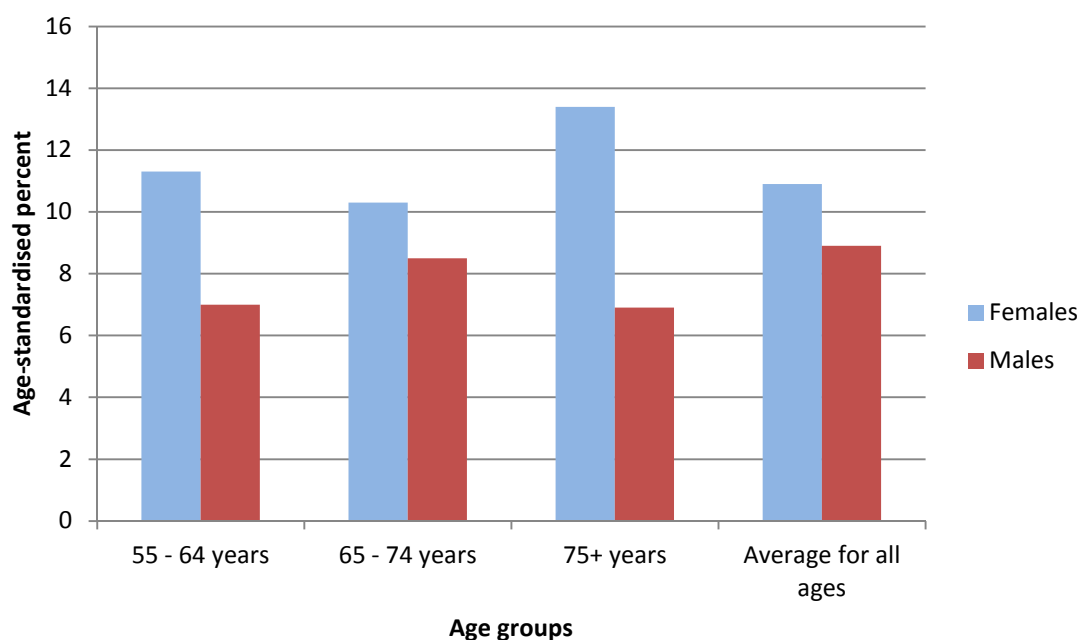


Figure 1-1: The prevalence of current asthma in older adults

The majority of older people with asthma can be classified into two groups; “long standing asthma” and “late onset asthma”^{6,7}. Those with long-standing asthma were diagnosed as children, whereas those with late-onset asthma were diagnosed after the age of 45 years when there is a noticeable change in asthma prevalence and it begins to co-occur with other health conditions⁶. The diagnosis of late-onset asthma can be complicated by a number of factors including the fact that breathlessness is often perceived as a normal sign of ageing⁷⁻¹⁰. Further, it has been suggested that because breathlessness is seen as “normal”, older adults feel unable to raise the issue with their GP in a meaningful way⁸. Secondly, older adults do not perceive the severity of their wheezing as accurately as younger adults¹¹. Thirdly, asthma symptoms can be similar to those of other diseases, particularly chronic obstructive pulmonary disorder (COPD), which are frequently seen in older people, complicating diagnosis;^{1,12,13}. The combination of these factors results in frequent misdiagnosis and under-diagnosis of asthma in older adults^{9,14}.

1.4 Self-Management of Asthma

Self-management has been described as a partnership between the patient and physician that addresses the medical, behavioural and emotional factors encountered when dealing with a chronic disease¹⁵. In Australia, optimal asthma self-management includes: self-monitoring, regular medication review by a doctor, and the use of a written asthma action plan¹⁶. For the majority of people active asthma self-management produces effective symptom control, fewer attacks, reduced morbidity and increased quality of life compared to passive management^{17–20}.

1.5 Self-Management by Older Patients

Asthma self-management in older patients can be complicated by the physical decline often seen with ageing (e.g. poor co-ordination, hand weakness due to arthritis, failing eye sight and declining cognitive function)^{21,22}. Further, it has been found that people with long-standing asthma often rely on coping methods learnt in childhood, which can be outdated and sub-optimal, compromising their asthma control²³.

As people age they are more likely to develop multimorbidities²⁴. A review of Australian studies found 80% of people over 65 years had three or more chronic conditions²⁵. The occurrence of asthma with other diseases complicates asthma diagnosis and management and increases the likelihood of adverse drug interactions^{7,13,21}.

1.6 Online Self-Management

Information technology can increase both understanding and participation in health care which in turn can increase empowerment²⁶. Internet self-management education programs are relatively cheap to deliver once initial set-up costs have been met and can be easily updated and edited. From a participant's view point such programs do not have the geographical or time constraints of traditional face-to-face programs and can be revisited as needed, at a time and place convenient to the participant. Internet delivered chronic disease self-management interventions have great potential, with previous studies and reviews variously showing improvements in self-efficacy,

disease knowledge, treatment adherence, health behaviours and health outcomes^{27–31}. However, such interventions have rarely targeted older adults despite the burden of chronic disease lying with this demographic, meaning that interventions targeting older adults can potentially produce the greatest benefits. This is particularly true for asthma where not only do older adults shoulder the burden of asthma mortality and morbidity, but there is also a current lack of asthma education specifically targeting this group.

1.7 Study Aims and Overview

This study was the first time an online self-management education program had been developed specifically for older adults. This PhD project aimed to:

1. Develop and pilot an Internet-delivered asthma self-management education program for older Australians.
2. Evaluate the feasibility and acceptability of an Internet-delivered asthma self-management education program for older Australians with asthma.

The term ‘older adult’ is used to refer to people aged 55 years and over. User-centred design methodology was utilised in order to achieve these aims. This involves the end-user in all stages of product development, ensuring that the final product matches its purpose. Thus the following steps were undertaken: (1) a paper-based survey was developed and sent to 9,000 randomly selected older adults residing in New South Wales, Australia. The survey was carried out by both PhD students with individual sets of questions pertinent to each project. The results from the pilot study were used to establish the number of older adults using the Internet (Chapter 2), while the results from the main study identified sources of health information used by older adults’ (Chapter 3). (2) An extensive literature review was conducted to identify the components of effective Internet interventions targeting older adults (Chapter 4). (3) Focus groups were conducted to determine the best ways to present information to older asthmatics (Chapter 5). (4) AsthmaWise, an online asthma self-management education program, was developed based on the results of the formative research (points 1 – 3), the Australian National Asthma Treatment Guidelines¹⁶ and the Theory of Planned Behaviour³³. Usability testing was conducted with a group of

end-users. An independent researcher also carried out a ‘cognitive walk through’ and the readability of the content was also assessed (Chapter 6). (5) AsthmaWise was subsequently refined and piloted for a three-month period at the beginning of 2012. Pre and post-test matched data were obtained from 51 individuals (Chapter 7).

1.8 Thesis Style

This work was one of two PhD projects funded by an Australian Research Council Industry Linkage Grant between the Centre for Health Initiatives, University of Wollongong and Asthma Foundation of New South Wales. This thesis has been prepared in Style 2, Journal Article Style format, which fulfils the requirements of Doctor of Philosophy³². Each chapter has either been published or submitted for publication and is presented in the style that it was submitted to each journal.

1.9 Significance and originality of this research

This PhD thesis presents innovative research that used a user-centred approach to design, develop and pilot test an online self-management education targeting older adults with asthma. Despite older adults being recognised as shouldering the burden of asthma mortality and morbidity and having a “unique” asthma experience due to their age, I believe this is the first time that an online asthma education has focussed solely on older adults.

Chapters 2 and 3 add to the current, limited knowledge base regarding use of the Internet and sources of health information utilised by older adults. While this is a continually changing landscape, these papers provide a snapshot of current trends in Australia.

The literature review (Chapter 4), identified problems in the consistency of reporting of internet interventions. This resulted in the proposal of the Internet Self-Management Uniform Reporting Framework (iSMURF) a standardised reporting framework that can be adopted by researchers testing interventions targeting chronic diseases. Future adoption of iSMURF would enable easy comparison of online interventions and ultimately progress the field of internet interventions by aiding the

identification of the “active ingredients” – those component(s) that make online self-management education successful.

Chapters 5 and 6 detail the formative research undertaken to guide content delivery and presentation style, as well as the usability testing conducted with the AsthmaWise prototype. These findings are novel as little has been written about older adults’ preferences regarding the presentation of health information. Further, I could find no evidence of reporting of older adults using Moodle as an education platform nor information on the use of Morae for usability testing with this population.

The final chapter, Chapter 7, shows that online asthma education can be successfully used amongst older adults, with results indicating significant improvements in asthma knowledge, asthma control and asthma quality of life. The thesis concludes with a chapter discussing the overall findings and limitations from this body of work.

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CHAPTER 2

RIDING THE WAVE OR PADDLING IN THE SHALLOWS? UNDERSTANDING OLDER AUSTRALIANS' USE OF THE INTERNET

This chapter was published in the August 2012 issue of the Health Promotion Journal of Australia.

Burns P, Jones SC, Iverson D and Caputi P. (2012). Riding the wave or paddling in the shallows? Understanding older Australians' use of the Internet. *Health Promotion Journal of Australia*; 23 (2): 145-8.

This chapter uses the data gained from the pilot survey of 115 older adults to explore Internet use amongst older Australians. The majority of respondents reported using the Internet; however, use decreased with age. Those online reported high confidence levels, long-term use and a history of searching for health information. These results suggest that older adults have the skills to access online health information.

2.1 Abstract

Issues addressed

Australia's ageing population is set to become an increasing burden on an already over stretched primary health care system. Potential strategies to alleviate this pressure need to be investigated. Increased knowledge of older Australians' use of the Internet would allow the appropriateness of online health intervention to be assessed.

This initial, exploratory study examined the proportion of people aged 55 years and over who accessed the Internet, and investigated their duration of use, level of comfort, use of the Internet to seek health information and perceived reliability of information found on the Internet.

Methods

A paper based survey was distributed to a purposive sample of adults in metropolitan New South Wales. Complete data was received from 115 respondents.

Results

Sixty two percent of respondents reported Internet use, with use decreasing with age. The majority of respondents who used the Internet reported high confidence levels and long-term use. The majority had used the Internet to search for health information which was generally perceived to be reliable. Logistic regression showed tertiary education and household income greater than \$40,000 per annum predicted use of a computer to access the Internet.

Conclusions

The majority of older Australians surveyed were successfully riding the Internet wave. They have both the skills and equipment to access health information online and many are already doing so.

So what: These results suggest that older adults are likely to access e-health initiatives and that such strategies have the potential to complement existing health services.

2.2 Introduction

The ageing of the Australian population will be accompanied by an increase in chronic disease incidence and prevalence, and general declining physical health¹. It is recognised that these changes will push primary health care services beyond capacity².

The internet has long been recognised as an appealing channel for the communication of health information. It is a low cost, dynamic medium with a vast reach – that allows users to view information at a time and place convenient to them, and revisit the information as and when they need it. This reduces the burden of both time and travel on the user; for some conditions the stigma associated with attending face-to-face clinics. The internet has been shown to provide information that can result in changes to health knowledge, attitudes, skills and behaviour whilst also enhancing social support³⁻⁵.

Consumer e-health is an umbrella term used to describe online health information resources. These resources have been divided into five categories: peer to peer online support groups; self management applications; decision aids; personal health records; and internet use⁶.

Whilst the potential of e-health is undisputed, little is known about the extent of internet use amongst the Australian population aged 55 years and over. Such knowledge would allow health practitioners to develop targeted internet campaigns for older adults.

In August 2010, we conducted a small-scale survey study with a convenience sample of adults, who were aged 55 years and over. The aim of the survey was to establish the health practices, beliefs, attitudes of older Australians towards asthma. This article reports on the findings related to internet use. We describe respondents' demographic characteristics and the relationship of these characteristics to internet use, use of the internet to find health information and perceived reliability of information on the internet.

2.3 Methods

Potential respondents were approached on trains travelling between two metropolitan regions in New South Wales. One hundred and fifty six surveys were distributed, with 118 completed and returned (response rate of 75.6%). Respondents who returned the questionnaire were offered a five-dollar coffee voucher. The survey contained 14 questions which asked about computer and internet use.

Prior to the study, question validity was ensured through expert review and the use of cognitive interviews⁷. Approval for this study was granted through the University's Human Research Ethics Committee.

2.4 Results

One hundred and fifteen of the returned surveys were from respondents who met the study's age requirement and provided complete data. This included 72 people (62%) who reported using a computer to access the Internet.

Internet use decreased with age (Table 2-1). The majority of Internet users spoke English (96%), were tertiary educated (70%), owned their own home (84%), had an income of \$40,000 or less per annum (54%), with 50% receiving a government pension, allowance or benefit, and reported being in good health (88%).

A direct logistic regression analysis was performed which aimed to predict use of a computer to access the Internet. Five independent variables were used as predictors: age bracket, health status, education level attained, household income, and language spoken at home.

Table 2-1: Demographic characteristics of respondents

Variable	Used the Internet (%)	Never used Internet (%)
Gender		
Male	24 (73)	9 (27)
Female	48 (64)	27 (36)
Age		
55-59	11 (85)	1 (15)
60-64	15 (71)	3 (29)
65-69	20 (61)	12 (39)
70-74	15 (58)	9 (42)
75+	11 (50)	11 (50)

A test of the full model with all five predictors was statistically reliable ($\chi^2(df=10, n=115)=29.908, p=.001$) indicating that the variables as a set reliably distinguish between people who use computers to access the Internet and those who do not.

Prediction success was high, with 90% of Internet users being correctly classified; 57% of non-users correctly being identified. The overall prediction success rate was 80%.

According to the Wald criterion two variables made a significant contribution to the prediction: tertiary education ($z=8.604, p=.003$) and household income greater than \$40,000 per annum ($z=4.515, p=.034$).

Over half of the respondents had used the Internet to search for health information (Table 2-2). Logistic regression was again used to predict the use of the Internet to find health information. Five independent variables were used: age bracket, health status, education level attained, household income and perceived reliability of information found online. The test was not statistically significant ($\chi^2(df=9, n=115)=12.164, p=.204$), suggesting that these variables do not explain predilection to find health information on the Internet.

More than two-fifths of respondents who used the Internet, perceived information found on the Internet to be mostly or completely reliable (Table 2-2). Logistic regression was used to predict the perceived reliability of information on the Internet. Three independent variables were used: age bracket, education level attained and household income. The test was not statistically significant ($\chi^2(df=7, n=115)=6.882, p=.441$), suggesting that these variables do not explain perceived reliability of online information.

In terms of computer hardware and software, most respondents owned a computer that was less than three years old (71%), and the majority were using Internet Explorer as a web browser (75%). The average respondent spent 3.2 hours using the Internet each week; 89% reported having an email address.

In our sample most Internet users were long-term users with high comfort levels, who accessed the Internet through broadband connections at home or at work (Table 2-2).

2.5 Discussion

The results show high rates of internet use amongst our sample with the majority of 55-59 year olds reported internet use (85%), and 50% of those aged 75 year or older reported having been online. By comparison the Internet Access at Home report, using data from 2006/07, noted that just over half (52%) of 55-64 year olds in Australia had used the internet, with the rate falling sharply to just 11% of those aged 75 years and older⁸. The difference in reported internet use is likely to be due to the combined effects of our sampling frame and changes in internet access over time. It is argued that the current heterogeneous profile of online seniors will change as the baby boomers age, as this generation is likely to retain the information technology skills learnt in the workplace⁹⁻¹¹.

Table 2-2: Demographic characteristics of respondents who used the Internet

Variable	Total (%)	Respondents aged 55 – 64 years (%)	Respondents aged 65 years and over (%)
Level of education			
Completed primary school/ Some secondary school	4 (5.7)	2 (7.6)	2 (4.5)
Completed secondary school	17 (24.3)	7 (26.9)	10 (22.7)
Completed tertiary studies	49 (70.0)	17 (65.4)	32 (72.7)
Household income			
< \$40,000	37 (53.6)	10 (40.0)	27 (61.4)
>\$40,001	27 (39.1)	13 (52.0)	14 (31.8)
Don't know	5 (7.2)	2 (8.0)	3 (6.8)
House ownership			
Owned outright/with a mortgage	59 (84.3)	21 (84.0)	38 (84.4)
Rented privately/ occupied rent free	7 (10.0)	2 (8.0)	5 (11.1)
Rented from Government Authority	3 (4.3)	2 (8.0)	1 (2.2)
Aged care facility	1 (1.4)	0 (0)	1 (2.2)
Health rating			
Very good/ Excellent	35 (52.2)	11 (47.8)	24 (54.5)
Good	24 (35.8)	8 (34.8)	16 (36.4)
Poor/Fair	8 (11.9)	4 (17.4)	4 (9.1)
Years using the Internet			
< 1 year	6 (8.3)	3 (11.5)	3 (6.5)
1–5 years	17 (23.6)	3 (11.5)	14 (30.5)
>5 years	49 (68.1)	20 (76.9)	29 (63.0)
Comfort level with using the Internet			
Not at all	5 (6.9)	1 (3.8)	4 (8.7)
Comfortable/ very comfortable	67 (93.0)	25 (96.1)	42 (91.2)
Hours spent using the Internet each week			
<2 hours	29 (40.8)	10 (38.4)	19 (42.3)
3-9 hours	27 (38.0)	9 (34.6)	18 (40.0)
>10 hours	15 (21.2)	7 (26.9)	8 (17.8)
Internet access location, at least weekly (multiple answers permitted)			
Home	60 (84.5)	21 (80.7)	39 (86.7)
Work	12 (25.0)	9 (47.4)	3 (10.3)
Library	4 (7.9)	3 (15.0)	1 (3.2)
Phone	4 (7.9)	3 (15.8)	1 (3.1)
Friend/relative's	1 (2.0)	1 (5.3)	0 (0)
Computer age			
<3 years	50 (70.5)	18 (69.3)	32 (71.1)
>3 years	17 (23.9)	5 (19.2)	12 (26.7)
Don't know /don't own a computer	4 (5.6)	3 (11.5)	1 (2.2)
Internet browser (top three answers displayed)			
Internet Explorer	52 (75.4)	20 (76.9)	32 (74.4)
Firefox	8 (11.6)	3 (11.5)	5 (11.6)
Safari	6 (8.7)	2 (7.7)	4 (9.3)
Type of Internet connection			
Broadband	55 (77.5)	19 (73.1)	36 (80.0)
Dial-up	9 (12.7)	4 (15.4)	5 (11.1)
Mobile phone	1 (1.4)	0 (0)	1 (2.2)
Satellite	1 (1.4)	0 (0)	1 (2.2)
Don't know/other	5 (7.0)	3 (11.5)	2 (4.4)
Health information			
Used the Internet to search for health information	46 (63.9)	18 (69.2)	28 (60.9)
Reliability of health information on the Internet			
Not at all/Not very	20 (30.8)	9 (37.5)	11 (26.9)
Mostly/Completely	28 (43.1)	11 (45.8)	17 (41.5)
Not Sure	17 (26.2)	4 (16.7)	13 (31.7)

Numbers have been rounded by SPSS

Strong associations between level of education attained, household income and internet use were seen which is consistent with other studies^{8,12,13}. This indicates that both level of education and level of household income continue to create a digital divide, separating those who use the internet from those who do not.

Reported average weekly internet usage among our sample was less than other studies examining similar populations. It is possible that this difference was due to face-to-face recruitment and use of a paper based survey tool which may have enabled capture of data from light to moderate internet users, as opposed to the use of an online tool and online recruitment which is predisposed to attract people who are online more frequently¹².

Internet use for more than five years was higher than expected in our sample (68%). Patterns of long-term internet use reported by other Australian studies vary, with a 2009 study finding just 47% of people aged eighteen years and older reported internet use of 5-10 years¹³. Another study, looking at internet use among people aged 55 years and over (the same as our sample), reported approximately 80% of respondents had used the internet for more than five years¹⁴. However, this study utilised purposive online sampling, which would have excluded both less experienced internet users and those who were off-line.

High rates of online health information seeking were found; which is consistent with US studies conducted between 2003 and 2008¹⁵⁻¹⁷. While trust in online health information was moderate among our respondents (43%), this is likely to increase over time as the baby boomers are reported to have greater trust in online sources than those aged over 65 years¹⁸. Further research is needed to explore the factors that contribute to trust in online health information sources in this population, including both website design and recommendations from health professionals.

The recruitment of participants on trains proved highly successful; this is likely due to relatively long journey times. The number of respondents who spoke English at home was higher than that for the NSW population as a whole¹⁹, this may be attributed to the nature of the research tool, a written survey in English.

The generalisability of the results is limited by both small sample size and place of residence as it is recognised that people living in regional and remote Australia are less likely to be online⁸. Further, the survey did not attempt to identify ex-internet users or explore reasons for not using the internet. Nor did it attempt to elicit what if any action occurred as a result of the health information found online. Future, larger studies looking at Australian populations should explore the relationship between use of the internet to obtain health information, and self-reported health status.

Our results suggest that future e-health strategies aimed at this demographic should be optimised for viewing in Internet Explorer using relatively new computers. While the internet has many benefits as a source of health information, it also has a number of drawbacks that need to be acknowledged. These include: access to the internet (both physical access and technological literacy) and access to the information presented (health literacy)²⁰; sites presented only in English are likely to exclude those from culturally and linguistically diverse backgrounds (CALD)⁵; concerns about confidentiality of personal details entered online; and site quality and credibility as the nature of the internet allows anyone to publish a website or blog²⁰. This final point may be somewhat overcome by encouraging health care practitioners to recommend trustworthy sites to patients⁶.

Research is needed to investigate the format of e-health information that older Australians find most acceptable. This knowledge could be utilised to develop e-health education aimed at older adults to complement existing services. There has been little research into the use of e-health in health promotion, and this has been attributed to the dearth of models available to guide the design and evaluation processes²⁰.

Our results show that older adults are riding the internet wave, with more being online than expected. The majority of respondents were confident, long-term users, with up-to-date equipment, who utilise health information online. Further, it is likely that the profile of online older adults will continue to change with the ageing of the population. This makes the internet an attractive and economical mode for health communication, particularly as older adults are the greatest users of health care

resources. However, since both level of household income and level of education achieved continue to function as barriers to internet access and usage, the internet should not be the sole channel of health communication with older adults.

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CHAPTER 3

WHERE DO OLDER AUSTRALIANS GET THEIR HEALTH INFORMATION? HEALTH INFORMATION SOURCES AND THEIR PERCEIVED RELIABILITY

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This chapter explores results from the paper based survey (n=4,066, response rate = 46.8%) looking at where older adults receive their health information and their perception of the reliability of each source. Doctors and pharmacists were the most commonly reported sources of health information and were also perceived as most reliable. While nurses were not reported as often providing health information, they were perceived as reliable sources of health information. The Internet was the third most likely source of health information, however, perceived reliability was low. However, the popularity of the Internet as a health information source is likely to increase as the Baby Boomers age.

(A copy of the survey appears in Appendix A)

3.1 Abstract

Background

Chronic disease prevalence is increasing, in part due to the ageing population, adding further pressure to Australia's over-stretched primary health care services. While patients are encouraged to self-manage their chronic disease(s) in order to minimise the impact on their day-to-day functioning, little is known about where older adults' receive health information and their perceptions of the reliability of these sources. Such knowledge would facilitate the development of self-management support strategies using health information sources that are acceptable to older adults.

Methods

A cross-sectional design was utilised to investigate where older adults receive their health information and their perceptions of the perceived reliability of these sources. A paper-based survey was completed by 4,066 randomly selected adults (response rate = 46.8%) aged 55 years and older, who were resident in New South Wales, Australia.

Results

Doctors (96%), pharmacists (60%) and the Internet (24%) were the most frequent providers of health information. Less than one-fifth of respondents reported having received health information from a nurse (18%). However, the health information sources perceived to be the most reliable were doctors (98%), pharmacists (74%) and nurses (34%).

Discussion

Our results suggest that in Australia older adults primarily use doctors as a source of reliable health information and that nurses are underutilised in the provision of health information. The reasons for this need to be further investigated to ensure that nurses play an optimal role in the primary health care team. Although the Internet proved to be a popular source of health information, levels of perceived reliability were comparatively low. Future research should investigate whether the promotion of credible websites by health care professionals can overcome this barrier.

3.2 Introduction

In Australia it is projected that by 2051 more than one in four people will be aged over 65 years¹; a potential doubling of the current older adult population. As chronic disease prevalence increases as people age^{2,3}, this will result in a rise in the burden of chronic disease, which in turn will lead to an increasing number of General Practitioner (GP/Family Physician) encounters and a greater number of health problems being presented at each encounter. GPs are already reporting working under mounting pressure caused, in part, by the rising number of older patients with chronic disease(s)⁴. Some of the factors identified which contribute to this pressure include lack of funding, lack of time and lack of space in which to provide chronic disease self-management support⁵.

Chronic disease self-management encourages patients to be actively involved in the management of their disease(s). This encompasses managing their symptoms and treatment as well as reducing the impact of their illness on their lifestyle^{6,7}. Effective self-management requires patients to work in partnership with their family, carers and healthcare provider(s) to manage their disease. The Australian National Chronic Disease Strategy describes self-management as supporting the patient to:

- (1) understand the nature of their illness including risk factors and co-morbidities,
- (2) have knowledge of their treatment options and be able to make informed choices regarding treatment,
- (3) actively participate in decision making in partnership with health professionals, family and carers and other supports in terms of continuing care,
- (4) follow a treatment or care plan that has been negotiated and agreed with their health care providers, family and carers and other supports,
- (5) monitor signs and symptoms of change in their health condition and have an action plan to respond to identified changes,
- (6) manage the impact of the disease on their physical, emotional and social life and have better mental health and wellbeing as a result,
- (7) adopt a lifestyle that reduces risk and promotes health through prevention and early intervention, and

(8) have confidence in their ability to use support services and make decisions regarding their health and quality of life³.

It is clear that individuals need to have a broad skill base in order to maximise their quality of life through self-management. These skills include: communication, information seeking, analysis and decision making – which, in turn, necessitates access to reliable health information. However, little is known about where older Australians receive their health information or what sources they perceive as reliable.

Despite access to health information being central to chronic disease self-management, little reference to health information sources could be identified in the literature, with only one research paper from 1989 that looked at age⁸. This is surprising as it can be assumed that older adults would have a greater need for health information than other age groups, as people tend to develop more health issues as they age. The other papers identified were specific to cancer patients^{9,10}, focused solely on the Internet as a source of health information^{11–14}, or examined provision of information about prescription drugs¹⁵. Improved knowledge regarding the health information sources used by older adults has health promotion implications, as it can be used to increase access to health information.

This paper explores the effects of demographic variables - age, sex, level of education attained and household income - on health information sources used by older adults', and their perception of the reliability of these sources. Such knowledge used in the future provision of self-management support through health information sources that are both used and trusted by the target population. This information will become even more pertinent as the population continues to age and the burden of chronic disease increases.

3.3 Methods

This study utilised a descriptive, cross-sectional design to investigate where older adults receive their health information and their perceptions of the perceived reliability of these sources.

3.3.1 Survey instrument development

A paper-based survey was developed to examine the beliefs and attitudes of older adults towards asthma. The survey was reviewed by experts in the field of asthma to ensure face validity. Cognitive interviews, using the think-aloud technique, were conducted with a convenience sample of 13 older adults, to ensure that the questions were interpreted correctly^{16,17}. The researchers visited participants in their homes and recorded all interviews. The participants were asked to read the survey questions and response options out-loud and to explain their thought process. As a result of this process survey questions were re-ordered and the survey format was altered. The survey was subsequently piloted with a second convenience sample (n=115) accessed through community groups or whilst they were travelling on public transport. This pilot study led to further survey refinements such as changes to response scales in order to minimise question skipping and missing data.

The final survey contained three items related to health information sources. The first item asked respondents “Which of the following sources have you used to obtain health information?” - GP/doctor; nurse; pharmacist; relative/friend; brochures/pamphlets; Internet websites; magazines; television; newspapers; and radio. A second item asked respondents to identify “Which of the following sources of health information would you rate as reliable (providing accurate information)?”. An open-ended question was used to explore why participants felt sources were or were not reliable.

3.3.2 Recruitment and sampling

In October 2010, the survey was mailed to 9,000 people aged 55 years and over, living in three discreet regions of New South Wales, Australia, whose details had been randomly selected by the Australian Electoral Commission. The areas included metropolitan, regional and remote locations. Participants were sent a package containing: a letter explaining the research, a survey form, and a reply paid envelope. Reminder postcards were mailed out after three weeks and a second copy of the package was sent out four weeks subsequently. This amended version of Dillman’s tailored design method was used to optimise the response rate¹⁷. Surveys were coded

to avoid unnecessary contact with those participants who had already responded. Ethics approval was obtained from the University's Ethics Committee; consent to participate was implied by the return of the survey.

3.3.3 Data analysis

The survey data were entered and analysed in SPSS v. 17. To check data entry accuracy, five percent of responses were re-entered, yielding an error rate of 0.175%. Pearson's chi-square tests were initially run to assess differences in the use of the various health information sources. Hierarchical log-linear analyses were subsequently used to investigate the impact of demographic variables (age, sex, level of education achieved and household income) on use of each health information source (doctors, nurses, pharmacists, relatives, brochures, websites, magazines, television, newspapers and radio).

Pearson's chi-square tests were also conducted to investigate differences between the perceived reliability of each health information sources. Chi-square tests for goodness of fit allowed the examination of the perceived reliability of the health information provided by health care providers. Hierarchical log-linear analyses were then used to investigate the impact of demographic variables (age, sex, level of education achieved and household income) on the perceived reliability of each health information source (doctors, nurses, pharmacists, relatives, brochures, websites, magazines, television, newspapers and radio). Cohen's w was calculated as a measure of effect size, providing a measure of the strength of the relationship between the variables¹⁸.

Responses to the open ended question were explored using Leximancer v3.5, a text analytics tool which produces theme and concept maps from text based documents¹⁹. The data were exported into Microsoft Word. A spell check was run and abbreviated words were replaced (e.g. Dr was replaced with doctor). The file was then opened in Leximancer and a thematic map produced. Because the responses being analysed were from a short-answer survey both 'sentences per block' and 'concept learning settings, phrase separation' were reduced to one. The following concepts were

merged: 'info' and 'information'; 'doctor' and 'GP'; and 'nurse' and 'nurses'. The terms 'usually' and 'etc' were removed. The thematic map was developed several times to ensure concept stability²⁰.

3.4 Results

A total of 4,066 eligible surveys were returned (response rate of 46.8%). The mean age of respondents was 67.9 years (SD=9.01; range =55-96 years), with slightly more females (54.8%) than males. Six percent of respondents spoke a language other than English at home.

3.4.1 Health Information Sources

Table 3-1 summarises the percentage of respondents receiving health information from each source and their perceived reliability of each sources. Doctors (96%) and pharmacists (60%) were most frequently used to obtain health information and were also perceived to be most likely to provide accurate health information (98% and 74% respectively). The radio was the least frequently reported source of health information (11.6%). Few people reported perceiving health information gained from media sources as reliable: television 6.3%, radio 4.8%, magazines 4.3% and newspapers 4.3%.

Pearson's chi-square test results indicated a significant difference ($p < .001$) in use of each health information source. Hierarchical log-linear analysis showed that demographic variables were found to have a statistically significant impact on choice of health information source (Table 3-2). The use of doctors as a health information source was only associated with age, with those aged over 75 years significantly less likely to have received health information from doctors than respondents in other age groups ($p = .007$). While respondents who had completed tertiary education were significantly more likely to have used nurses as a health information source ($p = .000$). The use of both friends/relatives and newspapers were significantly influenced by all variables except age (sex, $p = .019$; education $p = .037$ and household income

Table 3-1: Summary of health information sources and perceived reliability

Health Information Source	Source used (%)	Perceived as reliable (%)	Source used & perceived as reliable (%)	Source used & not perceived as reliable (%)	Source not used but perceived as reliable (%)	Source neither used nor perceived as reliable (%)	Chi-square test p value
Doctors	95.8	97.9	95.1	0.7	2.8	1.3	.000
Nurses	17.8	34.1	15.4	2.4	18.7	63.6	.000
Pharmacists	59.6	73.9	56.4	3.2	17.5	22.9	.000
Relatives/friends	15.1	6.3	5.2	9.9	1.1	83.8	.000
Brochures/pamphlets	23.4	15.6	11.4	12.0	4.2	72.4	.000
Internet websites	24.5	13.7	11.5	13.0	2.2	73.4	.000
Magazines	15.8	4.3	3.6	12.2	0.7	83.5	.000
Television	19.7	6.3	5.3	14.4	1.0	79.3	.000
Newspapers	14.7	4.3	3.5	11.2	0.8	84.5	.000
Radio	11.5	4.8	3.8	7.7	1.0	87.4	.000

$p = .037$); whereas the use of brochures and the television for health information was impacted by all variables except income. The results indicate that the use of some health information sources was impacted by the combined effect of two or more demographic variables. Some of these results were highly significant ($p < .01$): both age and education impacted the use of doctors as a health education source ($p = .005$); and age, income and education affected the use of pharmacists ($p = .004$) (Table 3-2).

3.4.2 Perceived reliability of health information sources

Pearson's chi-square tests showed significant differences in the level of perceived reliability across sources ($p < .001$). Significantly more respondents felt that health information obtained from doctors was reliable, compared to pharmacists [$\chi^2(1, N=3950)=134.12, p=.000$] or nurses [$\chi^2(1, N=3950)=1223.76, p=.000$]; and pharmacists were perceived as providing more reliable health information than nurses [$\chi^2(1, N=3950)=580.09, p=.000$]. When looking at the difference in trust between doctors and pharmacists Cohen's w was 0.140, indicating a small effect size. Conversely, the value calculated for doctors and nurses (0.484), and pharmacists and nurses (0.369) indicated a medium effect size.

Table 3-2: Relationships between demographic variables and health information source

Sources	Age (p-value)	Sex (p-value)	Education Level Attained (p-value)	Household Income (p-value)	Higher-Order Effects (p-value)
Doctors	.007	.520	.423	.645	.005 - age x education
Nurses	.113	.051	.000	.077	.031 - age x sex
Pharmacists	.002	.000	.037	.011	.004 - age x income x education
Relatives	.077	.019	.037	.037	
Brochures	.000	.000	.000	.063	
Websites	.000	.000	.000	.000	.026 - age x sex
Magazines	.000	.000	.015	.008	
Television	.000	.000	.005	.104	
Newspapers	.344	.017	.000	.000	.031 - income x education .049 - sex x education .044 - sex x income
Radio	.005	.013	.003	.000	.035 - sex x education

Hierarchical log-linear analysis showed that some demographic variables had a statistically significant impact on perceived reliability of health information source (Table 3-3). The age of respondents was seen to affect the perceived reliability of health information obtained from pharmacists ($p = .021$), websites ($p = .000$), television ($p = .032$) and magazines ($p = .025$). While respondents' sex affected perceived reliability of pharmacists ($p = .000$) and level of education attained by the respondents affected the perceived reliability of nurses ($p = .006$), pharmacists ($p = .000$), websites ($p = .000$) and newspapers ($p = .000$). Finally, household income was associated with perceived reliability of websites ($p = .000$), newspapers ($p = .001$) and radio ($p = .000$).

The results indicated that the perceived reliability of some health information sources was impacted by the combined effect of two or more demographic variables. Again, a number of these findings were highly significant ($p < .01$); the perception of pharmacists as a reliable source of information was determined by sex, age and education ($p = .001$) and the reliability of health information in magazines was impacted by both age and education ($p = .009$).

Table 3-3: Relationships between demographic variables and perceived reliability of health information sources

Reliability	Age (p-value)	Sex (p-value)	Education Level Attained (p-value)	Household Income (p-value)	Higher-Order Effects (p-value)
Doctors	.498	.287	.664	.708	
Nurses	.075	.980	.006	.188	.038 - sex x age x education
Pharmacists	.021	.000	.000	.608	.001 - sex x age x education
Relatives	.697	.548	.546	.199	
Brochures	.000	.000	.000	.038	.025 - sex x education
Websites	.000	.096	.000	.000	.043 - age x income
Magazines	.025	.750	.438	.155	.009 - age x education .018 - age x education x income
Television	.032	.601	.933	.293	.046 - age x education
Newspapers	.379	.781	.000	.001	.011 - age x education
Radio	.392	.868	.120	.000	.051 - age x sex .024 - age x education x income .023 - age x sex x income

Leximancer was used to produce a thematic map exploring the responses given to the open-ended question. The theme size was set at 20% and the visible concepts were set at 0%. The concepts are clustered into theme circles, which are named after the most prominent concept. Concepts that co-occur map closely indicating that they are related in some way. Larger shapes represent the concepts that occurred most frequently in the responses. The most common connection between concepts is shown by the grey pathway. The Leximancer insight dashboard was used to explore the reasons behind these concepts. Figure 3-1 shows that ‘training’ and ‘qualified’ grouped closely with ‘GP’ and ‘trust’. Many of the responses referred positively to the training or education received by health care professionals.

“They are reliable because of the amount of study they do.”

“They are reliable due to their level of education and ongoing updates in their care of patients/customers.”

“This is what they were trained for.”

3.4.3 Healthcare Professionals

Exploration of the concepts related to health care professionals (doctors, nurses and pharmacists) again reflect the importance of the health care practitioner’s training and education.

“GP/doctors and pharmacists are well qualified and offer unbiased information.”

“I expect the doctors, pharmacist would be updating their knowledge, often, so as to be able to help patients with new and modern (current) information on cures or medications to assist their patients’ wellbeing.”

“If you can't trust your doctor who can you trust?”

While there was some acknowledgement of nurses' training and experience in health care, many comments referred to respondents' social exposure to nurses, often through family relationships.

"Doctors, pharmacist and nurses have experience and health is their vocation. Therefore usually very reliable advice is given."

"My daughter is a nurse of 30 years experience (at) XXXX Hospital."

"My wife is a nurse and explains things simply to me."

3.5 Discussion

Doctors (96%) and pharmacists (60%) were the two most frequently cited sources of health information, suggesting that older adults in Australia prefer to receive their health information face-to-face from their health care practitioners. However, just 18% of respondents reported using nurses to obtain health information, making nurses the sixth most likely source of health information. It is not clear why older Australians do not more readily use nurses as a source of health information. It is notable that many older adults perceive nurses as providing reliable health information, but had not received health information from a nurse (18.7% - Table 3-1). This figure was higher than the number of respondents who perceived nurses as a reliable source of health information and reported having received health information from a nurse (15.4% - Table 3-1). This suggests that Australian nurses have potential to provide greater amounts of health information to older adults in the future. This discrepancy between use of nurses for health information and the perceived reliability of health information gained from nurses may be unique to Australia, as traditionally nurses in Australia have been hospital based. This differs from their role in both the UK and US where nurses have played an integral role in primary health care for many years^{21,22}. In the past, only people admitted to hospital in Australia would have had much contact with nurses. However, the gradual introduction of Practice Nurses into primary health is likely to increase the numbers of people having contact with nurses, increasing their use as providers of health information. Further research is needed to explain why nurses are not currently used

as a source of health information by older adults in Australia and whether this perceived lack of utility is related to the perceived knowledge and training of nurses or to older adults exposure to nurses, in both medical and social settings.

The Internet was the third most commonly used source of health information amongst our sample (24%). The use of the Internet as a health information source was inversely related to age with 40.4% of 55-60 year olds using this channel compared to just 0.3% of respondents aged over 75 years; this is consistent with other work²³⁻²⁵. These rates suggest that there is scope for the provision of health information via the Internet for the young olds. Further, it has been postulated that the Baby Boomers, those born between 1943 and 1960 (currently aged 53 – 70 years)²⁶, will be the first generation to reach older age that have acquired computer skills in the workplace, and that these information technology skills will be retained as they age^{27,28}. Over time, this skill retainment will shift the demographic profile of Internet users, creating an older e-generation that have the computer skills, equipment and desire to search, find and utilise online health information. Therefore, it is likely that in future online health information will have a much wider reach amongst older adults, than it currently does.

Pamphlets/brochures were the print media most frequently used to find health information (23%) while television was the broadcast media source most frequently used (20%); ranking fourth and fifth overall.



Figure 3-1: Leximancer map showing themes and concepts associated with reliability of health information sources

3.5.1 Perceived reliability

Doctors and pharmacists were perceived as providing the most reliable health information, which is consistent with previous studies^{15,29}. This perceived reliability was attributed to their 'knowledge' and 'training'. An Australian study conducted in 1989 also found doctors (93%) and pharmacists (72%) to be perceived as the most reliable health information sources with traditional media sources (newspapers 13%, and magazines 14%) rated amongst the least reliable⁸. These rates are comparable to our findings, despite the prior study being over 20 years old – before the advent of the Internet - and having a sample frame of adults aged over 17 years.

Nurses were perceived as the third most reliable source of health information (34%), which is considerably less than the 54% reported in the 1989 study⁸. Further research is needed to understand why these rates are so low. In order for nurses to be effective in the collaborative management of chronic disease in Australia it is necessary that they are seen as providing reliable health information. A recent study found that older adults' reluctance to have GP registrars manage their chronic conditions could be countered by maintaining a relational link with their regular GP³⁰. Models such as this should be investigated to see whether they can be extended to Practice Nurses, allowing nurses to contribute optimally to the primary health care team whilst also helping to alleviate pressure on GPs.

The perceived reliability of health information found on the Internet also decreased with age. Again, this is consistent with findings from other research^{23,31}. It is known that Internet health information that is usable and reliable empowers patients to participate in their health care¹⁴. Therefore, the promotion of credible websites, to both health care practitioners and patients, would be a worthwhile endeavour. While there has been a steady growth in the number of Australian health care practitioners recommending websites to patients³² it is not known whether this addresses the concerns of older adults with respect to the reliability of health information from the Internet. Further research into the factors that affect older adults' trust of information on the Internet is recommended.

The results from this large, paper-based survey have provided information on the sources of health information used by older Australians and the perceived reliability of this information. However, the results are limited by the use of dichotomous variables, which provided no information on source ranking. We did not collect information on the frequency of use of each source of health information, nor did we investigate whether the health information obtained impacted behaviour. While our questions asked about nurses, we did not specify nurse role (e.g. hospital nurse versus primary health care nurse). Future studies should investigate whether nursing role impacts the use of nurses as a source of health information and whether respondents' exposure to nurses, both through healthcare settings and socially, influences the perceived reliability of the information provided. Finally, our survey had a low number of respondents who spoke a language other than English at home (6%) as compared to rates for New South Wales (26%)³³, which may be attributed to the use of a survey tool written in English.

3.5.2 Conclusions

While doctors and pharmacists were reported as the most frequently used and most reliable sources of health information, the impact of the current ageing population means that there is a need to utilise other sources. Nurses are ideally placed to provide collaborative management of chronic diseases. While the results suggest that there is significant scope to increase their role as providers of health information, practice models need to be investigated to effectively utilise this potential.

The importance of the Internet as a source of health information for older adults will continue to increase as the population ages and older adults have greater information technology skills. It is likely that the use of the Internet for health information can be aided by the promotion of credible websites by healthcare professionals. The combined use of nurses and the Internet to provide health information, particularly self-management education, would help alleviate the current pressures on GPs.

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CHAPTER 4

INTERNET SELF-MANAGEMENT UNIFORM REPORTING FRAMEWORK: THE NEED FOR UNIFORM REPORTING CRITERIA WHEN REPORTING INTERNET INTERVENTIONS

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This paper presents the results of a literature review which aimed to identify the “active ingredients” present in Internet interventions that successfully support older adults to self-manage their chronic disease(s). The Model of Internet Interventions was used as a framework to structure the review. While many interventions were successful, their breadth and diversity of reporting made it difficult to identify the ‘active ingredients’. This resulted in the proposal of Internet Self-Management Uniform Reporting Framework (iSMURF) a minimum data reporting set with six domains; website design, support, study design, website use, user characteristics and reporting outcomes. Future use of iSMURF by researchers would provide standardised data resulting in an increased understanding of the effectiveness of Internet interventions and allowing the identification of the “active components”.

4.1 Abstract

A review of the literature was conducted to identify the “active ingredients” needed to produce successful Internet interventions that support older adults to self-manage their chronic disease(s). The term “Internet intervention” was used as an umbrella term to include all online self-management programs. Thirteen papers were found to meet the inclusion criteria from the initial 204 papers identified. Ritterband’s Model of Internet Interventions was used as a framework to classify the intervention components reported. It was found that online self-management interventions can improve outcomes for some older adults. However, the wide diversity of interventions and the measures reported, coupled with the complex nature of the studies, made it difficult to identify the “active ingredients”. To overcome this problem the authors propose a minimum reporting set, the Internet Self-Management Uniform Reporting Framework (iSMURF), which can be used in the reporting of all interventions. iSMURF proposes the collection of specific data from six domains: website design, support, study design, website use, user characteristics and reporting outcomes. The adoption of iSMURF would enable easy comparison of online interventions targeting chronic diseases.

4.2 Introduction

4.2.1 Chronic disease and self-management

Older people are more likely to experience deteriorating health and to develop chronic disease(s). Like many Western countries, Australia has an ageing population, with 80% of Australians over 65 years of age found to have three or more chronic conditions¹. Although chronic diseases cannot be cured, many can be effectively self-managed. Self-management has been defined as a partnership between the patient and physician that addresses the medical, behavioural and emotional factors encountered when dealing with a chronic disease². This definition encompasses specific behaviours such as adherence to the treatment plan, symptom management, health behaviour changes, and coming to terms with the change in life role from ‘healthy’ to ‘sick’³. Self-management can be both complicated and dynamic as the

aetiology of chronic diseases is often unpredictable, with periods of wellness followed by sudden deterioration in health.

Optimal self-management can often be constrained due to the nature of primary health care services, which may limit the amount of support and education available to patients. Important information about the diagnosis, disease and its self-management is often presented to patients in the physician's office at the time of diagnosis; however, many people experience increased stress at this time and thus have a reduced ability to absorb the information. Further, short appointment times limit patient-physician contact and mean that information is usually given just once⁴. The Internet overcomes these problems by offering immediate access to health care information, at any time of day or night.

4.2.2 Internet Health Interventions

Internet interventions are a cheap and accessible means of offering self-management education, with the main costs being incurred during the development of the intervention⁵. Patients using Internet interventions do not incur the time and monetary costs that they would encounter through attending traditional group-based self-management programs. Internet interventions are accessible to everyone with Internet access irrespective of their geographical location, and can be visited at a time and place convenient to the person. The intervention can be revisited as often as necessary, reinforcing concepts and providing further information as required. Benefits for providers of interventions include the ability to easily update information and the capacity to individually tailor information for each person.

Many previous literature reviews have examined various aspects or types of intervention. This is in part due to the variety of Internet interventions that have been developed targeting chronic disease self-management. For example, a 2011 review of the benefits of online patient education for chronic disease identified 49 papers reporting on studies which showed significant improvements in: health outcomes, disease knowledge, and treatment adherence⁶. Another review, also published in 2011, identified 12 randomized control trials that investigated the efficacy of e-

health⁷ and found that most reported a small to moderately positive effect on primary health outcomes. A 2008 review identified 17 previously conducted systematic reviews addressing Internet-delivered treatments for long-term conditions³. This review concluded that Internet interventions increased participants' knowledge about their condition, impacted positively on self-efficacy and had some impact on health behaviours, including improving physical exercise, adopting a healthy diet and promoting smoking cessation³. It is notable that these examples of previous reviews have focused on participant outcomes and not the components of the interventions. As Internet interventions are typically comprised of many parts that may act together or independently, there is considerable uncertainty about which parts are the “active ingredients” that make an intervention successful in creating changes in patient health behaviours and health outcomes³.

4.2.3 Internet Interventions and Older Adults

Older adults have the most to gain from Internet interventions, as they shoulder the greatest burden of ill-health, but little is known about the effectiveness of such interventions for this population. Users of Internet interventions need to have Internet access and be computer literate. While older adults are less likely to be “connected” than other age groups; 34% of 70 – 75 year olds in the United States reported being online in 2012⁸ – these users have been shown to frequently use the Internet to search for health information⁹. However, older adults may experience cognitive and physical decline as they age, impacting their ability to use the computer and Internet^{10,11}.

4.2.4 Model of Internet Interventions

Ritterband et al. proposed the Model of Internet Interventions to explain how Internet interventions improve disease symptoms through behaviour change (Figure 4-1)¹². The model, which was developed from multiple theories and practical experience, facilitates the identification of factors influencing the success of Internet interventions to be identified, observed and measured. The model has nine major components: user characteristics; website use; support; website design; mechanisms of change; behaviour change; symptom improvement; treatment; maintenance and

the environment (Figure 4-1). Each component can be divided into areas, and each area can be further sub-divided into elements. For example:

Component: website

Area: appearance of the website

Element(s): Layout and organisation of the website

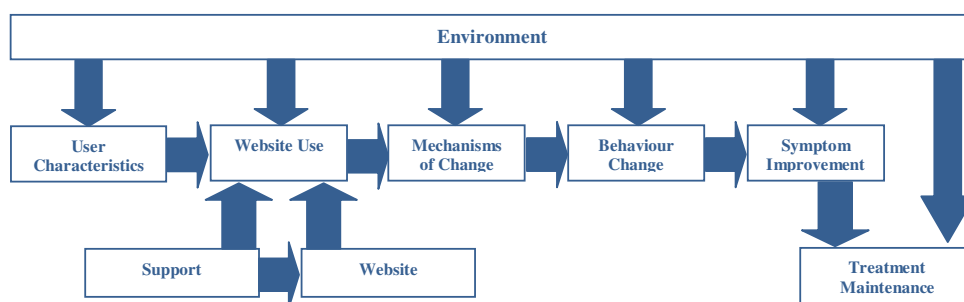


Figure 4-1: Model of Internet interventions

4.2.5 Purpose

The purpose of this paper is to report the results of a review aimed to identify the “active ingredients” needed to produce Internet interventions that successfully support older adults to self-manage their chronic disease(s). The Model of Internet Interventions was adapted to provide a framework for the review. For the purpose of this research, the term “older adults” refers to people aged 55 years and over. The term “Internet intervention” is used as an umbrella term to include all online self-management programs, irrespective of their individual tailoring or level of interaction¹³.

4.3 Methods:

Literature searches were conducted, during May 2012, using the Scopus and Web of Science databases; these two databases currently provide the most comprehensive coverage of the health science literature.

4.3.1 Search Terms

The following search terms were used in both databases: self-management OR patient education AND chronic disease OR chronic illness OR chronic disease management AND computer-based intervention OR Internet OR e-health OR Web-intervention. These terms were derived from the key-word lists of relevant articles that had been obtained previously through a broad exploration of the literature.

4.3.2 Search Restrictions

In Web of Science the search terms were restricted to “topic” and lemmatization was enabled - allowing the automatic finding of words with alternate spellings. In both databases, searches were restricted to articles published since 2002, due to the advances in technology that have occurred in this period.

These searches identified 204 papers. The abstracts were reviewed and papers were excluded if they: were not in English; were reviews, discussion papers or proposed protocols; had samples with a mean age of less than 55 years; targeted clinicians or carers; or involved telemedicine. Papers were not excluded on methodological quality.

In order to ensure methodological rigour, a second researcher reviewed each abstract. The researchers disagreed on the inclusion or exclusion of six articles. These papers were subsequently discussed; the decision to retain or exclude each paper was reached by mutual agreement. Papers were excluded for the following reasons: did not report on an intervention targeting a patient (113), age of participants (27), review (20) and use of telemedicine (10). This process resulted in the selection of 33 papers - one of the selected papers was identified by both databases. The papers were obtained and reviewed in full to ensure they met the selection criteria. When no age information was provided the paper was excluded. Review of the complete papers resulted in a further 20 papers being excluded (10 were excluded due to the type of intervention being reported; seven were excluded due to age of participants, and three were classified as telehealth interventions), leaving a final sample of 13 papers. These papers were read and data extracted using a review matrix devised for this

project¹⁴. The matrix included the nine components identified by the Model of Internet Interventions: Environment; User characteristics; Website use; Support; Website; Mechanism of change; Behaviour change; Symptom improvement; and Treatment maintenance. A copy of the matrix can be obtained from the authors.

4.4 Results:

The 13 selected papers reported on 11 distinct initiatives (Table 4-1); two papers reported different aspects of two different studies¹⁵⁻¹⁸. The 11 studies targeted people with a broad range of chronic diseases: type 2 diabetes (n=6)^{15,16,19-22}; heart disease (n=3)²³⁻²⁵; multi-morbidities (n=3)^{17,18,26}; and overactive bladder (n=1)²⁷.

The number of participants completing each intervention ranged from 15 to 354, with intervention drop-out rates ranging from 0% to 52%. The mean age of participants ranged from 55.5 to 69.0 years. Most of the research was carried out in the USA; however, there were two studies from the Netherlands and one study each from the UK, Canada and Korea. Nine of the identified studies utilised a randomised-control trial design, suggesting the results should be valid and reliable. For most papers the date of actual research was difficult to establish, so was estimated based on the date of publication. The components of each intervention were categorised under the headings proposed by the Model of Internet Interventions (Table 4-2).

4.4.1 User characteristics

All 13 papers provided some information on the demographics of the participants, such as age, sex, education level attained and level of computer skills. While some interventions included strategies to up-skill participants with limited Internet experience (see Support), only one attempted to investigate how Internet experience impacted participants' use of the intervention²³. This study used qualitative methods to determine that while participants knew where to access technical help, many did not seek help as they were embarrassed to reveal their lack of computer skills or to admit that they had forgotten the instructions²³.

4.4.2 Website use

Nine papers provided data related to use of the intervention. However, the type of data collected varied among papers and included information such as the number of participants visiting the site, the number of visits each participant made, the visit duration, total time on the site and the time of site visit. Some authors reported participant engagement as the percentage of participants using the intervention for the whole trial²⁴, while one paper classified usage as no, low and high²³. Four studies reported usage decreasing with time^{16,20,21,24}.

4.4.3 Support

For this review, both technical and clinical support were coded as ‘support’. Two studies provided computers for participants to use^{16,24}, whilst others provided technical training to participants either as individual sessions^{20,23} or when attending clinic appointments²⁷. One study utilised online moderators to remind participants to log-in, offer encouragement and model behaviours such as action planning; and a companion book to act as a reference manual to the material presented²⁶. One study provided users with a technical manual to accompany the intervention²⁰.

Many interventions offered participants peer-support, often in the form of online forums^{15–18,23–27}. The impact of such support is unclear and was often not investigated as a separate component of the intervention. However, in one study, participants given access to an information based intervention with peer support did not experience statistically significant changes in behaviour and symptoms when compared to a group provided with information only¹⁶. By contrast, another study found perceived support increased most when the intervention included a forum¹⁵, although the effect was moderated when offered in combination with a personal coach. The authors did not offer an explanation for this finding.

4.4.4 Website design

Four papers provided information about the design of their website^{18–20,22}, but the breadth of the information provided varied widely between studies. Two papers provided descriptive information, with one including screen shots^{18,22}; the other two included insights gained from the participants^{19,20}.

4.4.5 Mechanisms of change

A number of studies measured parameters that can be mediators for change (n=6). These parameters included knowledge, self-efficacy, self-esteem and acceptance of illness. In five studies, at least one of the reported measures showed significant improvement after the intervention^{15,17,19,22,27}. Due to the differences between interventions the current review did not attempted to compare or contrast these measures.

4.4.6 Behaviour change

Only four studies reported measuring behaviour change^{16,21,22,26}. A range of measures were assessed which were specific to the intervention types. These included: changes in aerobic exercise, stretching and strengthening exercise, practice of stress management²⁶, diabetes care behaviour^{16,22}, eating patterns^{16,21}, physical activity^{16,21} and medication adherence²¹. While positive behaviour changes are needed in order for symptom improvement to occur¹², not all studies attempted to measure these changes.

Table 4-1: Summary of Internet interventions targeting older adults with chronic disease

Author	Study year	Participants completing intervention	Dropout from intervention group	Participant characteristics	Mean age (years)	Country	Paper aim	Study design
Chronic disease focus: diabetes								
Heinrich et al., 2012	≤2012	43	7 (14%)	Patients with DM2	56.0	The Netherlands	To evaluate the Web-based self-management programme. Participants were allocated to either: the experimental group who were given access to Diabetes Interactive Education Programme (DIEP); a control group; or a post test control group.	RCT
Nijland, van Gemert-Pijnen, Kelders, Brandenburg, & Seydel, 2011	≤2011	34	16 (32%)	Patients with DM2	61.0	The Netherlands	To explore the factors affecting initial and long term use of Diabetes Coach.	Longitudinal study
Glasgow et al., 2011	≤2011	Website alone = 137; Website & support = 133	Unknown	Patients with DM2	60.0 *	USA	To report long-term implementation, outcomes and generalisability of results. A Website, My Path, (available in English and Spanish) was offered alone or in combination with support via phone and group meetings.	RCT
Song et al., 2009	2006	15	16 (52%)	Patients with newly diagnosed DM2.	56.3 (Web group)	Korea	To develop and apply a Web-based education program. Participants assigned either to Web-based self-management group or lecture group.	Quasi-experimental (control group not matched)

Author	Study year	Participants completing intervention	Dropout from intervention group	Participant characteristics	Mean age (years)	Country	Paper aim	Study design
Glasgow, Boles, McKay, Feil, & Barrera, 2003	≤2003	Info only = 33 Peer support = 30 Tailored self-management = 37 **	Info only = 7 (21%) Peer support = 10 (25%) Tailored self-management = 3 (9%)*	Patients with DM2	59.0	USA	To calculate indices of Website engagement of Diabetes Network (D-Net). Participants randomised to: information only, tailored self-management or information and peer support.	Randomised design – no control group
Barrera, Glasgow, McKay, Boles, & Feil, 2002	≤2002	Info only = 31 Coach = 31 Social support = 30 Social support & coach = 31	Info only = 9 (23%) Coach = 9 (23%) Social support = 10 (25%) Social support & coach = 9 (23%)	Patients with DM2	59.3	USA	To determine whether the intervention changed participants' perceptions of social support. Participants were randomly assigned to one of four groups: information only; personal coach & information; social support & information; or personal coach, social support & information. Trial ran for three months.	RCT
Chronic disease focus: heart disease								
Kerr et al., 2010	≤2010	129	31 (19%)	Patients with CHD	66.8	UK	To explore the potential of a Web-based intervention (Comprehensive Health Enhancement and Social Support - CHESS) for reaching a large number of patients	Prospective cohort study
Flatley Brennan, Casper, Kossman, Burke, & Brennan, 2007	2005-2006	24	Unknown	Patients with complex cardiac disease	69.0	USA	To describes the use of HeartCareII to support patient self-management, symptom interpretation and self-monitoring. HeartCareII formed the core of a Technology Enhanced Practice nursing model.	RCT

Author	Study year	Participants completing intervention	Dropout from intervention group	Participant characteristics	Mean age (years)	Country	Paper aim	Study design
Verheijden et al., 2004	2002-2003	24	16% (however, 48, 66% - did not access the intervention)	Patients with a diagnosis of: hypertension, type 2 diabetes and/or dyslipidemia	63.0	Canada	To assess the effectiveness of Web-based nutrition counselling (HeartWeb) in addition to usual care. The control group received usual care.	RCT
Chronic disease focus: other chronic disease								
Ruiz et al., 2011	≤2011	25	0 (0%)	Presence of overactive bladder for at least three months	62.9	USA	To determine the usability and outcomes, including knowledge, self-efficacy and quality of life, for older adults using OAB-SMIP (Over Active Bladder – Self-Management Internet-Based Program).	Cohort
Chronic disease focus: multiple conditions								
Cudney & Weinert, 2012	2007-2009	123	22 (14%)	Rural women	56.2	USA	To describe the development and evaluation of the online health teaching units (Women-to-Women).	RCT
Weinert, Cudney, Comstock, & Bansal, 2011	2007-2009	118	37 (24%)	Rural women	55.5	USA	To report the effect of a computer intervention (Women-to-Women) on psychosocial adaptation	RCT
Lorig et al., 2006	≤2006	354	103 (23%)	> 18 years with heart disease, chronic lung disease or type 2 diabetes	57.4 (online intervention)	USA	To determine the efficacy of the Internet chronic disease self-management program. Subjects randomised to experimental or usual care groups.	RCT

* Two different mean ages are reported in this paper; ** Details extracted from McKay et al 2002.

Table 4-2: Components from the Model of Internet Interventions identified in each paper

Components from the Model of Internet Interventions								
Authors	Environment	User characteristics	Website use	Support	Website design	Mechanisms of change	Behaviour change	Symptom improvement
Heinrich, de Nooijer et al		*	*		*	↑		
Nijland, van Gemert-Pijen et al		*	*	*	*			
Glasgow, Christiansen et al		*	*	*			*	*
Song, Choe et al		*		*	*	↑	↑	↑
Glasgow, Boles et al		*	*	*			↑	↑
Barrera, Glasgow et al		*		*		↑		
Kerr, Murray et al		*	*	*				
Brennan, Casper et al		*	*	*				
Verheijden, Bakx et al		*	*	*				-
Ruiz et al		*	*	*		↑		↑
Cudney & Weinert		*		*	*			
Weinert, Cudney et al	*	*		*		↑		↑
Lorig, Ritter et al		*	*	*		-	*	↑

*Measures reported;

↑ At least one measure was seen to improve; - Measure taken, but no changes observed

4.4.7 Symptom improvement

Six papers reported measures of participants' symptoms at baseline and at the end of the intervention. These measures included: glycosylated haemoglobin (HbA1c)²², total cholesterol¹⁶, low density cholesterol¹⁶, triglycerides¹⁶, pain²⁶, shortness of breath²⁶, fatigue²⁶ and a patient-reported measure of bladder condition symptoms²⁷. In five of these studies at least one of the measures had improved significantly^{16,17,22,26,27}. In one study, which examined nutritional counselling and social support, participants receiving the Internet intervention showed no improvement in any of the symptom measures²⁵.

4.4.8 Treatment maintenance

Two of the papers reported medium or long-term follow-up measures. One study reported significant improvements in health status at one-year after baseline²⁶. Another study reported continued improvements in five of the six psychosocial outcomes measured at 24 weeks (the intervention ceased at 11 weeks): self-esteem, acceptance, depression, stress and loneliness¹⁷.

4.4.9 Environment

Environment was defined as support provided external to the intervention; using this definition only one paper investigated social support¹⁷. This study found that participants with higher scores for social support were most likely to drop-out of the intervention. Conversely, married women were more likely to remain in the study, suggesting that spousal support and social support are not directly correlated.

4.5 Discussion:

This review showed that online self-management interventions can improve outcomes for some patients completing some interventions, the wide diversity and complexity of interventions along with the lack of detail provided in the articles makes it difficult to identify the “active ingredients” needed to create effective interventions for older adults. These results support the need for a standardised set of reporting criteria that can be used by researchers in the future³⁰. Based on the

findings of this review, we offer suggestions for a minimum reporting set, addressing four of the nine components from the Model of Internet Interventions: user characteristics, website use, support and website design (Figure 4-2, the Internet Self-Management Uniform Reporting Framework – iSMURF). While the variability of Internet interventions makes it difficult to suggest a relevant reporting set for all of the components of the Model of Internet Interventions, these four components are more standardised and are applicable to all interventions irrespective of the theoretical underpinnings and target age group. Two other areas of data collection “study design” and “reporting outcomes” have been included in the proposed iSMURF. These components were identified by comparing the different reporting styles used by the papers identified through this literature review.

4.5.1 The Internet Self-Management Uniform Reporting Framework

The following section discusses the rationale for including each of the six iSMURF reporting domains: Website design, Support, Study Design, Website use, User Characteristics and Reporting Outcomes.

4.5.2 Website Design

The papers which provided information around website design often provided little information regarding the technology supporting the intervention. This may occur due to the complexities of interventions, meaning that only limited information can be reported in each journal article. However, the reporting of such information is useful and could increase collaboration between professionals working within e-health. iSMURF proposes that at a minimum the following points are reported: 1) type of technological platform used, and 2) use of evidence based guidelines in site design. Reporting of information on how website content is presented e.g. text only or use of videos, would also be pertinent. However, this has not been included as iSMURF serves as a minimum reporting set.

Website design	
Technological platform	
Use of evidence based guidelines in site design	Yes/no – Name of guidelines
Support	
Provision of computer/ technical equipment to participants	Yes/no
Provision of technical support	Yes/no
Use of clinicians/moderators	Yes/no
	Frequency of contact
	Mode of contact e.g. phone, email etc
Provision of peer support e.g. forums	Yes/no
Was intervention incorporated into usual care	Yes/no
Study design	
Date of study	
Length of study	
Recruitment methods	Online/offline
Potential reach of intervention	Open to everyone
	After clinical assessment
	Invited user group
Use of incentives	Times and amounts
Use of reminders	Times and amounts
Website use	
Engagement	Total number of visits
	Average number of visits by participants
	Most viewed page
Exposure	Total duration of viewing
	Average viewing time by participants
Attrition	Over time e.g. baseline and post intervention as minimum
User characteristics	
Age	Mean
	Range
Sex	
Ethnicity	
Computer confidence/internet experience	
Level of education	
Health literacy	
Number of co-morbid conditions	e.g., arthritis, COPD, cancer, heart disease, depression, diabetes, high blood pressure,
Reporting Outcomes	
Inclusion of costs/ cost effectiveness data	Yes/no
Participant satisfaction	Qualitative/quantitative

Figure 4-2: The Internet self-management uniform reporting framework (iSMURF)

4.5.3 Support

The support category has been included to capture information covering three distinct areas: technical support, peer support and clinician support. Collection of this information increases the transparency of interventions.

4.5.4 Study design

Some of the study methodologies reported potentially played a role in the success or failure of the intervention, but were not captured by the Model of Internet Interventions. One example is the recruitment of participants; techniques ranged from the use of targeted invites sent to participants identified via physician computer systems to general advertisements using low-tech paper flyers. Recruitment strategies influence the reach of each intervention and potential participation²⁹. They also play a large role in determining the representativeness of the sample recruited and potentially the success of the intervention³². As such, iSMURF suggests reporting whether participants were recruited using online or offline methodologies and who could register (Figure 4-2 – iSMURF). Further, information on incentives to encourage participants should be reported. Some studies utilised financial incentives to reduce drop-out rates^{17,21,26}, while others reported sending reminder emails to encourage participants to log-in^{21,25,26}. The potential importance of incentives in the effectiveness of Internet interventions is reflected by their inclusion in the suggested reporting criteria (Figure 4-2 – iSMURF).

The interventions identified showed considerable variation in duration, ranging in length from two weeks¹⁹ to two years²⁰. It is unclear from this review what the optimal length of use of an Internet intervention is or the amount of exposure participants need (or how this could be determined reliably with so many uncontrolled variables). However, reporting of duration adds to the knowledge base about Internet interventions, thereby justifying its inclusion in the iSMURF reporting criteria (Figure 4-2 – iSMURF).

Finally, there are a number of evidence based guidelines available for the development of websites targeting older adults^{33,34}, however, their use in the studies

reviewed were not mentioned. It is suggested that use of these guidelines and identification of which guidelines be reported (Figure 4-2 – iSMURF).

4.5.5 Website Use

The reporting of website use is fundamental to advancing our understanding of Internet interventions. While most studies reported high dropout rates (the law of attrition)³¹, the use of attrition as a measure of usage remains controversial when it does not show fluctuations in use over time, or the impact of push factors (methods to encourage use of interventions, such as reminder emails). Further, participants can experience a ‘ceiling effect’ when they feel that their condition is under control and that they are ‘doing well’ and no longer need the intervention²⁰. Total duration of use, average time of all visits and most viewed pages are all frequently utilised as measures of website use. These measures have been included in iSMURF as a minimum measure (Figure 4-2 – iSMURF). However, the best methods of measuring website engagement are currently the topic of debate and are likely to include composite measures of engagement and exposure³².

4.5.6 User Characteristics

The collection of information on users’ characteristics is generally self-explanatory and includes basic demographics such as age, sex and ethnicity; although it is suggested that both mean age and the age range of participants are reported, as this would provide useful information to future researchers, specifically those working with defined populations, such as older adults. iSMURF suggests collecting information on the number of chronic disease diagnoses each participant reports. While it is recognised that self-report methods are not ideal this measure would provide some indication of the self-management burden faced by each individual. Finally, in this category, iSMURF suggests the collection of a measure of health literacy. While, this measure would ideally come from a standardised instrument, it is recognised that different instruments suit different protocols. Health literacy has been included as it may play a role in intervention effectiveness and can also be used to show which population segments are accessing Internet interventions.

4.5.7 Reporting Outcomes

Two measures have been included in this category; participant satisfaction and cost effectiveness. Participant satisfaction with the interventions was reported in only one study and this study utilised qualitative research methods to establish participant satisfaction²³. Various tools can be utilised to measure participant satisfaction. Danaher (2009) champions the use of global measures of satisfaction, e.g., participant satisfaction, program relevance or whether participants would recommend the program to others³². Such generic measures overcome potential problems encountered when users and researchers use different words to describe the same part of an intervention. iSMURF suggests the inclusion of a measure of participant satisfaction; at a minimum this should be a quantitative measure of global satisfaction. The need for information on costs and cost effectiveness of Internet interventions has been identified elsewhere³⁵. Both measures have been included in the iSMURF criteria as a cue to researchers working in the area.

4.5.8 The Relationship between iSMURF and the Model of Internet Interventions

The Model of Internet Interventions was developed as a theoretical model to help explain behaviour change and symptom improvement. The Model has been previously praised for its comprehensive nature²⁹, and provided a useful framework on which to structure the results of this and similar reviews. iSMURF furthers the work carried out by Ritterband and colleagues in developing the Model of Internet Interventions, by proposing reporting guidelines at a micro level. iSMURF has purposefully excluded some of the components suggested by the Model of Internet Interventions such as Mechanisms of Change e.g. changes in participants' knowledge; Behaviour Change e.g. changes in participants' levels of physical activity; and Symptom Improvement as these measure are often disease specific and not easily comparable across interventions.

Consideration of how to collect the information suggested by iSMURF should be integral in the design phase of studies to ensure that the data collected provides a comprehensive report of intervention implementation. Collection of these measures would facilitate easy comparison of interventions and could, in the future, be used to

help identify the “active components” of Internet interventions. It should be acknowledged that iSMURF outlines a minimum data reporting set and researchers are encouraged to provide information about their interventions over and above that suggested. Further, it is recognised that iSMURF will undergo various changes and iterations as its adoption spreads. However, it represents the first step in unified reporting of Internet self-management interventions.

4.5.9 Importance of this Work

While many literature reviews have examined the effectiveness of online health education, we believe that this is the first review to specifically analyse the components of the Internet interventions and not simply the outcomes. Further, we believe this is the first review to investigate self-management interventions targeting older adults – those who can benefit most from such interventions. While the study was a systematic literature review, no attempt was made to identify studies not listed through the databases (gray literature). Secondly, many of the studies identified had small numbers and targeted specific chronic diseases limiting the generalizability of the results.

4.5.10 Conclusions:

This research began as a review of the Internet intervention literature to identify the components that create successful interventions for older adults, using the Model of Internet Interventions as a way of structuring the findings. It was discovered that the information reported across interventions varied widely and inhibited easy comparison, resulting in the proposal of iSMURF, a minimum reporting framework to be used by researchers working on Internet interventions. The availability of standardised data will, over time, allow an increased understanding of the effectiveness of Internet interventions and the identification of the “active components” that make interventions successful.

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CHAPTER 5

THE DEVIL IS IN THE DETAIL: HOW OLDER ADULTS WANT TO LEARN ABOUT THEIR ASTHMA

This chapter has been published in the Journal of Asthma and Allergy Educators.

Burns, P., Jones, SC, Iverson, D, & Caputi, P. (2013). The Devil Is in the Detail: Determining the Content of an Internet Intervention for Older Adults With Asthma. *Journal of Asthma & Allergy Educators, Early Online*, doi:10.1177/2150129713495057.

This mixed methods paper reports on the formative research undertaken to determine the content and technology preferred by older adults in an online asthma education program. Results from the survey showed that older adults with asthma were primarily interested in learning about: how to avoid their asthma triggers, the latest information in asthma management, and how to deal with an asthma attack. Findings from the focus group suggest that the target audience could see little benefit in the inclusion of blogs and forums on an asthma education site. The involvement of end-users in the design and presentation of an asthma education site is novel and helped to ensure the creation of a product that met the users' needs.

5.1 Abstract

Introduction: The Internet can support people to self-manage their asthma, while overcoming barriers frequently found in primary care. A user-centred design process was utilised to explore the types of asthma information older adults perceived to be beneficial in helping them manage their asthma and the website features they felt were desirable for an asthma education website.

Methods: A survey package was mailed to 9,000 adults aged 55 years and over, whose contact details had been obtained from the Australian Electoral Commission. Four focus groups were also conducted covering: asthma management; asthma Internet information; and website features. The Technology Acceptance Model was used as a framework to structure results.

Results: Survey respondents indicated that they wanted information about identifying and avoiding asthma triggers, dealing with asthma attacks and the latest information on asthma management. Whilst focus group participants stated that asthma blogs, Internet forums and control assessment quizzes would not be useful to them. However the use of videos was seen as beneficial. Internet forums were the only feature discussed where older adults expressed concerns with their ability to use them effectively.

Discussion:

While older adults indicated a desire for basic asthma information the individual nature of asthma needs to be taken into consideration when creating website content. Both survey respondents and focus groups participants showed little interest in the use of blogs or forums on asthma. These results have implications for professionals providing self-management education to older adults with asthma and other chronic diseases.

5.2 Introduction

5.2.1 Asthma

Although asthma is often considered a childhood illness, most asthma deaths in Australia occur in older adults¹. While asthma, like other chronic diseases, cannot be cured, it can be effectively self-managed, leading to improved quality of life^{2,3}. Active self-management is important in older adults as this age-group face unique challenges in managing their asthma, primarily, due to the increased co-occurrence of asthma with other chronic diseases. A review of Australian studies showed that 80% of patients aged over 65 years had three or more chronic conditions⁴ – highlighting levels of multi-morbidity. The occurrence of other diseases in conjunction with asthma complicates disease management, as patients' symptoms are often overlapping and they frequently have multiple medications. Further, the occurrence of asthma with other chronic diseases increases the likelihood of adverse drug reactions due to polypharmacy⁵. These issues are compounded by short face-to-face consultations patients have with their primary care physicians, which inhibits the provision of adequate self-management education⁶⁻⁸. The time pressures faced by primary care physicians will increase with the ageing of the population, prompting researchers to suggest that alternate methods of service delivery need to be investigated in order to provide quality healthcare⁷. While these pressures will be felt by all patients, they will acutely affect older adults due to the increased likelihood of them having multiple issues that need to be addressed during each consultation with their primary care physician.

The Internet offers a platform to provide health information which overcomes the problem of short physician visits and enables patients to receive the support they need. The Internet, allows the provision of current healthcare information, which can be viewed at a time and place convenient to the patient⁹. This is important as it facilitates easy access to information and allows the information to be revisited when the patient wants to learn more or their disease symptoms change. Further, there are no geographical constraints⁹ – an important factor in a country as vast as Australia, where many people do not live near large towns or cities. From a developers' perspective, such applications are relatively cheap to run once the initial development costs have been met¹⁰, and can easily be updated and edited.

Additionally, their appeal can be enhanced by the incorporation of interactive components, such as video clips, quizzes, Internet forums and blogs¹¹. Internet interventions targeting chronic diseases have been shown to significantly increase patients' disease knowledge, health behaviours, health outcomes and subsequently increase their empowerment^{12–15}. Previous research has identified the need to investigate the efficiency and effectiveness of the Internet as a way of providing self-management support to older adults¹⁶. As far as can be discerned, online asthma self-management education has never solely targeted older adults; despite such interventions holding greatest potential for this population segment as they shoulder the burden of asthma mortality and morbidity.

One of the biggest drawbacks to providing older adults with online self-management education is the presumption that they have limited computer skills. This can be partially overcome by the use of the research based guidelines that provide guidance on how to make websites accessible to older adults^{17–19}. These guidelines tend to focus on the appearance and organisation of information, offering recommendations on size of font, navigation structures and amount of information presented. However, guidelines on the incorporation of interactive content, such as blogs, Internet forums and video sharing, on sites targeting at older adults is scant, despite knowledge that interactive content increases user participation, resulting in a richer user experience²⁰.

This paper describes formative research undertaken to inform the design of an asthma self-management education website, for adults aged 55 years and over, with asthma. A user centred design process was utilised which involved users early in the design process. This approach was adopted as it aims to understand the end-users (older adults, with asthma), as opposed to using simple demographics to describe the target population²¹. The aim was to explore the types of asthma information older adults want, as well as ways of presenting such information on an asthma website, with particular reference to the perceived usefulness of online communities created through blogs and Internet forums. A paper-based survey was used to determine the types of information that were of interest to the audience. Focus groups were subsequently conducted to investigate older adults' opinions on the benefits of the

use of current web technologies in learning about asthma. Approval for this study was granted through the University's Human Research Ethics Committee

5.3 Methods

5.3.1 Survey development

A paper based survey was developed to investigate the health beliefs, behaviours and attitudes of older Australians towards asthma. The survey included sections on participants': demographics, general health, opinion on asthma and asthma management. The survey was reviewed by experts in the field of asthma to ensure face validity. Cognitive interviews in the form of think-alouds²² were subsequently conducted with a convenience sample of 13 older adults, both with and without an asthma diagnosis. Participants were visited in their homes by one of two researchers and were asked to talk through the survey, voicing their thoughts. Interviews were recorded and the researchers took notes. As a result of this process a number of changes were made to the survey, most notably in the way the survey was bound. This changed from a staple in the left corner to booklet format, in order to reduce respondents overlooking the questions on the back of the pages.

The survey was subsequently piloted with a second convenience sample of older adults (n=115). These were approached through community groups or while they were travelling on public transport. Again, there was a mixture of respondents, both with and without an asthma diagnosis. Further refinements were made to some of the scales within the survey in order to minimise missing data.

The refined survey was 79 items in length and printed in 14-point font to account for the decrease in visual acuity that many older adults experience²³. All respondents were asked to complete the first part of the survey, whilst only those respondents with an asthma diagnosis were asked to complete the second, asthma specific section. The asthma specific questions sought to elicit information on respondents' health service use, their self-management practices, and the asthma topics they felt they needed to learn more about in order to best control their asthma (rated as: of no

benefit; of some benefit; of great benefit). The list of 29 asthma topics (Figure 5-1) was derived from an audit of information available through current national asthma websites, such as National Asthma Council Australia (<http://www.nationalasthma.org.au/>), Asthma UK (<http://www.asthma.org.uk/>) and Asthma Society of Canada (<http://www.asthma.ca/>).

5.3.2 Survey distribution

In October 2010, a survey package was mailed out to 9,000 adults aged 55 years and over, whose contact details had been obtained from the Australian Electoral Commission. The package contained a copy of the survey, a letter explaining the research and a reply paid envelope. Reminder postcards were sent out approximately three weeks later when the initial response rate began to slow. The surveys were coded in order to reduce contact with people who had returned their survey. A second copy of the survey package was sent out four weeks after the postcard. This amended version of Dillman's tailored design method was used in order to maximise the response rate²⁴. Surveys received after January 31, 2011 are not included in the analyses presented in this paper. The survey data were entered into SPSS v. 17 by three researchers. Five percent of responses were re-entered to check for accuracy, giving an error rate of 0.175%.

5.3.3 Focus Groups

Focus groups were conducted between November 2010 and April 2011 and continued until data saturation was reached. A total of four groups were conducted (N = 26; group 1 = 5; group 2 = 9; group 3 = 9; group 4 = 3). Focus groups were chosen as they were able to provide in-depth information and a greater breadth of understanding around the asthma information needs of older adults with an asthma diagnosis²⁵.

1. What is asthma
2. Asthma symptoms
3. Asthma research advances
4. The latest information on asthma management
5. Tips to control my asthma
6. Doing a quiz to see how well controlled my asthma is
7. Asthma service providers in my area
8. Asthma and other disease e.g. diabetes
9. How to use my asthma medications
10. How asthma medications work
11. The side effects of asthma medications
12. Cleaning my inhaler/spacer
13. Asthma and complementary or alternative medicines
14. Asthma and exercise
15. Asthma and the seasons – pollen/bush fire etc.
16. Asthma in the home – heaters/bedding etc.
17. Products to help my asthma
18. Creating an asthma friendly garden
19. Identifying my asthma triggers
20. Avoiding my asthma triggers
21. When to see my doctor
22. When to attend the Emergency Department
23. How to deal with an asthma attack
24. Testing my knowledge of what to do in an asthma attack
25. Reading other people's asthma stories
26. Sharing my asthma story online
27. Participating in online discussion forums about asthma
28. Participating in online (Internet) asthma education programs
29. Interacting with a health professional online –to discuss your asthma/ get information and support

Figure 5-1: The list of asthma topics respondents were asked to rate

5.3.4 Focus Groups Recruitment

Participants in focus groups 1 and 2 were recruited through flyers placed on community noticeboards. Due to the limited response received, participants for focus groups 3 and 4 were recruited via emails sent to people registered with Asthma Foundation New South Wales; a non-profit organisation that provides asthma information, education, training and advocacy to the community. Where possible, up to eight people were scheduled to attend each group with the aim that at least six would attend. In all cases, participants were required to be aged 55 years or over and to have a diagnosis of asthma.

5.3.5 Focus Group Sessions

The first two focus groups were held in a library in regional New South Wales (NSW), Australia, and the remaining two were held in the offices of Asthma Foundation NSW, located in Sydney, NSW. In both locations, one focus group was held during the day and the second after business hours to accommodate participants in full-time employment.

Each session lasted approximately two hours, including the administration processes. On arrival participants were asked to read the Participant Information Sheet and provide informed consent. A short survey was subsequently completed by the participants in order to obtain demographic data.

Each session was facilitated by the first author utilising a standardised discussion guide. The guide covered three topics: asthma management; asthma Internet information; and web site features. Each focus group was split into two sessions. The first session covered the first two topics and ran for approximately 45 minutes, before a short refreshment break. The second session ran for approximately 30 minutes. The focus groups were structured in this way to allow the participants to concentrate on the topic matter being discussed, without running out of energy²⁵.

The sessions were audio-recorded and notes were made on a white board, which were either printed out or photographed. At the conclusion of each focus group participants were given a gift voucher to acknowledge their time and contribution.

The recordings from the focus groups were transcribed and de-identified. NVivo 8 was used to code responses by question. A second independent reviewer reviewed the thematic analyses prior to the final interpretation. The key results were divided into information on ‘website behaviour’ and ‘website features’. Responses to the topic ‘website features’ were further coded under themes derived from the Technology Acceptance Model (TAM).

5.3.6 Technology Acceptance Model (TAM)

The TAM was developed by Davis to explain how users accept and use technology and is an extension of Ajzen and Fishbein’s Theory of Reasoned Action^{26,27}. TAM suggests that perceived usefulness and perceived ease of use are two important variables in determining whether information technology will be accepted or rejected. Perceived usefulness refers to the increased use of systems believed to enhance job performance; in this instance job performance is synonymous with asthma control through self-management. However, perceived usefulness is moderated by how easy a system is to use; “perceived ease of use”. It is postulated that people are more likely to persist with a hard to use system if they perceive the benefits to their performance, in this case asthma control, to be worthwhile. We used the TAM as a framework through which to interpret the results of the focus groups. This model was chosen as it is the most widely accepted model in the technology acceptance literature. However, it should be noted that while the TAM has undergone several iterations it was originally developed to explain the use of information systems in the workplace and not predict the use of specific features of a system to aid chronic disease self-management.

5.4 Results

5.4.1 Survey Responders

A total of 4,060 eligible surveys were returned (response rate = 46.8%). Participants with current asthma, that is a diagnosis of asthma by a health professional and symptoms or treatment for asthma in the previous 12 months, numbered 466 (11.5%). All further analyses of survey data refer to this subset of respondents. Respondents had a mean age of 67.7 years (range: 55 – 94 years), were predominantly female (68%, N=315), mostly retired (70%, N=320), typically born in Australia (86%, N=399) and just over one-third had completed tertiary studies (37.4%, N=173) (Table 5-1). Respondents' age at time of asthma diagnosis was almost equally split, with 49% (N=221) being diagnosed before the age of 45 years. The most frequently reported co-morbidities were arthritis (57.3%, N=266) and high blood pressure (50.9%, N=236).

5.4.2 Focus Group Participants

Participants in the focus groups were slightly older with a mean age of 68.4 years (range: 55 – 85 years) and were almost equally split between males (N=14, 54%) and females (N=12, 46%). The majority had completed tertiary studies (N=20, 74%), were retired (N=15, 56%) and had been born in Australia (N=20, 77%). All had been told by a health professional that they had asthma and the majority had been diagnosed before the age of 45 years (N=19, 73%). The most frequently reported co-morbidities were arthritis (N=12, 46%) and allergic rhinitis (N=9, 35%). Participants were generally confident, long-term Internet users; with 18 (69%) reporting being comfortable, quite comfortable or very comfortable with using the Internet and 21 (81%) reported having used the Internet for more than five years. Average reported weekly Internet usage was between six and nine hours.

Table 5-1: Survey respondents' demographic characteristics

	Survey respondents with current asthma	Regional Focus Groups	Metropolitan Focus Groups
Number of participants	466	14	12
Age (years)			
55 – 64	187	5	4
65 – 74	166	7	5
75+	113	2	3
Gender			
Male	150*	6	8
Female	315*	8	4
Education			
Never went/completed primary school	33*	0	0
Some secondary school	142*	1	1
Completed secondary school	115*	2	2
Completed tertiary education	173*	11	9
Internet use			
Non-users	216*	0	0
<1 year	6*	0	0
1-2 years	17*	1	1
2 – 5 years	36*	2	1
>5 years	164*	11	10

*Does not total 466 due to missing data

5.4.3 Asthma

Focus group participants were invited to provide an overview of their history with asthma. There were many recollections of childhood asthma treatments that participants had been exposed to, which differed from the current medical recommendations, such as drinking ginger ale and being injected with adrenaline. Participants also spoke about the way asthma used to be perceived as an emotional or psychological condition and how they felt this has shifted with time to a general acceptance of asthma as a physical illness.

“People don’t think people with asthma are abnormal any more – when I was a child they did. We were from another planet”

Focus group participants spoke about discovering new asthma puffers when they saw other people with asthma, often younger members of their family, use them. In every group there were lengthy discussions regarding individual asthma triggers, such as

pets, geographic location and weather events. It became clear from the discussions that everybody's triggers were unique, and what caused an asthma attack for one person may ease symptoms in another.

"...there's so much variety in asthma and how the symptoms manifest themselves in people."

"I think one of the tricks there, because we don't know where we stand in the hierarchy of asthmatics."

Further discussions showed that not only were peoples' asthma triggers unique but each individuals' experiences of asthma were quite different and that participants were aware of these differences. Some participants spoke of struggling to see how and where their disease experience fitted on the asthma spectrum. This awareness of individual differences in the way that asthma presents suggests that one-size fits all asthma education programs might be limited in their perceived effectiveness.

5.5 Asthma Topics of Interest

Survey respondents identified the five asthma topics they felt they needed to learn more about: avoiding my asthma triggers; the latest information on asthma management; how to deal with an asthma attack; identifying my asthma triggers; and asthma and the seasons (Table 5-2). Chi-square tests showed that there was no significant variation in topics of interest between those with a long-standing diagnosis of asthma and those with late-onset asthma (Table 5-2).

Table 5-2: Top five asthma topics rated as being of great benefit

Topic	Total (N=466) *			Late onset asthma (N=230) *			Long standing asthma (N=221) *		
	Number	Valid Percent (%)	Ranking	Number	Valid Percent (%)	Ranking	Number	Valid Percent (%)	Ranking
Avoiding my asthma triggers	212	50.5	1	91	45.5	3	116	55.8	1
The latest information on asthma management	208	49.5	2	97	48.5	2	105	50.7	4
How to deal with as asthma attack	206	49.4	3	99	50.0	1	103	49.8	5
Identifying my asthma triggers	206	49.2	4	86	43.9	4	114	54.5	2
Asthma and the seasons	202	48.3	5	87	43.9	4	110	53.1	3

*Not all respondents answered every question

5.6 Website Features

Focus group participants' statements were coded as relating to 'perceived usefulness' of the technology and/or 'perceived ease of use'. These categories were derived from the TAM. As privacy concerns were raised frequently they were coded separately in the analysis.

Focus group participants felt that the inclusion of relevant video(s) on an asthma website would be useful as they are information rich and can reinforce what the doctor has already said (Table 5-3). Responses to photos currently used on asthma websites targeting older adults indicated that people did not want to look at pictures of old-old people. There were also comments that the people in the photographs looked too happy.

"None of us want to look that old – do we? We want to look just over 55."

"They don't look like there is anything wrong with them, they look so happy."

These comments suggest that photos of younger people who look sick or in pain might be more effective in illustrating disease website targeting older adults.

Focus group participants were unanimously reluctant to read blogs written by other people with asthma; although a few participants conceded a well written asthma blog might be of interest (Table 5-3). It was also acknowledged that this view was likely to be different from younger people and that such information might be of use to others.

“But I do think young people – they live like that – have to be out there to be known; you’re asking a group of oldies who would be against it.”

These findings suggest that blogs written by people with asthma would be of little value to older adults. Comments further reinforced the idea that because asthma is a unique experience little could be learnt from reading about someone else’s experience with asthma.

Similarly, focus group participants were dubious about the value of sharing their own experiences with the disease through their own blog (Table 5-3). Like blogs, the inclusion of an asthma control quiz was seen as positive, for other people with asthma, but not for themselves (Table 5-3). While focus group participants were open about their use of Internet forums for other health issues, they were hesitant about the benefits of using a forum for people with asthma (Table 5-3). Of note, the comments relating to Internet forums were the only ones where comments were coded under both TAM domains, ‘ease of use’ and ‘usefulness’.

Survey responders were also generally negative in their response to the inclusion of interactive components on an asthma website, with the majority rating these functionalities a “of no benefit” to them: participating in online discussion forums about asthma (76.9%, N=297); and sharing their asthma story online (74.9%, N=290). The only exception was reading other people’s asthma stories (47.4%, N=193), with just over 50% perceiving some value in such information.

Focus group participants were reluctant to have another password and felt that they already had too many passwords and would struggle to remember another one; the only exception being if they perceived that the site would be highly beneficial to them (Table 5-3). Participants also expressed concerns about sharing personal information through the registration process which may open themselves up to the receipt of junk mail.

Focus group participants expressed a desire to be able to contact people about their asthma either through email or by phone numbers displayed prominently on websites;.

“I can use the Internet, but gee sometimes I hate it because you get no phone numbers, you can’t speak to a person.”

The older adults felt that being able to contact a “real” person through a website was hugely beneficial as they spoke of frequently forgetting to ask questions during visits to their physician. Such a facility should be considered when providing self-management education to older adults.

5.7 Website Behaviour

Focus group participants felt that they would visit an asthma education website either after they experienced breathing problems and prior to or after a visit to their doctor;

“If you got an attack for the first time ... or if you’ve got breathing problems”

“If I couldn’t see my doctor”

“The only reason I would go to any site is if I went to the doctor and he said you’ve got this, I would go and look at the site and see what were the side effects of the medication.”

In terms of the provision of online asthma information, these findings show that it is imperative that accurate and up-to-date asthma management information is provided online, as people are most likely to look for asthma information when they are experiencing breathing difficulties. Further, participants also spoke about searching for information after a doctor's visit, suggesting a role for health care providers in the recommendation and promotion of trustworthy sites.

Focus group participants were asked 'what would encourage you to read an asthma website on a regular basis?'. Responses indicated that participants were keen to learn about the latest advances in asthma treatment and also to help communicate information about asthma with their friends and family;

“And also to keep, you know, family and friends informed. I still think that's critical, so people around you know what's going on”.

Participants also responded positively to the suggestion of email reminders as a way of encouraging people to revisit a site. These findings suggest that reminder emails highlighting the latest advances in asthma treatment or with information targeting family and friends of people with asthma would be effective in driving people to view an asthma education website.

Table 5-3: Categorisation of technologies by ‘usefulness’ and ‘ease of use’

Technology	TAM category	Other themes	Example quote
Videos	Useful		<p><i>“Moving picture is much more informative than the still...” Participant FG 1</i></p> <p><i>“I think it’s good to have that because the doctor might go through, or the pharmacist ‘this is what you do’ but if you’re sick you don’t concentrate very well. But if you take it home you can do the first step and look at it 10 times if you didn’t get it.” Participant FG 2</i></p>
Blogs	Useful – for someone else		<p><i>“There are some people who would find that a good support tool.” Participant FG 1</i></p> <p><i>I sort of can’t see why I’d want to because it’s sort of someone’s personal opinion; I had a bad night, I couldn’t breathe, this happened, this happened.” Participant FG 2</i></p> <p><i>“Absolutely nothing!” Participant FG 3</i></p> <p><i>“I’m stuck with it [asthma], there’s nothing I can do, I want to associate with the non-asthma people ... Because my fear is that you end up dealing with a morbid lot who end up feeling sorry for themselves.” Participant FG 3.</i></p>
Authoring a blog	Useful - for someone else		<p><i>“There are some people who would find it a good support tool.” Participant FG1</i></p> <p><i>“If I could convince someone how serious asthma is, ... I might put it on a blog....If it helped someone to realise that it can kill, asthma, if you don’t treat it properly...Would anybody read it?” Participant FG 2.</i></p> <p><i>“Unless you’d had a remarkable reversal from a very bad experience you’d like to let other people know about.” Participant FG 4</i></p>

Technology	TAM category	Other themes	Example quote
Forums	Ease of use	Privacy	<i>"I don't consider my asthma is a major problem or a major issue, but I can see it may be useful for other people."</i> Participant FG 2
	Useful – for someone else		<i>"I think I'd be too scared because I'm not familiar enough with the Internet."</i> Participant FG 2
			<i>"I have used forums but for other issues."</i> Participant FG 2
			<i>"I might do it, I'm just not that into forums but if I has a pressing enough issue and I felt that I needed the support and input of other people yes, I might so it. Particularly if it's the idle of the night and I thought of something."</i> Participant FG 2
			<i>"I'm not particularly keen on giving information on the Internet, personal information of this sort."</i> Participant FG 3
			<i>"I did it with weight watchers a few times – they have a forum and I've got relevant information from there which was very helpful to me. I haven't used this sort of forum, but maybe I would if I was seeking information, maybe I would."</i> Participant FG 3
			<i>"Well if I'd been looking for singing and asthma treatment I'd be very interested and taking part in that and finding out what people normally do."</i> Participant FG 4
Asthma control quiz	Useful – for someone else		<i>"It could be useful to people if they were thinking they were well controlled when they weren't or reassuring that yes... so it's not a useless thing to do, it's just not something I would do because I don't think I need it."</i> Participant FG 2

Technology	TAM category	Other themes	Example quote
Passwords	Ease of use	Privacy	<p><i>"So long as it's not linked to any other sites and they start sending you junk mail and that sort of thing."</i> Participant FG 1</p> <p><i>"If I thought I'd be getting valuable information from the site, it's pretty much a priority I will do that."</i> Participant in FG 2</p> <p><i>"I don't know why they want it and what sort of information they're trying to track."</i> Participant FG 2</p> <p><i>"That's the problem – too many passwords."</i> Participant FG 3.</p> <p><i>Logging on, you've got so many bloody code names to remember."</i> Participant FG 4</p>

5.8 Discussion

The major underlying theme that emerged through the focus groups related to the unique asthma experience; all of the groups acknowledged that different people were affected by their asthma in different ways and that the severity of people's asthma can vary significantly. This often resulted in participants stating that while some things would not be useful for them, they might be useful for someone else. It also incorporated the change in the way asthma has been perceived over time. This issue was salient with those participants with long-standing asthma and has been reported by other researchers conducting qualitative research with older adults with asthma²⁸. Other researchers have divided older adults with asthma into two groups²⁹; those who have suffered with asthma from childhood are referred to as having long-standing asthma, whilst those who develop the disease later in life are described as having late-onset asthma. This division is a useful reminder that the experiences and problems encountered by the two groups can vary widely²⁸, with those with long-standing asthma often having decades' worth of personal knowledge on how best to manage their asthma; although sometimes this knowledge may be dated. This theme highlights the need to provide tailored information on an asthma education website that takes into account users' individual experiences, including their time of diagnosis.

5.8.1 Asthma Topics of Interest

The top five asthma topics that respondents wanted to know more about included basic self-management information such as identifying and avoiding asthma triggers and how to deal with an asthma attack. Previous research has also found that older adults want to know more non-drug aspects of asthma management and in particular their asthma triggers^{30,31}. Surprisingly, we found little variation between the asthma topics of interest nominated by respondents with long-standing asthma compared to those with late onset asthma, contrary to findings of previous research²⁸. It is interesting to note that length of time since asthma diagnosis did not appear to affect respondents' desire for basic information, such as identifying and avoiding triggers. However, it is possible that while the asthma topics identified were the same, the depth of information desired may vary between these two groups.

5.8.2 Website Features

While Internet forums and blogs are frequently touted as being able to provide a sense of community to those with chronic diseases³², the respondents showed little interest in utilising such technology to learn more about their asthma. This finding was consistent amongst the results from both the survey and the focus groups. One of the main reasons given for the perceived lack of relevance of asthma blogs and forums was the individual nature of the disease, which has been recognised in other research³³. These findings are contrary to other research which reported participants finding online peer support and electronic discussion groups a positive, non-judgemental source of support that facilitated information exchange and was available 24 hours a day, facilitating information exchange and providing emotional support³⁴. Our results suggest that older adults see little value in participating in online communities, such as blogs and forums, to help them in the management of their asthma. It is not clear whether these results would be replicated if the disease in question was another chronic disease other than asthma.

The results suggest that the use of videos to supplement written information would be positively received by an older audience. This is consistent with earlier work that has found inclusion of videos on websites facilitates engagement and comprehension of the content³⁵. Interestingly, many older adults would prefer to view pictures of younger-old people online as compared to old-old people. This finding supports previous research which found that older adults do not see themselves as old³⁶. However, they expected these people to look ill. It is likely that these findings can be extrapolated to the age of characters seen in video information and should be considered prior to the production of audio-visual materials targeting older adults.

Focus group participants generally expressed hesitation about acquiring another password, particularly if this required the sharing of personal information. Nevertheless, the majority of participants were willing to register for an online asthma education website provided they could identify benefits for themselves. The general apathy towards passwords, and the privacy concerns expressed, are consistent with other findings³⁴. As such, it is suggested that if a password system is

to be implemented on websites targeting older adults, the benefits of registering for access to the site are made very clear.

5.8.3 Website Behaviour

Respondents' in the focus groups suggested that they were most likely to visit an asthma education website either before or after visiting the doctor or after experiencing problems breathing. However, the discussions suggested that regular visits to an online education website could be encouraged through the presence of information on the latest advancements in asthma treatment, asthma information to share with friends and family and also through receiving reminder emails.

5.8.4 Limitations

It is likely that both focus group participants and the people who returned completed surveys had a greater interest in asthma than people that did not self-select. However, the results are strengthened by the ability to compare the data on usage of website features from the survey with that obtained from the focus groups, giving a wider understanding of the way in which older adults want information on the management of asthma presented.

It is notable that the focus group sample was comprised mainly of confident, long-term Internet users. It is likely that less savvy computer users would have expressed greater concerns regarding the 'ease of use' of the various technologies discussed and be even more reticent to engage with technology. Further, it is possible that participants in the focus groups would have responded differently had they been able to interact with and explore the websites shown, rather than simply responding to website screenshots.

It is likely that the focus group sample experienced better health than other people with asthma, as other research has shown over 60% of people with asthma also have arthritis⁴, compared to 46% in this study. Although the majority of focus group participants reported having had asthma since childhood, this is unlikely to have impacted on the results reported here as these concentrate on the use of technology

on an asthma website. Finally, the occurrence of multi-morbidities in older adults makes it possible that participants had been misdiagnosed with asthma, as a number of other chronic diseases have symptoms similar to asthma¹⁶.

Content	Include	Exclude	Consider Inclusion
Avoiding my asthma triggers	✓		
Identifying my asthma triggers	✓		
Asthma and the seasons	✓		
The latest information on asthma management	✓		
How to deal with as asthma attack	✓		
Content Presentation			
Videos	✓		
Photos of 'young-old'	✓		
Asthma Control Quiz		✓	
Blogs – sharing own story		✓	
Blogs – reading someone else's story		✓	
Forums		✓	
Site Design			
Password			✓
Registration			✓
Individual Tailoring	✓		
Contact number/email provided	✓		
Email reminders	✓		

Figure 5-2: Recommendations for content and features for an online asthma education tool targeting older adults

5.8.5 Implications and Future Developments

Figure 5-2 summarises the type of asthma content, presentation and site design preferred by older adults. These findings are important because no other guidelines around the asthma information older adults want could be identified. Similarly, no

information on website design preferred by older adults could be identified. These results show that despite many participants having had asthma for most of their lives they were still seeking basic information about asthma. Secondly, the individual nature of asthma was identified as an important underlying theme and may be best addressed through the provision of individual asthma information, achieved by tailoring websites to meet each user's needs. Finally, the inclusion of the latest technology in website design may not always be desired by older adults e.g. blogs and forums. This formative research was used to inform the development and piloting of an online asthma education tool aimed at older adults, which has been reported in detail elsewhere^{37,38}. There is scope for future research to explore how best to deliver the asthma self-management information desired by end-users in conjunction with current management guidelines, without over burdening users with information.

5.8.6 Conclusions

The participation of end-users, in formative research, to guide the development of an online asthma education tool was novel. The findings provide a better understanding of the asthma information sought by older adults and preferred ways of presenting this information. Due to the lack of literature in this area, these findings have implications for health care professionals providing self-management education to older adults with both asthma and other chronic diseases.

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CHAPTER 6

USABILITY TESTING OF ASTHMAWISE WITH OLDER ADULTS

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This paper reports on the usability testing of AsthmaWise – an online self-management education program that was developed based on findings from the formative research undertaken for this thesis. Three types of testing were undertaken: usability-testing with a sample of end users; a cognitive walk through by an independent researcher and page readability. Testing allowed usability issues to be identified and rectified prior to the piloting of AsthmaWise. Testing was successfully conducted by a non-expert (the candidate) and proved relatively easy and inexpensive. Involvement of the end-users and the expert (web designer) in the process proved invaluable.

6.1 Abstract

There are many reasons why online self-management education is attractive to both patients and providers. AsthmaWise, an online self-management program was developed using a Moodle platform, to enable older adults to learn asthma self-management skills. The study aimed to improve AsthmaWise through conducting: usability testing with a sample of end users; a cognitive walk through undertaken by an independent health researcher; and assessment of content readability. A Perceived Health Web Site Usability Questionnaire score of 67% was achieved indicating that there were usability issues that needed to be addressed. The cognitive walk through and readability assessment identified unique issues that were not identified through usability testing with end-users. The testing process allowed issues to be identified and rectified prior to piloting AsthmaWise, creating a more accessible and refined end-product. The involvement of the site designer in the testing process was valuable and is highly recommended. This study shows that usability testing involving both end-users and experts is an essential part of the design process that is relatively easy and inexpensive to undertake and can be effectively conducted by a non-expert.

6.2 Introduction

The potential of e-health as a source of consumer health information and support is wide ranging and undisputed. Consumer e-health applications have been classified into five categories: self management applications; peer-to-peer support groups; decision aids; personal health records and internet use¹. While all of these categories have strengths and weaknesses, this paper focuses on the development of a self-management application for older adults, with a current diagnosis of asthma. Some of the benefits of online self-management education include the potential reach of such applications, their ready availability, and ability to overcome barriers of time and geography². Such sites are relatively inexpensive to set-up and launch, once initial development costs have been met³. Further, information can be readily updated in a timely manner.

As the biggest users of health care resources, older adults potentially have the most to gain from online self-management education. While, traditionally older adults

have not been considered “tech-savvy” they are moving online in increasing numbers. This has been documented in the United States where the online population of people aged between 70-75 years was reported as 34% in 2012⁴. Further, a recent exploratory study found that many older Australians are online (62%) and most of those who are connected feel comfortable using the internet (93%)⁵. Once online, adults aged between 51 - 59 years and those over 70 years were most likely to use email and search for health information⁶.

6.2.1 Asthma

Asthma is a common disease of the airways, which is characterised by episodes of wheezing, breathlessness, chest tightness and persistent cough⁷⁻⁹. While asthma is often thought of as a childhood illness, mortality is greatest in those aged over 60 years¹⁰. Although there is currently no cure for asthma, it can be effectively controlled through self-management which minimises the impact of the disease on a patient’s day-to-day activities¹¹⁻¹³. However, research suggests that primary care workers have insufficient time during appointments to teach patients new self-management skills¹⁴⁻¹⁶. A recent survey of UK GPs found that 46% felt there was not enough time to educate their patients about asthma¹⁷.

6.2.2 AsthmaWise

AsthmaWise was an asthma education site, designed specifically to help adults, aged over 55 years, learn about asthma self-manage. It was produced by the University of Wollongong in collaboration with Asthma Foundation New South Wales following extensive formative research with the target population^{5,18,19}. AsthmaWise was developed using Moodle (Moodle, Perth, Australia) an open source, e-learning software platform that allows educators to create online courses.

It was envisaged that AsthmaWise would have a total of six modules that would be completed by participants in their own time. At the time of usability testing only three modules were complete and visible to participants due to technical issues that had occurred. These modules were: Learn More About Asthma; Managing Your Asthma and Asthma Attacks.

6.2.3 Usability Testing

Usability testing is the process of ‘observing and learning from you users, who are working with your product to perform tasks that are real and meaningful to them’²⁰. It is often part of a larger user-centred design process, which has an iterative nature (i.e. the product is tested and modified a number of times in order to enhance the users experience) resulting in a well refined product. This is an important process as it has been shown that even experience web users can easily become confused on an unfamiliar site by the information architecture or small usability problems²⁰. Testing can be conducted either during development (formative testing), or once the site is complete (summative testing)²⁰; it is seen as an essential process in website development that ensures the product meets the needs of the end users, rather than the developer. As such, usability testing needs to be both broad and inclusive and include input from both end-users and experts²¹. While usability guidelines are available to guide design around general user behaviour as well as for specific site genres, but it is recommended that individual usability tests are conducted in order to obtain detailed information about specific sites²². Usability testing is particularly important with older adults as the ageing process is known to complicate computer and internet use^{23–25}. Possible issues include vision and hearing loss which may impact users’ contrast sensitivity and result in problems reading small fonts and hearing sounds embedded on sites^{20,26,27}. Further, older adults may also experience: cognitive decline (both short-term memory and speed of processing) which creates difficulty for users in recalling previously viewed information; and motor limitations due to physical decline may complicate mouse use^{20,24–27}. Despite these known challenges, there is a paucity of usability testing research reported in this population, with health websites²⁸.

The purpose of this study was to assess and subsequently improve the usability of AsthmaWise through the combined use of: usability testing, conducted with a sample of end users; a cognitive walk through of the proposed site undertaken by an independent health researcher; and assessment of readability using Flesch-Kincaid Grade Level and Flesch Reading Ease statistics. The cost of usability testing is also discussed as this process is often overlooked due to perceived expense. The results were used to inform refinement to AsthmaWise prior to the site going live.

6.3 Methods

6.3.1 Design

Usability testing was undertaken using a think-aloud process and Morae Recorder 3.2.1 (TechSmith, Okemos, Michigan). The think-aloud process involves participants explaining what they are doing or thinking during testing. Morae is usability testing software that allows user interactions in the form of visual, audio and mouse movements to be recorded and analysed. Testing involved an initial short demographic survey, followed by five set tasks, before the administration of the Perceived Health Web Site Usability Questionnaire (PHWSUQ) for Older Adults²⁹. Approval for this study was granted through the University's Human Research Ethics Committee.

6.3.2 Sample

A convenience sample of 13 adults, who had previously been involved in formative research that informed the design of AsthmaWise, were recruited. To be considered for inclusion participants were required to be aged 55 years or older; have received a diagnosis of asthma from a health professional; have used the internet; and be willing to be recorded during the usability testing process.

6.3.3 Questionnaire

A modified version of the PHWSUQ for Older Adults was utilised to assess participants' overall opinion of the AsthmaWise site. The questions are categorised under three domains: satisfaction; ease-of-use; and usefulness. Participants were asked to indicate their responses to items using a numeric seven-point likert scale, where 1 equalled very unsatisfied and 7 very satisfied. Question three, which asks about ease of listening to audio-information, was excluded as it was not relevant to AsthmaWise. Question 10, which asks how the web site helped people understand their health problem(s), was reworded to ask specifically about asthma. An additional open-ended question was included at the end of the survey to allow participants to note any further comments they had about AsthmaWise. The usability and reliability of this tool have been reported elsewhere²⁹.

6.3.4 Procedure

Participants were asked to register for AsthmaWise at home, prior to attending the usability testing session. The registration process involved answering seven questions: age; asthma diagnosis by a health professional; current asthma; postcode; town; first name and email address. Some of these questions had previously been asked during the recruitment process, over the phone, but were included to ensure that they would be functional in the final version of AsthmaWise where they would be used to screen for eligibility and obtain a method of contacting participants.

The testing was carried out individually in an office on the university campus. On arrival, participants read the participant information sheet and completed a consent form. They were then asked to complete a short, background demographic survey, using Morae. Morae worked as a pop-up that displayed over the site being tested, and administered the questions and tasks. Participants were subsequently presented with five sequential tasks that they were asked to complete (Figure 6-1). The first four tasks were based on the AsthmaWise site while task five required participants to view and provide feedback on a video showing how to use a metered-dose-inhaler (puffer). Finally, participants were asked to complete the PHWSUQ. Participants were encouraged to use a think-aloud process to voice their thoughts on AsthmaWise during the testing procedure; these comments were recorded using Morae.

Task 1

Look around the first screen and share your first impressions.

- What do you think you can do here?
- What first action would you take?
- Are there any words or labels that don't make sense?
- What's your general impression of the site?

Task 2

Now I'd like you to work through the section called "Learn More About Asthma".

Task 3

Use the site to find out what to do when you have an asthma attack.

Task 4

Which triggers affect YOUR asthma?

Show me how you would find information about these triggers?

Task 5

Please review the video and tell me your thoughts.

Figure 6-1: The five usability tasks

Usability testing was undertaken during a two-week period in December 2011. The researcher (PB) conducting the testing refrained from engaging in conversation or helping participants during the testing process. However, help was given if it became apparent that the participant was very frustrated or if an individual task was taking longer than 10 minutes. The researcher kept a record of her own observations during the testing process. At the completion of the test, participants were given a \$30 voucher to acknowledge their time and assistance. Data from both the initial demographic survey and the PHWSUQ were analysed using descriptive statistics; the recorded data and researcher's notes were explored using content analysis³⁰.

6.3.5 Cognitive Walk Through and Readability Assessment

An independent health researcher worked through the three AsthmaWise modules sequentially. She was asked to check that the content was clear, concise and used simple English; that formatting was consistent; and that the images related to the text, and had IMG ALT attributes (that is, text describing the image which is visible when you mouse-over an image and allows people using screen readers to interact with the images).

In a parallel procedure, the text of each page was copied into Microsoft Word and the Flesch Kincaid Grade Level and Flesch Reading Ease Scale were used to establish readability using the grammar check function. The Flesch-Kincaid Grade Level analyses the average number of syllables per word and words per sentence to produce a reading grade based on U.S. school grades³¹. We aimed for a target score of eight, which indicates that the content can be understood by an eighth grade student. Flesch Reading Ease is a 100 point scale with documents written in plain English scoring between 60-70 and documents that are harder to read scoring lower³².

6.4 Results

6.4.1 Participant Demographics

The mean age of the 13 participants was 65.8 years (range: 57 – 86 years); seven participants were female (54%); the majority of participants were born in Australia (85%); and only one spoke a language other than English at home. Six participants reported a household income of below AUD \$40,000 per annum (46%); while four reported a household income higher than AUD \$80,000 (31%).

Nearly half the participants were classified as having late-onset asthma, having been diagnosed with asthma after the age of 45 years (46%)³³. Four participants had been diagnosed in their mid thirties (31%) and three had had asthma since childhood (23%). All participants reported having used the internet for more than five years; and seven participants stated that they were very comfortable using the internet (64%). The majority of participants reported using the internet for more than 10 hours each week (69%), and almost all (85%) had previously used the internet to find health information.

The average time taken to complete all five tasks was 32.73 minutes \pm 4.95 (range 19.63 - 48.15 minutes). The mean times taken to complete each task were: task 1=3.47 minutes; task 2=14.21 minutes; task 3=8.40 minutes; task 4=2.20 minutes and task 5=4.44 minutes. On eight occasions, participants took over 10 minutes to complete a task; however, all of these occasions were due to the participant moving off task. As these off-task activities were relevant to other task(s) the researcher allowed them to complete what they were doing.

6.4.2 Registration

Three people reported that the registration process was “moderately complicated”. However, only six participants (46%) successfully created a profile, suggesting that the other participants encountered problems registering, which they did not report.

“It's a little complicated” Participant 3

“The button at the bottom left hand corner of page was very difficult to find.”

Participant 8

6.4.3 Perceived Health Web Site Usability Questionnaire

The PHWSUQ for Older Adults has three domains: satisfaction; ease of use; and usefulness. The total mean-converted score for the PHWSUQ was 67% indicating that there was scope for improvement in the overall usability of AsthmaWise (Table 6-1). Satisfaction was the highest scoring domain (70%) whilst the usefulness domain received the lowest score (61%).

*Table 6-1: Perceived Health Web Usability Questionnaire
total and subscale mean scores*

Dimension	Score range	Mean (SD)	Mean converted*
Satisfaction	(5 – 35)	24.60 ± 3.41	70.3%
Ease of use	(3 – 21)	13.92 ± 1.68	66.3%
Usefulness	(3 – 21)	12.77 ± 1.91	61.0%
Total	(11 – 77)	51.30 ± 5.76	66.6%

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

6.4.4 Satisfaction

There were five questions in the satisfaction domain. These asked about the ease of finding specific information; the ease of reading the information; the appearance of the site; the quality of the graphics; and the quality of the video information presented. The first five participants all commented on the small font size; because of this feedback, the font size was increased before further usability testing. This resulted in no further comments about font size being recorded. All participants encountered problems navigating from the log-on page to the homepage due to the many options available. Most did not understand what the available options were (the labels included ‘forum’, ‘blog’ and ‘tags’); the lack of content on these pages further compounded their confusion.

Once participants reached the homepage most found the use of toggles (arrows that could be clicked on to display the modules available) confusing to operate. Navigation between pages in a module was undertaken using forward and back buttons on the screen. However, the button size and their placement on the page varied which also created confusion. The time taken for pages to load was often lengthy (greater than 10 seconds) which created confusion as participants were often not sure if they had clicked the link, and became frustrated with the untimely response.

While the site content was generally well understood, many participants commented on the amount of text and suggested that greater use of sub-headings and colour would facilitate the reading process. Participants also felt that there could be more graphics and that the ones that were on the site could be bigger. While participants liked the bar chart showing asthma prevalence, the axis labels were not clear and many had problems interpreting the meaning. The addition of extra graphics may also improve recall as the testing process indicated that many participants did not remember visiting pages they had read just minutes earlier.

“Site had too much words [sic], maybe more use of pictures or icons. Too hard to see where you were going...” Participant 8

“More detail is needed in certain areas, better explanations and introduction of advice brought in earlier.” Participant 3

Participants also offered feedback around the use of language on AsthmaWise. The meanings of many words, used every day by health professionals (jargon), were questioned. These included asthma specific words such as ‘reliever’, ‘preventer’ and ‘spacer’, as well as generic terms such as ‘cure’. Additionally, while participants liked the quick quizzes the use of negative wording was confusing for many e.g. ‘Which of the following is NOT a common asthma symptom?’ and ‘You CAN’T get asthma for the first time as an adult’. Problems with some of the titles of the modules were also identified, with participants consistently looking for information on asthma attacks under ‘Managing your asthma’ rather than ‘Asthma attack’.

Participants also provided feedback on content that they felt was missing from AsthmaWise. This included the lack of information provided for white-collar workers on the page called ‘work’, specifically in relation to office-based triggers and stress management. Participants also suggested that a link providing emergency advice on how to get help during an asthma attack should be included on AsthmaWise.

“I would like information about bronchitis (how is it different from asthma, for example). I'd also like advice on how to relieve congestion from the chest (I suffer from severe chest infections which trigger asthma attacks).”

Participant 2

6.4.5 Ease of Use

The second domain, ease of use, contained three questions: I found this website easy to learn; finding information requires a lot of mental effort; and overall this website is easy to use. AsthmaWise was seen as easy to learn and easy to use, with modal values being six for both categories. The category ‘requires a lot of mental effort’ was reverse scored and had a modal value of four suggesting that the site navigation could be more intuitive and was reflected in participants’ comments.

“Redesign the website - make it easier to use and understand.” Participant 3

“A good attempt, layout of this site could be improved.” Participant 12

6.4.6 Usefulness

The domain of usefulness also had three questions: using this website will help me understand my asthma (modal value = 6); using this website will improve my knowledge of health (modal value = 3); and using this website will help me maintain better health habits (modal value = 4). Overall, this domain scored lowest of the three domains, despite the majority of participants reporting that AsthmaWise helped them understand more about their asthma.

“Knowledge base was excellent as were the examples... Overall a good site.”

Participant 12

6.4.7 Cognitive Walk Through and Readability Assessment

The reviewer was able to identify inconsistencies across the site. These included screens that did not appear in a logical order (i.e. they could only be reached by using the back button), inconsistencies in the presentation of information, grammatical errors and formatting problems. The results of the readability checks are presented in Table 6-2. The target readability scores were a Flesch-Kincaid Grade Level of eight or below and a Flesch Reading Ease score between 60 and 70. It was found that fourteen pages had a Flesch Kincaid Grade Level above nine and 11 pages had a Flesch Reading Ease Score below 60. The pages with scores outside the target range were rewritten; the Flesch-Kincaid Grade Level for these pages was reduced from 10.24 ± 0.41 to 9.74 ± 0.76 ; while the Flesch Reading Ease Score increased from 54.92 ± 3.81 to 59.81 ± 2.43 .

Table 6-2: AsthmaWise readability analysis

	Words	Sentences	Flesch-Kincaid Grade Level	Flesch Reading Ease
Average	182.05 \pm 41.5	8.03 \pm 1.9	8.18 \pm 0.65	64.93 \pm 3.4
Range	32 - 529	1 - 25	3.3 – 11.8	39.6 – 93.8

Flesch-Kincaid Grade Level target = 8
Flesch Reading Ease target = 60-70

6.5 Discussion

The usability testing undertaken was part of the iterative, user-centred design of AsthmaWise. The findings from this testing experience are important, as no previous published work on the suitability of Moodle as a platform for delivering health education modules for older adults, or the use of Morae, with this population were found. While current design and usability guidelines were utilised to inform the development of AsthmaWise, there was a discrepancy between the recommendations and what the site developers thought would work. Allowing the site designer to witness the usability testing was a powerful process as it allowed the problems users encountered to be seen, and demonstrated that anticipated user behaviour often did

not occur. While site designers often have extensive experience developing generic site targeting whole-populations, this usability testing process has demonstrated that the nuances associated with designing and developing usable sites for specific segments of the population, such as older adults, can be easily learnt by watching the target population undertake tasks with the application. The testing process also allowed issues such as the slow page load time to be investigated prior to the site going live; this resulted in image optimisation being undertaken along with other backend changes.

While previous research suggests that the think-aloud process can be hard for many participants^{34,35}, this was not our experience with only one participant struggling with the process. This person revealed during testing that they had an acquired brain injury. We found that numerous variables affected task completion time, independent of the site's usability. These factors included participants who skimmed content versus those that read every word aloud; participants who forgot their reading glasses; and those that became side tracked recounting personal stories. This latter point has been noted previously in research with older adults³⁶.

The use of Morae with older adults was efficient; however, many participants found the pop-up windows distracting and were confused between the program being tested (AsthmaWise in Moodle) and the program conducting the testing (Morae). In future, this could be overcome by improving the introduction of participants to the testing setting. While the researcher took time to explain to each participant what to expect and how long testing would take, the inclusion of a short task to complete prior to commencement of testing may have been effective in overcoming this problem.

Font size was the issue most commented upon; this is consistent with findings from other studies^{24,34,35}. Hudson found text size problematic with 50% of respondents aged over 60, although further qualitative research suggested that this number was much higher²⁶. None of the participants in this study tried to resize the text by changing the browser settings or searching for other controls; this again is consistent with other research and reinforces the necessity of having font optimally sized^{26,37}.

Hudson's finding that older adults frequently blame themselves rather than the program or equipment they are using might explain the discrepancy between the reported ease of registering for AsthmaWise and the actual number of profiles created²⁶. Creating a profile involved navigating to the registration page, and answering seven questions to ensure eligibility for the study and contact details. None of the participants expressed any privacy concerns around these questions.

In keeping with the findings of others, some participants questioned the credibility of the information they read³⁵. A review by van den Haak and van Hooijdonk suggests that this problem is heightened when people are looking for information for themselves as opposed to taking part in a usability test³⁴ suggesting that this issue is likely to be more problematic when people view the content in their own home. A number of strategies have been suggested to the site designer to circumvent this problem including: adding the date last updated on each page; displaying appropriate logos on each page; and providing the source(s) of information^{38,39}.

The PHWSUQ allowed us to obtain quantitative data reflecting participants' satisfaction and perceived ease of use and usefulness of AsthmaWise. The ease of use category received the second lowest score, which reflects the problems encountered with the navigation. Researchers planning to use PHWSUQ in future should consider the relevance of the generic health questions when using the tool to assess disease specific websites. Participant feedback indicated that few understood the concept "health hygiene" and many felt that asking if their knowledge of health had improved was too large a target for a site focussed on asthma.

Both the cognitive walk through and readability assessments were quick and inexpensive processes that yielded valuable information above that made by the usability testing alone, reinforcing the need for multiple testing methodologies²⁰. This allowed mistakes to be corrected and pages that ranked poorly to be rewritten prior to piloting, creating an improved final product. There is scope for the readability scores of AsthmaWise to be improved further in the future. Ideally, the cognitive walk through would have been conducted prior to usability testing. However, due to time constraints this was undertaken as a parallel process.

In an ideal world a site designer, with extensive usability knowledge would be employed. Standards for the site would be set at the start of the project and built into a quality improvement process which concludes with the final revisions to the site after piloting. In addition, the site would be reviewed prior to usability testing to ensure that basic usability standards are met. However, our experience shows that in a real-world setting, with a multi-agency approach and tight deadlines, the inclusion of usability testing, a cognitive walk through by an independent researcher and assessment of readability were of significant value to the site development process.

Usability testing was relatively cheap, costing less than AUD \$2,000 including the purchase of the software licence and incentives for participants. It is notable that while the researcher who undertook the testing is not an IT professional, she was able to set up and run the usability testing at a level that resulted in significant usability issues being identified and addressed resulting in a refined end-product.

6.5.1 Strengths and Limitations

The usability testing process undertaken had many strengths including guidance by a usability specialist and use of dedicated usability software which facilitated recording and analysis of the sessions. It has been shown that usability testing with five participants identifies 85% of problems⁴⁰, so usability testing with 13 participants, coupled with the cognitive walk through and assessment of readability is likely to have provided a robust testing of AsthmaWise and identified the majority of usability issues.

All of the participants had previously been involved in formative research for this project either through completion of a paper-based survey and/or participation in focus groups facilitated by the same researcher. Their continued involvement in the project may represent an emotional investment, which is possibly reflected in more positive responses. Secondly, only one participant was aged over 75 years; in light of findings by other researchers, it is likely that older participants may find using AsthmaWise more challenging⁴¹. Thirdly, all the participants were long-term web users and web experience has been identified as a predictor of task performance⁴².

This suggests that internet naive participants may have taken longer to complete the tasks set and may have encountered more usability problems. Finally, the majority of respondents spoke English at home, which would make understanding the content of the site more achievable than for someone from a non-English speaking background.

6.5.2 Conclusions

This usability testing process has shown the importance of involving both end-users and experts during testing. The involvement of the site designer in testing was incredibly valuable and is strongly recommended. The issues identified through usability testing were addressed and significantly improved the functionality of AsthmaWise; despite testing being undertaken at minimal cost. While the importance of usability testing with unique target populations is well accepted, this study shows that a non-expert can effectively conduct usability testing with an older population.

6.6 References

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CHAPTER 7

ASTHMAWISE: A FIELD OF DREAMS? THE RESULTS OF AN ONLINE EDUCATION PROGRAM TARGETING OLDER ADULTS WITH ASTHMA

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Burns, P, Jones, SC, Iverson, D, & Caputi, P. (2013). AsthmaWise - a field of dreams? The results of an online education program targeting older adults with asthma. *Journal of Asthma*, Early Online, 1–8. doi:10.3109/02770903.2013.799688.

Following refinements made as a result of the usability testing, AsthmaWise was piloted for a three month period at the beginning of 2012. The main aim of the pilot study was to establish the acceptability and feasibility of AsthmaWise. Asthma knowledge, asthma quality of life, asthma control and self-management efficacy were also measured pre and post intervention to assess changes as a result of participation. One hundred and six people registered to take part in the pilot study and matched data was obtained from 51 participants. Exposure to AsthmaWise resulted in significant improvements in asthma knowledge, asthma control and asthma quality of life.

(A copy of the post-test survey appears in Appendix D).

7.1 Abstract

Objectives

The aim of this study was to establish the feasibility and acceptability of an online asthma self-management program developed for older Australians with asthma.

Methods

AsthmaWise, an internet education self-management program was piloted for a three month period at the beginning of 2012. Participants were recruited using both online and offline strategies, and were required to complete surveys, both pre and post intervention, in a repeated measures design.

Results

Matched data was collected from 51 participants; the results showed AsthmaWise to be a feasible and acceptable method of delivering asthma education to the target population. Self-reported measures showed an increase in participants' asthma knowledge, asthma control and quality of life. Results from the Perceived Health Web Site Usability Questionnaire (PHWSUQ) showed improvements between usability testing and implementation.

Conclusion

The need for asthma self-management education will continue to increase as the population ages and a greater number of older adults are living with asthma. This small pilot study indicates that an online asthma self-management education program can result in improved outcome measures in a target group not normally considered technologically literate.

7.2 Introduction

Approximately one in ten people have an asthma diagnosis, which equates to over two million people in Australia alone^{1,2}. The associated mortality and morbidity creates a large burden on the Australian health system² which currently lies mostly with older adults^{3,4}. Significantly, asthma is associated with poorer quality of life, with sufferers reporting a higher proportion of days with reduced activity than people without asthma¹. While there is currently no cure for asthma, effective self-management has been shown to lead to: fewer attacks, effective symptom control, and improved quality of life⁵⁻⁹. Current Australian asthma self-management guidelines incorporate: self-monitoring, regular medication review, and the use of a written asthma action plan¹⁰. While the management of asthma in the elderly does not differ from that in younger patients, it can be complicated by the decline in physical and cognitive functioning often seen with aging. Further, asthma is more likely to occur along with other co-morbidities in older adults, altering the presentation of the asthma and complicating disease management. It has been recognised that asthma management amongst the elderly is likely to improve if educational interventions are tailored to their specific needs^{5,11}. However, there is currently a lack of asthma management support targeted specifically at this age group.

Asthma education has the potential to be delivered online; however, to date, most of these self-management tools have included the monitoring of symptoms and the involvement of healthcare professionals such as the patient's physician or an asthma nurse¹²⁻²⁰. Some of these interventions have shown improvements in asthma control^{13,14,20} and lung function²⁰, but little change in quality of life²⁰ or asthma exacerbations²⁰.

Online patient education has a wider reach than traditional face-to-face methods. Its flexible delivery allows recipients to view materials at convenient times and locations, reducing the burden of travel incurred when attending traditional face-to-face patient education. Most of the provider costs are incurred during development, while additions and corrections are quick and relatively inexpensive to undertake and deploy. Further, it is recognised that information technology can increase both

understanding of, and participation in, health care which, in turn, can increase empowerment²¹ and provide users with a more comprehensive understanding of their asthma than standard asthma education²². Trials of online asthma education have not, as far as can be discerned, previously focused solely on older adults.

This paper discusses the piloting of AsthmaWise, an online education site for older adults with asthma. AsthmaWise was created by a University research group in partnership with Asthma Foundation New South Wales (AFNSW), following two years of formative research with the target population. AsthmaWise contained six education modules, which were written in English and could be completed in any order. The module topics were designed to take a maximum of 15 minutes each to complete. The content was guided by Asthma Foundation NSW and was in accordance with the Australian National Asthma Treatment Guidelines¹⁰. The modules were also informed by the Theory of Planned Behaviour²³ as it is known that programs based on behavioural theories are more likely to produce positive outcomes^{22,24–26}. The levels of interaction and tailoring proposed for AsthmaWise were guided by previous work^{25,27–32}. Website design guidelines were used to optimise accessibility and usability for the target audience^{33–35}.

The program aimed to increase users' understanding of asthma and provide them with the tools needed to adequately self-manage their disease through the delivery of six modules. The modules were: (1) Asthma: what is it, what causes it and who gets it?; (2) Asthma treatments: medications and complementary therapies; (3) Asthma triggers: what makes your asthma worse?; (4) Asthma control check: are you in control?; (5) Asthma and life: exercise, gardens, food, smoking and products; and (6) Managing an asthma attack: what to do. AsthmaWise was password protected and could only be accessed after the user had completed registration.

This study aimed to establish the feasibility and acceptability of an online asthma self-management program amongst older Australians with asthma. Changes in asthma knowledge, asthma control, asthma self-management efficacy and asthma quality of life were also measured.

7.3 Methods

7.3.1 Formative Research

AsthmaWise was developed based on findings from two years of formative research. First, a paper-based survey was sent to 9,000 randomly selected older adults in New South Wales, Australia (response rate = 46.8%, n=4,066) to explore the health beliefs, attitudes and behaviours of older Australians towards asthma. This information was used to inform the content of AsthmaWise. Second, four focus groups were conducted to explore the type of interactivity older adults felt would be beneficial on an asthma education site, with particular reference to blogs and forums (n = 26). Based on these results AsthmaWise was subsequently developed by AFNSW using Moodle (Moodle, Perth, Australia), an open source learning management system that enables educators to create dynamic web sites. Usability testing was undertaken on the AsthmaWise prototype with older adults (n=13) who completed tasks on three sections of AsthmaWise. A cognitive walk through by an independent researcher and readability testing of the pages were also conducted³⁶. AsthmaWise was subsequently refined and piloted for a three month period at the beginning of 2012. The revised Flesch-Kincaid Grade Level for the modules tested was assessed at 9.74 ± 0.76 ; while the Flesch Reading Ease Score was 59.81 ± 2.43 . These were slightly outside the target ranges of eight or below for the Flesch-Kincaid Grade Level and 60 to 70 for the Flesch Reading Ease³⁶. Approval for this study was granted through the University's Human Research Ethics Committee.

7.3.2 Recruitment and Registration

A mixture of online and offline methods were utilised to recruit adults, aged 55 years and over, with asthma. Offline promotional flyers were distributed to dispensing pharmacies, and participants from previous stages of the research were invited to take part in the pilot. Online, two Facebook adverts targeting older adults in New South Wales were deployed; in addition two targeted emails from First Direct, a subsidiary of Australia Post, were sent to email addresses of older adults in NSW with asthma. AsthmaWise was also publicised by the following organisations: Pharmacy Guild NSW; General Practice NSW; Council on the Ageing NSW

(COTA); Country Women's Association of NSW (CWA); Seniors Clubs NSW; and the Illawarra Shoalhaven Medicare Local.

People interested in taking part in the piloting of AsthmaWise were asked to register their interest online. The registration process contained seven items; the first five items screened for eligibility (age, asthma diagnosed by a health professional, current asthma, postcode and suburb); participants were required to be aged 55 years or over and have current asthma. Initially geographic location was restricted to two regions of New South Wales, but lower than expected recruitment resulted in the intervention being opened up to residents throughout New South Wales. The final two items asked for contact information (name and email address). Due to difficulties recruiting participants, recruitment was left open during the pilot period.

7.3.3 Pre-test survey

On the day AsthmaWise went live, registered participants were emailed a link to the pre-test questions, via Informz (email marketing software). These questions had to be completed before people were able to access AsthmaWise. The pre-test survey contained 10 groups of items including information on participants' demographics, internet use and health.

A modified version of the consumer asthma knowledge questionnaire³⁷ was incorporated. Four questions were excluded on the advice of AFNSW who perceived them to be not consistent with current asthma management guidelines; and two items were omitted. The other six questions were scored 'true' or 'false'. A high mean score indicated better asthma knowledge. Psychometrics for this tool have been previously report³⁷. Cronbach's Alpha for the scale at pre-test was .54. While this value indicates low internal consistency, we continued with this tool for the purpose of this research.

Asthma control was measured using the RCP3 tool³⁸. The RCP3 consists of three questions, which are answered either 'no' (score = zero) or 'yes' (score = 1). A total RCP3 score of zero indicates well controlled asthma; a score of one indicates

medium morbidity, while a score of two or three indicates high morbidity. A low mean value indicated good asthma control. The RCP3 has been previously shown to reliably measure asthma control³⁹. Cronbach's Alpha for the scale at pre-test was .72 indicating acceptable internal consistency. The RCP3 was chosen as the Asthma Control Questionnaire was unavailable for computer delivery⁴⁰ and matching data from the Asthma Control Test to participants' other information would have proved problematic⁴¹.

Asthma quality of life was measured using statements developed to capture the ways in which asthma and its treatment may affect people⁴². Participants were asked to choose one of the five response options for each statement: 'not at all', 'mildly', 'moderately', 'severely' and 'very severely'. A low mean value indicates better asthma related quality of life. Psychometrics for this tool have been previously report^{42,43}. Cronbach's Alpha for the scale at pre-test was .97 signifying excellent internal consistency.

Asthma self management efficacy was measured using the Partners in Health Scale⁴⁴. The scale comprised of 11 questions which were amended to make them specific to asthma. Questions were scored on a nine-point scale, 0 = very good, 4 = satisfactory and 8 = very poor. As such, a low mean value indicated high self-management efficacy. The Partners in Health Scale has been shown to be a valid and reliable measure of chronic condition self-management⁴⁴. Cronbach's Alpha for the scale at pre-test was .92 this is representative excellent internal consistency.

7.3.4 Post-test survey

AsthmaWise could be accessed from February to April 2012. Emails reminding participants of AsthmaWise were sent out mid-way through the intervention. At the end of the intervention an email was sent to participants, via SurveyMonkey, which provided a direct link to the post-test evaluation questions. The post-test survey contained 77 items, including those that were administered in the pre-test, thus allowing matching to pre-test data. A modified version of the PHWSUQ for Older Adults⁴⁵ was used to assess participants' overall opinion of AsthmaWise, with 10

questions across three domains: satisfaction; ease-of-use; and usefulness. Participants were asked to answer each question using a seven-point likert scale (1 = very unsatisfied to 7 = very satisfied). The usability and reliability of this tool have been reported elsewhere⁴⁵. Cronbach's Alpha for the scale at post-test was .93 indicating excellent internal consistency. Health literacy was measured using the screening question "how confident are you at filling out forms by yourself", which has been shown to be useful for detecting people with inadequate health literacy⁴⁶.

Two participants were not sent the post-test survey as they had previously indicated they did not want to be contacted by SurveyMonkey. Another three participants contacted the researchers and asked to be excluded as they felt that they had not spent enough time on SurveyMonkey to complete the evaluation. A further person was excluded due to issues accessing the site, leaving a sample of 100 people.

Participants' scores for asthma knowledge, asthma control, asthma self-management efficacy, and asthma quality of life including the four asthma quality of life sub-scales (breathlessness, mood, social and concerns) were summed pre and post intervention. Paired t-tests were run and Pearson's correlation coefficient (r) was calculated as a measure of effect size.

7.3.5 Web usage data

Throughout the pilot, web-log data was collected using Google Analytics. This included information on the number of unique site visits; visit duration; and the operating systems and browsers used by participants.

7.3.6 Non-responders

A reminder email was sent to both non-responders and participants who had not fully completed the post-intervention survey a week after the first email was sent. A second email was sent to non-responders approximately two months later asking them to provide information on six items (age; age at diagnosis; seriousness of asthma; and the three RCP3 questions), allowing a comparison of responders to non-responders. An independent t-test was run to compare responders' and non-

responders' age. Age at diagnosis, asthma control and perceived seriousness of asthma were explored using χ^2 tests.

7.3.7 The Internet Self-Management Uniform Reporting Framework (iSMURF)

The Internet Self-Management Uniform Reporting Framework (iSMURF) was used to capture intervention detail under six domains: website design, support, study design, website use, user characteristics and reporting outcomes⁴⁷. iSMURF has been proposed as a minimum reporting set, which can facilitate easy comparison of internet self-management interventions target chronic diseases.

7.4 Results

One hundred and six people registered and completed the pre-test survey for AsthmaWise; matched pre and post test data was collected from 51 of these participants. Participant demographics are given in Table 7-1. Most participants reported good health (70.6% had good, very good or excellent health status) and had been diagnosed with asthma as an adult but more than five years ago (56.9%). At baseline, 90.2% (n=46) had uncontrolled asthma, based on their answers to the RCP3 questions and 17.6% (n=9) had visited the Emergency Department in the last 12 months because of their asthma. The most frequently reported co-morbidities were arthritis and bronchitis, with 58.8% of the sample reporting each condition. Most participants reported being long-term internet users (62.7% had been online for more than five years), with high comfort levels (74.5% reported being very comfortable online), and high usage rates (86.3% spent more than 10 hours online each week).

7.4.1 Acceptability of AsthmaWise

The total mean-converted score for the PHWSUQ was 75%, which was significantly better than the score obtained during usability testing (Table 7-2). The ranking of the individual domains remained consistent with those obtained during usability testing, with satisfaction scoring highest (81%) and usefulness scoring lowest (73%).

Table 7-1: User characteristics

Website design	
Technological platform	Moodle
Use of evidence based guidelines in site design	Yes
Utilisation of Web 2.0 technology	No
Support	
Provision of computer/ technical equipment to participants	No
Provision of technical support	No
Use of clinicians/moderators	No
Frequency of contact	N/A
Mode of contact	N/A
Provision of peer support e.g. forums	No
Was intervention incorporated into usual care	No
Study design	
Date of study	February – April 2012
Length of study	3 months
Recruitment methods	Unpaid Online & offline
Potential reach of intervention	Open to adults aged 55 years and over with a diagnosis of asthma
Use of incentives	A draw to win a 32" LED TV was open to participants who registered early A draw to win one of 3 x \$100 gift vouchers – open to those who completed both pre and post-test.
Use of reminders	Yes – 1 email
Website use	
Engagement	Total number of visits Average number of visits by participants Most viewed page
Exposure	Total duration of viewing Average viewing time by participants
Attrition	Over time e.g. baseline and post intervention as minimum
User characteristics	
Age	Mean = 62.5 yrs (n=51, SD=6.73) Range 50-85 yrs
Sex	Female = 66.7% (n=34)
Ethnicity	English as a second language = 17.6% (n=9)
Computer confidence/internet experience	Quite comfortable or very comfortable = 94.1% (n=49)
Level of education	Completed primary school = 5.9% (n=3) Some secondary school = 15.7% (n=8) Completed secondary school = 70.6% (n=36) Completed tertiary studies = 7.8% (n=4)
Health literacy	Limited/marginal = 17.6% (n=9)
Number of co-morbid conditions	2+ chronic diseases = 82.4% (n=42)
Reporting Outcomes	
Inclusion of costs/ cost effectiveness data	No
Participant satisfaction	Qualitative/quantitative

Most participants reported being long-term Internet users (62.7% had been online for more than five years), with high comfort levels (74.5% reported being very comfortable online), and high usage rates (86.3% spent more than 10 hours online each week).

Table 7-2: AsthmaWise pilot Perceived Health Web Site Usability Questionnaire results

Total and Subscale Mean Scores									
Dimension	Score range	Usability Testing		Intervention		t	p	df	r
		Mean (SD)	Mean converted*	Mean (SD)	Mean converted*				
Satisfaction	(4 – 28)	19.40 ± 5.44	69.30%	22.60 ± 4.39	80.71%	2.22	.030	61	.27
Ease of use	(3 – 21)	13.92 ± 1.68	66.30%	16.42 ± 3.23	78.20%	.54	.591	61	.07
Usefulness	(3 – 21)	12.77 ± 1.91	61.00%	15.40 ± 4.34	73.33%	1.92	.059	61	.24
Total	(10 – 70)	46.07 ± 1.40	65.71%	52.30 ± 2.71	74.71%	2.02	.048	61	.25

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

Most participants (68.6%) had decided to visit AsthmaWise to learn more about how to manage their asthma, the majority found AsthmaWise useful (94.1%).

“I had forgotten some of the detail of some of the things my doctor told me when I was first diagnosed. It was good to be able to refresh and update my knowledge.” Female, aged 71 years.

“It was a good check on what I am currently doing.” Male, aged 67 years.

Tracking of the site by Google Analytics showed that during the pilot period there were 10,265 page views by 633 unique visitors, which included the 106 registered users. It is likely that some of these visitors found AsthmaWise through Google or other search methods and so did not register to take part in the pilot. The majority of visitors were from Australia (97.67%), with most residing in Sydney (67.7%). The average visitor viewed 10.89 pages and stayed on the site for 8.31 minutes.

All further results discussed refer to the 51 participants with matched data. Most participants accessed AsthmaWise from home (94.1%) and found it to be an acceptable length (74.5%). Participants reported that the content was very easy or extremely easy to understand (80.3%) and that they were very or extremely confident that the content presented was accurate (84.3%). Most participants reported knowing more about how to manage their asthma after visiting AsthmaWise (78.4%); with almost half reporting that they had experienced an improvement in their asthma symptoms (49.0%). Over one-third had made changes to their asthma management as a result of AsthmaWise (36%), and a further 14% planned to make changes to their asthma management in the future. Reported changes included: monitoring their asthma symptoms (20%); making sure that they took their medication regularly (16%); visiting their General Practitioner (GP) for an asthma review (12%); and requesting an action plan from their GP (4%). The barriers most frequently reported, which hindered participants from making changes to their asthma management, were remembering to: monitor their asthma symptoms (28%) and take their asthma medication (16%). Over one quarter of participants reported having insufficient time to visit AsthmaWise as frequently as they would have liked (26%). However, almost all participants said they would recommend AsthmaWise to others with asthma (94%).

“Especially for those newly diagnosed like late age patients.” Male, aged 68 years.

“It would be of assistance to long time sufferers who have not consulted a GP for a long time in relation to asthma.” Male, aged 67 years.

7.4.2 Self-reported changes in asthma related health

Asthma knowledge, asthma control and asthma quality of life were all seen to significantly improve after using AsthmaWise (Table 7-3). Scores for the three subscales, breathlessness, mood and social also showed significant improvements, while changes in the concerns subscale were not significant (Table 7-3). The results

indicate that participants' asthma self-management efficacy decreased after exposure to the intervention (Table 7-3).

Table 7-3: Paired t-test results showing changes in asthma knowledge, asthma control, asthma quality of life and asthma self management efficacy

	Pre-test		Post-test		df	t	p	r
	Mean	SE	Mean	SE				
Asthma Knowledge	3.50	.12	5.13	.13	44	-11.82	.000	.87
Asthma Control	2.16	.15	1.34	.16	49	4.95	.000	.58
AQoL	3.20	.34	2.54	.29	49	2.61	.012	.35
AQoL Breathlessness	8.06	.78	6.38	.70	49	2.20	.032	.30
AQoL Mood	7.70	.68	6.02	.65	49	2.53	.015	.34
AQoL Social	6.18	1.07	4.64	.82	49	2.64	.011	.35
AQoL Concerns	7.52	1.03	6.18	.82	49	1.98	.053	.27
Asthma self management efficacy	19.36	2.44	28.20	2.25	49	-4.06	.000	.50

A higher mean score indicates an improvement in asthma knowledge, whereas lower mean values indicate improved asthma control, asthma quality of life and self-management efficacy.

7.4.3 Comparison of post-test non-responders to responders

Just over one quarter of the 49 participants who did not complete the post-intervention survey responded to the emailed follow-up questions (26.5%). There was no significant difference in the age, age at diagnosis or asthma control between the responders and non-responders. However, non-responders were significantly more likely to perceive asthma as not serious when compared to responders [$\chi^2(1, N=71)=134.12, p=.000$].

7.4.4 The Internet Self-Management Uniform Reporting Framework (iSMURF)

Data has been provided under all six iSMURF domains (Table 7-1) as the publication of this information adds to the body of knowledge regarding the effectiveness of online self-management education for chronic diseases, by providing detail not just about the users but also in-depth information about the intervention design.

7.5 Discussion

AsthmaWise was an online asthma self-management education program, which allowed participants to learn more about managing their asthma. Although AsthmaWise targeted older adults aged 55 years and over, the mean age of participants was fairly young (62.5 years). While this was somewhat influenced by the inclusion of five participants aged between 50 and 55 years which occurred due to a technical error, which should have prevented people under the age of 55 from progressing past the registration phase. These participants were included in the analyses due to the relatively small number of total participants and because it may suggest, that such interventions have significant appeal to the young-old. Like other internet delivered education programs, usage of AsthmaWise was dependent upon participants being computer literate and having access to the internet. The majority of participants had been online for over five years (86.3%) and used the internet for more than 10 hours a week (62.7%). These rates of Internet engagement are considerably higher than reported elsewhere (68% and 21% respectively)⁴⁸ highlighting the appeal of AsthmaWise to older adults who utilise the internet extensively. Obviously, this finding has ramifications for older adults that are not long-term confident users as well as for those that are not online at all. Recent Australian research suggests that while 85% of 55 – 59 year olds use the internet, this rate falls to 50% of those aged 75 years and over⁴⁸. However, it is expected that levels of internet use seen in those aged 75 years and over will increase as the Baby Boomers age, reducing the need for alternate delivery channels. It is therefore suggested that practitioners providing online health education targeting older adults, in the near future, should consider using other delivery channels in conjunction with the Internet. This will increase the potential reach of the program whilst also ensuring that population segments are not excluded.

The majority of participants were female (66.7%), which is higher than the proportion in NSW (50.7%)⁵². Most participants reported having two or more chronic diseases, with 59% reporting that their asthma co-occurred with arthritis; a proportion identical to other research findings⁵³. While the proportion of responders who did not speak English at home (17.6%) was lower than the rate for NSW (26.5%)⁵², this is likely to have been due to AsthmaWise being provided solely in

English. It is likely that AsthmaWise users were also highly e-health literate - that is skilled in the ability to find, understand and assess health information online⁴⁹. High e-health literacy is most common amongst younger, more educated people⁵⁰, like the AsthmaWise sample. Future iterations of AsthmaWise and other online self-management education programs should consider how to engage people from culturally and linguistically diverse backgrounds (CALD) as well as those with low e-health literacy. The value of including a tool such as eHEALS⁵¹ to measure participants' e-health literacy should also be considered.

The discrepancy between the relatively large number of unique visitors and the lower number of registered participants may have been caused by casual visitors or due to problems with the registration process. While the researchers were contacted by participants during the pilot period, this was never in relation to registration difficulties suggesting that the difference was due to casual visitors. However, since visits were factored in to the data supplied by Google Analytics it is likely to have resulted in mean values significantly lower than those that would have been obtained if only data from the registered participants was examined. For instance, while the average visit length was reported as 8.31 minutes, which was considerable longer than that reported by the German Asthma Information Centre at 1.57 minutes⁵⁴, it is likely that registered users visited for longer periods of time. Although fewer people completed the post-test survey than the pre-test survey, such drop-out rates are not unusual with internet intervention trials⁴⁷. Further, follow-up of non-responders resulted in us acquiring data for just over two-thirds of participants who completed the original pre-test survey.

Results from the PHWSUQ indicated that while the usability of AsthmaWise had improved since usability testing, there was still scope for further improvement in terms of its overall usability. Our results indicate that exposure to AsthmaWise significantly improved participants' asthma knowledge, asthma control and asthma quality of life. While other interventions targeting asthma have also shown significant improvements in asthma control²⁰, reported changes to quality of life have varied from those showing improvements⁵⁵ to those finding minimal improvement⁵⁶. Although it has been argued that improved asthma knowledge is likely to lead to

improved asthma management⁵⁷, these results should be interpreted with caution as a Cochrane review concluded that asthma education alone can improve perceived asthma symptoms but not health outcomes⁵⁸. The reduction in asthma self-management efficacy following exposure to AsthmaWise contradicts current knowledge which links high self-efficacy with better asthma control and asthma related quality of life^{59,60}. It is possible that this drop in self-management efficacy occurred because, prior to exposure to AsthmaWise, participants were unaware of the seriousness of asthma.

The use of both online and offline recruitment methods is likely to have increased visibility of AsthmaWise, with a number of people who were not regular computer users contacting the researchers to ask if they could participate. While previous research has shown that people with asthma are willing to use both the internet and their phones to help them manage their asthma⁶¹, the difficulty experienced in recruiting participants would suggest that older adults are not as open to the idea as younger persons. This reinforces the demographic profile of AsthmaWise users, as relatively young, long-term, confident internet users.

While non-responders were seen to not differ significantly from responders in terms of age, age at time of asthma diagnosis or asthma control, they were significantly more likely to perceive asthma as not being serious. This is consistent with previous research which has shown that adults aged over 65 years with a mix of co-morbidities, tend not to view asthma as serious⁶². These results suggest that perceived seriousness of asthma may play a pivotal role in how users engage with a self-management program.

The value of tailoring AsthmaWise to meet the needs of each individual user should be investigated. Such customisation would allow the program to provide dynamic, individualised care, which can adapt both to the users' disease experience and their environment thereby reinforcing findings both from the development of AsthmaWise and other studies^{63,64}.

This study had strengths including the use of a repeated-measures design. Further, the use of standardised questions allowed the easy comparison of demographic data, while the scales for asthma knowledge, asthma control, asthma quality of life and the partners in health scale have established validity and reliability. However, our findings should be interpreted with caution due to the relatively short period that AsthmaWise was available for viewing (just three months); possible sample bias due to self-selection, which resulted in a young, computer literate sample; and the lack of a control group. The evaluation relied on self-reported measures of physical change. It was not possible to calculate actual participation rates as we do not know how many eligible people saw the adverts for AsthmaWise and of those what percent met the eligibility criteria. Finally, the overlapping nature of respiratory diseases in older adults makes it possible that participants had a chronic disease with similar symptoms as asthma but had been misdiagnosed as having asthma^{3,65}.

It is suggested that the findings from this pilot study of AsthmaWise be incorporated into prospective versions of the intervention, and that in future the site remains live for a longer period of time. This would allow more participants to register and access AsthmaWise, which in turn would allow more complex analyses of the outcome variables. In particular, it would be possible to look at usage when users are segmented by asthma severity and/or medication use.

7.5.1 Conclusions:

This small pilot study indicates that an online asthma self-management education program can result in improved self-reported asthma knowledge, asthma control and asthma quality of life. Importantly, this occurred with a target group not normally considered to be technically literate. The need for asthma self-management education programs will continue to increase as the population ages and there are more older adults are living with asthma.

The results suggest that online programs could be successfully used to teach self-management skills for other chronic diseases. Such programs could help to alleviate current GP time pressures. As recruiting participants proved harder than expected, it

is suggested that future initiatives targeting this age group provide resources to support participants to accessing and utilising the appropriate technology.

7.6 References

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CHAPTER 8

CONCLUDING COMMENTS

The research in this thesis has extended current knowledge regarding the use of an online self-management tool, AsthmaWise, in targeting asthma in older Australians. The tool was developed in order to help older Australians better manage their asthma as it is known that well controlled asthma can result in improved quality of life. This chapter summarises the research findings that led to the development, refinement and piloting of AsthmaWise, an online self-management education site aimed at older adults with asthma. The adoption of user-centred design methodology during the development of AsthmaWise ensured the creation of an appropriate product, which met the needs of the target audience. The involvement of the target population in the design process was important as it recognised that older adults are not a homogenous group, but have various levels of experience and confidence with both their asthma and their use of computers and the Internet.

8.1 Overview of Findings

Results from the pilot study of the baseline survey (Chapter 2) showed that the majority of respondents were confident, long-term Internet users, with up-to-date equipment. This finding showed that the development of an online self-management tool targeting older adults with asthma was viable. Results from the final survey, indicated that older adults are most likely to gain health information from traditional sources, such as doctors and pharmacists; the Internet is currently the third most popular source of health information. This finding further supported the provision of health information online to an older audience. The importance of the Internet as a source of health information for older adults is likely to increase, driven in part by the ageing of the Baby Boomers, those adults currently aged between 48-66 years¹, who have frequently gained computer and Internet skills through exposure in the workplace. This increase in skilled users will be so great that it has been argued that the ageing of this cohort will result in the digital divide repairing itself².

The literature review (Chapter 4) aimed to identify the “active ingredients” needed to produce successful Internet interventions that support older adults to self-manage their chronic disease(s). The Model of Internet Interventions was used as a framework for the review. Two hundred and four papers were initially identified under a two-step review process which found that 13 papers met the inclusion criteria. While it was established that online self-management interventions can improve outcomes for some older adults, further supporting the development of an online asthma self-management education program. However, the complex nature of the studies coupled with the diversity of interventions and the different measures reported made it difficult to identify the “active ingredients” – that is, the unique components of Internet interventions that are paramount in creating successful outcomes. The findings resulted in the design of an innovative framework, iSMURF (Internet Self-Management Uniform Reporting Framework), a minimum data reporting set that researchers reporting online self-management interventions should aim to collect. iSMURF proposes the collection of data under six domains: website design, support, study design, website use, user characteristics and reporting outcomes. The use of iSMURF by researchers would provide standardised data resulting in easy comparability between studies, which should in turn result in an increased understanding of the effectiveness of Internet interventions and, most importantly, lead to the identification of the “active components” that make interventions successful.

In order to inform the development of the intervention, four focus groups were conducted exploring asthma management, use of asthma Internet information, and preference for different web site features. The results were presented in a mixed methods paper (Chapter 5) which showed that older adults with asthma were primarily interested in information pertaining to the identification and avoidance of their asthma triggers, how to deal with asthma attacks, and how to find out about the latest information on asthma management. These findings were reflected in the content of AsthmaWise. The Technology Acceptance Model^{3,4} was used to structure the focus group results, and showed that respondents had limited interest in learning such information through the incorporation of interactive technologies, such as forums and blogs. These findings are unique as it is often assumed that the latest,

most interactive methods of presenting information are the best. However, the participants felt that these options may have value for other users. Interestingly, videos were perceived to be a useful learning tool.

AsthmaWise was developed using a Moodle platform⁵, which enabled the creation of a dynamic website. The content was driven by the findings from the formative research, the Australian National Asthma Treatment Guidelines⁶ and the Theory of Planned Behaviour⁷. The pilot version of AsthmaWise contained six education modules, written in English.

Usability testing of the AsthmaWise prototype was completed with 13 end-users (Chapter 6), allowing feedback from the target population. A cognitive walk-through by an independent researcher and an assessment of the content readability were also conducted. AsthmaWise achieved a Perceived Health Web Site Usability Questionnaire⁸ score of 66%, indicating usability issues that needed to be addressed prior to the piloting of AsthmaWise. This end-user testing is recommended as it informed the refinement of AsthmaWise and ensured maximum usability for the target population. Interestingly, the cognitive walk through and readability assessments identified unique issues that were not noted by the end-users. This testing was quick and relatively inexpensive to undertake. This reinforces the need to use multiple methodologies when undertaking usability testing and also the accessibility of such methodologies to researchers. The involvement of the site designer in the usability testing was very powerful and added value to the process above that which would have been achieved from a report alone. This involvement further strengthened the design of AsthmaWise. The findings from this chapter are important, as no previous published work on the suitability of Moodle as a platform for delivering health education modules for older adults, or on the use of Morae, were identified with this population. The development platform (Moodle) provided an accessible manner of presenting health information to older adults, which was also acceptable to the audience. This finding is of importance, as due to the open-source nature of Moodle, it is widely available and cost-effective. Morae proved to be invaluable in undertaking usability testing as it presented the task to be completed, while also capturing audio, video of the participant and also of the action on screen.

While some participants found the presentation of tasks confusing, this could be easily overcome in the future.

AsthmaWise was subsequently refined by Asthma Foundation NSW prior to the site being piloted at the beginning of 2012. Participants were recruited using both online and offline strategies, and were asked to complete pre and post intervention surveys, in a repeated measures design. One hundred and six people registered to take part in the pilot study and matched data was obtained from 51 participants. Such high drop-out rates are common with internet interventions. The results showed AsthmaWise to be a feasible and acceptable method of delivering asthma education to the target population. Results from the Perceived Health Web Site Usability Questionnaire (PHWSUQ) showed improvements since usability testing (at 75% up from 66%) and self-reported outcome measures showed a significant increase in participants' asthma knowledge, asthma control and quality of life. Comparison of post-test responders to non-responders indicated that the perceived seriousness of asthma influences older adults' participation in the online education pilot. This finding is pivotal, as the knowledge that perceived seriousness of asthma can influence participation in an online self-management program can be used in the future to increase engagement. Further research is needed to see if, and how, perceived seriousness of asthma impacts the way in which older adults manage their asthma.

8.2 Contributions to the Literature

This thesis has made two significant contributions to the literature. First, an online self-management education tool was developed, specifically targeting older adults with asthma. This was the first time that an online asthma initiative had specifically targeted older adults, despite the fact that this group shoulders the greatest asthma mortality and morbidity. Results from the pilot study showed that online self-management education is both a feasible and acceptable way of providing support to older adults, which led to significant improvements in participants' asthma knowledge, asthma quality of life and asthma control. These findings have important implications for the provision of self-management education for asthma and other chronic diseases, outside of the primary healthcare setting. This is especially important since Australia has an ageing population and older adults are the greatest

users of health care resources; as these results suggest that adequate self-management support can be provided online, thus alleviating pressures in the primary healthcare system. Second, the development and proposal of iSMURF has the potential to significantly impact the development of online self-management education, by facilitating the comparison of data between interventions

8.3 Key Learnings and Future Research

The need for asthma education will continue to increase as the population ages and a greater number of older adults have asthma that they need to self-manage. It is predicted that the number of Australians aged over 65 years will almost double between 2006 and 2026 - from 2.7 million to 5.1 million⁹. Providing adequate face-to-face support to patients is impossible due to the constraints facing the primary care workforce. The Internet offers an attractive and economical health communication channel that can overcome issues of time and location as they can be visited at times and location that suit the patient. What is more, they can be revisited as and when the patient feels that they require further information.

The collaboration of two organisations proved challenging and resulted in compromises throughout the project, due in part to the differing primary goals of each organisation. However, the project was strengthened by the involvement of stakeholders with expertise in both research and asthma and is reflective of research in a real-world setting.

Ideally, the next iteration of AsthmaWise will allow tailoring of information to meet individual users' needs and reflect changes in their asthma control and circumstances. The work in this thesis has shown that both health literacy and perceived seriousness of asthma may be effective ways of segmenting the user group. Further research is needed to ascertain the best methods to reach older adults who do not view their asthma as serious and engage them in asthma self-management education. This view of asthma as not being serious when compared to other chronic diseases is compounded by the more frequent occurrence of multi-morbidities in this population, and needs to be taken into consideration when providing asthma self-management education.

It was found that older adults frequently receive health information from health care professionals - such as general practitioners, pharmacists and practice nurses. As such, the involvement of healthcare practitioners in the promotion of health educational websites, such as AsthmaWise, needs to be considered. The participation of health professionals would also help to overcome some of the issues around trust and credibility of online information. The involvement of health care practitioners could be taken a step further with the integration of AsthmaWise into standard care, thereby allowing the storage of asthma action plans and recording of asthma symptoms. Future iterations of AsthmaWise should look at the feasibility of adapting the program to run as a mobile phone application (app), which would allow easier integration into many users' everyday lives¹⁰, which is likely to become more desirable as the Baby Boomers age.

8.4 Limitations

Each stage of the research had its own set of limitations, which have been addressed in the preceding chapters. As such, this section discusses some of the limitations of AsthmaWise as a whole. Primarily, it should be recognised that many asthma sufferers do not understand that their condition will improve with the correct treatment regimen¹¹, and so may not be motivated to participate in self-management education programs such as AsthmaWise. The over-lapping nature of asthma symptoms with symptoms of other chronic diseases is acknowledged as complicating both diagnosis and management of asthma in older adults. It is unknown what, if any, affect this overlap had on the participants who took part in the development and piloting of AsthmaWise.

The provision of self-management programs for older adults with chronic disease(s) makes several assumptions. First is the supposition that older adults are willing to participate in shared decision making with their doctor around their chronic disease. Older patients are acknowledged as often accepting a paternalistic relationship with their doctor, which sees the patient playing a passive role^{12,13}. As such, they may be less likely to be involved in their own care or to seek information than younger generations. Second, self-management programs presume that all patients have both

the ability and the desire to manage their disease⁶. It can be deduced that some older adults either choose or are not able to be involved in the management of their asthma.

The efficacy of online self-management education depends upon participants having access to a computer and the Internet, in addition to being literate, computer literate (able to use a computer) and e-literate (able to seek, find and assess health information online). While use of computers and the internet currently decreases with age, it is worth remembering that the Baby Boomers (those currently aged between 48 and 64 years) are the first generation to age with computer skills acquired in the workplace. It is highly likely that these skills will be retained as this cohort ages and that the number of older computer and internet users will vastly increase. However, it is worth also acknowledging that computer and Internet use by older adults can be complicated by visual impairment, hearing impairment, cognitive decline (short term memory, speed of processing) and motor limitations caused by physical decline^{14,15}. While such impairments can often be overcome by the use of disability aids or software, older adults are often reluctant to use such aids¹⁵. As such, it is recommended that at this point in time the Internet should not be the sole channel of health communication with older adults, and that an offline version of programs be made available for those who rarely or never use a computer. Allowing a choice of delivery channels would further increase the reach of such programmes.

8.5 Summary

This body of work has shown that online self-management education is both feasible and acceptable to older adults. It was shown that the Internet is already being used by older adults and it is postulated that usage will increase as the Baby Boomers age, as this is the first generation to have been exposed to technology in the workplace. The literature review resulted in the proposal of iSMURF, providing a framework for the reporting of online chronic disease self-management interventions. The use of this framework will increase the quality of intervention reporting, aiding comparisons between interventions and hopefully leading to the identification of the “active ingredients” that make such interventions successful. The use of user-centred design methodology is novel and has rarely been reported in this population. The finding

that there is little difference in asthma topics of interest irrespective of time of diagnosis shows that basic asthma knowledge is still lacking. Further the lack of interest in blogs and forums as a way of learning about asthma was unexpected as it is often presumed that people prefer to learn through interactive experiences. Participants who took part in the piloting of AsthmaWise showed significant improvements in asthma knowledge, asthma control and quality of life over a relatively short period of time. This suggests that providing online self-management education to older adults is both acceptable and effective. This has important implications for the provision of self-management education for targeting older adults with both asthma and other chronic diseases in the future.

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ADDENDUM

As chapters 2-7 of this thesis have already been published or accepted for publication, comments from the examiners have been addressed in this addendum.

1. The iSMURF (Internet Self-Management Uniform Reporting Framework) system was chosen as a means of standardising the information reported. What were the relative strengths and weaknesses of this decision?

The use of iSMURF made it very easy to decide what intervention information was to be reported. It is hoped that the adoption of iSMURF by other researchers will allow easy comparison of online self-management interventions, ultimately leading to the identification of the 'active ingredient(s)' - those functionalities that need to be included to create an effect. There were no apparent weaknesses in using iSMURF, as there are currently no other reporting frameworks available that the author was aware of.

2. What is the generalisability of the findings in Chapter 2 to low-income, Aboriginal or low-health literate individuals?

The findings reported in Chapter 2 should be generalised with caution, primarily because of the small sample size. While over 50% of respondents had an income of \$40,000 per annum or less, most had undertaken tertiary education (70%), which is not reflective of the older Australian population as a whole. Although health-literacy was not reported in this paper, it is known to be correlated with educational achievement, so would have likely been skewed in this sample. Finally, Aboriginal Australians comprise approximately 2.5% of the Australian population, so again the sample was not large enough to draw reliable conclusions.

3. Were there any significant differences between respondents and non-respondents (Chapter 3)? How does the data fit with the reality that most people are poor judges of risk and reliability?

Due to cost and timing constraints no attempt was made to follow up the nearly 5,000 non-responders. It is acknowledged that most people are poor judges of risk and reliability, however, this chapter presents self-reported data on where older adults get information about health and how trustworthy they perceive the information from these sources to be. Future studies could attempt to measure the reliability of these sources of health information.

4. Chapter 5 could be improved by focusing on whether people actually change their behaviour as a result of internet information and greater consideration of health literacy and non-psychological determinants of health.

Chapter 5 presented data from a paper-based survey and focus groups. Information on how older adults change their behaviour based on information found on the internet was not collected in either research phase. Nevertheless, this is an important issue and future research could investigate how older adults use the health information they find on the Internet.

Work by other researchers suggested that time of asthma diagnosis influenced the type of asthma information desired by older-adults, this was not supported by our findings. The next logical step would be to consider how health literacy impacts the type of asthma information required.

5. Was there any clinical testing of respiratory function of participants or their use of medications?

Participants' respiratory function was not measured as both pre and post test surveys were conducted online. Further, participants were recruited from across New South Wales, Australia, which due to distance would have made the logistics of clinical testing complicated and time consuming.

In the pre-test survey, participants were asked to provide information on the use of the asthma preventer they had used in the previous two-weeks. Future papers may look at what impact AsthmaWise had on participants' medication regimes.

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APPENDIX A: BASELINE SURVEY

The NSW Survey of Adults Aged 55 Years and Over

The first section (Q1-Q58) is for all community members to complete. The second section (Q59-Q79) is specifically for people with asthma.

Thank you for your time!

Please tick ☒ one box for each question unless otherwise stated.

Your General Health

1. In general, how would you rate your health?

- ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2. Compared to last year, how would you rate your health?

- ☐ Much better ☐ Better ☐ About the same ☐ Worse ☐ Much worse

3. Which of the following best describes your smoking status?

(This includes cigarettes, cigars and pipes)

- ☐ I smoke daily
☐ I smoke occasionally
☐ I don't smoke now, but I used to
☐ I've tried a few times but never smoked regularly
☐ I've never smoked

4. Have you ever been told by a health professional that you have any of the following? (Please tick ☒ all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Allergic Rhinitis (Hay fever) | <input type="checkbox"/> Eczema (allergic skin rash) |
| <input type="checkbox"/> Angina/heart attack/heart failure | <input type="checkbox"/> High blood pressure |
| <input type="checkbox"/> Anxiety or panic attacks | <input type="checkbox"/> Nasal polyps/Sinusitis |
| <input type="checkbox"/> Arthritis | <input type="checkbox"/> Parkinson's disease |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Pneumonia |
| <input type="checkbox"/> Chronic bronchitis | <input type="checkbox"/> Sleep apnoea |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Tuberculosis (TB) |
| <input type="checkbox"/> Emphysema | |
| <input type="checkbox"/> Chronic obstructive pulmonary disorder (COPD) – a disease of the lungs | |
| <input type="checkbox"/> Other _____ | |

Please turn to the next page →

Your Opinion about Asthma

5. For each statement, please tick ☒ whether you think it is TRUE or FALSE.

	TRUE	FALSE
a. Asthma cannot be cured	<input type="checkbox"/>	<input type="checkbox"/>
b. Asthma can usually be managed without medication	<input type="checkbox"/>	<input type="checkbox"/>
c. People with asthma cannot exercise or play hard	<input type="checkbox"/>	<input type="checkbox"/>
d. Asthma is a common reason for many school/work absences	<input type="checkbox"/>	<input type="checkbox"/>
e. Asthma tends to run in families	<input type="checkbox"/>	<input type="checkbox"/>
f. Asthma is mainly an emotional illness	<input type="checkbox"/>	<input type="checkbox"/>
g. When asthma attacks stop, you don't have asthma anymore	<input type="checkbox"/>	<input type="checkbox"/>
h. You cannot have asthma as an adult without having it as a child	<input type="checkbox"/>	<input type="checkbox"/>

6. This is a list of things that may or may not be a sign of asthma.

(Please tick ☒ YES if it is a sign of asthma or tick ☒ NO if it is not a sign of asthma.)

	YES	NO
a. Is shortness of breath a sign of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
b. Is tightness in the chest a sign of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
c. Are severe headaches a sign of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
d. Is a cough at night a sign of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
e. Is wheezing after exercise a sign of asthma?	<input type="checkbox"/>	<input type="checkbox"/>

7. This is a list of things that may or may not trigger asthma.

(Please tick ☒ YES if you think it is an asthma trigger or tick ☒ NO if you do not.)

	YES	NO
a. Are pets with fur a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
b. Are mosquito bites a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
c. Is mould a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
d. Is cigarette smoke a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
e. Is a poor diet a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>
f. Is pollen a trigger of asthma?	<input type="checkbox"/>	<input type="checkbox"/>

8. Please tick ☒ the extent to which you think the following statements are true.

	NEVER TRUE	RARELY TRUE	SOMETIMES TRUE	OFTEN TRUE	ALWAYS TRUE
a. Being admitted to hospital for asthma is preventable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Asthma symptoms can be prevented with the right medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. People with asthma that get relief from over the counter drugs still need to see their doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Asthma is a serious health problem in Australia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Asthma care is expensive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. When a person has an attack they should see a doctor immediately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. The emergency department is the best place to get treated for an asthma attack	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. People can get addicted to their asthma medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Children with asthma have overprotective mothers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Stress makes asthma worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. What do you think is the likelihood of you getting asthma?

Very unlikely Unlikely Somewhat likely Likely Very likely

☐ ☐ ☐ ☐ ☐

☐ Not applicable, I have asthma

10. How serious do you think asthma is?

Not at all serious Not serious Somewhat serious Serious Very serious

☐ ☐ ☐ ☐ ☐

Please turn to the next page →

11. These questions are about your health – even if you do not have asthma.
(Please tick ☒ on the scale the extent to which each statement has applied to you over the past FOUR WEEKS.)

	NOT AT ALL	MILDLY	MODERATELY	SEVERELY	VERY SEVERELY
a. I have been troubled by episodes of shortness of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I have been troubled by wheezing attacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I have been troubled by tightness in the chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I have been restricted in walking down the street on level ground or doing light housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I have been restricted in walking up hills or doing heavy housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I have felt tired or a general lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I have been unable to sleep at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I have felt sad or depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I have felt frustrated with myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I have felt anxious, under tension or stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. How many times have you visited your GP in the last 12 months?

None Once 2-3 times 4-11 times 12 or more times

☐ ☐ ☐ ☐ ☐

13. When do you go to see your GP? (Please tick ☒ all that apply)

- ☐ For health check-ups, health screening and prevention
- ☐ As soon as I start to feel unwell
- ☐ If I am unwell and not improving after a few days
- ☐ Only if I'm feeling extremely unwell
- ☐ Other (please specify) _____

14. What stops you from regularly visiting your GP?

(Please tick ☒ all that apply)

- ☐ Time ☐ Do not think I need to ☐ I cannot get an appointment
☐ Cost ☐ Cannot be bothered ☐ I do not want to find out something bad
☐ Nothing, I visit my GP regularly
☐ Other (please specify) _____

15. What do you think are benefits of regularly visiting the GP?

(Please tick ☒ all that apply)

- ☐ Preventative health/early detection ☐ Receiving advice on healthy living
☐ Monitoring my health conditions ☐ Review of ongoing prescriptions
☐ My GP knows me & my medical history
☐ None, there is no benefit
☐ Other (please specify) _____

When answering the next two questions (Q16 and Q17), please try to imagine what it would be like to have asthma. If you have asthma, please answer from experience.

16. How confident are you that you could keep the physical discomfort or pain of asthma from interfering with the things you want to do?

- | Not at all
confident | Not very
confident | Somewhat
confident | Quite
confident | Extremely
confident |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. How confident are you that you could keep the emotional distress caused by asthma from interfering with the things you want to do?

- | Not at all
confident | Not very
confident | Somewhat
confident | Quite
confident | Extremely
confident |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please turn to the next page →

Your Use of Media

18. When do you usually watch television? (Please tick ☒ all that apply)

- ☐ Morning ☐ Middle of the day ☐ Afternoon ☐ Evening
☐ Never, I don't watch television

19. When do you usually listen to the radio? (Please tick ☒ all that apply)

- ☐ Morning ☐ Middle of the day ☐ Afternoon ☐ Evening
☐ Never, I don't listen to the radio

20. Which newspapers do you read? (Please tick ☒ all that apply)

- ☐ Community (free) newspapers
☐ Regional newspapers (e.g. the Illawarra Mercury)
☐ State newspapers (e.g. the Sydney Morning Herald)
☐ National newspapers (e.g. The Australian)
☐ None, I don't read newspapers

21. When do you usually read newspapers? (Please tick ☒ all that apply)

- ☐ Weekdays ☐ Saturday ☐ Sunday
☐ Never, I don't read newspapers

Your Sources of Health Information

22. Which of the following sources have you used to obtain health information? (Please tick ☒ all that apply)

- | | |
|--|--|
| <input type="checkbox"/> GP/Doctor | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Relative/Friend |
| <input type="checkbox"/> Brochures/Pamphlets | <input type="checkbox"/> Internet websites |
| <input type="checkbox"/> Magazines | <input type="checkbox"/> Television |
| <input type="checkbox"/> Newspapers | <input type="checkbox"/> Radio |

23. Which of the following sources of health information would you rate as reliable (providing accurate information)? (Please tick ☒ all that apply)

- | | |
|--|--|
| <input type="checkbox"/> GP/Doctor | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Relative/Friend |
| <input type="checkbox"/> Brochures/Pamphlets | <input type="checkbox"/> Internet websites |
| <input type="checkbox"/> Magazines | <input type="checkbox"/> Television |
| <input type="checkbox"/> Newspapers | <input type="checkbox"/> Radio |

a. Why do you think these sources are or are not reliable?

Your Internet Use

24. Have you ever used a computer to access the Internet or email?

☐ Yes

☐ No

If NO, please go to the
"About You" section (Question 42)
on Page 9

25. How many years have you been using the Internet?

☐ Less than 1 year

☐ 1-2 years

☐ 2-5 years

☐ More than 5 years

☐ I don't use the Internet

26. Overall, how comfortable are you with using the Internet?

Not at all
comfortable

Somewhat
comfortable

Comfortable

Quite
comfortable

Very
comfortable

☐
☐
☐
☐
☐

27. During an average week, roughly how many hours do you spend using the Internet or checking email?

☐ Less than 1 hour

☐ 1-2 hours

☐ 3-5 hours

☐ 6-9 hours

☐ 10-15 hours

☐ More than 15 hours

Please turn to the next page →

28. Have you ever used the Internet to find health information?

☐ Yes ☐ No

29. How often do you access the Internet from home?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐

30. How often do you access the Internet from work?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐

31. How often do you access the Internet from library/community centre?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐

32. How often do you access the Internet from a friend or relative's house?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐

33. How often do you access the Internet on your mobile phone?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐

34. Do you have an email address?

☐ Yes ☐ No

35. How often do you access your email?

Daily Weekly Monthly Less often Never
☐ ☐ ☐ ☐ ☐
☐ I do not have an email address

36. Which Internet browser do you use most frequently? (Please tick ☒ one)

☐ Internet Explorer  ☐ Firefox 
☐ Opera  ☐ Safari 
☐ Other (Please specify) _____ ☐ I don't use the Internet

37. What type of Internet connection do you use most frequently?

- | | | |
|---------------------------------------|---|--|
| <input type="checkbox"/> Dial-up | <input type="checkbox"/> Broadband | <input type="checkbox"/> Wireless Broadband |
| <input type="checkbox"/> Mobile Phone | <input type="checkbox"/> Satellite | <input type="checkbox"/> I don't have Internet |
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Other (please state) _____ | |

38. How old is your computer?

- | | | |
|---|--|--|
| <input type="checkbox"/> Less than 1 year | <input type="checkbox"/> 1 – 3 years | <input type="checkbox"/> More than 3 years |
| <input type="checkbox"/> Don't know | <input type="checkbox"/> I don't have a computer | |

39. How often do you print off information from the Internet?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Daily | Weekly | Monthly | Less often | Never |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

40. What type of printer do you have access to?

- | | | |
|--|---------------------------------|---|
| <input type="checkbox"/> Black and white | <input type="checkbox"/> Colour | <input type="checkbox"/> I don't have access to a printer |
|--|---------------------------------|---|

41. Can you hear sound/music from your computer?

- | | | |
|------------------------------|-----------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> I don't have access
to a computer |
|------------------------------|-----------------------------|---|

About You

42. How old are you today? _____ (age in years)

43. Are you: ☐ Male ☐ Female

44. What is your postcode?

45. In the last 4 weeks, which of the following best describes your employment status?

- | | |
|--|--|
| <input type="checkbox"/> Employed full-time (paid) | <input type="checkbox"/> Employed part-time (paid) |
| <input type="checkbox"/> Employed casual (paid) | <input type="checkbox"/> Unpaid work/Volunteering |
| <input type="checkbox"/> Unemployed/Looking for work | <input type="checkbox"/> Retired |

Please turn to the next page →

46. What is the highest level of education you have completed?

- ☐ Never went to school
- ☐ Completed primary school
- ☐ Some secondary school
- ☐ Completed secondary school
- ☐ Completed tertiary studies (TAFE, Uni etc)

47. In which country were you born? _____

48. Do you usually speak a language other than English at home?

- ☐ Yes ☐ No

a. If yes, what language do you usually speak at home? _____

49. Are you of Aboriginal origin or Torres Strait Islander origin?

- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both Aboriginal and Torres Strait Islander
- ☐ No

50. Apart from Medicare, are you currently covered by private health insurance?

- ☐ Yes ☐ No ☐ Don't know

51. Do you currently receive a government pension, allowance or benefit?

- ☐ Yes ☐ No ☐ Don't know

52. Do you have a concession card that gives you access to low cost medications?

- ☐ Yes ☐ No ☐ Don't know

53. What is your annual household income before tax?

- | | |
|---|---|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$20,000 to \$40,000 |
| <input type="checkbox"/> \$40,000 to \$60,000 | <input type="checkbox"/> \$60,000 to \$80,000 |
| <input type="checkbox"/> More than \$80,000 | <input type="checkbox"/> Don't know |

54. Is your house/apartment...

- | | |
|---|---|
| <input type="checkbox"/> Owned outright | <input type="checkbox"/> Owned with a mortgage |
| <input type="checkbox"/> Being occupied rent-free | <input type="checkbox"/> Rented from Government Authority |
| <input type="checkbox"/> Rented privately | <input type="checkbox"/> In an aged care facility |

55. How confident are you filling out medical forms by yourself?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Not at all
confident | Not very
confident | Somewhat
confident | Quite
confident | Extremely
confident |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

56. How often do you have someone help you read medical materials?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| None of the
time | A little of the
time | Some of the
time | Most of the
time | All of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

57. How often do you have problems learning about a medical condition because of difficulty reading medical materials?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| None of the
time | A little of the
time | Some of the
time | Most of the
time | All of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

58. Have you ever been told by a doctor or nurse that you have asthma?

- ☐ Yes ☐ No



**If NO, you have finished the survey.
Thank you for your time!**
If you are interested in being in the draw to win one of
ten \$100 Coles Myer vouchers or in participating in
future research, please provide your contact details on
the last page of this survey

Please turn to the next page →

59. How old were you when you were first told you had asthma?

_____ years old

60. How old were you when you first had symptoms of asthma?

_____ years old

61. Have you had symptoms or treatment for asthma in the last 12 months?

☐ Yes

☐ No

62. During the last 4 weeks did your asthma interfere with your ability to manage your day-to-day activities?

Not at all

A little bit

Moderately

Quite a lot

Extremely

☐☐☐☐☐

About Your Breathing

63. In the last four weeks, have you used any inhalers (puffers) for your asthma?

☐ Yes (please provide as much detail as possible)

☐ No

Inhaler colour (E.g. blue)	Medication Name (e.g. Ventolin)	How Often (e.g. daily, twice a week)

64. In the last four weeks, have you taken any tablets for your asthma?

☐ Yes (please provide as much detail as possible) ☐ No

Tablet colour (E.g. white & round)	Tablet Name

65. In the last four weeks, have you used any natural/herbal medicines for your asthma?

☐ Yes (please provide as much detail as possible) ☐ No

Please specify the products

66. Do you do anything else to help manage your asthma?

(Please tick ☒ all that apply)

- ☐ Breathing exercises
☐ Light exercise
☐ Use special bedding
☐ Use special cleaning products
☐ Other (please state)

67. Do you regularly use any of the following to manage your asthma?

(Please tick ☒ all that apply)

- ☐ Spacer ☐ Peak flow monitor ☐ None
☐ Nebuliser ☐ Other (please state) _____

Please turn to the next page →

68. Have you ever used an inhaler to help your asthma?

☐ Yes

☐ No

If NO, please go to the
"Health Service Use" section below (Q70)

69. Has anyone shown you how to use your inhaler?

☐ Yes

☐ No (if No, please go to question 70)

a. Who showed you how to use your inhaler?

☐ Doctor

☐ Nurse

☐ Pharmacist

☐ Other (please state) _____

b. Approximately how long did it take them to show you how to use your inhaler?

☐ Less than 5 minutes

☐ 5 minutes to 15 minutes

☐ More than 15 minutes

c. When did someone last show you how to use your inhaler?

☐ In the last 12 months

☐ Between 1 to 3 years ago

☐ More than 3 years ago

Health Service Use

70. In the last 12 months, have you:

a. Had a non-urgent visit with a GP or clinic about your asthma?

☐ Yes

☐ No

i. If YES, how often in the last 12 months? _____ times

b. Consulted a doctor urgently about asthma?

☐ Yes

☐ No

i. If YES, how often in the last 12 months? _____ times

c. Visited emergency/ casualty for asthma?

☐ Yes ☐ No

i. If YES, how often in the last 12 months? _____ times

d. Been admitted to hospital as an inpatient for asthma?

☐ Yes ☐ No

i. If YES, how often in the last 12 months? _____ times

71. Have you ever received asthma education? (This is a session lasting at least ten minutes with a nurse or other health professional).

☐ Yes ☐ No ☐ Don't know

72. Do you have a written asthma management/action plan from your doctor on how to treat your asthma? (An asthma management/action plan is written instructions for what to do if your asthma becomes worse or out of control).

☐ Yes ☐ No ☐ Don't know

73. Does your GP regularly review your asthma with you?

☐ Yes ☐ No

a. How often does this occur? _____/year

74. Do you regularly monitor your asthma control?

- ☐ Yes, through asthma symptoms
- ☐ Yes, through peak flow monitoring
- ☐ Yes, through both asthma symptoms and peak flow
- ☐ No, I don't monitor asthma control
- ☐ Other (please state) _____

Please turn to the next page →

75. To what extent do you agree with the following?

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
a. Asthma is an illness that comes and goes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I'm happy taking my asthma medication in front of other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Asthma is a long-term condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Asthma can be effectively managed through medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Asthma isn't really important compared with my other health issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I know enough about asthma to manage my asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I conceal my asthma symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

76. Which of the following asthma related topics do you feel that you need to learn more about, in order to better control your asthma?

(Please tick ☒ one box for each item)

	OF NO BENEFIT	OF SOME BENEFIT	OF GREAT BENEFIT
a. What is asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Asthma symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Asthma research advances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The latest information on asthma management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Tips to control my asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Doing a quiz to see how well controlled my asthma is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Asthma service providers in my area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Asthma and other disease e.g. diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. How to use my asthma medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. How asthma medications work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(Please tick ☒ one box for each item)

	OF NO BENEFIT	OF SOME BENEFIT	OF GREAT BENEFIT
k. The side effects of asthma medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Cleaning my inhaler/spacer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Asthma and complementary or alternative medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Asthma and exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Asthma and the seasons – pollen/bush fire etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Asthma in the home – heaters/bedding etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Products to help my asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Creating an asthma friendly garden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Identifying my asthma triggers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. Avoiding my asthma triggers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u. When to see my doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v. When to attend the Emergency Department	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w. How to deal with an asthma attack	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x. Testing my knowledge of what to do in an asthma attack	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y. Reading other people's asthma stories	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z. Sharing my asthma story online	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa. Participating in online discussion forums about asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb. Participating in online (Internet) asthma education programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc. Interacting with a health professional online –to discuss your asthma/ get information and support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

77. What other asthma related topics are you interested in learning more about?

Please turn to the next page →

17

78. Where do you get information about your asthma?

(Please tick ☒ all that apply)

- ☐ Doctor
- ☐ Nurse
- ☐ Other health professional
- ☐ Pamphlet/leaflets
- ☐ Internet
- ☐ Not interested in knowing about asthma
- ☐ Other (please state) _____

79. In the last 4 weeks, did you use the internet to obtain asthma information?

- ☐ Yes
- ☐ No

**You have finished the survey –
Thank you for your time!**



Dear

We would like to invite you to participate in a study being conducted by researchers at the University of Wollongong in collaboration with the Asthma Foundation of NSW. The research is called *The NSW Survey of Asthma in Adults Aged 55 Years and Over*. Our research aims to find out what you think about asthma and some information about how you manage your asthma if you suffer from the disease.

We are interested in the opinions of **all people aged 55 years and over** even if you and your family members DO NOT have asthma.

WE WOULD LIKE YOU TO: Complete the attached survey and return it to us in the enclosed, reply paid envelope.

The results of this survey will be used to develop an asthma awareness campaign and an online education tool targeted at this age group.

The Australian Electoral Commission (AEC) has supplied name, address, gender, and age-range information for this medical research study in conformity with Item 2 of subsection 90B(4) of the *Commonwealth Electoral Act 1918* and subregulation 9(a) of the *Electoral and Referendum Regulations 1940*. The information has been provided by the AEC on a confidential basis and will not be forwarded on or sold or otherwise disclosed or used for any purpose other than to contact participants for this medical research project.

All completed surveys will go into the draw to win one of 10 Coles-Myer vouchers valued at \$100 each.

If you have any enquiries about the research, you can contact Pippa Burns or Uwana Evers on 4221 5811 or Professor Sandra Jones on 4221 5106.

If you have any concerns or complaints regarding the way the research is or has been conducted, you can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

Thank you for your interest in this study!

Kind Regards,

Professor Sandra Jones
Director of the Centre for Health Initiatives
University of Wollongong

APPENDIX B: FOCUS GROUPS

Background Survey

1. Have you ever been told by a doctor or nurse that you have asthma?

☐ Yes ☐ No

2. How old were you when you were first told you had asthma or other breathing problems? _____ years old

3. Have you had symptoms or treatment for asthma in the last 12 months?

☐ Yes ☐ No

4. During the last 4 weeks did your asthma interfere with your ability to manage your day-to-day activities?

Not at all	A little bit	Moderately	Quite a lot	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. How many years have you been using the Internet?

Less than 1 year	1-2 years	2-5 years	More than 5 years	I don't use the Internet
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Overall, how comfortable are you with using the Internet?

Not at all comfortable	Somewhat comfortable	Comfortable	Quite comfortable	Very comfortable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. During an average week, roughly how many hours do you spend using the Internet or email?

Less than 1 hour	1-2 hours	3-5 hours	6-9 hours	10-15 hours	More than 15 hours
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. How old are you today? _____ (age in years)

9. Are you:

☐ Male

☐ Female

10. Which of the following best describes your smoking status? (This includes cigarettes, cigars and pipes)

☐ I smoke daily

☐ I smoke occasionally

☐ I don't smoke now, but I used to

☐ I've never smoked

☐ I've tried a few times but never smoked regularly

11. Have you ever been told by a health professional that you have any of the following? (Please tick ☒ all that apply)

☐ Allergic Rhinitis (Hay fever)

☐ Angina/heart attack/heart failure

☐ Anxiety or panic attacks

☐ Arthritis

☐ Asthma

☐ Chronic bronchitis

☐ Diabetes

☐ Emphysema

☐ Eczema (allergic skin rash)

☐ High blood pressure

☐ Nasal polyps/Sinusitis

☐ Parkinson's disease

☐ Pneumonia

☐ Sleep apnoea

☐ Tuberculosis (TB)

☐ Chronic obstructive pulmonary disorder (COPD) – a disease of the lungs

☐ Other _____

12. In the last 4 weeks, which of the following best describes your employment status? (Please tick ☒ one)

☐ Employed full-time (paid)

☐ Employed part-time (paid)

☐ Employed casual (paid)

☐ Unpaid work/Volunteering

☐ Unemployed/Looking for work

☐ Retired

13. What is the highest level of education you have completed? (Please tick ☒ one)

☐ Completed primary school

☐ Some secondary school

☐ Completed secondary school

☐ Completed tertiary studies

☐ Never went to school

(TAFE, Uni etc)

14. What is your postcode?

15. In which country were you born? _____

16. Do you usually speak a language other than English at home?

☐ Yes

☐ No

17. If yes, what language do you usually speak at home? _____

18. Are you of Aboriginal origin or Torres Strait Islander origin?

☐ Yes, Aboriginal

☐ Yes, Torres Strait Islander

☐ Yes, both Aboriginal &
Torres Strait Islander

☐ No

19. What is your annual household income before tax?

☐ Less than \$20,000

☐ \$20,000 to \$40,000

☐ \$40,000 to \$60,000

☐ \$60,000 to \$80,000

☐ More than \$80,000

☐ Don't know

20. Is your house/apartment...

☐ Owned outright

☐ Owned with a mortgage

☐ Occupied rent-free

☐ Rented privately

☐ Rented from Government Authority

☐ In an aged care facility

**Thank you for completing this survey. Please return it to the table
at the front of the room before we begin the focus group.**

Focus Group Prompts

Section 1 – Asthma management

1. Lets talk about your asthma and how you manage it. Who wants to start us off?
 - Do you have enough knowledge/skills to manage your asthma properly
 - Where did you learn about asthma?
 - i. What information do you need to know?
 - How confident are you in managing your asthma?
 - ii. What makes it hard to manage?

Section 2 – Asthma internet information

2. What sources have you used to obtain information about your asthma?
 - When do you use these sources?
(GP; nurse; pharmacist; relative/friend; brochures/pamphlets; internet websites; magazines; newspapers; TV; Radio)
3. When do you use the internet to find health information?
4. When would you search for asthma information on the internet?
 - Which sites have you used?
 - Why did you choose these sites?
 - What did you think of the websites you visited?
 - Did they meet your needs? (advice/interest)
 - Generally, who are you finding out information for?
 - How reliable do you think these websites are?

Section 3 – Vignettes

5. Vignette 1
 - John had thought about looking on the internet? What do you think of that idea?
 - Do you think he will find anything useful there?
 - How will John know if he can trust the information he finds? Etc etc
6. Vignette 2
 - How to deal with an attack
 - Identifying/avoiding triggers
 - Products to help my asthma
 - Asthma and the seasons
 - The latest information on asthma management
 - Tips to control my asthma

- Asthma in the home
- Information about medications

Section 4 – Web Site Features

7. This is the current Asthma Foundation of NSW website (<http://www.asthmafoundation.org.au/default.aspx>).
 - What's your first impression of this site?
 - What do you think about the way the information is presented?
8. This is their page for Asthma and Seniors (http://www.asthmafoundation.org.au/Asthma_and_seniors.aspx). What do you think about the page and the information being offered?
 - *Are there other information/ features would you want an asthma website to have?*
(words, printable downloads, videos, quizzes to test your knowledge etc)
 - *Contact with an asthma nurse*
9. What would encourage you to visit an asthma site for the first time?
 - What sort of name would the site have?
10. Web sites can be individually tailored, that means that you are asked a few questions and the website presents information that is specific to you. What do you think about using tailoring on an asthma website?
11. How would you feel about logging-on to the site?
(privacy, hassle, remembering passwords)
12. An online forum or discussion group are groups where people "talk" to each other by typing, through the Internet (http://ehealthforum.com/health/asthma_forum.html). What would prompt you to take part in a group about asthma?
13. What would encourage you to read about someone else's experience with asthma (Blog - <http://talk.nhs.uk/blogs/asthma/default.aspx>)?
 - *What would prompt you into sharing your asthma story online?*
14. What would encourage you to visit an asthma website on a regular basis?
(E-newsletters – type of information - frequency)
 - What features of a website would encourage you to spend more time browsing?

Participation Information Sheet for Asthma and Older Adults Focus Groups

Dear Community Member,

We would like to invite you to participate in a focus group being conducted by researchers at the University of Wollongong in collaboration with the Asthma Foundation of NSW. The research is called *Asthma and Older Adults*. For the purpose of our research an older adult is 55 years or older.

These are the people from the university involved in this study:

Pippa Burns, PhD Candidate, Centre for Health Initiatives

Professor Sandra Jones, Director, Centre for Health Initiatives

We would like you to: take part in a focus group with other people with asthma of a similar age.

A focus group is a group discussion, which is led by a trained facilitator. The focus group will involve approximately 8 people who will explore a number of questions around asthma. The questions will be about how you manage your asthma and what type of asthma information you use (if any). This research will provide us with information on what types of information can help older adults manage their asthma and will be used to develop an online tool aimed at helping older adults with asthma manage their condition.

It is anticipated that the focus group will take approximately one and a half to two hours, including refreshments. The focus group will be held in Wollongong. You will be advised about the exact venue and time at a later date if you choose to take part.

The focus group will be audiotaped and transcribed at a later date. Any identifying information will be removed from the documents and audiotapes will not be made available to any person outside the research team. Consent forms will be kept by the researchers in a locked filing cabinet.

Apart from the 90 minutes of your time for the focus group, we can foresee no risks for you. Your involvement in the study is voluntary and you may withdraw your participation from the study at any time. Data will not be identifiable so cannot be removed. Refusal to participate in the study will not affect your relationship with Asthma Foundation NSW or the University of Wollongong.

Findings from the whole study will be published in a doctoral thesis and also in academic journals. We will not use your name in any part of the research.

If you have any enquiries about the research, you can contact Pippa Burns or on 4221 5811 (email: pippa@uow.edu.au) or Professor Sandra Jones on: 4221 5106 or if you have any concerns or complaints regarding the way the research is or has been conducted, you can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

Thank you for your interest in this study.

APPENDIX C: USABILITY TESTING



The Development & Piloting of an Asthma Internet Intervention for Use by Older Adults Usability Testing

1. How old are you today? _____ (age in years)

2. Are you: ☐ Male ☐ Female

3. In the last 4 weeks, which of the following best describes your employment status? (Please tick ☒ one)

- | | |
|--|--|
| <input type="checkbox"/> Employed full-time (paid) | <input type="checkbox"/> Employed part-time (paid) |
| <input type="checkbox"/> Employed casual (paid) | <input type="checkbox"/> Unpaid work/Volunteering |
| <input type="checkbox"/> Unemployed/Looking for work | <input type="checkbox"/> Retired |

4. What is the highest level of education you have completed? (Please tick ☒ one)

- ☐ Completed primary school
- ☐ Some secondary school
- ☐ Completed secondary school
- ☐ Completed tertiary studies (TAFE, Uni etc)
- ☐ Never went to school

5. What is your postcode?

6. In which country were you born?

7. Do you usually speak a language other than English at home?

- ☐ Yes
- ☐ No (please go to Q9)

Please turn to the next page →

1

8. If yes, what language do you usually speak at home?

9. Are you of Aboriginal origin or Torres Strait Islander origin?

- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both Aboriginal and Torres Strait Islander
- ☐ No

10. What is your annual household income before tax?

- | | |
|---|---|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$20,000 to \$40,000 |
| <input type="checkbox"/> \$40,000 to \$60,000 | <input type="checkbox"/> \$60,000 to \$80,000 |
| <input type="checkbox"/> More than \$80,000 | <input type="checkbox"/> Don't know |

11. Is your house/apartment...

- | | |
|---|--|
| <input type="checkbox"/> Owned outright | <input type="checkbox"/> Owned with a mortgage |
| <input type="checkbox"/> Occupied rent-free | <input type="checkbox"/> Rented privately |
| <input type="checkbox"/> Rented from Government Authority | |
| <input type="checkbox"/> In an aged care facility | |

12. Have you ever been told by a doctor or nurse that you have asthma?

- ☐ Yes
- ☐ No (please go to Q14)

13. How old were you when you were first told you had asthma or other breathing problems? _____ years old

14. How confident are you filing out medical forms by yourself?

Not at all confident	Not very confident	Somewhat confident	Quite confident	Extremely confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. How often do you have someone help you read medical materials?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. How often do you have problems learning about a medical condition because of difficulty reading medical materials?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. How many years have you been using the Internet?

Less than 1 year	1-2 years	2-5 years	More than 5 years	I don't use the Internet
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Overall, how comfortable are you with using the Internet?

Not at all comfortable	Somewhat comfortable	Comfortable	Quite comfortable	Very comfortable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. During an average week, roughly how many hours do you spend using the Internet or email?

Less than 1 hour	1-2 hours	3-5 hour	6-9 hours	10-15 hours	More than 15 hours
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Do you ever use the internet to look up health or medical information

☐ Yes ☐ No ☐ Don't know

Please turn to the next page → 3

21. If you are happy to participate in further phases of this study, please leave your contact details (you are able to opt out of the study at any time):

Name: _____

Address: _____

Suburb: _____

Phone number: _____

Email address: _____



**Participation Information Sheet for
The Development & Piloting of an Asthma Internet Intervention for
Use by Older Adults
Phase 3: Usability Testing**

This study is being conducted by researchers at the University of Wollongong in collaboration with the Asthma Foundation of NSW. The research is called *The Development & Piloting of an Asthma Internet Intervention for Use by Older Adults*. For the purpose of the research an older adult is 55 years or older. The research aims to find out how useful and usable the web site we are developing is to older adults with asthma. The results will be used to further refine the development of the online.

These are the people from the university involved in this study
Pippa Burns, PhD Candidate, Centre for Health Initiatives
Professor Sandra Jones, Director, Centre for Health Initiatives
Professor Don Iverson, Pro Vice-Chancellor (Health)

We would like you to: complete a short survey that includes some questions about yourself, your asthma and your use of the internet. This is to ensure that we include a wide range of people in our research.

You will then be asked to perform some tasks on the computer. While you are doing this we'd like you to talk about what you are doing. The computer will make visual and audio recordings of what you say and what you do. Any identifying information will be removed from the documents and audiotapes will not be made available to any person outside the research team. Consent forms will be kept by the researchers in a locked filing cabinet.

Apart from your time for the usability testing, we can foresee no risks for you. Your involvement in the study is voluntary and you may withdraw your participation from the study at any time. Refusal to participate in the study will not affect your relationship with Asthma Foundation NSW or the University of Wollongong.

Findings from the study will be published in a doctoral thesis and also in academic journals.

All participants will receive a \$30 Coles-Myer voucher.

If you have any enquiries about the research, you can contact Pippa Burns on 4221 5811 or Professor Sandra Jones on: 4221 5106 or Professor Don Iverson on 4221 4677. If you have any concerns or complaints regarding the way the research is or has been conducted, you can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

Thank you for your interest in this study.

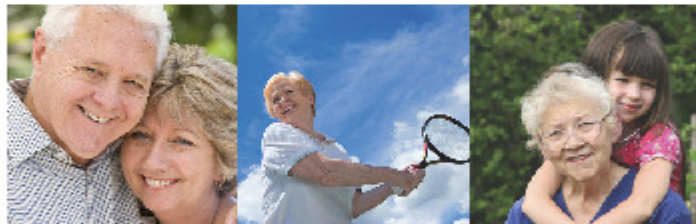
APPENDIX D: INTERVENTION

Learn to take control with...

Asthma Wise

Register to join this new online research project to help you take control of your asthma and learn how you can live life to the full. You'll get access to exclusive and FREE online training that will help you confront asthma today.

If you are 55 and over go to www.asthmawise.org.au and follow the instructions to register now.



Register by January 1st 2012 to go in the draw to win a 32" full LED LCD TV valued at RRP \$799. Full terms and conditions are available at www.asthmawise.org.au.



University of Wollongong



AsthmaWise Evaluation

We'd like to ask you some questions about your experience with AsthmaWise.

1. Where did you hear about AsthmaWise?

- ☐ Flyer
- ☐ Email
- ☐ Facebook
- ☐ Family member or friend
- ☐ Other (please specify)

2. What was the main reason you decided to visit AsthmaWise?

- ☐ To learn more about how to manage my asthma
- ☐ To gain information about a particular asthma problem I have
- ☐ Someone I know has asthma
- ☐ Curiosity
- ☐ Other (please specify)

3. Generally, where were you when you logged on to AsthmaWise?

- ☐ At home
- ☐ At work
- ☐ At a friend or relative's house
- ☐ At the library/community centre
- ☐ On my mobile phone

4. How useful did you find AsthmaWise?

- ☐ Not at all useful
- ☐ Not useful
- ☐ Somewhat useful
- ☐ Very useful
- ☐ Extremely useful

5. What did you think of the length of AsthmaWise?

- ☐ Too long
- ☐ Just right
- ☐ Too short

AsthmaWise Evaluation 2

6. Was the content of AsthmaWise easy to understand?

- ☐ Not at all easy to understand
- ☐ Somewhat easy to understand
- ☐ Very easy to understand
- ☐ Extremely easy to understand

7. Did you feel confident that the content presented was accurate?

- ☐ Not at all confident
- ☐ Somewhat confident
- ☐ Very confident
- ☐ Extremely confident

8. Do you feel that you know more about how to manage your asthma since visiting AsthmaWise?

- ☐ Not at all
- ☐ Not much
- ☐ Somewhat
- ☐ Very much
- ☐ Extremely

Please comment

AsthmaWise Evaluation 3

9. Did you make any changes to your asthma management as a result of AsthmaWise?

- ☐ Yes
- ☐ No, but I plan on making changes in the future
- ☐ No, my asthma is under control already

Asthma Management

10. What changes did you make to your asthma management as a result of AsthmaWise? (please tick all that apply)

- ☐ I made sure that I took my medication regularly
- ☐ I monitored my asthma symptoms
- ☐ I visited my GP for an asthma review
- ☐ My GP gave me an asthma action plan

Asthma Management 2

11. What stopped you from changing the way you manage your asthma? (please tick all that apply)

- ☐ Remembering to take my asthma medication(s)
- ☐ Remembering to monitor my asthma symptoms
- ☐ Cost of asthma medication
- ☐ Cost of visiting my GP for an asthma review
- ☐ Time needed to visit my GP
- ☐ Other

Please specify:

12. Did you visit AsthmaWise as often as you would have liked?

- ☐ Yes
- ☐ No

Asthma Management 2

13. If no, what stopped you from visiting AsthmaWise more often? (please tick all that apply)

- ☐ No new information
- ☐ Lack of time
- ☐ Lack of interest
- ☐ No computer at home
- ☐ Problems accessing the internet
- ☐ No need for asthma information
- ☐ Other (please specify)

14. Would you recommend AsthmaWise to others for help with their asthma management?

- ☐ Yes
- ☐ No

Please comment

Perceived Health Website Usability Questionnaire

We would like to know your opinions about the web site (AsthmaWise) that you have been using. Please choose one answer for each question.

15. Satisfaction

	Very unsatisfied	2	3	Neither satisfied or unsatisfied	5	6	Very satisfied
Ease of finding specific information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ease of reading the information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall appearance of the site	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall quality of graphics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Ease of use

	Strongly disagree	2	3	Neither agree or disagree	5	6	Strongly agree
I found the use of this web site easy to learn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding information on this website requires a lot of mental effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall, I find this website is easy to use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Usefulness

	Strongly disagree	2	3	Neither agree or disagree	5	6	Strongly agree
Using this website will help me to understand my asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using this website will help me to improve my knowledge about asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using this website will help me to maintain better asthma management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using this website will help me to improve my knowledge about health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using this website will help me to maintain better health habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your relationship with your doctor

These questions are about your relationship with the doctor/GP who you see about your general health.

18. How easy or difficult is it to talk with your general practitioner (GP/doctor)?

- ☐ Not at all easy
- ☐ A little easy
- ☐ More or less easy
- ☐ Very easy
- ☐ Completely easy

19. How much do you trust your general practitioner (GP/doctor)?

- ☐ Do not trust at all
- ☐ Trust a little
- ☐ Trust more or less
- ☐ Trust a lot
- ☐ Trust completely

20. How involved are you with your general practitioner (GP/doctor) in the decisions about your healthcare?

- ☐ I am not at all involved
- ☐ I am a little involved
- ☐ I am more or less involved
- ☐ I am very involved
- ☐ I am completely involved

21. How comfortable are you in calling your general practitioner (GP/doctor) to tell him or her that you have a new symptom or difficulty taking your medications?

- ☐ Not at all comfortable
- ☐ A little comfortable
- ☐ More or less comfortable
- ☐ Very comfortable
- ☐ Completely comfortable

22. How satisfied are you with the care that you receive from your general practitioner (GP/doctor)?

- ☐ Not at all satisfied
- ☐ A little satisfied
- ☐ More or less satisfied
- ☐ Very satisfied
- ☐ Completely satisfied

Managing my Asthma

23. Please choose one response for each question

	Very good				Satisfactory					Very poor
My knowledge of my asthma is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My knowledge of the treatment of my asthma is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to share in decisions made about the management of my asthma is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to arrange appointments as recommended by my doctor or health service provider is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My attendance at appointments is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to take my asthma medication as directed by my doctors is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Please choose one response for each question

	Very good				Satisfactory					Very poor
My understanding of why I need to observe, measure and record my asthma symptoms is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to observe, measure and record my asthma symptoms is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My understanding of what to do when my asthma symptoms get worse is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to take the right action when my asthma symptoms get worse is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My progress towards adopting habits that improve my health is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Asthma Severity

Please choose one answer for each question.

25. How serious do you think asthma is?

- ☐ Not at all serious
- ☐ Not serious
- ☐ Somewhat serious
- ☐ Serious
- ☐ Very serious

26. I have asthma symptoms, during the day:

- ☐ Daily
- ☐ More than once a week, but not every day
- ☐ Less than once a week

27. I have asthma symptoms at night:

- ☐ At least weekly
- ☐ More than twice a month, but not weekly
- ☐ Less than twice a month

28. I have asthma attacks:

- ☐ Frequently (more than once a month)
- ☐ Monthly
- ☐ Occasionally (a few times a year)
- ☐ Rarely (less than once a year)
- ☐ Never

For questions 25, 26 and 27 please list any medications that you have taken for your asthma in the last four weeks. For each medication please provide: the name of the medication (e.g. ventolin); the colour of the puffer or tablets (e.g. blue puffer or white tablet), the dose (e.g. 150 mcg) and how often you take the medication (e.g. daily).

29. Medication 1

Medication	<input type="text"/>
Colour	<input type="text"/>
Dose	<input type="text"/>
Frequency	<input type="text"/>

30. Medication 2

Medication	<input type="text"/>
Colour	<input type="text"/>
Dose	<input type="text"/>
Frequency	<input type="text"/>

31. Medication 3

Medication

Colour

Dose

Frequency

Asthma Attitudes

32. These are questions about your attitude towards your asthma.

Please choose one answer for each question.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I know what triggers my asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to avoid my asthma triggers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that I have the skills I need to manage my asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am happy taking my asthma medication in front of other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that I know enough to manage my asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asthma is not really important compared to my other health issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I frequently research new asthma treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I frequently research new asthma medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I conceal my asthma symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to prevent myself from having an asthma attack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Asthma Experience

33. Please answer the following questions by choosing either "true" or "false". If you do not know the answer or are not sure of the answer, move on to the next question.

	True	False
You can become addicted to asthma medications if you use them all the time	<input type="radio"/>	<input type="radio"/>
An asthma action plan can prevent hospitalisations due to asthma	<input type="radio"/>	<input type="radio"/>
When you know that you are going to be exposed to something that triggers your asthma, you should wait until you develop symptoms before taking your medication	<input type="radio"/>	<input type="radio"/>
With preventer medications, it does not matter if some doses are missed or if you go on and off them	<input type="radio"/>	<input type="radio"/>
If you get a cold or flu, you should increase your asthma medications	<input type="radio"/>	<input type="radio"/>
Some medications can trigger asthma attacks	<input type="radio"/>	<input type="radio"/>
Going from a cold to a hot environment can trigger asthma, but going from a hot to a cold environment does not trigger asthma	<input type="radio"/>	<input type="radio"/>

Asthma Symptoms

These questions are about your asthma symptoms.

34. Do you feel that using AsthmaWise improved your asthma symptoms?

- ☐ Not at all
- ☐ Not much
- ☐ Somewhat
- ☐ Very much
- ☐ Extremely

35. Do you have a written asthma action plan from your doctor on how to treat your asthma? (An asthma action plan is written instructions on what to do if your asthma becomes worse or out of control).

- ☐ Yes, and I use my action plan
- ☐ Yes, but I don't use my action plan
- ☐ No
- ☐ Don't know

36. In the last four weeks, have you had difficulty sleeping because of your asthma symptoms (including cough)?

- ☐ Yes
- ☐ No

37. In the last four weeks, have you had your usual symptoms during the day (cough, wheeze, chest tightness or breathlessness)?

- ☐ Yes
- ☐ No

38. In the last four weeks, has your asthma interfered with your usual activities e.g. housework, work, hobbies etc?

- ☐ Yes
- ☐ No

39. Did anything else occur since you registered with AsthmaWise that may have affected your asthma control?

Self Efficacy

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

40. How confident are you that you can keep the fatigue caused by your asthma from interfering with the things you want to do?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

41. How confident are you that you could keep the physical discomfort or pain of asthma from interfering with the things you want to do?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

42. How confident are you that you could keep the emotional distress caused by asthma from interfering with the things you want to do?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

43. How confident are you that you can keep any other symptoms of asthma you have from interfering with the things you want to do?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

44. How confident are you that you can do the different tasks and activities needed to manage your asthma so as to reduce your need to see a doctor?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

45. How confident are you that you can do things other than just take medication to reduce how much your illness affects your everyday life?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Not at all Totally
confident confident

Asthma Quality of Life

What follows is a series of statements describing the way in which asthma (or its treatment) affects some people. You are asked to choose the response to each statement which closely applies to you over the past four weeks.

46. I have been troubled by episodes of shortness of breath

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

47. I have been troubled by wheezing attacks

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

48. I have been troubled by tightness in the chest

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

49. I have been restricted in walking down the street on level ground or doing light housework because of asthma

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

50. I have been restricted in walking up hills or doing heavy housework because of asthma

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

51. I have felt tired or a general lack of energy

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

52. I have been unable to sleep at night

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

53. I have felt sad or depressed

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

54. I have felt frustrated with myself

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

55. I have felt anxious, under tension or stressed

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

56. I have felt that asthma is preventing me from achieving what I want from life

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

57. Asthma has interfered with my social life

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

58. I have been limited in going to certain places because they are bad for my asthma

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

59. I have been limited in going to certain places because I have been afraid of getting an asthma attack and not being able to get help

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

60. I have been restricted in the sports, hobbies or other recreations I can engage in because of my asthma

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

61. I have felt generally restricted

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

62. I have felt that asthma is controlling my life

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

63. I have been worried about my present or future health because of my asthma

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

64. I have worried about asthma shortening my life

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

65. I have felt dependent upon my asthma sprays (inhalers)

☐ Not at all ☐ Mildly ☐ Moderately ☐ Severely ☐ Very severely

Asthma and your health

66. What benefits do you think people gain from managing their asthma well? (please tick all that apply)

- ☐ They have fewer episodes of wheezing/breathlessness
- ☐ They have fewer asthma attacks
- ☐ They need less reliever medication
- ☐ Their asthma would not interfere with their daily activities
- ☐ Their asthma would not disturb their sleep

Other (please specify)

67. Compared to last year, how would you rate your health?

- ☐ Much better
- ☐ Better
- ☐ About the same
- ☐ Worse
- ☐ Much worse

68. Have you had symptoms or treatment for asthma in the last 12 months?

- ☐ Yes
- ☐ No

69. Compared to this time last year,

	Many less	Less	About the same	More	Many more
How many non-urgent visit with a GP or clinic, for your asthma, have you had?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How many urgent consults, about asthma, with a GP have you had?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How many visits to emergency/casualty, for your asthma, have you had?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How many admissions to hospital, for your asthma, have you had?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

70. How serious do you think the following disease/illnesses are?

	Not at all serious	Not serious	Somewhat serious	Serious	Very serious
Arthritis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowel cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes (type 1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart disease/ heart failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lung cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

71. How confident are you filling out forms by yourself?

- ☐ Not at all confident
- ☐ Not very confident
- ☐ Somewhat confident
- ☐ Quite confident
- ☐ Extremely confident

72. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

73. How often do you have problems learning about your medical condition because of difficulty understanding written information?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

74. How would you most like to receive information about managing your asthma?

- ☐ From my doctor
- ☐ From my pharmacist
- ☐ From peer educators (someone else with asthma)
- ☐ Online (via my computer)
- ☐ Other (please specify)

75. Overall, how comfortable are you with using the internet?

- ☐ Not at all comfortable
- ☐ Somewhat comfortable
- ☐ Comfortable
- ☐ Quite comfortable
- ☐ Very comfortable

76. Before using AsthmaWise, had you ever use the internet to find information about asthma?

- ☐ Yes
- ☐ No

77. How old are you today? (age in years)

Thank you for registering with AsthmaWise and for taking the time to complete this survey. Your responses are really appreciated and will be used to guide the future development of AsthmaWise.

**APPENDIX E: ASTHMAWISE: HELPING OLDER ADULTS MANAGE
THEIR ASTHMA**

Burns P. (2012). AsthmaWise: Helping older adults manage their asthma. *Australian Nursing Journal*; 19 (9): 45.

The Centre of Health Initiatives, part of the University of Wollongong's School of Nursing, Midwifery and Indigenous Health, has been working with Asthma Foundation NSW to develop and test an online asthma self-management programme for older adults.

Although asthma is often thought of as a childhood illness, it can occur at any age, with approximately one in ten people living in Australia have a diagnosis of asthma¹. People with asthma report worse health and a poorer quality of life than those not affected by the disease¹.

While asthma cannot be cured, good self-management has been shown to reduce symptoms such as wheezing and breathlessness². However, the skills needed to self-manage often cannot be taught effectively in short appointment times³⁻⁵. The internet can overcome this barrier by enabling patients to visit a website at any time, for as long as they want to, and to revisit the information as often as necessary. Online programs do not have the geographical constraints of face-to-face programs, saving patients travel time and money. From a provider's perspective, online education is relatively cheap to deliver, once initial set-up costs have been met, and can easily be updated with the latest information.

Despite the typical stereotype of older adults not being comfortable with the computer, initial research has shown that many older adults are online and looking at health information for themselves or their partners⁶. This trend is likely to increase as the ageing population increasingly consists of people who have gained computer skills from the workplace⁷.

We developed and piloted an online education site, AsthmaWise, commencing in February 2012, with registration open to adults aged 55 years and over, with a diagnosis of asthma. The site provides six interactive learning modules for participants to work through at their own pace. The results will be of interest to

nurses working with older adults affected by asthma or other chronic diseases as they will provide guidance on the use of the internet as an education source to improve chronic disease self-management among this age group.

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APPENDIX F: THIS IS NOT NORMAL – IT’S ASTHMA

Rationale:

Asthma mortality and morbidity will become a major disease burden amongst older adults in Australia over the next twenty years.

This symposium focuses on *communication in chronic conditions* (asthma) the utilisation of **patient participation and perspectives** to inform campaign development and the acceptability of **communication technology and e-learning** as a self-management aid amongst older adults.

The aim of this session is to achieve expert input on how best to develop the asthma awareness social marketing campaign and online asthma self-management intervention, based on the pilot results presented.

Name: Professor Sandra Jones

Department: Centre for Health Initiatives

Institute: University of Wollongong, NSW, Australia

Abstract: In Australia, as in other countries, awareness of adult asthma and adherence to self-management strategies is intractably low. This presentation will address the role of social marketing in increasing awareness and adherence and present results from a series of formative research projects designed to inform interventions targeting adults with asthma.

Name: Pippa Burns

Department: School of Nursing, Centre for Health Initiatives

Institute: University of Wollongong, NSW, Australia

Abstract: The evaluation results from the piloting of Asthma Wise, an online self-management intervention targeting older adults with asthma, will be presented. The intervention has been developed based on extensive review of the literature and two years of formative research to establish the needs and capabilities of the target population.

Name: Uwana Evers

Department: School of Psychology, Centre for Health Initiatives

Institute: University of Wollongong, NSW, Australia

Abstract: Consumer orientation and insight into target audience perceptions are two key elements of social marketing interventions. Older adults have actively participated in the development of a community-based asthma awareness campaign, enabling us to better understand their health beliefs and tailor the intervention to meet their needs.

**APPENDIX G: BREATHING NOT WHEEZING: DEVELOPING AN
INTERNET INTERVENTION FOR OLDER AUSTRALIANS WITH
ASTHMA**

Burns P, Jones S and Iverson D (2012). Breathing not wheezing: developing an Internet intervention for older Australians with asthma (presentation and poster). Positive 2012. Wollongong.

Overview:

Issues

Asthma is a disease of the airways, characterised by wheezing, breathlessness, chest tightness and persistent cough. While asthma is often thought of as a childhood disease, it causes greatest mortality and morbidity amongst older adults.

Although asthma cannot yet be cured it can be effectively managed to reduce symptoms and increase quality of life. However, many asthma sufferers do not realise that with the correct treatment regime their condition will improve.

The Internet presents great potential for interventions targeting chronic disease self-management, including asthma. Such interventions are relatively cheap to deliver, can be up dated easily, are accessible at any time and do not have the geographical constraints of traditional face-to-face programs. However, little is known about their appeal to, and usability for, older adults.

Approach

A 20 page survey was developed to explore the health beliefs, behaviours and attitudes of older Australians. The survey was mailed to 9,000 adults, aged 55 years and over, across three regions of NSW. Participants were recruited through a random sample obtained from the Australian Electoral Roll Office. An amended version of Dillman's tailored design method was used to maximise responses (response rate = 46.8%).

Key findings

Our results suggest that, despite the stereotype of older adults being digitally disconnected, the majority are in fact online and are confident, long-term Internet users.

People who reported high levels of asthma self-efficacy (Lorig's scale for managing chronic disease) were more likely to report better health status and better quality of life scores for breathlessness and mood (Marks' asthma quality of life scale). However, nearly half of respondents reported that their asthma had interfered with their ability to manage their day to day activities.

The results also allowed us to elicit the top five asthma topics of interest to this age group and to assess the acceptability of Web 2.0 functionalities.

Implications

Our results suggest that older adults with asthma have the skills and resources to utilise an asthma Internet intervention and that many could experience improved quality of life through better asthma management.

Further, our results suggest that older adults who receive asthma education will report increased self-efficacy, leading to: better health, better quality of life and less emergency health care visits for asthma.

Conclusions

An Internet intervention aimed at improving asthma self-management through increased self-efficacy is currently being developed for piloting, in older adults.

**APPENDIX H: THE IMPACT OF SELF-EFFICACY ON ASTHMA
MANAGEMENT AMONGST OLDER AUSTRALIAN ADULTS**

Burns P, Jones S and Iverson D (2011). The impact of self-efficacy on asthma management amongst older Australian adults. Emerging Researchers in Ageing Conference (pp. 28). Sydney.

Overview/Abstract:

Australian asthma rates are high by international standards with approximately 10% of people having an asthma diagnosis. While asthma is often thought of as a childhood disease, it causes greatest mortality and morbidity amongst older adults, with three-quarter of asthma deaths occurring in people aged over sixty. In Australia, the Asthma Cycle of Care is the initiative used by GPs to manage asthma. It includes regular visits to the GP, provision of an asthma action plan and asthma education, yet the effectiveness of current management approaches, amongst older adults, remains largely unknown. This paper looks at the relationships between self-efficacy, health status, asthma management practices, emergency health care use and quality of life. A 20 page survey exploring the health beliefs, behaviours and attitudes of older Australians, was mailed out to 9,000 adults (response rate = 46.8%), aged 55 years and over, across three regions of NSW. Participants were recruited through a random sample obtained from the Australian Electoral Roll Office. Initial analysis shows that people with high asthma self-efficacy were more likely to rate their health highly, have better quality of life scores and have received asthma education. They were less likely to report that asthma had interfered with their day to day activities or that they'd had an emergency health care utilisation for asthma. Regular GP reviews, owning an asthma action plan and monitoring asthma control did not appear to impact self-efficacy. The results suggest that asthma education is the most important element in the Asthma Cycle of Care for increasing older adults' confidence in managing their disease. Further, it is postulated that older adults who receive asthma education will benefit from increased self-efficacy, better health status, better quality of life and less emergency health care visits for asthma.

**APPENDIX I: PROFILING THE SILVER SURFERS: WHICH OLDER
AUSTRALIANS ARE USING THE INTERNET?**

Burns P, Jones S and Iverson D (2011). Profiling the silver surfers: which older Australians are using the Internet? Emerging Researchers in Ageing Conference (pp. 22). Sydney.

Overview/Abstract:

As Australia's population ages more people will develop chronic diseases, increasing both the burden on the health care system and the need for ongoing self-management. The Internet has great potential to provide self-management education; helping participants increase their quality of life. Internet interventions are relatively cheap, can easily be updated and can be revisited at a time and location suitable to the participant. However, little is known about the extent and nature of older Australians' use of the Internet. This paper aims to describe the associations between Internet use and health and other demographic variables amongst older Australians. A survey was mailed out to 9,000 adults, aged 55 years and over, across three regions of NSW, randomly selected from the electoral roll (response rate = 46.8%). Just over half of the respondents reported using a computer to access the Internet. The majority of Internet users had been using the Internet for more than five years, had high levels of comfort with use, and used the Internet to obtain health information. The presence of some chronic diseases was associated with not using the Internet, although having asthma, anxiety or sleep apnoea did not appear to reduce Internet use. Internet users were more likely to be younger ($p=.000$); well educated ($p=.000$); have a higher household income ($p=.000$); and report good health ($p=.000$). However, there was no significant difference in Internet use between male and female respondents as well as between those born in Australia and overseas. Internet interventions have the potential to reach older adults, although there is still a distinct digital divide between Internet users and non-users, suggesting that such interventions should not be the sole method of self-management education for this age-group. However, it is likely that this divide will narrow as the baby boomers age.

**APPENDIX J: HEALTH LITERACY AND OLDER ADULTS WITH
ASTHMA**

Burns P, Jones SC and Iverson D (2011). Health literacy and older adults with asthma. Primary Health Care Research Conference (pp. 189). Brisbane.

Overview:

Rationale & Aims:

Successful asthma control can be achieved through active self-management

Methods:

Survey mailed to 9,000 NSW residents aged 55 years or over, randomly selected from the electoral roll. Response rate of 47% (4,131 surveys returned) 466 (11%) had been told by a health professional that they had asthma AND had symptoms of, or treatment for, asthma in the last 12 months. A validated single item question was used to screen for inadequate health literacy (Chew et al J Gen Intern Med 23(5):561-6).

Findings:

26% of older adults with asthma had inadequate health literacy. Exposure to asthma education, ownership of an asthma action plan and asthma monitoring did not appear to be related to health literacy. People with asthma with adequate health literacy were more likely to report higher health status (2 (4, N=460) =40.18, p=.000). People with asthma with adequate health literacy were less likely to report that their asthma interfered with their ability to manage daily tasks (2 (1, N=463) =11.72, p=.001).

Conclusion:

The findings suggest that older adults with adequate health literacy are better able to utilise asthma education and self-management strategies, resulting in better health and less impact on their day-to-day activities.

Implication:

Targeting asthma education to a person's health literacy level will help to ensure that everyone has the skills and understanding to obtain asthma control. We explored the relationship between health literacy and asthma-management among older adults in Australia.