

Advance Directives in an E-Health Environment: South Australian Preferences and Baby Boomer Choices

Sandra L Bradley

**RN, Bachelor of Science, Bachelor of Arts,
Bachelor of Nursing, Graduate Certificate Education (Tertiary), Master of Research**

Faculty of Medicine, Nursing and Midwifery and Health Sciences

School of Medicine

Flinders University

Doctor of Philosophy Thesis

December 2015

TABLE OF CONTENTS

LIST OF TABLES	XII
LIST OF FIGURES	XV
PREFACE	XVIII
ABSTRACT	XIX
DECLARATION	XX
ACKNOWLEDGEMENTS	XXI
VALE.....	XXIII
<i>Family.....</i>	<i>xxiii</i>
<i>Work colleagues.....</i>	<i>xxiii</i>
<i>Friends and acquaintances.....</i>	<i>xxiii</i>
GLOSSARY OF TERMS	XXIV
ABBREVIATIONS	XXVI
CHAPTER 1 – INTRODUCTION.....	1
Overview.....	1
Advance directives.....	1
<i>International perspectives.....</i>	<i>1</i>
<i>National perspectives.....</i>	<i>2</i>
<i>Local perspectives.....</i>	<i>3</i>
The Baby Boomers	3
ADs in the online environment	6
Research question	9
Purpose	10
<i>How does this PhD research relate to palliative care and CareSearch?.</i>	<i>10</i>
Significance	12
<i>Why focus on the Baby Boomer generation?.....</i>	<i>12</i>
Timeliness.....	12
Theoretical approach	13
<i>Classical Grounded Theory (CGT).....</i>	<i>13</i>

<i>Transtheoretical Model (TTM)</i>	14
<i>Knowledge Translation (KT)</i>	16
<i>Epidemiology</i>	16
Methods used to conduct the three thesis projects	17
Overview of chapters in the thesis	18
Chapter conclusion	18

**CHAPTER 2 – PROJECT 1 – A SYSTEMATIC REVIEW OF THE EFFECTIVENESS OF
COMPUTER-BASED, INTERACTIVE ONLINE METHODS FOR FACILITATING AD COMPLETION**19

Introduction.....	19
Aim and significance.....	20
Objectives of this Systematic Review	20
Method used for conducting this Systematic Review	21
<i>Search strategy</i>	21
<i>Selection of studies</i>	22
<i>Inclusion and exclusion criteria</i>	23
<i>Screening</i>	24
<i>Data extraction</i>	25
Results	25
<i>General characteristics of the included studies</i>	28
Discussion	41
Limitations of this systematic review	44
Chapter Conclusion	45

**CHAPTER 3 – PROJECT 2 – PREVALENCE AND PREFERRED MECHANISMS OF
ENGAGEMENT WITH ADVANCE DIRECTIVES AND THE E-HEALTH ENVIRONMENT IN SOUTH
AUSTRALIA**47

Introduction.....	47
<i>Previous knowledge of AD and computer use in Australia</i>	47
<i>A new AD framework and its importance to South Australia</i>	48
AD use in the e-Health environment	50
Aim	51

Significance of the project	52
Research objectives.....	52
Methods.....	53
<i>South Australian Health Omnibus Survey methodology</i>	53
<i>Survey questions for this study</i>	55
<i>Composition of studies with Overall population</i>	57
A secondary analysis of those aged 47–66 incorporating the Baby Boomer generation.....	57
Statistical analysis.....	59
Results.....	61
<i>Demographic Information for Main Analysis and Secondary Analysis</i>	61
Part 1 – Main Analysis: Overall population (N=3055) – Completion (Primary Outcome), Assistance and Agency with Advance Directives.....	65
<i>Frequency and prevalence of completion by the Overall population (N=3055) – (Q1) for the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Anticipatory Direction/Living Will (LW) and Will</i>	65
<i>Frequency and prevalence of assistance for the Overall population (N=3055) (Q2) of EPA, EPG, MPA, Living Will and Will</i>	70
<i>Frequency and Prevalence of agency through the Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG) for the Overall population (N=3055) (Q3)</i>	75
<i>Multivariate logistic regression analysis of the Overall population (N=3055) comparing non-completion, non-assistance and non-agency (Questions 1-3) with sociodemographic characteristics</i>	78
<i>Results of multivariate analysis for the Overall population (N=3055) for non-completion (Q1) of Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Living Will and Will</i>	81
<i>Results of multivariate analysis for the Overall population (N=3055) with non-assistance (Q2) to others with the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney</i>	

<i>(MPA), Living Will and Will.....</i>	<i>82</i>
<i>Results of multivariate analysis for the Overall population (N=3055) for non-agency (Q3) through the Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG)</i>	<i>83</i>
<i>Summary of results on completion, assistance, agency and non-completion, non-assistance and non-agency for the Overall population (N=3055) (Q1-3).....</i>	<i>83</i>
Part 2 - Main analysis: Overall population (N=3055) - Comfort and use with computers, online devices and the online environment as well as preferred mechanism for online Advance Directive knowledge	85
<i>Frequency and prevalence of comfort with computer, online devices and online use by the Overall population (N=3055) (Q4)</i>	<i>85</i>
<i>Use of a computer or the Internet on a daily/weekly basis by the Overall population (N=3055) (Q4).....</i>	<i>90</i>
<i>Comfort and use of online devices and environment for seeking information by the Overall population (N=3055) (Q4).....</i>	<i>91</i>
<i>Multivariate logistic regression analysis of non-use of a computer or online device by sociodemographic characteristics for the Overall population (N=3055) (Q4).....</i>	<i>92</i>
<i>Results of multivariate analysis for non-use of the computer or online devices for the Overall population (N=3055) (Q4).....</i>	<i>93</i>
<i>Summary of results on comfort and use of the computer and online devices for the Overall population (N=3055) (Q4).....</i>	<i>94</i>
<i>Frequency and prevalence of the Overall population (N=3055) (Q5) to use various online and offline mechanisms for learning about Advance Directives.....</i>	<i>95</i>
<i>Multivariate logistic regression comparing non-interest in learning about ADs with sociodemographic characteristics of the Overall population (N=3055) (Q5)</i>	<i>102</i>
<i>Results of multivariate analysis for non-interest in ADs for the Overall population (N=3055) (Q5).....</i>	<i>104</i>
<i>Summary of results for online and offline preferences for learning about Advance Directives by the Overall population (N=3055) and non-interest</i>	

<i>in learning about Ads (Q4 and 5)</i>	104
Part 1 – Secondary Analysis: People aged 47–66, incorporating the Baby Boomer generation (N=993) – Completion, Assistance and Agency with Advance Directives	105
<i>Frequency and prevalence of completion by the Baby Boomer population (N=993) (Q1) for the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Anticipatory Direction/Living Will (LW) and Will</i>	105
<i>Prevalence of completion, assistance and agency of the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Living Will and Will by those aged 47-66 incorporating the Baby Boomers (N=993) (Q1-3).....</i>	112
<i>Multivariate logistic regression analysis of the 47-66 age group incorporating the Baby Boomers (N=993) (Q1-3) comparing non-completion, non-assistance and non-agency with sociodemographic characteristics.....</i>	114
<i>Summary of results on completion, assistance, agency and non-completion, non-assistance and non-agency for the age group 47-66 incorporating the Baby Boomers (N=993) (Q1-3).....</i>	116
Part 2 - Secondary Analysis: People aged 47–66, incorporating the Baby Boomer generation (N=993) – Comfort with the online environment and preferred online mechanism for engagement with advance directives (ADs).	118
<i>Secondary analysis of those aged 47-66 incorporating the Baby Boomers (N=993) (Q4) for frequency and prevalence of of comfort with computer, online devices and online use</i>	118
<i>Prevalence of use of a computer or the Internet on a daily/weekly basis by the Baby Boomer population (N=993) (Q4)</i>	121
<i>Prevalence of accessing a computer or the Internet on a daily or weekly basis by those aged 47-66, incorporating the Baby Boomers (N=993) (Q4).....</i>	121
<i>Prevalence for comfort and use of online devices and environment for seeking information by the Baby Boomer population (N=993) (Q4).....</i>	122
<i>Multivariate logistic regression analysis by sociodemographic characteristics of non-computer and non-online device use by those aged</i>	

<i>47–66 incorporating the Baby Boomer generation, (N=993) (Q4)</i>	<i>123</i>
<i>Results of multivariate analysis for non-use of the computer or any online device by participants aged 47-66 years incorporating the Baby Boomer generation (N=993) (Q4).....</i>	<i>124</i>
<i>Summary of results on comfort and use of the computer and online devices for the Baby Boomer population (N=993) (Q4).....</i>	<i>125</i>
<i>Frequency and prevalence of participants aged 47–66 incorporating the Baby Boomer generation (N=993) (Q5) to use various online and offline mechanisms for learning about Advance Directives.....</i>	<i>126</i>
<i>Multivariate logistic regression analysis of participants aged 47–66 incorporating the Baby Boomers (N=993) (Q5) comparing non-interest in learning about ADs with sociodemographic characteristics.....</i>	<i>131</i>
<i>Results of multivariate analysis for non-interest in learning about ADs for participants aged 47–66 incorporating the Baby Boomers (N=993) (Q5)</i>	<i>132</i>
<i>Summary of results for online and offline preferences for learning about Advance Directives by those aged 47-66 incorporating the Baby Boomers (N=993) (Q5) and non-interest in learning about ADs</i>	<i>132</i>
Discussion	133
<i>The effect of age.....</i>	<i>134</i>
<i>The effect of gender</i>	<i>135</i>
<i>The effect of location</i>	<i>136</i>
<i>The effect of race or country of birth</i>	<i>137</i>
<i>The effect of marital status</i>	<i>138</i>
<i>The effect of education</i>	<i>141</i>
<i>The effect of occupation</i>	<i>142</i>
<i>The effect of income</i>	<i>142</i>
<i>Agency</i>	<i>143</i>
<i>Independent predictors of non-completion, non-assistance and non-agency.....</i>	<i>144</i>
<i>Independent predictors of non-computer use and non-interest in ADs..</i>	<i>145</i>
<i>Recommendations from this research</i>	<i>145</i>

<i>Implications of this research study</i>	149
<i>Strengths and limitations of the study</i>	151
Conclusion	153
CHAPTER 4 – PROJECT 3 – RANDOMISED CONTROLLED TRIAL OF TWO COMPUTER- BASED, INTERACTIVE ONLINE FORMATS TO ENHANCE COMPLETION OF ADVANCE DIRECTIVES BY A SAMPLE OF SOUTH AUSTRALIAN BABY BOOMERS.....	155
Introduction	155
Background.....	155
Rationale	156
Aim	158
Research question	158
Objectives	159
<i>Randomised Controlled Trial (RCT) as an empirical method for meeting the objectives of this study</i>	159
<i>Ethics</i>	160
Research study method	160
<i>Research study design</i>	160
Trial design	161
<i>Eligibility criteria and participant sample</i>	162
<i>Method of recruitment</i>	163
<i>Setting</i>	165
Material used in Project 3.....	165
<i>Intervention (Prompt Group): Email prompts</i>	165
<i>Intervention (AD Module Group): AD education module</i>	166
<i>Outcome Measure Instruments: Pre-Survey</i>	167
<i>Outcome Measure Instruments: Post survey</i>	169
Sample size	170
Randomisation.....	171
Data collection and analysis.....	173
Outcomes	174

Statistical methods.....	177
Participants.....	177
Timelines and final recruitment to study.....	180
Results	184
<i>Demographics</i>	185
Primary analysis	187
<i>Main effects of one of two interventions on completion rates of four legal ADs compared to no intervention.....</i>	187
Secondary analysis.....	190
Secondary outcomes	192
<i>Prevalence for Question 2B (other document completions)</i>	192
<i>Prevalence for Question 4 (receiving assistance with ADs)</i>	195
<i>Prevalence for Question 5 (discussion about ADs)</i>	199
<i>Prevalence for Question 6 (helping others complete documents)</i>	203
<i>Prevalence for Question 7 (acted as substitute decision-maker under the particular proxy documents).....</i>	207
Other outcomes	211
<i>Supporting questions on AD use (Q3, Q8, Q31–32 Post-survey).....</i>	211
<i>Other Pre- and Post- question responses not directly related to the interventions</i>	214
<i>Supporting questions on use of the online environment (Q7A–Q14A – Pre-survey questions only)</i>	215
<i>Supporting questions on use of the online environment, including the AD module in this study for AD assistance (Q9–12, Q17, Q19, Q21, Q24–25, Q29 Post-survey questions only)</i>	220
<i>Supporting questions about the effectiveness of surveys, prompts and other dimensions of study design (Q13-Q16, Q23, Q27 Post-survey questions only)</i>	229
Open commentary	232
<i>Question 2 (completions of ADs): No. of comments received Pre-, Post- and Prompt-surveys = 7</i>	232

Question 3 (<i>why weren't ADs completed?</i>): No. of Post-survey comments received = 18.....	232
Question 4 (<i>who did you receive assistance from?</i>): No. of Pre- and Post-survey comments received = 28	232
Question 5 (<i>who did you discuss ADs with?</i>): No. of Pre- and Post-survey comments received = 4.....	233
Question 6 (<i>did you help anyone with an AD?</i>): No. of Pre- and Post-survey comments received = 3	233
Question 7 (<i>did you act as a substitute decision-maker?</i>): No. of Pre- and Post-survey comments received = 4	233
Prompt Question 7 (<i>since Pre-survey have you used any of the following for information about ADs?</i>): No. of comments received = 3	233
Question 12 (<i>other types of devices that helped person learn about ADs</i>): No. of Post-survey comments received = 6.....	234
Question 13A (<i>which software applications were used?</i>): No. of Post-survey comments received = 12	235
Question 14 (<i>what would you find helpful for learning about ADs?</i>): No. of Post-survey comments received = 2	235
Other comments received.....	235
Discussion	242
<i>Strengths and limitations of this study</i>	243
<i>Generalisability</i>	248
<i>What this means: Utility of the online environment for AD completions</i>	249
<i>Identifying sociodemographic characteristics of those most likely to complete ADs using the online environment</i>	250
<i>More than just about the medium</i>	251
<i>Utilising the medium to improve AD completions</i>	253
<i>Knowledge Translation and stages of behaviour change in this study..</i>	254
Summary and implications	255
CHAPTER 5 – DISCUSSION, IMPLICATIONS AND CONCLUSIONS	257
Summary of key findings.....	257

<i>Contribution of the studies to the literature on the effectiveness of the online environment to enhance completion rates of ADs</i>	263
<i>Contribution of population survey for determining the rates of AD completions, computer and Internet use in South Australia</i>	263
<i>Contribution of studies to the measurement of effectiveness of computer-based, interactive online mediums to actuate AD completions.....</i>	264
<i>Influence of sociodemographic characteristics on AD completions and computer-based, interactive online use</i>	265
<i>Application of studies to theory generation on willingness of Baby Boomers to be autonomous decision-makers</i>	265
Implications	267
<i>Implications for health consumers</i>	267
<i>Implications for health professionals.....</i>	268
<i>Implications for services and organisations.....</i>	269
<i>Implications for disciplines and professional bodies.....</i>	270
<i>Implications for developers of online resources</i>	271
<i>Implications for health systems.....</i>	272
<i>Implications for CareSearch.....</i>	273
<i>Implications for researchers.....</i>	274
Conclusions	281
APPENDICES	283
Appendix 2.1: Search strategies for all databases searched.....	283
<i>PsycINFO (OvidSP) search strategy (1806 to February Week 3 2014).</i>	284
<i>JBI search strategy (1998 to 19 February 2013).....</i>	284
<i>Cochrane search strategy (to 12 January 2014)</i>	285
<i>PubMed search strategy (1946–2014).....</i>	285
<i>CINAHL search strategy (1982 – February 2012).....</i>	286
<i>Ageline search strategy (1978 to 2013)</i>	286
<i>Informit search strategy (in Health and Law, to 2013).....</i>	287
Appendix 2.2: Data extraction form for SR*	288

Appendix 2.3: Excluded articles and reasons: N=55	291
<i>Key</i>	291
Appendix 4.1: Recruitment flier	296
Appendix 4.2: Website and email version of recruitment	298
Appendix 4.3: Information Sheet for Project 3	299
Appendix 4.4 Consent form for participation in Project 3	301
Appendix 4.5: Permission to advertise for recruitment to Project 3.....	302
Appendix 4.6: Advertisement in newspapers for recruitment for Project 3.....	304
Appendix 4.7: Pre-survey	306
Appendix 4.8: Surveys sent as email prompts for completing ADs (same survey sent for each prompt occasion)	318
Appendix 4.9: Post-survey Group A	322
Appendix 4.10 Example of Coding and Categories from Open Commentary Provided to Other Outcomes Questions (3-32)	335
REFERENCES	336

LIST OF TABLES

Table 2.1: General and specific elements of inclusion and essential criteria	29
Table 2.2: Patient and study demographics	33
Table 2.3: Articles meeting review inclusion criteria	34
Table 3.1: Demographic variable distribution of participants for Overall population (weighted and unweighted, N=3055)	61
Table 3.2: Demographic variable distribution of participants for those aged 47–66 (incorporating the Baby Boomer population, N=993)	64
Table 3.3: Q1 - Frequency of one or more completed documents by the Overall population, N=3055	66
Table 3.4: Q1 - Univariate analysis of the prevalence of <i>completion</i> of individual documents for the Overall population (N=3055)	67
Table 3.5: Q2 - Univariate analysis of the prevalence of <i>assistance</i> with individual documents for the Overall population (N=3055)	72
Table 3.6: Q3 - Univariate analysis of the prevalence of <i>agency</i> through EPA or EPG for the Overall population (N=3055)	77
Table 3.7: Multivariate analysis for the Overall population (N=3055), Q1–3: <i>non- completion, non-assistance, non-agency</i>	79
Table 3.8: Q4 - Univariate analysis of the prevalence of comfort with and use of the computer and online environment for the Overall population (N=3055)	88
Table 3.9: Multivariate analysis for the Overall population (N=3055) Q4:– <i>non-use of a computer or online device</i>	93
Table 3.10: Q5 - Univariate analysis of the prevalence by the Overall population (N=3055) of preferred online and offline means for learning about Advance Directives	98
Table 3.11: Multivariate analysis for the Overall population (N=3055) Q5: non- interest in learning about Advance Directives	103
Table 3.12: Q1 - Univariate analysis of the prevalence of <i>completion</i> of individual documents by the age group 47–66 incorporating the Baby Boomers (N=993)	109
Table 3.13: Q2 - Univariate analysis of the prevalence of <i>assistance</i> with individual documents by the age group 47–66 incorporating the Baby Boomers (N=993)	110
Table 3.14: Q3 - Univariate analysis of the prevalence of <i>agency</i> through the Enduring Power of Attorney or Enduring Power of Guardianship (EPG) by the age group 47–66 incorporating the Baby Boomers (N=993)	111
Table 3.15: Multivariate analysis for people aged 47-66 incorporating the Baby	

Boomers (N=993) in the HOS - Q1-3: <i>non-completion, non-assistance, non-agency</i>	115
Table 3.16: Q4 - Univariate analysis of the prevalence of comfort with and use of the computer and online environment by the age group 47–66 incorporating the Baby Boomers (N=993)	120
Table 3.17: Multivariate analysis for participants aged 47–66 incorporating the Baby Boomer generation, (N=993) - Q4: <i>Non-use of computer or any online device</i>	124
Table 3.18: Q5 - Univariate analysis of the prevalence by those aged 47-66, incorporating the Baby Boomers (N=993) of preferred online and offline means for learning about Advance Directives	129
Table 3.19: Multivariate analysis for participants aged 47–66 incorporating the Baby Boomer generation (N=993) Q5: <i>non-interest in learning about Advance Directives</i>	132
Table 4.1 Gantt chart of timeline interventions	182
Table 4.2: Demographics of 189 participants with Pre-and Post-survey responses in RCT who have been included in analysis	186
Table 4.3 Primary outcome: Post-survey results of individuals per group completing any of the 4 legal Advance Directive documents as a result of one or more interventions [§] . Analysis also includes which individual documents were completed per group.....	188
Table 4.4 Univariate analysis Q2A: Post-survey completion of any of four legal Advance Directives comparing Prompt/Non-Prompt groups v AD module /non-AD module groups [§] (N=189).....	189
Table 4.5 Multivariate analysis Q2A: Post-survey completion of the four legal Advance Directives comparing Prompt/Non-Prompt groups v AD module /non-AD module groups [§] (N=189).....	191
Table 4.6 Multivariate analysis Q2B: Pre-survey to Post-survey completion of other documents comparing Prompt/Non-Prompt groups v AD module/non-AD module groups (N=189).....	194
Table 4.7 Univariate analysis Q4: Post-survey responses of participants of assistance provided by others to participants with any documents comparing Prompt/Non-Prompt groups and AD Module /non-AD Module groups (N=189)	197
Table 4.8: Multivariate analysis Q4: Pre- to Post-survey assistance provided by others with any documents comparing Prompt/Non-Prompt groups and AD Module /non-AD Module groups (N=189)	198
Table 4.9: Univariate analysis Q5: Post-survey responses of number of participants who discussed Advance Directives with someone comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)	201

Table 4.10: Multivariate analysis Q5: Post-survey of number of participants who discussed Advance Directives with someone comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)	202
Table 4.11 Univariate analysis Q6: Post-survey responses of individuals who helped someone with any document during the course of the study comparing Prompt/non-Prompt groups and AD/non-AD Module groups (n=189)	205
Table 4.12 Multivariate analysis of Q6: Post-survey of number of participants who helped others with planning documents or Advance Directives during study comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)	206
Table 4.13 Univariate analysis Q7: Post-survey responses of individuals who acted as a substitute decision-maker during the course of the study comparing Prompt/non-Prompt groups and AD/non-AD Module groups (n=189)	209
Table 4.14 Multivariate analysis Q7: Post-survey of number of participants who acted as substitute decision-makers during study comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)	210
Table 4.15: Websites participants visited during study	234
Table 5.1: Key findings from each of the three Projects in this thesis	260

LIST OF FIGURES

Figure 1.1: Stages of Change – Transtheoretical Model (TTM)	15
Figure 2.1: Article inclusion and exclusion criteria	23
Figure 2.2: Flow chart of retrievals and excluded or included articles	26
Figure 3.1: Introductory statement and questions asked in HOS survey.....	575
Figure 3.2: Q1 - Frequency of <i>completion</i> of individual Advance Directives by the Overall South Australian population (N=3055)	65
Figure 3.3: Q2 - Frequency of <i>assistance</i> with individual Advance Directives by the Overall population (N=3055).....	70
Figure 3.4: Q3 - Frequency of <i>agency</i> under the formal Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG) for the Overall population (N=3055)	75
Figure 3.5: Q4 - Frequency of comfort with and use of the computer, online devices or the Internet for the Overall population (N=3055)	86
Figure 3.6: Q5 - Frequency of online or offline means of engagement for learning about Advance Directives and non-interest in learning about Advance Directives for the Overall population (N=3055)	96
Figure 3.7: Q1-3 - Frequency of completion, assistance and agency of individual Advance Directives by people aged 47–66 incorporating the Baby Boomer generation, (N=993).....	107
Figure 3.8: Q4 - Frequency of comfort with and use of the computer, online devices or the Internet for people aged 47–66 incorporating the Baby Boomer Population, (N=993).....	119
Figure 3.9: Q5 - Frequency of online or offline means of engagement for learning about Advance Directives and non-interest in learning about Advance Directives for those aged 47–66 incorporating the Baby Boomer generation, (N=993)	127
Figure 4.1: Diagram of 2 x 2 factorial design of Project 3	160
Figure 4.2: Stratified categories for randomisation	172
Figure 4.3: Computer generated email from submitted Pre-survey.....	172
Figure 4.4: Example of randomisation spreadsheets*.....	173
Figure 4.5: Factors to consider when developing criteria for “types of outcomes”*	175
Figure 4.6: Flow diagram of inclusions and exclusions based on CONSORT recommendations*	179
Figure 4.7: Number of participants excluded due to completion of documents at Pre- survey.....	185

Figure 4.8: Q2B - (completion of other documents). Number and type of other documents completed - Post -Survey	193
Figure 4.9: Q4 (assistance from others). Number and type of person providing assistance to participant with any Advance Directive document – Post Survey	196
Figure 4.10: Q5 (discussion with others).Prevalence of person chosen- Post-survey	200
Figure 4.11: Q6 (helped others). Type of documents and number of participants who helped others during course of study.....	204
Figure 4.12: Q7 (acted as substitute decision-maker).Number of responses and types of documents participants acted under as substitute decision-maker for others – Post survey.....	208
Figure 4.13: Q3 (why didn't you complete?). Prevalence of responses and reasons - Post-survey	211
Figure 4.14: Q8 (would you act as a substitute decision-maker?). Prevalence of responses and reasons - Post-survey	212
Figure 4.15: Q32 (likelihood of completing an AD in the next 3 months). Prevalence of responses and reasons - Post-survey.....	213
Figure 4.16: Q31 (do you know more about ADs now?). Prevalence of responses and reasons - Post-survey.....	214
Figure 4.17: Q7A (comfort with computer use). Percentage of participants comfortable with computer and particular level of comfort - Post-survey – Pre-survey.....	215
Figure 4.18: Q9A (comfort with the Internet). Percentage of participants comfortable with computer and particular level of comfort - Pre-survey	216
Figure 4.19: Q12A (type of online devices being used). Prevalence of response - Pre-survey.....	217
4.20: Q13A (software applications used and type of software used). Prevalence of response - Pre-survey	218
Figure 4.21: Q14A (what form of online or other method would you have found helpful?). Prevalence of response - Pre-survey	219
Figure 4.22: Q9 (which online or offline format assisted learning of ADs). Prevalence of response - Post-survey.....	220
Figure 4.23: Q10A (which was helpful for completing ADs prevalence of response?). Prevalence of response - Post-survey	221
Figure 4.24: Q12 (which type of software was helpful for completing ADs). Prevalence of response - Post-survey	222
Figure 4.25: Q11 (which hardware devices assisted with learning about ADs). Prevalence of responses - Post-survey	223

Figure 4.26: Q17 (did AD module encourage completion of any documents?). Prevalence of response - Post-survey	224
Figure 4.27: Q21 (was language in AD module easy to understand?). Prevalence of response - Post-survey.....	225
Figure 4.28: Q24 (choices for improvement of AD module). Prevalence of response - Post-survey	226
Figure 4.29: Q25 (would you recommend AD module?). Prevalence of response – Post-survey	227
Figure 4.30: Q29 (how online information about ADs can be improved). Prevalence and type of response - Post- survey	228
Figure 4.31: Prevalence of response to Q14 (did surveys help you to contemplate doing an AD?). Prevalence of response to Q15 (if surveys were helpful, which ones were most helpful?). Prevalence of response to Q27 (did you find the surveys easy to use?) - Post-survey	229
Figure 4.32: Q13 (type of social media for reminders about completing ADs). Prevalence of responses - Post-survey.....	230
Figure 4.33: Q16 (when is the best time for a reminder to complete an AD?). Prevalence of responses - Post-survey.....	231

PREFACE

Although dying has never been easy it is increasingly becoming more difficult. In essence, we now have to make decisions about how long we want to live, how we choose to cope with illnesses that we may have carried throughout our lives or get later in life, who we expect to assist us when we need care, and what technology can improve that care. This thesis is part of the story of South Australians' willingness to understand that the world has changed in our relationship to illness, dying and death (in a country that is not in armed conflict on its home soil).

Advance directives are instruments that enable competent people to record future financial, healthcare and lifestyle choices to be made on their behalf when they become incompetent or lose capacity for decision-making. My previous research on South Australian Baby Boomer use of ADs ("I know I should but I haven't: South Australian Baby Boomers Forever Contemplating Advance Care Directives" – Master of Research Thesis) provided insight into the barriers and facilitators to creating advance directives (ADs). The title of this research describes the findings – SA Baby Boomers contemplate doing these documents for a long time for a variety of reasons before completing them.

This PhD thesis explores those reasons in more depth by trying to alleviate one of the barriers named by the previous research participants – that is, flexible and online access to information or documents. The research contained herein includes a systematic review of other studies which have used the online environment to increase advance directive use; a population-based survey to understand which documents South Australians, including Baby Boomers, have completed as well as their preferred online means of gaining information on ADs; and a randomised controlled trial to explore which of two online options enhances completion of ADs by South Australian Baby Boomers. I hope the findings from this research are thought-provoking, helpful and able to stimulate further research in this complex and intriguing area of decision-making.

ABSTRACT

This thesis explores the willingness of South Australians to embrace personal autonomy in future healthcare decision-making through completion of advance directives (ADs) using the e-Health environment. Advance directives are financial, healthcare and lifestyle documents that provide instructional and/or proxy information to be followed when a person is incompetent or lacks capacity for decision-making. Advance directive documents referred to and measured in this thesis are the four legal documents in South Australia (SA) prior to 1 July 2014: Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA) and Anticipatory Direction (Ant Dir) otherwise known as the Living Will (LW).

The projects that comprise this thesis include a systematic literature review; a population survey; and a randomised controlled trial. These three methods of data collection provided a comprehensive overview of the effectiveness of the online environment to assist South Australians with AD completion.

Results of this thesis found that: first, overall SA rates of completion of ADs are low with more financial (EPA and Will) than healthcare directives (EPG, MPA and LW) completed. Secondly, although use and comfort with the online environment is relatively high in South Australia (>65%) that in and of itself does not facilitate completion of ADs. Finally, when two different e-Health methods of AD information (an online education module or email-prompting to complete ADs) were offered to South Australian Baby Boomer participants (born 1946–1965) in the randomised controlled trial; neither method facilitated completions to the point of clinical effect. Instead, there were a number of other factors that detracted from AD completion, such as being too busy or “not the right time”.

Policy makers and others may find results in this thesis useful for education and promotion of these documents in South Australia or for comparison with the new South Australian ACD form.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

ACKNOWLEDGEMENTS

I would like to acknowledge first and foremost the people of South Australia who participated in these studies and were generous in their assistance and openness in communicating their preferences regarding AD use and the online environment.

Thank you also to the Australian Department of Health and CareSearch for the PhD scholarship that enabled me to conduct this thesis. I would also like to thank Flinders University, CareSearch and Professor Paddy Phillips for additional financial and resource support.

I would like to acknowledge the superb supervisory team that assisted me with this thesis. Associate Professor Jennifer Tieman, Director of CareSearch, acted as a wonderful mentor and devil's advocate on AD use, the online environment and many other things and cannot be beaten on reducing complicated thoughts into one sentence synopses. Professor Richard Woodman guided me through the maze of statistical processing, SPSS, and how to describe in academic and lay terms the results of population-based surveys with the utmost patience and encouragement. Professor Paddy Phillips is incomparable in his ability to provide excellent support and guidance in a succinct and eloquent manner.

Professional editor David Alston provided copyediting and proofreading services, according to the conditions laid out in the university-endorsed national guidelines, 'The editing of research theses by professional editors'.

I would also like to thank the many friends and work colleagues who had to listen through many years of argument, pro and con, about my varied positions on AD use and their place in South Australian society. Your patience and support has been tested and tried and still you had lunch or dinner with me – much appreciated. All of you have helped me understand the decisions that people make even if I may never understand why.

Finally, I would like to thank my family both in South Australia and overseas. Thank you, Tom, a husband who bore the brunt of many a frustration but withstood the uncertainties of future decision-making to take this journey with me. Although no longer here, I thank my mother- and father-in-law, Lorna and Bert Bradley who died (both aged 94) during the course of this thesis and showed me the way of the future. And, certainly not least, this thesis is for you Mum and Dad. You brought me into this world at the ages of 15 and 18, respectively, stuck together through thick and

thin for over 56 years, taught me the value of curiosity, humour, persistence, passion and patience and sacrificed so that I could be the first in both your families to get a university degree and now the first doctorate. This one's for you.

VALE

I would like to honour those in my life who died over the past seven years during the course of both my Masters and PhD – all of whom have taught me so much about death and dying.

Family

Lorna Bradley, 94, mother-in-law

Herbert Bradley, 94, father-in-law

Carl McComb, 60's, uncle

Brett Stromberg, 20's, cousin

Evan Stromberg, 40, cousin

Work colleagues

Marion Seal, 55

Friends and acquaintances

Larry Evans, 67

Alistair Tutte, 60's

Fay O'Brien, 80's

Sheila Wesley-Smith, 80's

Audrey Abbie, 93

Libby James, 80's

Bob Such, 60's

Lila Youssef, Sr., 80's

Robert F Brown, 94

Dale C Rumbelow, 51

GLOSSARY OF TERMS

Advance Directive (AD)	In South Australia, this term is now being used to specify the Enduring Power of Attorney only but for this thesis represents any of the four ADs prior to 1 July 2014 (EPA, EPG, MPA, Ant Dir).
Advance Care Directive (ACD)	A general term for statutory instruments that enable a competent adult to ensure their wishes, instructions or decisions about health, life-management or financial affairs are known and acted. These instruments can also appoint a substitute decision-maker.
Advance Care Plans (Planning)	Advance care planning is a process whereby individuals, in consultation with healthcare providers and relatives, describe their personal values and life goals and put in place advance care plans for their future healthcare, in case they become incapable of making such decisions personally at a later time. There are multiple versions of this instrument: <i>The Good Palliative Care Plan</i> (Palliative Care Australia 2008) and the <i>Statement of Choices</i> (Respecting Patient Choices Program 2015) which act as anticipatory directions in palliative care and advance care planning programs, respectively. In addition, there are <i>Ulysses Agreements</i> in mental healthcare planning and the <i>Life Values Statement</i> produced by the South Australian Voluntary Euthanasia Society which defines unacceptable circumstances that would be worse than death itself to help guide medical decision-making.
Anticipatory Direction (Ant Dir)	This is an instructional document and in other localities is known as a “living will” In South Australia, this instrument only comes into effect when the end of life is near and records the treatment a person wants or does not want in the terminal phase of a terminal illness or in a persistent vegetative state (PVS).
Capacity	The measure of a person’s ability to make personal decisions or to make a particular personal decision.
Competence	A legal term used to describe the mental ability required for an adult to sign a legal document while understanding the consequences of his or her decisions.
Computer	Any electronic device for storing and processing data according to instructions given to it in a variable program (Hanks1996a, p. 298).
Enduring Power of Attorney (EPA)	This is the most commonly known Advance Directive. This instrument nominates a surrogate to make decisions on financial/legal matters only but its application is often extended into other areas of care.

Enduring Power of Guardianship (EPG)	This Advance Care Directive nominates a surrogate who can refuse or consent to medical treatments as well as healthcare, more generally, that involves other health professionals. In addition, the surrogate can also make lifestyle decisions, which include, but are not limited to – residential, employment and holiday arrangements and particular instructions can be written to inform the substitute decision-maker of other requirements and/or how the instructions should be interpreted.
Healthcare Professionals (HCP)	Health professionals include medical, dental, nursing and social work practitioners, ambulance paramedics and allied health staff; these are often called clinicians.
Interactive	In this study, interactive refers to any means used to actuate or record a person's AD completion including third party assistance. For example, this may include the use of clerical assistance for sending reminders or entering completed AD documents into an online system as well as direct completion of ADs online (Hanks 1996b, p.732).
Medical Power of Attorney (MPA)	This Advance Care Directive nominates a surrogate who can refuse or consent to medical treatments.
Medical treatment	Administration of therapy by either physical, surgical or psychological means, or administration of medications to prevent disease, to restore or replace body function in the face of disease or injury, or to improve the comfort and quality of life. Medical treatment can be administered by a range of health professionals.
Online	Refers to "(Of an activity or service) available on or performed using the Internet or other computer network" (Oxford Dictionaries 2015).
Palliative care	An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, e.g. physical, psychosocial and spiritual. Palliative care intends neither to hasten nor postpone death but provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process.
Terminal phase of a terminal illness	Terminal illness means an illness or condition that is likely to result in death; and terminal phase of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).
Ulysses Agreement	A record of an agreement between a patient, their psychiatrist, relatives and others, about treatment to be provided and arrangements to be made during future episodes of mental illness.

All definitions unless otherwise noted are from the South Australian Government Department of Health Advance Directives Review: Planning ahead – your health, your money, your life – First Report of the Review of South Australia's Advance Directives (South Australian Government Department of Health 2008).

ABBREVIATIONS

AD – Advance Directive

ACD – Advance Care Directive

ACP – Advance Care Planning

AHMAC – Australian Health Ministers' Advisory Council

Ant Dir – Anticipatory Direction

BB – Baby Boomer

BSPP – Basic Social Psychological Process

CGT – Classical Grounded Theory

DNR – Do-Not-Resuscitate

EOL – End of Life

EPA – Enduring Power of Attorney

EPG – Enduring Power of Guardian

GP – General Practitioner

HCP – Healthcare Professional

HOS – Health Omnibus Survey

KT – Knowledge Translation

LW – Living Will

MPA – Medical Power of Attorney

NHMRC – National Health and Medical Research Council

QOL – Quality of Life

RCT – Randomised Controlled Trial

RHD – Research Higher Degree

SA – South Australia

SAG – South Australian Government

SAGDOH – South Australian Government Department of Health

SR – Systematic Review

SDM – Substitute Decision-maker

TTM – Trans Theoretical Model

CHAPTER 1 – INTRODUCTION

Overview

This thesis presents research on the use of advance directives (ADs) by South Australians and how the online environment may assist people contemplating AD completion. Included in this thesis is research that describes the effectiveness and use of computer-based, interactive online systems to assist South Australian (SA) Baby Boomers (born 1946–1965) to commence or complete ADs. Advance directives, a term initially coined by Kutner (1967, cited in Hong and Lee, 1996), are legal instruments enabling a person to instruct or appoint others for future financial, healthcare or lifestyle decision-making at a time when the person may not be able to make or voice decisions themselves (Kerridge, Lowe & Stewart, 2009). The implementation of ADs for such a time ensures the personal autonomy or self-determination of the person is preserved (Kerridge, Lowe & Stewart, 2009).

Advance directives

International perspectives

At present in Europe some forms of ADs are legally recognised (Denmark, UK, Netherlands, Belgium, France, Spain, Austria, Hungary and France) – as well as in all states in the United States and most Canadian provinces (Besirevic 2010). Advance directives are also recognised in New Zealand and all Australian states and territories under either common law or legislation (Australian Health Ministers' Advisory Council (AHMAC) 2011). However, there are still many countries which do not engage with ADs, therefore the use of these documents remains firmly connected to those countries which place value on the concept of personal autonomy in decision-making.

Since their inception, research and discussion about the effectiveness of ADs to ensure personal autonomy at the designated time of use has been extensive and ongoing with over 289,000 references to the subject when the search term “advance directive” is entered into Google Scholar (2015). Evaluating the effectiveness of ADs has been conducted through a variety of research objectives such as: satisfaction of use (Jackson, Derderian et al. 2012); willingness to use or implement these instruments (Clements 2009, Emanuel 1995, The SUPPORT Investigators 1994, The SUPPORT Investigators 1995) and actual completion rates of ADs (Braun, Onaka & Horiuchi 2001, Campbell, et al. 2007, Jezewski, et al. 2007, Wilkinson, et

al. 2007). McLaren (2009) and Olszewski, et al. (2012) also studied registration and use of these instruments in a dedicated repository whilst Drinka, Spears and Voeks (1993) and others (Dharmarajan, et al. 2010, High 1993, Silverman, et al. 1995) researched the use of ADs in various settings and patient cohorts.

The “bulk of the debates about advance directives took place within the national ethical and legal systems” of those countries proposing their use (Besirevic 2010, p. 106). These debates argued either for or against the right of individual autonomy with issues such as validity, implementation and alteration causing difficulties in the ability of the documents to protect patient interests, facilitate healthcare provision and protect healthcare professionals (HCPs) from liability (Besirevic 2010, Street & Ottman 2006, Wilkinson, et al. 2007).

Included in these debates has been the use of completion rates as a measure of AD engagement (Fagerlin & Schneider 2004, Lynn & Teno 1993, Wilkinson, et al. 2007). This is because despite interventions to improve completion rates, rates of completion of ADs have remained low; therefore the argument has been that measuring completion rates of ADs is not indicative of the use or effectiveness of these instruments (Street & Ottman 2006). However, if completion rates remain low even with interventions to assist completion, then it means that completing these documents must be more complicated psychologically and socially than logistically. Therefore measuring completion rates is not a waste of time but instead may indicate additional factors, such as sociodemographic characteristics or research methods, influencing completion and measurement of completion of these documents. Assessing completion rates on an ongoing basis may also serve as a means for monitoring the public’s acceptance or denial of death especially in the current environment where chronic illness is increasing at the same time that the promise of longevity is advertised (Gillick 2006, Rubin 2007).

National perspectives

The Australian National Framework on Advance Care Directives (AHMAC 2011, p. 6) states that “there are no data available on how many ACDs (Advance Care Directives) are completed in Australia or how many are used for decision-making, although there is evidence that advance care planning programs are increasing the uptake in health, institutional and aged care settings for people with a known condition”. However, this lack of information was rectified when White et al. (2014) provided the first evidence for nationwide use of ADs in Australia. They found that the average completion rate of ADs across Australia was 14% with variation on the

types of ADs completed and an emphasis on financial ADs and Wills (Wills are not ADs). White et al. (2014) concluded that as planning for future wealth distribution through financial ADs and Wills seems to have been adopted by the Australian public as a normal part of ageing, presenting opportunities to engage in future healthcare planning at the same time might enhance completion of healthcare and lifestyle ADs. They also recommended that providing regulatory frameworks that are consistent between states could also improve uptake (White et al. 2014).

Local perspectives

In South Australia, the recognition of the need to provide better legislative mechanisms for protecting future autonomous healthcare decision-making, including the right to die, began in the 1980s with the establishment of the *Natural Death Act 1983* (South Australian Government (SAG) 1983), the *Powers of Attorney and Agency Act 1984* (SAG 1984) and later the *Guardianship and Administration Act 1993* (SAG 1993) and *Consent to Palliative and Medical Treatment Act 1995* (South Australian Government Department of Health (SAGDOH) 1995). These Acts resulted in the creation of four separate AD documents in South Australia: the Enduring Power of Attorney (EPA – financial matters); the Enduring Power of Guardianship (EPG – healthcare and lifestyle decision-making); the Medical Power of Attorney (MPA – medical treatment decision-making only); and the Anticipatory Direction (Ant Dir – end-of-life care). In July 2013, new legislation created the *Advance Care Directive Act 2013* (SAGDOH 2013) which combined the EPG, MPA and Ant Dir into one form to assist the general public with completing healthcare and lifestyle ADs. This thesis will not refer to this new form of legislation as it occurred after the research projects in this thesis had been completed.

Notwithstanding that South Australia has been a leader in the legislation of ADs it has, as in the rest of the country, lacked definitive information about the completion rates of all legal AD documents available in the State. Without this information, promotional efforts for use of these instruments may be mistimed, misunderstood and potentially misdirected to audiences with less willingness to engage in these documents.

The Baby Boomers

There has been much research conducted on different target audiences for AD engagement spanning a wide range of ages (Wilkinson, et al. 2007). Many advanced western countries including Australia recommend these documents be

completed by those aged 18 and older (AHMAC 2011) yet they remain the provenance of the terminally ill or frail aged (Wilkinson, et al. 2007). Older age has played a dominant role in the targeting of and research on engagement with ADs. In a meta-analysis of AD studies spanning three countries (United States, Canada and Australia), Bravo, Dubois and Wagneur (2008) found that the median age of participants was 70 years, ranging from 44 to 90 years. However, some of the research studies exploring different age group use of ADs have found that the generational context and ageing process itself may influence the willingness to use these instruments for future life events (American Association of Retired Persons (AARP) 2009, Bradley 2012, National Seniors Productive Ageing Centre (NSPAC) 2012, Pruchno 2012).

As far back as 1997, research conducted in South Australia by Brown et al. (1997) found that younger age groups were less likely to complete ADs because it was not the right time of life for them to complete them. For older people who did complete ADs, a reason given for completion was to relieve the burden of decision-making for younger family members when substitute decision-making was required (Brown et al. 1997). Brown et al. (1997) recommended the need for communication between family members about ADs be done multiple times throughout life and with and across generations.

Yet, much of the research conducted with ADs continues to involve people aged 65 and older or in an age range that encompasses several generations with very different experiences of healthcare provision and perspectives of autonomy in healthcare decision-making (Pruchno 2012, Reuben 2009). Few researchers have explored whether different points in the life course or different generations are more interested in or influenced by AD use but this area of research is becoming more of a target for investigation (Carrese, et al. 2002, Humpel, et al. 2009, Pruchno 2012, Reuben 2009). As the Baby Boomer generation enters older age, increased care commitments to younger and older generations at the same time (Australian Bureau of Statistics (ABS) 2012a) may see them think about these documents more often not only in relation to the care of elderly parents but also in relation to care for their dependent children.

More recent research in the US by Carr (2012a, 2012b) and Moorman and Inoue (2013) suggests that adults who matured *prior* to the 1960's Civil Rights movements in the US (which is when the Baby Boomers matured) had less access to education, literacy, wealth management, home ownership and other social variables that today

influence those who are more likely to complete ADs. In the US, these sociodemographic variables may also be confounded by ethnicity as in the US some ethnic groups that have been studied with regard to ADs comprise larger numbers of younger people who are more likely to not engage in advance care planning (Carr 2012a). Carr (2012a) recommended that studies should adjust for these potential confounding variables when seeking to measure completion or non-completion of ADs as factors such as ethnicity may actually be reflecting age-related intent rather than the ethnic variable (Carr 2012a).

In addition, most previous studies on AD use have focused on those who seek care in a hospital or in nursing home under institutionalised arrangements (Carr 2012b). These locations may enforce or detract from AD completions based on institutional policies rather than individual choice (Moorman & Inoue 2013). In their study, Moorman and Inoue (2013) identified that age and health status had independent relationships to formal and informal aspects of advance care planning. Twenty-eight per cent of their study participants aged 18-64 had completed an AD with completion occurring more with older adults than younger adults especially as older adults intersected with healthcare institutions more when health deteriorated (Moorman & Inoue 2013). Carr's (2012a, 2012b) and Moorman and Inoue's (2013) research hints that engagement with ADs is subject to factors that are not just about ill health but encapsulate social factors influencing this decision-making. These social influences may differ for different generations. For example, it may be that those who matured at a time when Civil Rights movements defined the social milieu of the day are more amenable to efforts at protecting personal autonomy than previous generations where such civil rights ideologies were less prevalent. To explore whether such social and generational differences may exist in relation to ADs, this thesis investigates how the generation known as the Baby Boomers may consider ADs as they approach their retirement and older age.

In Australia, the Baby Boomer generation is described as those born between the years 1946–1965 (ABS 2003). The Baby Boomer population in Australia is predicted to have more chronic health problems as they age than previous generations with some researchers predicting that Baby Boomers may not live as long as their parents (ABS 2003, Hugo 2013a, 2013b).

Much of the empirical evidence on factors influencing Baby Boomer ageing concentrate on Baby Boomer care commitments for others (Christian 2004, Fingerman et al. 2012, Guberman et al. 2012) and whether Baby Boomer finances

are sufficient for retirement (NSPAC 2012, O'Loughlin, Humpel & Kendig 2010) rather than whether Baby Boomers are completing ADs to meet their future healthcare and lifestyle needs. Since this generation has developed a culture of personal autonomy and consumer choice (Center for Ageing and Educational Research (CARES) 1997, Gillick 2006, Kaplan 2009, Rubin 2007), it is important to see whether this ideological perspective carries through to AD completions which enshrine personal autonomy in legislative authority.

In South Australia, the South Australia Strategic Plan in Health and All Policies (SAGDOH 2011) does not address changing demographic trends with very few targets having a specific ageing focus and most lacking specific attention to different age groups. This sends a false message to the wider community about the significance of any trends such as those relating to the Baby Boomers (Barnett 2013). Yet, knowing what the Baby Boomers will be willing to do in relation to their future healthcare and lifestyle decision-making, including intent to complete ADs, will be important if policy initiatives seeking to protect personal autonomy in healthcare decision-making are to be successful.

Advance directive policy initiatives that target specific generations such as the Baby Boomers may generate greater rates of AD completions if initiatives targeted to specific generations such as the Baby Boomers include documents that are proffered in an environment with which they are familiar and which enable greater flexibility, accountability and utility for registering ADs. Recent research shows that Baby Boomers are increasing their access to and preference for computer-based, interactive online technology to manage many aspects of their social lives, including the use of these technologies to gain information about healthcare (Anderson 2012, ABS 2011b, Australian Communications and Media Authority (ACMA) 2009, McCrindle Research ND).

ADs in the online environment

The terms used to describe the online environment as used in the literature on ADs have been variable. The term "online" may mean information within an intranet system (in-house computer system), Internet system (World Wide Web), or as part of a computer-based system (videos and CDs with educational information) and studies such as those by Aronsky et al. (2004) have also defined online as meaning electronic medical records.

The use of online electronic medical or health records may provide an opportunity for measuring AD completion rates of overall *patient* populations but not of a population in general. Nevertheless, for patient populations, the use of electronic record systems for monitoring AD completions can yield benefits. For example, in a retrospective audit of Do-Not-Resuscitate (DNR) orders over a five year period across different wards of the Department of Medicine at Georgetown University Medical Centre, Sulmasy and Marx (1997) found that although chart conversations about ADs increased significantly, the incidence of DNR orders did not differ. Their research also showed that more treatment decisions were being entered into the DNR orders even if ADs were not being registered; for example, instead of just pain relief and discharge planning choices being recorded, there were also notes about intubation or tube feeding reflective of conversations between physicians and patients about end-of-life choices as opposed to actual recording of these statements in a registered AD. Therefore, this suggests that the formal recording and registering of an AD may not be as preferable as having a conversation about choices with a knowledgeable expert.

To identify whether these face-to-face conversations could be substituted with an online version of similar content, the use of interactive computer-based decision and documentation guides for patients and families (sometimes called decision aids) (Butler et al. 2014, Tung et al. 2011) and Web-based repositories for ADs (McLaren 2009, Olszewski et al. 2012, Sudore et al. 2014) have been developed. In addition, Green and Levi (2009) and others (Hossler et al. 2011, Levi, Heverley & Green 2011) have applied interactive computer-based, online technology to help patients and family members actually complete an AD online.

These various online mechanisms of assisting AD completion rates have had mixed and imprecise results, often because the research under which these computer-based, online mechanisms have been tested are combined with other mechanisms for dissemination of the AD message, (e.g. brochures, pamphlets, face-to-face assistance), or AD completion is seen as a secondary outcome without definitive Pre- and Post- results (Buchtel, et al. 1996, Cintron, Phillips & Hamel 2006, Durbin, et al. 2010, McCannon et al. 2012, The SUPPORT Investigators 1995, Sulmasy, et al. 1996, Volandes et al. 2009). Also obfuscating evidence of the direct effectiveness of the online environment for facilitating AD completion has been the testing of computer-based, interactive online mechanisms on particular illness groups but not more broadly with those who may be well but inclined to forward planning (AARP

2009). In addition, published reports of the results of experimentation with such computer-based, interactive online mechanisms may not be generally available either because the technology is at a pilot stage (Butler et al. 2014, Sudore et al. 2014) or the information is held as commercial-in-confidence (ADVault Incorporated, personal communication by email, January 2014). This makes assessment of the effectiveness of such computer-based formats to facilitate AD completions difficult to judge.

Volandes and colleagues (2007; 2008; 2009; 2010; 2012a and 2012b) have been prolific in using computer-based, online videos of people living real lives with various health conditions to influence participants in their studies on AD choices and completion. However, there can be significant risks with this format such as: videos being developed then not updated; videos being maintained in a way that doesn't ensure their intended message; accessibility only to particular audiences; or videos being subject to user pays.

Wetle (1994) suggests that the environment in which AD information is conveyed can have an influence on acceptance or further actions on these documents so that if information is not updated or relevant to the individual, it may not be seen as being helpful for AD creation. As an example, Berg (2012) found that social media, such as Facebook, one of the newer forms of online technologies, was fast becoming a repository for AD discussion and documents. Butler et al. (2014) cautions however that these online technologies may create over-reliance on Web-based forms of AD information which could disadvantage populations without easy access or affordability for such formats.

From another perspective, the dissemination and contemplation of AD information through technologies that are still rapidly developing could see a divergence emerge between those generations with more or less technological ability and comfort with the online environment. This divergence could become evident with people who have less access to online technologies having less opportunity to learn about ADs. It might also mean that for people who do have access to online technology but have lower levels of education, the information being conveyed may not be understood. For example, Tieman (2011) and others (Adams 2009, Morrow 2006) have found that e-Health literacy, that is understanding the context and evidence of healthcare provided through a computer-based online environment, is an important factor to consider when conveying information on healthcare in this environment.

In Australia and South Australia, the measurement of AD completions and use of the computer-based, interactive online environment for completion of ADs is limited, if not non-existent. There are a number of websites that provide AD information Australia-wide such as CareSearch (2015), Advance Care Planning (2015), Start2Talk (Alzheimer's Australia National Quality Dementia Care Initiative 2015) and others specific to State governments or organisations, law or disease oriented websites. In South Australia such websites include those of the Office of the Public Advocate (2015), SAGDOH (2015), Legal Services Commission of South Australia (2015), and Australian Government Seniors Information Services (2015). However, these websites largely disseminate information about patient choices and provide forms rather than monitoring completion of ADs; therefore, little is known about the effectiveness of these sites by themselves to enhance completion rates of ADs across the general public.

Nevertheless, the importance of such websites in disseminating information on ADs is not to be underestimated. A study by Bessel et al. (2002) regarding the use of the Internet to access healthcare information in South Australia found that over 87% of participants used the Internet for research, news and browsing. People in the age bracket of 55–64 (the older of the two decades comprising the Baby Boomer demographic) showed the largest increase in proportion of people accessing the Internet (71% in 2010–11). Those in the 45–54 aged group (younger decade of the Baby Boomer demographic) accessed the Internet at rates of 80% or greater.

Although knowing particular information about the likelihood for certain age groups to use the computer and Internet is important as a first step for providing AD information, evaluating the effectiveness of this environment to facilitate AD completions is equally as important. Without information on the latter, it could be argued that the computer-based, interactive online environment may be no more successful in providing the means and opportunity for completion of ADs than other methods of engagement such as brochures, support groups or face-to-face counselling.

Research question

The aim of this thesis was to investigate how one aspect of palliative care practice in the form of AD information delivered through a computer-based, interactive online environment could assist health consumers and health professionals with AD completions. The resulting research question that underpins this thesis is “Will

computer-based, interactive online information on ADs and/or email prompting facilitate an increase in completion rates of ADs by South Australians, specifically South Australian Baby Boomers (born 1946–1965)?”

To answer the research question, three studies were developed: a systematic review (Project 1); a population survey (Project 2); and a randomised controlled trial (Project 3). The targeted population for research in Project 2 was the general South Australian public and in Project 3, the South Australian Baby Boomer generation.

In reference to this thesis, a *computer-based, interactive online environment* refers to the use of any electronic device or environment such that AD completions can be recorded, monitored, scanned, copied or otherwise facilitated using the Internet or other computer network (see Glossary for full definitions). Such an environment which facilitates the transfer of health resources and healthcare by electronic means is called an e-Health environment (World Health Organisation (WHO) 2014). Chapters 1 and 2 of this thesis focus on the effectiveness and preference for AD information and completions using the e-Health environment while Chapter 3 describes how this method of healthcare information and dissemination affects AD completion rates by SA Baby Boomers.

Purpose

How does this PhD research relate to palliative care and CareSearch?

Palliative care is considered a complex environment that encompasses a multiple number of care elements, including: identification, assessment and treatment of pain and physical, psychological and spiritual distress of people with life-threatening illness (Australian Institute of Health and Welfare (AIHW) 2014). Palliative care is also recognised as a service that provides care delivered by health professionals who specialise in the palliative domain (SAGDOH 2009). Increasingly, palliative care is being looked upon to engage with people who have chronic illness, such as dementia, chronic obstructive pulmonary disease and congestive cardiac failure, and have long dying trajectories requiring healthcare decision-making over a long period of time (Alter et al. 2012, Aziz, Miller & Curtis 2012, Cartwright, 2011, Tobler et al. 2012). Governments such as those in South Australia are looking to palliative care providers to provide assistance to people with these and other similar diseases in relation to future healthcare decision-making (Hill, 2009, SAGDOH 2009). One of the ways in which palliative care providers can assist people with a life-limiting illness and their families is by engaging with them in advance care planning (ACP),

a process which may or may not include the creation of advance directives (ADs). A recent study by Kupensky et al. (2015) showed that the use of palliative medicine consultations in the US was significantly more likely to lead to documented ADs for geriatric patients presenting in the acute care environment as well as those severely injured but not necessarily of older age. These consultations are not only influential for decision-making by the person under consideration but also provide an opportunity for family members to learn about and have experience with ADs in relation to future healthcare planning events for themselves.

Legal ADs are the only documents that clinicians, patients, families and others should use to implement a person's preferred medical, healthcare and lifestyle needs at a time when the individual may not be able to communicate their preferences themselves. However, a number of barriers have precluded people from creating or implementing ADs at the appropriate time. Carr, Moorman and Inoue (2013) showed that for those younger and healthier, ADs are not felt to be of relevance unless a health condition necessitates it and yet the emphasis in promotion of ADs completion is to complete them prior to any healthcare crisis (Advance Care Planning 2015, AHMAC 2011, SAGDOH 2008). Knowing when is the best time to target people for AD completions such that the targeting will actually yield results is still not clearly known.

Another barrier to AD completion is that many people do not understand the difference between or functions of the different legal and other non-legal forms of the documents (AHMAC 2011) so this may undermine any education which seeks to extend relevance to a non-terminal population. CareSearch (2015) and Advance Care Planning Australia (2015) are Australian online palliative care knowledge networks providing evidence-based information as a "one stop shop" for clinicians, consumers and patients. Both are national in scope and have funding support by the Australian Government Department of Health. CareSearch (2015) enables education of the general public on palliative care issues, including ADs.

The purpose of this research therefore was to explore, using CareSearch resources, the effectiveness of computer-based, online facilities to enhance knowledge and completion of a particular aspect of palliative care, that of AD completions by a particular population, being South Australians and a specific generation, the South Australian Baby Boomer population. Information resulting from this research will be useful for CareSearch, the palliative care community, as well as patients, consumers, families and healthcare professionals interested in learning more about

the completion of ADs using an e-Health environment.

Significance

There is scant generational research on AD use or how AD use may be affected by computer-based, interactive online mechanisms. Therefore the significance of this research is twofold: firstly, it provides new knowledge and insight into the completion of ADs by South Australians and a particular generation, the Baby Boomers; and secondly, it identifies the effectiveness of computer-based, interactive online methods for facilitating completion of ADs in this generational group.

In addition to providing, for the first time, baseline prevalence of all four ADs used in South Australia, this research also provides rates of prevalence of South Australians' assistance to others to learn about or complete ADs, South Australian agency (acting as a substitute decision-maker under the formal documents of EPA, EPG and MPA), and the comfort level and preferred use of the online environment by different age groups and the Baby Boomer generation.

Why focus on the Baby Boomer generation?

Participants in a previous research study on Baby Boomer use of ADs by Bradley (2012) suggested that AD completion could be enhanced through easily accessible online education and forms as well as prompts targeted to meaningful times, such as driver's licence renewal, Organ Donation Card completion, birthdays or retirement planning. In addition, and from a more pragmatic perspective, the Baby Boomer generation is now reaching a stage of retirement planning where completion of ADs, especially financial ones, is encouraged (AARP 2009, Humpel, et al. 2009, Humpel & O'Loughlin 2010, White et al. 2014). The three studies in this thesis were conducted, therefore, to identify if the use of electronic means of prompting combined with the use of online AD education material targeted to SA Baby Boomers could facilitate completion of ADs in this group above that which might occur without such assistance.

Timeliness

In a confluence of events within the same timeframe that this PhD research commenced, the South Australian government passed the new South Australian *Advance Care Directive Act 2013* (SAGDOH 2013). This Act created a new Advance Care Directive form focusing on healthcare and lifestyle decision-making made available in both hard copy and computer-based, interactive online formats.

Therefore, the timeliness of this PhD research is such that evidence derived from use of previous AD documents prior to the entry of the new ACD form may be useful for comparing the effectiveness of the new version before and after policy initiatives developed to improve AD completions.

Theoretical approach

There are a number of theoretical perspectives being used to investigate personal healthcare decision-making, such as the Theory of Planned Behaviour by Ajzen (1991 cited in Grol et al. 2007) and the Self-efficacy Theory of Bandura (1986 cited in Grol et al. 2007). These theories provide valuable insight into the potential drives that motivate people to change or adopt behaviours. For this thesis, however, the primary aim was to test factors which could enact behaviour change rather than theoretically explore why the change may or may not have occurred. Therefore, the theoretical lenses that contributed to the construction of the research projects in this thesis included:

- Classical Grounded Theory (Glaser & Strauss 2008 (1967)) to identify from the participants themselves reasons for completing or not completing ADs to enhance theoretical development of results gained by Bradley (2012) in a Master of Research thesis
- The Transtheoretical Model of Behaviour Change (Prochaska & Velicer 1997) to understand how the contemplative stage of behaviour of those considering ADs might be changed to an action phase
- Knowledge Translation theories (Grol et al. 2007) to understand the way in which knowledge on ADs may be interpreted and translated to meet a designated outcome; and
- Consideration of epidemiological approaches for assessing use of ADs and the online environment by South Australians.

A brief explanation follows of how each of these theoretical perspectives assisted in the creation of the research projects described in this thesis.

Classical Grounded Theory (CGT)

Classical Grounded Theory (CGT) posits that to generate new theory about a phenomenon under investigation, the phenomenon needs to be investigated from the “ground up” without any influence from other theoretical perspectives during the time of data collection and analysis (Glaser & Strauss 2008 (1967)). The definitive

outcome from a CGT study is to define the basic social psychological process (BSPP) that explains the phenomenon under investigation.

The basic social psychological process of SA Baby Boomers in relation to completion of ADs as described in the CGT study by Bradley (2012) was that of contemplation. Contemplating the creation of ADs involved three stages: contemplating knowledge and experience of people who did or did not complete ADs and the consequences of that decision-making; contemplating relationships and the choice of substitute decision-maker (SDM); and finally, contemplating actions or inactions to take with regard to completing ADs, such as timeliness, accessibility, and communication (Bradley 2012).

Based on the results of this research, a preliminary theory was developed that SA Baby Boomers would be prepared or ready to engage in AD completion when all of the right variables were in place: 1) they had experience and knowledge of ADs; 2) knew who to choose as their SDM; and 3) had access to, and completion of forms in a readily available format. As I could not, as a researcher, influence experience of ADs or choice of SDM, this thesis was formulated to test the third element, that is, whether access, communication and timeliness of information on ADs could enhance completion rates. By testing this aspect with a different group of SA Baby Boomers from my original study (Bradley 2012), I could advance and test my preliminary BSPP of contemplation for its applicability to all members of the designated group (SA Baby Boomers) informing another step in the Classical Grounded Theory process of experimentation and development of middle-range theory (Glaser & Strauss 2008 (1967)).

Transtheoretical Model (TTM)

Once the choice of which element to test from my preliminary theory on SA Baby Boomer AD behaviour had been made, I used the Transtheoretical Model (TTM) of Stages of Behaviour Change to provide guidance on the factors that might influence transition from contemplation to action with regard to AD completions.

The Transtheoretical Model was developed from competing theories of psychotherapy and behaviour change (Prochaska, DiClemente & Norcross 1992, Prochaska & Velicer 1997). Stages of behaviour change represent the temporal dimensions of change over time such that social and psychological factors influencing change can be identified and incorporated into the temporal (Glaser 1978; Glaser & Strauss 2008 (1967)).

In Figure 1.1 (replicated from Prochaska & Velicer 1997, p. 43) the stages of change describe the psychological processes that underpin each stage of change.

Transtheoretical Model (TTM) Stages of Change					
	Pre-contemplation	Contemplation	Preparation	Action	Maintenance
Processes	Consciousness raising Dramatic relief Environmental reevaluation	Self-reevaluation	Self-liberation	Contingency management Helping relationship Counter conditioning Stimulus control	

Figure 1.1: Stages of Change – Transtheoretical Model (TTM)

Prochaska and Velicer (1997) identified that: “behaviour change is a process that unfolds over time through a sequence of stages ... without planned interventions populations will remain stuck in the early stages and that specific processes and principles of change need to be applied at specific stages if progress through stages is to occur” (p. 41).

For the purpose of this PhD thesis research, the elements involved in the behaviour stages identified by Prochaska and Velicer (1997) of Contemplation through to Action were considered in the design of Project 3. The elements considered were the following: when a person reaches the stage of **Contemplation** (intending to change in next six months), they are generally aware of pros and cons and consequences of their behaviour (self-re-evaluation) such that in the **Preparation Stage** (intending to take action in immediate future, usually 30 days), they usually have a plan of action and are most receptive to health promotion strategies at this stage (self-liberation). Therefore, using CareSearch resources, the design of Project 3 focused on providing information in the form of computer-based, interactive online mechanisms (stimulus control and helping relationship) such that participants, specifically SA Baby Boomers, could advance to the next stage of behaviour, the **Action Stage** in which specific changes to behaviour occur within six months of a person who has been in the Contemplation stage entering the Preparation stage and usually seeking only one outcome, such as a completed AD.

Knowledge Translation (KT)

To determine the mechanism that could be most effective for acceleration from the Contemplation to the Action stage for participants in Project 3, a third theoretical model influential in the research design of this thesis was that of knowledge translation (KT). Knowledge translation theories encompass theories that create understanding about how knowledge occurs, how it is interpreted or translated, the best methods for translating knowledge and the anticipated outcomes that should be expected (Straus, Tetroe & Graham 2011).

Different models of cognitive, educational, motivational and communicative strategies of KT were explored. These included but were not limited to behaviour and motivation models such as the Theory of Planned Behavior by Ajzen (1991 cited in Grol et al. 2007, p. 109), and Self-efficacy theory by Bandura (1986, cited in Grol et al. 2007, p. 109) both of which are often used in the area of health promotion to measure behaviour change benefits from healthcare knowledge and promotion. These theories concentrate on determining the individual's motivation and ability to change based on internal and external foci of control and look for norms, attitudes and social beliefs influencing motivation and ability to change. As it is important to consider not just the change in behaviour but also the justification for the change, some elements of Project 3 in the thesis explored why people did or did not choose to complete ADs, but this exploration was not the primary concern of this thesis so has been done as a secondary analysis only.

Theories of KT centring on communication were also important to consider as there are multiple components to communicating a healthcare message. These components include persuasion-communication models which consider the exposure to a message, attention to that message, comprehension of the arguments and conclusions, acceptance of the arguments, and retention of the content such that attitudes are changed (McGuire 1985 cited in Grol et al. 2007, p. 110). In addition, the adoption of new ideas and technologies may also influence communication of information (Rogers 1995 cited in Grol et al. 2007, p. 112).

Epidemiology

Based upon the preceding theoretical perspectives, the design of the research of Projects 2 and 3 in this thesis were discussed with an epidemiologist. Epidemiology is a multi-disciplinary science combining medicine, social science, health science and statistics to not only describe and identify causes of disease but also to provide

data for the management, evaluation and planning of healthcare services (Australian Epidemiology Association (AEA) 2015). Epidemiology uses rigorous methodological statistics and theory to validate observed phenomena (Field 2011). Using the services of an epidemiologist for Projects 2 and 3 assisted with survey construction and data analysis such that specific questions could be designed to assess elements of engagement with ADs and the online environment as well as identify any sociodemographic factors that might explain any differences seen. Validating the results of survey analysis in Projects 2 and 3 with the epidemiologist ensured that observed phenomena would be reported correctly without misidentification of causality or association and ensure rigour and validation of the phenomena seen.

Methods used to conduct the three thesis projects

Having considered the theoretical perspectives previously described, this thesis used three methods of data collection to answer the overall research question posed in this thesis. In Project 1 a systematic literature review was designed to evaluate research studies that used electronic or computer-based interventions to facilitate AD completions. The literature review was conducted with the assistance of CareSearch for development and application of the search strategy.

Project 2 used the South Australian Health Omnibus Survey conducted by Harrison Health Research, a population-based epidemiological survey, to explore current levels of computer and online use and AD engagement by South Australians. A sub-analysis of these results looked specifically at online use and AD engagement with the age cohort encompassing the Baby Boomers. The survey enabled additional analysis of sociodemographic characteristics of those who did or did not use ADs as well as sociodemographic characteristics of those who did or did not prefer to use computer-based, interactive online means for facilitating AD knowledge and completion.

For Project 3, a randomised controlled trial was used to test two computer-based, interactive online mechanisms developed for facilitating completion of ADs. The two mechanisms tested were a computer-based, interactive online AD education module and email prompts for completing ADs. The Research Data Management System of CareSearch enabled the creation of online surveys, the online education module, email prompts, and data collection.

Overview of chapters in the thesis

The chapters in this thesis have been constructed as follows:

1. Chapter 1 is an Introduction to this thesis and incorporates an overview of the literature on ADs, Baby Boomers and the use of ADs in the online environment.
2. Chapter 2 provides a systematic literature review on the effectiveness of computer-based, interactive online AD models for enhancing completion rates of ADs.
3. Chapter 3 describes the development and results of the Health Omnibus Survey exploring AD and online use by South Australians and SA Baby Boomers.
4. Chapter 4 describes the development and results of a randomised controlled trial testing two computer-based, online interventions for increasing completion of ADs in a group of SA Baby Boomers.
5. Chapter 5 discusses the implications of the research conducted as well as limitations of the research and project outcomes and how this evidence compares with what is known in the literature. This chapter also includes future considerations for palliative care, CareSearch and AD research based on the research results from this thesis.

Chapter conclusion

This chapter has provided a brief overview of the purpose and conduct of the research in this PhD thesis. It has also described the theoretical underpinning influencing the research in this thesis as well as, briefly, the methodology of the projects and, finally, the chapters that constitute this thesis. The next chapter describes the literature review conducted to support the aims and methods of this thesis.

CHAPTER 2 – PROJECT 1 – A SYSTEMATIC REVIEW OF THE EFFECTIVENESS OF COMPUTER-BASED, INTERACTIVE ONLINE METHODS FOR FACILITATING ADVANCE DIRECTIVE COMPLETION

Introduction

The objective of this systematic review was to identify, appraise and summarise the research that has been published about computer-based, interactive online mechanisms which have AD completion rates as a nominated outcome. Learning about the different methods of computer-based, interactive online mechanisms used to enhance AD completion rates identified the barriers and facilitators to AD completion. The systematic review also provides data that may assist in answering the research question, e.g. the type of participants researched and any generational differences that might have been seen and could be relevant to the Baby Boomer generation.

In preliminary background research on this subject, a number of systematic reviews looking at the effectiveness of various measures to increase AD completions were found (Bravo, Dubois & Wagneur 2008, Jezewski, et al. 2007, Patel, Sinuff & Cook 2004, Ramsaroop, Reid & Adelman 2007, Rosnick & Reynolds 2003, Tamayo-Velazquez, et al., 2010 Wilkinson, et al. 2007). These reviews revealed that there was great heterogeneity in the research design of most of the studies highlighted in the reviews. Research design parameters involved in this heterogeneity included: different sample sizes; groups with particular illnesses or, conversely, were healthy; a variety of age ranges; a variety of settings; and a variety of AD instruments. Such heterogeneity in research design makes it difficult to compare directly the effectiveness of any particular format or intervention for increasing AD completion rates.

For example, in Bravo, Dubois and Wagneur's (2008) meta-analysis of research studies on the effectiveness of interventions to promote ADs, they found that fewer than 7% of the studies reviewed had a sample size of 500 or more participants. Participants in those studies encompassed an age range from 44 to 90 years old with no distinction made between generations. Participants also had a variety of disease states with only 13% of the studies reviewed looking at non-clinical populations (Bravo, Dubois & Wagneur 2008). The interventions tested included oral material, written material, forms and assistance with forms or combinations thereof

and the majority of studies were from the United States, United Kingdom, or other Anglo-Saxon dominated countries.

Tamayo-Velazquez et al. (2010) conducted an overview of the systematic reviews of interventions increasing AD completion rates. In this overview, the intent was to identify whether the systematic reviews themselves had homogeneity. Tamayo-Velazquez et al. (2010) found consistency in the outcomes of the systematic reviews, for example that multiple interventions consisting of an interactive component with personal or follow-up assistance were most effective for increasing rates of completion of ADs whilst passive mechanisms, such as provision of knowledge of ADs through any mechanism without individual support or guidance, were least effective. What all of the systematic review authors strongly encouraged for future research on this subject was the provision of detailed descriptions of the content, format and frequency of interventions used so they could be replicated by others (Patel, Sinuff & Cook 2004 cited in Tamayo-Velazquez et al. 2010, p. 17).

Aim and significance

This preliminary background research also found that since The SUPPORT study (1995) there have been a number of trials conducted using computer-based, interactive online mechanisms to facilitate AD completions. Measurement of the effectiveness of these mechanisms for AD completions was however less clear. Therefore, this systematic review sought to undertake the advice of Patel, Sinuff & Cook (2004) to identify those research articles which clearly articulated the mechanism of their interventions such that direct effects of any given intervention, in this case for completion of ADs, were measured and could be assessed objectively. The evidence generated from this systematic review was used for the development of Projects 2 and 3 in this thesis.

The significance of this systematic review is that the resultant evidence has eliminated those studies whose primary outcome involved ethical, legal or other philosophical arguments about ADs that often obfuscates empirical aims of measuring effectiveness. It also eliminated those studies whose primary outcome was to measure the satisfaction or dissatisfaction of people using the intervention rather than actual AD completion rates.

Objectives of this Systematic Review

The purpose of this systematic review was to clarify, appraise and summarise

methodically and rigorously the evidence to answer one aspect of the research question posed in this thesis; that is, the best computer-based, interactive online method for enhancing AD completion rates.

The objectives of this systematic review were therefore to:

- classify the types of computer-based, interactive online interventions used to actuate completion of ADs
- identify the completion rates of ADs for each of the types of interventions mentioned
- describe the methods used to assess the rates of completion of ADs
- identify the barriers or facilitators for completing ADs in the computer-based, interactive online environment within the interventions described; and,
- verify through randomised controlled trials, controlled trials, individual evaluation studies and meta-analyses the most effective computer-based, interactive online method for actuating completion of ADs.

Method used for conducting this Systematic Review

This systematic review evaluated randomised controlled trials, controlled trials, individual evaluation studies as well as any meta-analyses for computer-based, interactive online interventions that have facilitated AD completion as measured by AD completion rates. Focusing on trials, evaluation studies and meta-analyses offered the availability of the highest level of original research data to understand objectively measures of effectiveness and factors associated with the effect. Other systematic reviews have been excluded as they represent secondary analysis of data and do not provide original research data.

Search strategy

The search strategy was developed and conducted with the assistance of an expert librarian employed by CareSearch, Ms Sarah Hayman. The full search strategy is available in Appendix 2.1.

In the first instance, without limiting the type of online mechanism used, the search was conducted as sensitively as possible to capture all types of computer-based, interactive online mechanisms. Within the search strategy, terms chosen for the search were broadened or narrowed depending on the capability of the database to address the terms required.

Secondly, in addition to retrieving all articles relating to *advance directives in an online environment*, a second search was conducted within the same databases for English language articles on *online completion of advance care directives*. All database strategies used a combination of database-specific subject headings (such as MeSH in PubMed and Medline) and natural language terms, truncated if necessary. Search terms included: “electronic”, “online”, “web”, “Internet”, “telehealth”, “social media”, “computerized electronic record” and variations thereof to describe the online environment. Terms such as “proxy”, “living will”, “advance directive”, “durable power of attorney”, “guardianship”, “Ulysses contract” and variations thereof were used for advance directive. Throughout the search process, all authors reviewed the search strategy to make sure that the desired parameters were captured.

The search was conducted throughout the months of June 2013 to January 2014. Studies sought included randomised and controlled trials, individual evaluation studies and meta-analyses both qualitative and quantitative. Only those studies investigating adults aged 18 or older and published between the years of 1960 to 1 January 2013 were included for this review. Online platforms in the search strategy included those such as video, email, website, telehealth and others as defined in Appendix 2.1. Finally, articles searched must have described the evaluation methods including the process, mechanism and outcomes or reported effects.

Databases used for the search included: Ovid SP Medline (1946–2013), Scopus (including Embase records), PsycINFO (1806–2013), Joanna Briggs Institute EBP Database (JBI via Ovid), Cochrane Library, PubMed, CINAHL (1982–2013), Ageline, and Informit. Searches were also undertaken in the grey literature using databases such as Google Scholar, Science Direct, Australian Policy Online and Google to ensure that the search was as comprehensive as possible. Hand searching of reference lists was also conducted.

Selection of studies

Articles retrieved were restricted to English language literature as finances were limited for translation. Articles needed to show provision of the ability to complete an AD in the computer-based, interactive online environment or have a mechanism for monitoring completion of ADs after exposure to such content.

Inclusion and exclusion criteria

Figure 2.1 illustrates the criteria used to identify articles for inclusion and exclusion.

Systematic Review Inclusion and Exclusion Criteria
Include IF (must have all 4):
1= research study #
2= computer-based, interactive online *
3= about advance directives #
4= specifies completion rates [^]
RCT, controlled trial, evaluation
* excludes videos, CDs, DVDs if no interactive capacity (just played to the person)
any document referred to as an AD, e.g. Living Will, EPG, etc.
[^] completion rates refer to completed documents, not just recorded discussion
Exclude IF (any one of the 5 is missing):
1= not a research study #
2= not computer-based, interactive online *
3= does not deal with advance directives #
4= does not mention completion rates [^]
5= article unavailable
RCT, controlled trial, evaluation
* excludes videos, CDs, DVDs if no interactive capacity (just played to the person)
any document referred to as an AD, e.g. Living Will, EPG, etc.
[^] completion rates refer to completed documents, not just recorded discussion

Figure 2.1: Article inclusion and exclusion criteria

Essential criteria addressed when considering whether or not to include an article were as follows:

- Did the study mention completion rates of ADs as a primary outcome?
- Did the study define the computer-based, interactive online format?
- Did the study link the effect of the computer-based, interactive online format to AD completion?
- Did the study synthesise the results in a quantitative manner?

To be included, articles must have had all four of the inclusion criteria present.

Educational resources were included as long as there was an interactive component

that led to completion of ADs.

Exclusion of articles was based on the article having any one of five exclusion criteria:

- a) Interventions using videos, whether online, CD/DVD or in a television-type setting providing static content which did not provide the ability to complete an AD as a result of seeing the video. These articles were excluded as they could not provide a direct link between the online activity and AD completion.
- b) Articles where the intervention was computer-based but where written or oral material or assistance prior to computer use was part of the intervention. These articles were excluded as there was inconclusive evidence of the computer-based, interactive online activity being responsible for AD completion.
- c) If the measurement of effectiveness focused on increased rates of discussion of ADs by healthcare clinicians or the measurement was designed primarily to facilitate online education of healthcare clinicians to conduct AD discussions. These articles were excluded because the recording of a discussion by a healthcare professional does not equate to legally prepared instructions by an individual, e.g. completing an AD that is required to be followed by another healthcare professional at a time of crisis care. However, if a DNR order was obtained as a result of the discussion and the mechanism of initiating the discussion was a computer-based, interactive online mechanism then this counted as a completed AD based on the use of a computer-based, interactive online intervention to facilitate a completed AD, e.g. the DNR order.
- d) AD completion rates not mentioned at all. These articles were excluded because they did not provide direct evidence of AD completion rates.
- e) Article not available. These included articles that may have been commercial-in-confidence or not accessible through university library resources.

Screening

In the first instance, the title, abstract and keywords of all citations fitting the above search criteria were screened. When it was not possible to determine if a study measured the effect of a computer-based, interactive online intervention with completion rates of ADs by referring to title and abstract alone, the full article was retrieved. To determine that screening was rigorously applied, a sample of 60

retrieved abstracts was independently assessed by an expert at CareSearch (Director of CareSearch, Associate Professor Jennifer Tieman) against exclusion criteria for reliability of screening. This assessment yielded 100% inter-rater reliability such that there was confidence that the inclusion and exclusion criteria could identify appropriate titles for consideration.

A second level of screening was conducted for retrieved full articles meeting abstract inclusion criteria. In this screening, the 60 retrieved articles were dual peer-reviewed by myself and Dr Tieman to determine whether studies met all of the criteria for inclusion and to eliminate those that did not. At the conclusion of the discussion, there was 100% agreement on the final list of articles to be critiqued and included in the systematic review.

Data extraction

Data extraction was based on a structured form previously used and published by Tieman and Bradley (2013) (Appendix 2.2). This form provided a focus for extracting data directly linked to the computer-based, interactive online mechanisms such that assessment of the effectiveness of the online interventions against AD completion could be undertaken.

The data extraction form consisted of basic elements of reporting such as: author, names and web addresses of online resources as well as categories for website type; measurement focus; stage of development; and evaluation emphasis (Tieman and Bradley 2013). For this review, an additional category *completion rate of ADs pre and post intervention* was also included for assessment of whether the online resource actually measured AD completion rates.

Results

Figure 2.2 is a flow chart of retrievals, exclusions and final studies included in this systematic review and has been designed based on the PRISMA statement guidelines.

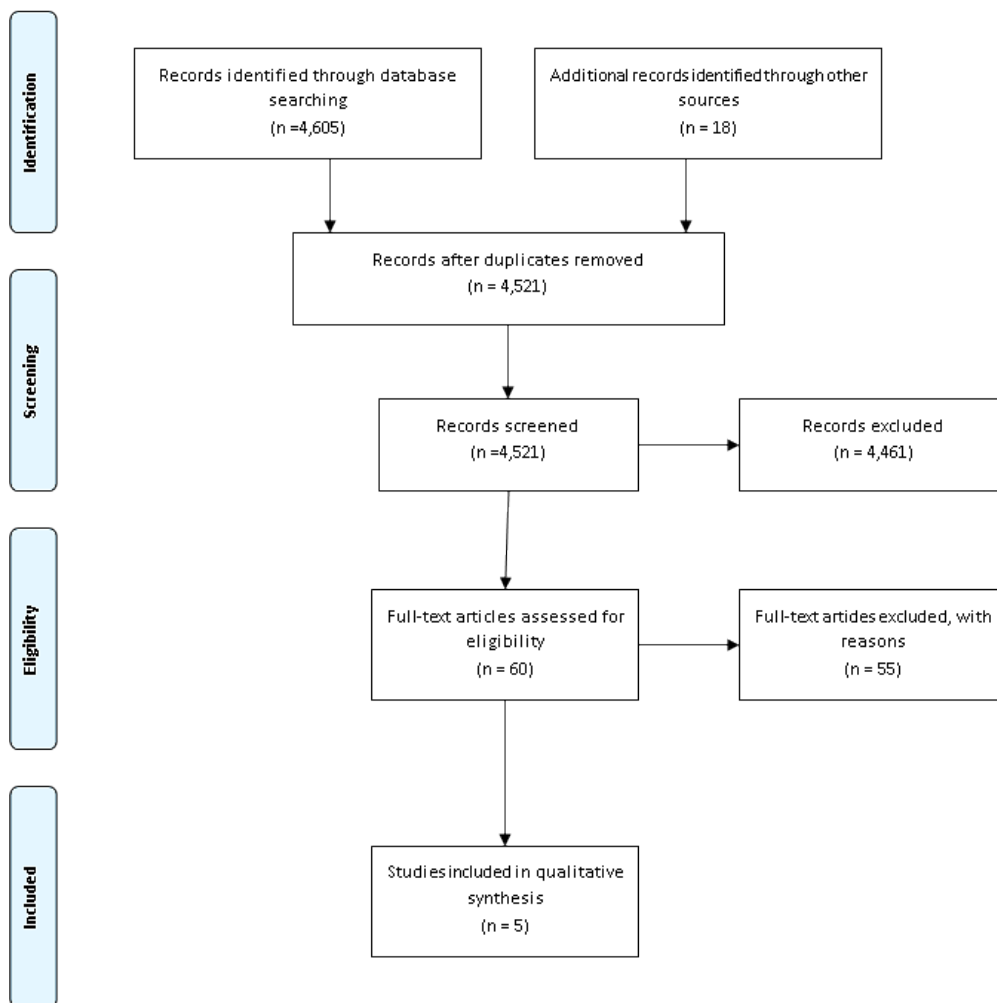


Figure 2.2: Flow chart of retrievals and excluded or included articles

A total of 4605 abstracts were initially retrieved via the search strategy. Assessment against title and abstract excluded the bulk of the abstracts. Duplicate abstracts were removed and articles found from reference list searches were added. This led to a total of 60 articles for assessment against all elements of the inclusion criteria.

From the 60 articles retrieved, 55 papers did not meet all four elements of the inclusion criteria. Appendix 2.3 describes the papers excluded and detailed reasons for their exclusion.

Of the excluded articles, one paper (Hickman et al. 2014) was published outside of the time period allowed. Nine papers (Barry 2002, Bose-Brill & Pressler 2012, Bricker, Lambing & Markey 2003, Caligtan & Dykes 2011, Lam 2012, Levi et al. 2010, McBride 2010, McCann et al. 1998 and Peto et al. 2004) described processes and development of tools with AD completion as part of the process, not as an outcome of the intervention. Fifteen papers (Beck et al. 2002, Betz-Brown et al. 1999, Cohen-Mansfield, Libin & Lipson 2003, Cugliari, Sobal & Miller 1999, Ditto &

Hawkins 2005, Durbin 2007, Epstein et al. 2013, Fagerlin et al. 2002, Finucane et al. 1988, Heffner et al. 1998, Ho et al. 2000, Kohut, Keeter & Doherty 2006, Mercer, Chirigoga & Sweeney 1997, Rucker et al. 2008, and Terry & Zweig 1994) did not have computer-based, interactive online interventions that actuated a completed AD. In some cases, such as Ho et al. (2000), the online intervention was accompanied by a questionnaire and hard copy or online access to a Living Will. However, there was a time delay in the measurement of completed ADs such that other factors may have influenced the completion of the AD apart from the educational video or online Living Will, thus mitigating any interactive, online effect with the educational video.

A further seven articles (Clark 2002, Frosch, Kaplan & Felitti 2003, Jain & Kahn 1995, McConatha, McConatha & Dermigny 1994, Morgan et al. 2000, Tulskey et al. 2011, and van Uden-Kraan et al. 2009) were excluded as they did not directly deal with ADs but rather other elements of advance care decision-making. For example, Clark's (2002) study was ethnographic in nature and collected information on social and emotional loneliness, computer skills and experience but not AD completions.

Finally, 23 articles (Barnato & Arnold 2013, Deep et al. 2010, Green & Levi 2009, Johnson-Greene et al. 1996, Levi, Heverley & Green 2011, Levi et al. 2013, Mamlin, Gramelspacher & Tierney 1996, Murphy, Sweeney & Chiriboga 2000, Olszewski et al. 2012, Reinke et al. 2011, Schubart et al. 2012, Sherman 1998, Siegert et al. 1996, Srebnik, Appelbaum & Russo 2004, Sulmasy & Marx 1997, Volandes 2007, 2008, 2009, 2010, 2012a, 2012b, Wilson et al. 2013 and Yamada et al. 1999) were excluded because they did not directly quantify completion rates of ADs as a primary outcome of the intervention. In some studies, such as those of Schubart et al. 2012, AD completion had already been done by the majority of participants prior to the intervention; therefore AD completion was actually part of the process of exploring reliability of information, rather than completion of ADs.

The Volandes articles (2007–10 and 2012 a and b) often described a variety of measured outcomes such as specific AD choices as a result of viewing videos of different healthcare states, but did not measure before and after completion rates of ADs such that a direct correlation could be made to the viewing of the video intervention. The inclusion criterion of direct measurement of AD completion rates as a primary outcome of the intervention was the key to identifying the final five articles (Dexter et al. 1998, Hossler et al. 2011, Klugman & Usatine 2012, Murphy, et al. 1997 and O'Carroll et al. 2011) critiqued for effectiveness of a computer-

based, interactive online intervention to facilitate AD completions.

General characteristics of the included studies

When critiquing the five studies, two Critical Appraisal Skills Programme (CASP, 2010a, 2010b) checklists were used to guide the critique, one for trials and one for cohort studies. Table 2.1 presents a list of the characteristics of the general and specific elements of each article that predicated their inclusion in the SR. Tables 2.2 and 2.3 provide more detailed analysis

Table 2.1: General and specific elements of inclusion and essential criteria

Dexter et al. 1998	<ul style="list-style-type: none"> • Country of study: USA • Participant group and setting: General Medicine Practice affiliated with an urban public teaching hospital. Participants included 1009 patients 75+ or those 50+ with serious underlying disease; 147 primary care physicians • Mean age: 64.6 +/- 9.8 years • percentage of males in study: 35% • Disease or practice categories mentioned as part of the study demographics: coronary artery disease, chronic obstructive lung disease, congestive heart failure, previous stroke, cancer, renal insufficiency, liver disease • Primary and other targets: primary = physicians; secondary = patients • Aim: increase AD discussions • Online intervention: computer-generated reminders recommending discussion of one or both types of ADs (instructional or proxy) compared with control group of no reminders • Primary outcome: Increase in AD discussions and recording of completed ADs received between enrolment in study and 30 days after final interview • Number with completed ADs pre-intervention = 4% • Number of ADs completed post-intervention = 3% in Proxy AD group; 7% in Instruction AD group; 15% across both groups; 4% in control group. Overall, from 1009 participants approximately 81 people completed ADs (completion rate of 8% overall) as a result of physician reminders. • Follow-up: ranged from 5 months after initial visit to 16 months after enrolment
Hossler et al. 2011	<ul style="list-style-type: none"> • Country of study: USA • Participant group and setting: one medical centre; participants with amyotrophic lateral sclerosis • Mean age: 60, range 44–86 • percentage of males in study: 59% • Disease or practice categories mentioned as part of the study demographics: amyotrophic lateral sclerosis (ALS) • Primary and other targets: primary = patients • Aim: pilot study to establish whether the computer-based decision aid called Make Your Wishes Known is user-

	<p>friendly for people with ALS (feasibility study)</p> <ul style="list-style-type: none"> • Online intervention: computer-based, interactive online decision aid called Make Your Wishes Known. • Primary outcome: completed ADs • Number with completed ADs pre- intervention = 12/17 (71%) • Number of ADs completed post-intervention = 17/17 (100%) • Follow-up: immediate
Klugman & Usatine 2012	<ul style="list-style-type: none"> • Country of study: USA • Participant group and setting: general public, two different online websites • Mean age: no information provided • percentage of males in study: No information provided • Disease or practice categories mentioned as part of the study demographics: No information provided • Primary and other targets: primary = general public • Aim: study to establish whether the Nevada Living Will (NVLW) website and the Texas Living Will (TLW) website are effective for assisting people to complete ADs (evaluation study) • Online intervention: websites that provide education, end-of-life AD forms, and other ACP guides and directives which when completed can be made into pdf documents for printing, signing, witnessing and notarization and can then be stored online • Primary outcome: variety of assessments including completion of AD • Number with completed ADs pre-intervention = no information provided • Number of ADs completed post-intervention = For NVLW there were 1800 accounts created in 1 year with 102 evaluations completed and 92 AD completions based on the question “why did you complete an AD”? This equates to 5% of those who created accounts and answered evaluation. For TLW there were 5002 accounts created in 3 years with 296 evaluations completed and 280 AD completions based on the response to the question “why did you complete an AD”? This equates to 6% of those who created accounts and answered evaluation • Follow-up: 1 and 3 years

Murphy et al. 1997	<ul style="list-style-type: none"> • Country of study: USA • Participant group and setting: veterans, Salt Lake City Medical Centre, 9980 possible participants • Mean age: no information provided • percentage of males in study: no information provided • Disease or practice categories mentioned as part of the study demographics: No information provided • Primary and other targets: primary = admitting clerks; secondary target = doctors and social workers; tertiary target = patients • Aim: lodgment of AD on computerized electronic medical record (evaluation study) • Online intervention: intranet computer of VA Hospital system, electronic prompt called Advance Directive Query completed by admitting clerks, referred to physicians and social workers for assistance with ADs • Primary outcome: either completed ADs or requests to complete ADs • Number with completed ADs pre-intervention = no information • Number of ADs completed post-intervention = 1150 from 9980 possible (11.5%) • Follow-up: 2 years
O'Carroll et al. 2011	<ul style="list-style-type: none"> • Country of study: UK • Participant group and setting: Healthy adult members of the general public accessed through social networking sites, university health psychology departments and workplaces • Mean age: 28.24, range 16–68 • percentage of males in study: 26% in AR group; 42% in other 2 groups. • Disease or practice categories mentioned as part of the study demographics: organ donor registration • Primary and other targets: primary = general public • Aim: randomised controlled trial to test manipulation theory (Theory of Planned Behaviour and Theory of Anticipated Regret) to increase organ donor registration • Online intervention: online website holding 3 different online questionnaires with links to the UK organ donation website. • Primary outcome: increased organ donor registration (for this study organ donor registration is seen to be an

	<p>advance directive as it provides instructions for future healthcare preferences)</p> <ul style="list-style-type: none">• Number with completed ADs pre-intervention = 28% of UK public are organ donors. Participants to this study could only be included if they had not yet registered as an organ donor• Number of ADs completed post-intervention = 12.9% of control group (no questions relating to TPB or AR); 8.5% of TPB group; 20.7% of AR group self-reported organ donor registration• Follow-up: 1 month
--	--

Table 2.2: Patient and study demographics

Author (Yr of Publication)	Number of Participants	Mean Age (where stated and in different groups)	Males %	Illness	Intervention setting	Follow-up (months)
Dexter et al. (1998)	1009 patients 147 primary care physicians	All Groups 65 +/- 10 years	35%	Coronary artery disease Chronic obstructive lung disease Congestive heart failure Previous stroke Cancer Renal insufficiency Liver disease	General Medicine Practice	Ranged from 5 months after initial visit to 16 months after enrolment
Hossler et al. (2011)	17 patients	60, range 44–86 years	59%	Amyotrophic Lateral Sclerosis	Medical Centre	Immediate
Klugman & Usatine (2012)	Doesn't say – estimate of 1800 for NVLW Estimate of 5002 for TLW	No information	No information	No information	Websites	1 year for NVLW 3 years for TLW
Murphy, et al. (1997)	9980 possible	No information	No information	No information	VA Hospital	2 years
O'Carroll, et al. (2011)	372 possible/ 286 eligible	28, range 16–68 years	26% in AR group 42% in other two groups	No illness – specifically for organ donation registration intention	Online invitation through social networking sites, university health psychology departments throughout UK and workplaces	1 month

Table 2.3: Articles meeting review inclusion criteria

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
Dexter et al. 1998	US	Annals of Internal Medicine Vol. 128	General Medicine Practice affiliated with an urban public teaching hospital 1009 patients 75+ or those 50+ with serious underlying disease – both groups at risk for acute deterioration due to advanced age or illness 147 primary care physicians (108 house staff, 39 faculty) a. Control group b. Computer-generated reminder for instruction doc c. Computer-generated reminder for proxy doc d. Computer-generated reminder for both	Primary target – physicians Secondary target – patients	Computer-generated reminders recommending discussion of one or both of 2 types of ADs compared with no reminders Instruction directives called ADs Proxy directives called healthcare representative documents	Intranet	Recruitment interviews asked if participants had already completed ADs – those who had were excluded. ADs = 2 separate forms (instruction directive and proxy directive). Forms were placed throughout practice and reception areas. Before study, the 3 physician-investigators discussed at grand rounds, + face-to-face explaining how to complete and process forms, encouraged to discuss ADs. Posted flyers in staff room. AD reminders followed by a choice list: a. discussed today b. next visit c. not applicable d. patient too ill e. patient refuses to discuss f. I disagree with ADs.	Discussions in notes. Completed AD forms received between enrolment and 30 days after final interview.	Sequence as follows: Participants – pt identified at risk, physician provided with computer-generated reminder at bottom of printed out patient detail sheet, if discussion had, noted in e-record. If patient then picked up form and completed, handed in to research assistant – entered completed AD into computer system. Forms then available for viewing through intranet patient record system.	Total of 1394 potential/ 1190 eligible/ 1042 enrolled. Physicians changed categories depending on number of sessions they were conducting. Excluded 3 patients because of these changes. Final results based on 1009 patients. Roughly 250 patients in each group. Physicians who had both reminders had patients who completed more forms (24%) than other groups. Physicians with 1 reminder had 14% completion rates for instructive and 8% completion rates for proxy – all over Control group.	Physicians or patients preference to discuss instructive AD reminders over proxy ones. Younger age patients would not be engaged in discussion unless they had a medical risk. Conducted in inner-city practice with poor and minority patients which may have influenced low rate of AD discussions, thus low rate of AD completions.	Intervention (reminder) was delivered during regularly scheduled primary care visits. Physicians with reminders had more discussions of ADs than physicians without reminders and this led to more completed ADs. Storage of completed ADs in online system accessible to all HCPs in health system. Long history of using computer reminders for primary care, e.g. vaccination schedules – meant physicians were accustomed to reminders on patient forms.

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
										Overall out of 1009 participants, approximately 81 people completed ADs (completion rate of 8%).		
Hossler et al. 2011	USA	Amyotrophic Lateral Sclerosis Vol. 12	17 patients being treated for amyotrophic lateral sclerosis at Penn State Milton S Hershey Medical Centre Mean age 60, range (44–86)	Pilot study Primary target – patients	Interactive, computer based decision aid	MakingYourWishesKnown: Planning Your Medical Future	Pre-intervention: Demographics and subjective health assessment Self-determination scale adapted from Pellino Post-intervention Same self-determination scale Satisfaction with ACP scale Decisional conflict scale Satisfaction with decision scale Time and effort scale	Completed and printed copy of individualised AD from computer program.	Pilot study Patients navigated way through computer program. If they didn't have sufficient upper limb capacity, loved one operated computer mouse. Upon completion of program, participant received hard copy individualised AD.	From 17 participants, 2/3 had an AD and 80% had a SDM prior to intervention. 17/17 were able to complete pre-questionnaires and computer-based AD.	Emotionality during process may delay or impede completion. Limited objective data on program as pilot study designed to see if this particular disease group could use an automated system for AD consideration and completion Participants already had ADs so largely amenable to AD completion Participants purposely selected for study	Participants satisfied with how the program provided information, helped them clarify their values and wishes for medical treatment; helped them put the words into the form of an AD and prepared them to discuss wishes with others. All able to complete ADs with assistance if required (physical assistance). None perceived the program as burdensome. Found the program when done with loved ones provided opportunity to have discussions with loved ones that they may not have had. Made it easier to provide copies of

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
											Limited sample size Single university centre No data comparing those who declined participation in the study	ADs to their clinicians (clinicians recommended patients to the study).
Klugman & Usatine 2012	USA	American Journal of Hospice & Palliative Medicine Vol. 30, No.7	Online Whoever visited site from establishment to closure (NVLivingWill closed after 1 year) No age range or ages given	Primary target – individuals	Websites (2 different ones) that provide education, end-of-life forms (ADs), letter to loved ones, values inventory, tools for starting the conversation, and links to out-of-hospital do-not-resuscitate orders. Free – Internet Provided in several languages (English, Spanish, Tagalog) Produces a pdf file of a completed AD which	NVLivingWill.com http://NVLivingWill.com TexasLivingWill.org http://www.TexasLivingWill.org http://www.LivingWillLockbox.com App – TLW	Evaluation form	Advance directives located on both websites	Visitors to site given option to complete evaluation tool to document experience of web site and reasons for completing AD.	NVLW = 1800 accounts in 1 year resulting in 102 completed evaluations (doesn't say how many completed ADs). TLW – over 3 years 5002 unique accounts and 296 evaluations completed (again no information on ADs). Reading between the lines of the question "why did you complete an AD" it looks as though 92 people completed NVLW (although there could have	Only 14 HC providers signed up to Lockbox limiting efforts to evaluate useability. Lack of finances for maintenance The major barrier to this study is the design of the evaluation tool. It asks why people visited the sites and asks if they came "to complete, edit or print" an AD. There is no clear info on whether they actually completed AD.	Participants found the format easy, straightforward. Engagement with both websites varied depending on where the initial info came from: traditional printed media vs. Internet searches and web links. High response to the resource being "free".

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
					<p>then needs to be printed, signed, witnessed or notarised.</p> <p>ADs can also be stored within both sites with access provided to users and HCPs through password and username.</p> <p>TLW form has app that enables read-only version of AD.</p>					<p>been more who just didn't bother with the evaluation tool) and 280 completed the TLW.</p> <p>Too much Texas-specific language in TLW from those interstate who wanted to use the website to complete LW.</p> <p>Self-selection by participants means only those interested in ACP visiting site</p> <p>Language descriptors different between Nevada and Texas</p>		
Murphy, et al. 1997	USA	HEC Forum	267 bed VA Hospital in Salt Lake City	<p>Primary Target – Admitting Clerks in the hospital</p> <p>Secondary target – doctors and social workers</p> <p>Tertiary target – Patients</p>	Computer AD through electronic medical record	Intranet	<p>Educated Admitting Clerks on ADs.</p> <p>Clerks educated patients on ADs by asking them if they had one and if not, asking if they wished to complete via social worker involvement.</p>	Medical record indicating whether patients had completed AD (copy scanned if so) or requested assistance with AD (via prompt to admitting physician who then prompted social worker).	New electronic medical record had AD Query prompt. Admitting clerks asked each patient admitted if they had AD, if not, then note entered into medical record for physician to prompt social worker to discuss with those requesting assistance.	<p>August 1993-June 1995, 9980 patients admitted. Of these patients, 1289 (12.9%) referred to social workers for assistance with ADs.</p> <p>Of the 1289, 1150 patients (89.4% of those referred) completed directives.</p>	<p>In initial stages, barriers to AD completion included admitting physician not forwarding request for assistance to social worker. Major increase in workload for social workers.</p>	<p>Yellow card to admitting physician with prompts as to procedure for initiating social worker assistance for AD.</p> <p>Provision of Patient Handbook with AD info to each admitting patient.</p> <p>Group informational sessions for patients and staff in outpatient department.</p>

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
									<p>Other patients who did not have nor want assistance also recorded.</p> <p>Modification to method included giving patients yellow card to present to admitting physician on ward so admitting physician would make social worker request (as they had a high rate of not doing so just through electronic prompt).</p> <p>Yellow card then prompted physician to ask AD questions and answer queries, then refer to social worker if further assistance required.</p>			Electronic medical record provides a better method for tracking ADs and those requesting assistance with them.

Author, Date	Country of Study	Journal Published	Participant Group and Setting	Primary and Secondary Target	Online Intervention	Online URL	Additional Interventions	Measure used for AD completion	Method	Completion rates of ADs based on Intervention	Barriers to online intervention or limitations to research design	Facilitators for online intervention or strengths of research design
O'Carroll et al. 2011	UK	Health Psychology	Healthy adult members of the general public	Primary Target – General Public	3 groups given access to one of 3 questionnaires (Control, TPB-theory of planned behaviour, AR-anticipated regret) and link to UK organ donor website.	Online facilities included web-based info sheet on study which if participants agreed allowed participants to click on one of 3 web links associated with one of the questionnaires. The questionnaires contained a link to UK organ donor website. Then contacted by email 1 month later to complete another online questionnaire for follow-up.	None	Whether or participants had registered to become organ donor. The aim of this study was to manipulate behaviour via intention-inducing means, e.g. anticipated regret and elements of attitude, subjective norm and perceived control.	As described, participants allocated to one of 3 groups: Control, TPB group and AR group. All groups provided link to UK organ donation website at conclusion of questionnaire. One month later contacted by email to ascertain whether they had registered as organ donor.	Number of people who registered as organ donor. 12.9% of Control group, 8.5% of TPB group and 20.7% of AR group reported registering as organ donor. Found that AR mediated intention to register as organ donor.	Self-reported registrations – participants may have been “faking good”. Lack of true control. Lack of true randomisation as randomisation was modified if too many people chose same link. AR questionnaire may have been longer thus influencing more measured response and consideration to becoming donor.	Robust statistical design. Analysis of mediation effects with multiple tests. Acknowledgement that results are only significant as pilot study and require further studies with true randomisation and controls as well as equally matching questionnaires (for length).

Of the five studies critiqued, only two (Dexter et al. 1998, O'Carroll et al. 2011) were randomised controlled trials with a control group although in the case of O'Carroll et al. (2011) there was concern that the control group was not a "true" control as the researchers acknowledged that the control group received a questionnaire as "usual care" which could have influenced the way control participants behaved in the study. Three studies could be described as feasibility or evaluation studies (Hossler et al. 2011, Klugman & Usatine 2012, Murphy et al. 1997). Four of the studies were from the United States and one from the United Kingdom. The range of age of participants varied from 16 to 86 with two studies (Klugman & Usatine 2012, Murphy et al. 1997) having no information on age of participants. The number of participants ranged from 17 (Hossler et al. 2011) to 10,000 (Murphy et al. 1997). Intervention settings were most commonly in university medical centres with only Klugman and Usatine's (2012) websites being available to the general public through government funded resources.

The types of computer-based, interactive online interventions were of two specific types: electronic medical record prompting and recording of completed ADs (Dexter et al. 1998, Murphy et al. 1997); and websites or computer-based, interactive online formats with educational information on ADs, including online AD forms that could be completed and downloaded and/or stored (Hossler et al. 2011, Klugman & Usatine 2012, O'Carroll et al. 2011).

Only Klugman and Usatine's (2012) study and O'Carroll et al.'s (2011) study had no direct interaction with researchers reducing possible bias from non-online factors influencing completion rates. Nevertheless, it was still difficult to ascertain in Klugman and Usatine's (2012) study the exact rates of AD completions as the rates were not directly reported, nor did the study report how many of the people who completed the evaluation survey had ADs prior to engagement with the website. O'Carroll et al. (2011) noted that a limitation to their study was the self-reporting of organ donor registration as they did not have access to information regarding increases in the overall UK donor register during the time of the study. In the other studies, Hossler et al.'s (2011) participants had access to loved ones and researchers for assistance whilst in Dexter et al. (1998) and Murphy et al. (1997), clerical assistants and physicians were used to instigate discussions and completions of ADs. Although the influence of these face-to-face variables on the effectiveness of the computer-based, interactive online mechanism to actuate completed ADs was acknowledged, they nevertheless present an obfuscating factor

to the effectiveness of the computer-based, interactive online format to assist those who would not use or have face-to-face help.

Follow-up periods for assessing the effectiveness of the computer-based, interactive online mechanism to increase AD completions or other primary outcome objectives ranged from immediate (in the case of Hossler et al. 2011) up to three years (Klugman & Usatine 2011). The majority of studies (three out of five) mentioned disease or healthcare states of participants or targeted healthcare practices.

In summary, the systematic review identified five studies using computer-based, interactive online mechanisms and a measurement of AD completions. These studies identified two forms of computer-based, interactive online mechanisms that could effectively lead to an AD completion; those that provided information and allowed completion of an AD (Hossler et al. 2011, Klugman & Usatine 2011, O'Carroll et al. 2011) and those that prompted healthcare professionals to discuss or record AD instructions (Dexter et al. 1998, Murphy et al. 1997).

Discussion

A difficulty that arose in this review was narrowing the field of relevant articles to the intent of the research question because of the variety and format of online mechanisms described as well as the way that AD completions were measured.

Often what was described as an intervention was actually a process with AD completions occurring as part of the process rather than the intervention.

Nevertheless, as can be seen by the articles included, the most effective computer-based interactive online interventions followed two main pathways: e-medical records prompting physicians to discuss or record ADs (Dexter et al. 1998, Murphy et al. 1997); or computer-based, interactive online websites or decision aids that engaged the participant in answering questions, selection from an array of choices and eventuating in a completed AD that could be printed off for witnessing and signature (Hossler et al. 2011, Klugman & Usatine 2012, O'Carroll et al. 2011).

Determining the absolute and relative effectiveness of these two types of formats for actuating AD completions was hindered by four out of five studies (the exception being Klugman & Usatine 2012) which included additional supports or interventions that provided either guidance or AD knowledge to participants. The vast amount of literature in this area as detailed in Tamayo-Velasquez et al.'s (2010) review indicates that the most successful interventions, online or offline, for actuating AD

completions include some sort of face-to-face or guided assistance; yet, providing information prior to testing computer-based, interactive online formats may detract or obfuscate the effectiveness of the online format from other variables in the intervention. If information is provided prior to the testing of the use of the computer-based, interactive online mechanism then the resultant completed AD may be a function of the information received rather than the contents of the computer-based, interactive online format.

Only one study (Dexter et al. 1998) provided sufficient detail of the RCT components to assess the effectiveness of such a mechanism to enhance completion rates and it was the only study that had a control group and reported pre-AD completions (prior to intervention) and post-AD completions (after intervention). O'Carroll et al.'s study (2011) had a lack of true randomisation since the sample was self-selected and organ donor registrations were dependent on self-reporting and this was identified as a limitation of their study. In addition, the emphasis in O'Carroll et al.'s (2011) study was to manipulate behaviour to engender organ donation registration. Nevertheless, while their study used a peripheral measure of AD engagement, that is organ donation registration, it assessed the effect of online mechanisms to assist, engage and monitor participant activities for this phenomenon.

Three studies fell into the category of feasibility or evaluation of computer-based, interactive online interventions. The study by Hossler et al. (2011) was based on a decision aid created by Green and Levi (2009); however, because this study was testing the *Make Your Wishes Known* computer-based decision aid on a particular disease cohort in a terminal illness phase, many in the cohort already had ADs in place. Other publications testing *Make Your Wishes Known* were excluded from this review because they had additional interventions as part of the online component and/or many of the participants pre-selected already had ADs so the study outcome being researched was not for completion of ADs but rather factors associated with completion. Again, it was difficult to assess the effectiveness of the computer-based, interactive online component if these participants had already completed an AD, or completion of the AD is part of the process of exploring associated outcomes.

Many excluded studies failed to adequately report measures of completed ADs. When AD completions were described in the method, resultant AD completions were not always clearly identified in the results section, and if reported in the results section there was no clear pre-intervention measurement for comparison. For the five studies chosen for this review, an assessment could be made for both pre- and

post-intervention completion rates, albeit in the case of Klugman and Usatine (2012), this was by inference. This lack of precision in reporting completion rates creates confusion in determining the value of online interventions to facilitate AD completions in a stand-alone capacity.

It is possible that arguments made in the past by Teno, Hill and O'Connor (1994), Lynn, et al. (2000), and Fagerlin and Schneider (2004) against measuring completion rates as an indicator of the effectiveness of an AD intervention has inhibited researchers from clearly assessing this parameter as a primary outcome measure. However as Bradley (2012) and others (Abadir, Finucane & McNabney 2011, Ashby & Thornton 2011, Barnes et al. 2007) have since discovered, the contemplation involved prior to completing an AD takes place over a long period of time and includes assessing the knowledge, experience, timeliness and accessibility required to complete them - ingredients which few research studies measure at one time. Therefore, completion rates may still be a key indicator of the effectiveness of an intervention even if resultant increases in AD completions are lower than anticipated. Indeed measuring participation or rates of AD completion in the early stages of the intervention as well as completion rates afterwards may provide more direct and purposive evidence of the effectiveness of computer-based, interactive online systems to facilitate AD completions than just assessing satisfaction, useability or acceptance of the computer-based, interactive online format.

If AD completions are not measured rigorously, these computer-based, interactive online formats may not achieve the purpose for which they have ostensibly been designed (i.e. increasing AD completions). Not understanding the effectiveness of these formats to achieve AD completions could disadvantage those groups who are technology-literate, such as the Baby Boomer generation, and who might seek the use of computer-based, interactive online environments to facilitate AD completion.

This review has clearly identified that for those participant groups with a vested interest in having an AD due to disease or age, electronic medical recording of that AD is an effective means for measuring and assisting completion of ADs. For the general public however, and for the true purpose of an AD being created for times of crisis management, computer-based, interactive online formats which permit completion of an AD facilitated by online AD knowledge and/or storage may best suit this audience. Conclusive evidence of the most effective computer-based, interactive online mechanism for this latter audience still remains to be seen especially as "apps" and social networking sites are now playing a greater role in

storage and communication on this issue.

Designs of future studies should seek to isolate the effects of these other platforms and other means of accessing information on ADs, to ameliorate confusion of effects from these other measures with the computer-based, interactive mechanism being trialled. By doing so, this will create a real assessment of the effectiveness of the computer-based, interactive online format to actuate AD completion in an environment where the general public may be searching for websites randomly to assist them. The general public may not have preliminary experience, information or knowledge of ADs. Testing the effectiveness of websites with naïve subjects rather than previously informed ones more directly measures the behaviour change associated with the intervention. For true assessment of effectiveness, it is also necessary to have Pre- and Post-intervention AD completion rates known and, if possible, control groups without access to either information on ADs or other elements of the computer-based, interactive online format.

With an increasingly IT literate public who may want ease and accessibility for AD completions at a time that suits them, providing computer-based, interactive online formats that can be accessed prior to hospital engagement may provide a timely, important and sufficient platform for unassisted completion. Creating a continuum for access and knowledge of AD instructions through electronic medical recording of these ADs may assist family members, patients, and their clinicians in future care decision-making. The National Personal Electronic Healthcare Record in Australia (Australian Government Health Direct 2015) combines both websites and electronic medical recording to provide the public with a means for ensuring that their future healthcare and lifestyle decision-making will be respected, accessed and implemented through the online environment.

Limitations of this systematic review

The present systematic review has not included articles post January 2013 and there have been a number of articles released in the literature since then exploring computer-based, interactive online mechanisms for assisting AD completion rates (Butler et al. 2014, Capuro et al. 2014, Hickman et al. 2014, Sudore et al. 2014). This thesis did not continue the systematic review beyond January 2013 as the main purpose of this systematic review was to provide evidence for the types of mechanisms to test in the randomised controlled trial (Project 3) to be described in Chapter 4. This necessitated doing the systematic review first to allow for

completion of the other projects in a timely manner and have the mechanisms tested based on the best available evidence at the time. It is likely that for more advanced computer-based, interactive online mechanisms such as “apps” there may be more recent unpublished reports and conference presentations which have looked at the use of this mechanism and those in online social media which were not able to be accessed through this systematic review’s search strategy.

This review also excluded research using video representations to assist in choices to be made in ADs. Videos, as illustrated most recently in work by Volandes and colleagues (2007; 2008; 2009; 2010; 2012a and 2012b), are a useful tool for engaging people in contemplation of AD choices and decision-making, but the evidence is unclear on how these videos by themselves assist in actuating completion of ADs. This is because many of these studies provide educational materials on ADs to participants prior to the video viewing and do not consistently report Pre- and Post- completion rates of ADs.

This systematic review also did not include studies where the primary outcome was an increase in AD discussions. The recording of a discussion does not equate to a completed AD although it can facilitate decision-making in the absence of an AD or provide support for the decisions being made in the presence of an AD. Discussions are a very important part of advance care planning but may not be useful by themselves at the time of crisis care when ADs will be enacted because those who know what decisions should be made may not be accessible or available to voice those decisions at the time of need. Therefore, to be able to clearly ascertain the usefulness of ADs, it is essential that future research focus on the actual AD documents completed and their actual use at the time of need as well as what mechanisms assisted in the completion and implementation of the AD.

Chapter Conclusion

This systematic review has identified that two types of computer-based, interactive online formats seem to be effective for engaging and promoting AD completion. The first is that of prompting AD discussion and recording of ADs via electronic medical records. The second is that of a computer-based, interactive online website that enables individuals to access information on ADs and complete one online.

What this review has also identified is that future research designs investigating the effectiveness of particular models of computer-based, interactive online environments to assist completion rates of ADs should be rigorous in their method

and in their reporting of before and after intervention AD completion rates. Without this knowledge and the use of controls in a rigorous method, the assessment of computer-based, interactive online formats will continue to be subject to factors that may confound effect.

The next chapter describes a population survey conducted in South Australia informed by knowledge from this systematic review. The questions designed for the survey aimed to develop greater understanding of: the types of ADs people have completed; sociodemographic factors involved with completion by a general population; level of comfort with computer use and preferred means for engagement in the online environment for AD knowledge and completion. Information gained from the survey will then provide a platform for measuring the effectiveness of the two types of computer-based, interactive online interventions found in this review, i.e. prompting and online education for increasing AD completion rates by South Australian Baby Boomers in a randomised controlled trial.

CHAPTER 3 – PROJECT 2 – PREVALENCE AND PREFERRED MECHANISMS OF ENGAGEMENT WITH ADVANCE DIRECTIVES AND THE E-HEALTH ENVIRONMENT IN SOUTH AUSTRALIA

Introduction

Publication arising from the information in this chapter:

Bradley, SL, Woodman, RJ, Tieman, JJ & Phillips, PA 'Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012', *Medical Journal of Australia* 2014; V. 201; pp. 467–469

The purpose of this study was to provide objective evidence of the prevalence of all four types of AD use in South Australia and preferences for different online mechanisms to disseminate information on ADs. This study was conducted to provide a basis for understanding current general population use of these documents and how effective online initiatives to enhance AD completions using e-Health might be. The results of this study – Project 2 in this thesis – provide information from a population-based survey of all South Australians in the state of South Australia in Australia. Understanding the current level and type of ADs used across a given population and their preference for different formats in the online environment for provision of AD knowledge was used for determining the conditions of Project 3. The results of the research from this study (Project 2) have been published (Bradley et al. 2014). Secondary analysis of the dataset in this study (Project 2) also offered the opportunity to analyse the specific preferences of people in the age cohort that encompasses the Baby Boomer generation.

Previous knowledge of AD and computer use in Australia

Prior to 2014, the advance care planning research in Australia indicated that known evidence of completion of AD documents in the unwell or well populations ranged from approximately 0.2% to 25%, reflecting different time points of AD promotion and advancement as well as different populations, documents and facilities studied (Ashby & Thornton 2011, AHMAC 2011, Brown, et al. 2005, Foreman, et al. 2006, New South Wales Government (NSWG) 2004, Stewart 2005). Until 2014, however, there was no definitive or consistent empirical evaluation of the general rate of uptake of individual types of ADs by the overall population within or on a state-by-state basis.

In many states and territories in Australia, the creation of different documents for all avenues of decision-making, such as financial, healthcare and lifestyle led to confusion for individuals and healthcare practitioners as to which documents to complete and when; who was the rightful decision-maker; and which documents were valid for different types of decision-making (AHMAC 2011, Stewart 2005). The creation of so many different documents that varied between states and territories also made assessment of individual document completion difficult.

Nevertheless, many Australian states attempted to measure the effectiveness of these instruments by measuring completion rates of some of the documents pertinent to that state (Ashby & Thornton 2011, Brown, et al. 2005, Foreman, et al. 2006, NSWG 2004). For example, Ashby and Thornton (2011) measured rates of use of the Enduring Guardian document in Tasmania; however, there were other AD documents, such as the Power of Attorney, that were not studied.

In 2014, White et al. published evidence from a nationwide telephone survey of 2405 interviewees in Australia about their use of any document “where you make decisions about what sort of medical treatment you want or don’t want” (p. 7) and then the individual state document names were provided as a prompt. Overall, they found that 14% of the Australian population had an AD with state-by-state variation (Western Australia lowest at 8% and South Australia highest at 21% (Bradley et al. 2014, cited by White et al. 2014, p. 976)). This nationwide survey provided valuable evidence of AD use across Australia but still did not provide evidence of the use of any and all documents being used within each state and territory for all types of decision-making. Knowledge of which documents are being completed is as important as knowing the rates of completion of ADs as the former can identify whether the appropriate documents for healthcare planning are being completed as opposed to financial documents in addition to the effectiveness of efforts to promote and clarify ACP and healthcare and lifestyle AD use.

A new AD framework and its importance to South Australia

The Health Ministers of Australia sought to provide some standardisation to the AD process and created the National Framework for Advance Care Directives (ACDs) in 2011 (AHMAC 2011). The framework provides guidance for developing legislation and processes which make the task of creating and implementing ACDs more consistent across states and territories.

South Australia was one of the first states to act upon the new framework by

creating legislation for a separate Act for Advance Care Directives, *Advance Care Directive Act 2013* (SAGDOH 2013). Previously, South Australians could access one of four different AD legal documents: the Enduring Power of Attorney (EPA – for financial decision-making), the Enduring Power of Guardianship (EPG – for proxy decision-making on health and lifestyle), the Medical Power of Attorney (MPA – for medical treatment decision only), and the Anticipatory Direction (Ant Dir – for end-of-life decision-making). The situation under which each document was enacted was confusing for the public and healthcare practitioners and hampered their more widespread use (SAGDOH 2007, 2008). The new Act was created with the intent to alleviate such issues through provision of only one form combining the EPG, MPA and Ant Dir to focus on healthcare and lifestyle instructional and proxy decision-making, rather than financial decision-making. As the new ACD form was implemented in July 2014 and the research in this thesis took place between 2012 and 2014, the research in this thesis concentrates on the use of the previous four AD forms: EPA, EPG, MPA and Ant Dir or similar forms known as Living Wills.

Evidence of previous completion rates of ADs in South Australia in the published literature has generally been informed through projects and reports of small and disease-specific groups as an adjunct to other questions (Brown & Jarrad 2005, Foreman et al. 2006) or as part of unpublished studies (Austin Health 2006, Queen Elizabeth Hospital 2004). For example, Brown and Jarrad (2005) studied 18 people who were caring for a person with dementia (10 of whom had an EPA, eight had an EPG, one had MPA and most had some form of “advance directive”), whilst Foreman et al. (2006) looked at preferred place of death with an indirect question on AD completions (“awareness of Living Wills/advance directives/medical agents/power of attorney”). An example of unpublished data is that of the AD completions from residential aged care settings using the Respecting Patient Choices program. The report by Austin Health (2006) of the effectiveness of the Respecting Patient Choices program itself to increase advance care planning (ACP) showed uptake of the “Statement of Choices” document, a de facto Anticipatory Direction/Living Will, at rates of 5% to 80% depending on the phase of the study and the promotion or interest of the facility. However, the breakdown of actual formal South Australian ADs completed (EPA, EPG, MPA and Ant Dir) was not identified in that report.

Another survey conducted by the Queen Elizabeth Hospital in Adelaide in 2004 using the South Australian Health Omnibus Survey found that in the general

population there was an overall rate of 13% of ADs completed, with the EPG and MPA having rates of 8% and 1% completion, respectively. There was no specific information about completion rates of the EPA or Ant Dir.

Without a comprehensive understanding of the completion rates of each of the ADs at a given time, it is difficult to measure the effectiveness of new legislation or health promotion campaigns undertaken to improve AD use. This includes efforts to improve access to these forms through use of the online environment.

AD use in the e-Health environment

As demonstrated in Chapter 2, measurement of completion rates of ADs in the online environment has been undertaken using a variety of formats (Durbin, et al. 2010, Cintron, Phillips & Hamel 2006, Aronsky, et al. 2004, Buchtel, et al. 1996, Sulmasy, et al. 1996, The SUPPORT Investigators 1995). Chapter 2 identified that electronic medical records and websites providing access to information and online AD forms were the two most effective ways for engaging consumers in AD completion when using computer-based, interactive online methods. However, all of this research was performed in countries outside Australia.

In Australia, the effectiveness of the online environment to enhance AD completions is not known. Transmitting healthcare information through the use of online or electronic means is known as e-Health, a term that became prominent in 1999 (WHO 2014) but has only recently gained more traction in the research arena. E-Health encompasses three main areas:

- the delivery of health information, for health professionals and health consumers, through the Internet and other telecommunications
- using the power of IT and e-commerce to improve public health services, e.g. through the education and training of health workers; and
- the use of e-commerce and e-business practices in health systems management

To understand whether e-Health would be of benefit to consumers for AD completions, information on consumer preference for engaging with e-Health is required, as well as the capacity of the population to engage on healthcare issues using this environment. Indications are that capacity is prevalent but with some considerations. For example, a study by the Australian Bureau of Statistics (2011b) found that 79% of Australian households had Internet access at home in

2010–11 and 77% of households were using the Internet every day. In this same study, South Australia had approximately 70% of people using the Internet at home with nearly 80% of homes having a computer. The primary purpose attributed to Internet use as found in the study was emailing (91%); research, news, general browsing (87%); or paying bills or online banking (64%)(ABS 2011b).

Age was a factor in online use with the proportion of persons aged 60+ using the Internet at any location equaling 41% in 2009 (ABS 2011b). The same ABS study revealed that in 2010-2011, people in South Australia in the age bracket of 55–64 (the older decade of the Baby Boomer generation) showed the largest increase in proportion of people accessing the Internet (71%). Those in the 45–54 age group (the younger decade of the Baby Boomer generation) accessed the Internet at rates of 80% or greater. The report also showed that 95% of people with a Bachelor degree accessed the Internet and that the majority of people accessed the Internet at home (95%), work (49%) or someone else's house (36%) (ABS 2011b).

Although being able to navigate healthcare information as complex as ADs may be more conveniently done in the online environment, those with low healthcare literacy or less access to online resources may be disadvantaged (ABS 2006, Mueller, Reid & Mueller 2010). In Australia, 46% of Australians aged 15–74 had reading and comprehension skills at levels 1 and 2 out of 5 with 5 being the highest level of literacy (ABS 2006). With literacy levels across nearly half of the Australian population at the lower end of the scale, it may be that Baby Boomer capacity for e-Health is high but their interest or ability to engage in AD completions using the e-Health environment may be complicated by their ability to comprehend information about these rather complex documents.

Aim

The aim of Project 2 was twofold: firstly, to ascertain the prevalence and type of ADs used by the general population in South Australia as well as their preference for using e-Health methods to access information on ADs; and secondly, to determine any differences, if possible, between those aged 47-66 at the time of the study (born 1946–1965) and other age groups. Those aged 47-66 at the time of the study incorporate members of the Baby Boomer generation.

The survey used to accomplish this aim was statistically powered to provide prevalence data for a general population, independent of health status, across a

wide range of ages (15–96). The greatest number of people in the survey were in the age range 45–64 (n=990) encompassing the majority of the Baby Boomer generation who were aged 47–66 in 2012 when the survey was performed.

Significance of the project

The significance of this project lies in its ability to provide the first empirical evidence of use of all four individual documents as well as preferences for the e-Health environment for AD knowledge and use in South Australia. It is also significant for providing the first empirical evidence of potential Baby Boomer use of these documents in Australia and this age group's preferences for AD knowledge using e-Health formats.

Research objectives

The specific research objectives for this project were to:

- determine the general prevalence of reported completion of the following documents: Enduring Power of Attorney (called “Power of Attorney” in the survey); Enduring Power of Guardianship (called “Power of Guardianship” in the survey); Medical Power of Attorney; Anticipatory Direction (otherwise called and known as a “Living Will” and other similar-type forms); as well as measuring the reported prevalence of those people who have not completed any of the documents
- determine the general prevalence of self-reported assistance to others with AD documents
- determine the prevalence of self-reported experience of acting as a substitute decision-maker (SDM) or agent for others using the formal Power of Attorney or Guardianship instruments
- assess the prevalence of the South Australian public's reported use of computers and the Internet
- determine the prevalence for preferred e-Health formats to access information on and/or completion of ADs; and to
- explore demographic characteristics and differences between the Overall population and the Baby Boomers with regard to each of the above.

Methods

South Australian Health Omnibus Survey methodology

The South Australian Health Omnibus Survey (HOS) is a service that has been provided by Harrison Health Research since 1991 to government and non-government organisations involved in meeting the healthcare of South Australians through examining their health and wellbeing (Harrison Health Research 2012). The omnibus survey enables multiple organisations to share the cost of conducting face-to-face interviews of a large and statistically valid population sample. Each organisation pays only for those questions of direct relevance to their information requirements whilst also being provided with sociodemographic information of the population in the survey. The omnibus goal is that of collecting, analysing and interpreting data to be used to plan, implement and monitor various research, government and non-government programs and initiatives. Using the HOS provides organisations with the opportunity to generate population statistics of relevance, program impacts and other important data at an affordable cost (Harrison Health Research 2012).

A particularly attractive feature of the HOS is that it is conducted using a rigorous sampling procedure. This sampling procedure involves several steps to obtain the overall final minimal sample of approximately 3000 households across the state of South Australia. The sampling steps for the HOS used in this study were as follows:

- Collector Districts (CDs) from the ABS were selected with probability of selection proportional to size. For the country sample, all cities and towns with a population size of 10,000 or more (2006 Census) were selected automatically. The balance of the country sample was chosen from centres with a population of 1,000 or more (2011 Census) with probability proportional to size – this made the country sample of 130 CDs self-weighting. For the metropolitan sample, 390 CDs were selected (2006 Census) with probability of selection proportional to size.
- From the total of 520 CDs used for the survey in this study, a stratified random sample of 10 households per CD was defined from a random starting point and by a fixed skip interval. Initially, this involved a total of 5200 households being contacted to participate in the study. In the 2006 Census there were 583,958 households in South Australia.
- Stratification of the population for the study was conducted using gender (male/female); age (18–24; 25–34; 35–44; 45–54; 55–64; and 65+); and

location (metropolitan/rural). The sample comprised 75% of participants selected from the Adelaide metropolitan area with the remainder drawn from country centres with a population of 1000 or more.

- Data collection included a minimum of six visits to each household before classification to a non-contact status.
- To reach the final sample size of approximately 3000 interviews up to 6 separate visits were undertaken to reach the selected correspondent. If the household was vacant or individual selected was not able to participate, the household was not replaced with another.
- The overall methodology and completed questionnaire for this HOS survey was submitted for approval to the University of Adelaide Ethics Committee and the surveys were managed and conducted through Harrison Health Research.

Additional information about data collection and quality control

- Interviews were conducted on a face-to-face basis with the person with the most recent birthday aged 15 or older.
- Prior to the main survey, a pilot study of 50 interviews was conducted to test questions, validate the survey instrument and assess survey procedures.
- Within each survey, approximately 10 background demographic questions were asked: age, gender, household income, marital status, education, country of birth, location, and others. The data from this information was included without charge to all clients in the survey so client data could be cross tabulated with these demographics.
- Data collected was weighted by the inverse of the individual's probability of selection as well as the response rate in metropolitan and country regions. The sample was then re-weighted according to the age and gender distribution of the survey based on benchmarks derived from the 2011 Estimated Residential Population from the 2011 ABS Population Census.
- To validate the responses provided, 10% of respondents were re-contacted and interviewed again on selected questions.
- Data entry was fully verified (double punched) to ensure accuracy of data capture.

Before conducting the survey, a quality control committee representing users of the survey conducted a watching brief over all facets of the survey. Surveys were not

conducted until a total of 150 questions had been purchased for the next round of HOS surveys. In general, the HOS is conducted in the spring or autumn and the survey for this study was conducted in the spring quarter (September to December) 2012. As part of the survey, participants were asked for permission to be re-contacted for future research opportunities subject to Ethics Committee approval.

Data was presented to researchers by Harrison Health Research in the raw format on a CD using SPSS. For this study, the author conducted independent analysis of the data using SPSS version 19.

Survey questions for this study

This study used a set of five questions to assess completion rates and types of ADs completed as well as interest in completing ADs in the online environment. The questions were developed and piloted with a small (n=10) sample of healthcare professionals conversant with ADs, including a statistician and an expert in survey design. People may confuse different planning documents such as Wills with an AD (Brown & Jarrad 2005) so to compensate for such misunderstandings and the generic terminology used by the public for an AD (e.g. power of attorney), an introductory statement about South Australian ADs including brief definitions of each of the instruments was provided at the interview stage. Survey interviewers were also provided with a more detailed description of the documents for any questions that arose and to establish the correct document being referred to, such as Anticipatory Direction for Living Will or vice versa and Will vs. Living Will or vice versa. For purposes of consistency, clarity and accuracy I will describe the documents by their formal names except for the Anticipatory Direction which will be called Living Will (as the literature preferences this term to any other). The introductory statement and question construction is outlined in Figure 3.1.

ADVANCE CARE DIRECTIVES
<p>This section will ask you for responses to questions about advance directives. An advance directive is a legally binding document that expresses a person’s wishes or directions in advance in the event that mental capacity is lost in the future. There are currently different documents in South Australia to cover specific areas of decision making. (Office of the Public Advocate of South Australia, 2011)</p>
<p>D1 Have you completed any of the following forms for yourself? <i>Show prompt card</i> <i>D.1 Multiple response If respondent has registered to donate organs via the organ donor website this can be included under “Living Will”.</i></p> <ol style="list-style-type: none"> 1 Power of Attorney (for finances) 2 Power of Guardianship (for healthcare and welfare)

- 3 Will (for after you have died)
- 4 Medical Power of Attorney (for healthcare)
- 5 "Living Will" (advance care plan, statement of choices, life values statements, organ donation card or other)
- 6 None of the above
- 7 Don't know/refused

D2 Thinking about your family and friends, have you helped someone learn about or complete any of the following forms? Show prompt card D.1 Multiple response

- 1 Power of Attorney (for finances)
- 2 Power of Guardianship (for healthcare and welfare)
- 3 Will (for after you have died)
- 4 Medical Power of Attorney (for healthcare)
- 5 "Living Will" (advance care plan, statement of choices, life values statements, organ donation card or other)
- 6 None of the above
- 7 Don't know/Refused

D3 Using a power of attorney or guardianship, have you ever had to make decisions for someone else?

- 1 Yes
- 2 No
- 3 Don't know/Refused

D4 We would now like to learn about your use of the computer or online devices, including devices such as iPhone and iPad. Please choose the options that apply. Show prompt card D.2 Multiple response

- 1 I use a computer or online device on a daily or weekly basis
- 2 I access the Internet on a daily or weekly basis
- 3 I do not use a computer or online device
- 4 I do not access the Internet
- 5 I often use the computer or online devices to look up information on items of interest
- 6 I rarely use the computer or online devices to look up information on items of interest
- 7 I am comfortable using the computer or online devices to learn more about items of interest
- 8 Don't know/Refused

D5 We would like to find out if you think the Internet would be helpful in your further understanding or completion of advance directives. Please choose the form of information or assistance that you would find particularly helpful. Show prompt card D.3 Multiple response

- 1 Information on the Internet about advance directives
- 2 Advance directive forms that I could download as a paper copy
- 3 Online training about how to complete advance directives
- 4 An online register to file my advance directives in case I want to change it or let others see it
- 5 Speaking with a legal or healthcare professional online to answer questions on advance directives
- 6 I would prefer other means of learning about or completing advance directives, such as face-to-face or telephone consultation
- 7 I am not interested in learning about advance directives
- 8 Don't know/refused

Figure 3.1: Introductory statement and questions asked in HOS survey

The survey questions, methodology and analysis for this study were approved by the Flinders University Social and Behavioural Sciences Ethical Committee (Project No. 5748).

Composition of studies with Overall population

Demographic data collected for the HOS survey involving the overall South Australian population was regrouped from the raw data categories and used for the sociodemographic analysis in the following manner: gender (male/female); education level (Left school Year 12 or before, still studying, Certificate/Diploma/Trade or Apprentice, and Bachelor degree or higher); occupation based on ANZSCO codes (professionals, clerical and sales, blue collar, never worked/student/home duties); household income (\$0-\$40,000, \$40,001-\$80,000, \$80,001+, not stated); country of birth (Australia, other); marital status (married, separated/divorced, de facto, widowed, never married); and area of residence (rural/regional or metropolitan).

A secondary analysis of those aged 47–66 incorporating the Baby Boomer generation

A secondary analysis of the data was performed to discover how those aged 47–66 at the time of the survey engaged with ADs. It should be noted that for this secondary analysis, this age group was not removed from the Overall population when comparing their responses to the Overall population. Instead, the reporting of

this age group's responses represents a more detailed look at how this specific age group acted in this study in regard to AD and computer use.

Throughout this chapter, this group may be referred to as the Baby Boomers although it is emphasised that the questions in the HOS were not specifically designed to identify generational responses. Demographic data analysed for this secondary analysis involved the following:

- age - a new category was created to represent the age of Australian Baby Boomers born 1946–1965 (aged 47–66 in 2012; n=993, 33% of the overall population in the study) which varies only slightly from the categorical variable 45–64 in the Overall population (n=990, 32%).
- gender (male/female)
- location (rural/regional or metropolitan)
- marital status – for the Baby Boomer population, those widowed represented a very low percentage of the age group (n=41/993, 4%) whereas not married represented 19% (n=188/993) of the cohort and married represented 77% (n=794/993) of the cohort. Therefore, it seemed logical to group widows with those not married as widowhood conveyed a non-marital status.
- education level (Left school Year 12 or before, Certificate/Diploma/Trade/Apprentice, and Bachelor degree or higher). Still Studying (n=17/993) was regrouped and included with Cert/Dip/Trade/Apprentice due to the low number of people in the Still Studying variable for this age group. It was decided not to classify them with Bachelor degree or higher as still studying indicates that they have not yet completed a tertiary or other degree.
- occupation based on Australian New Zealand Standard Classification of Occupations (ANZSCO) codes (professionals, clerical/sales/blue collar, never worked/student/home duties). The occupational variable *blue collar* was added to the clerical/sales grouping to create occupational groups roughly equivalent to no employment, blue collar and white collar employment; and
- household income (\$0-\$40,000; \$40,001-\$80,000; \$80,001+, not stated). The majority of Baby Boomers were in the \$40,000+ level of income but there was a significant number (n=179/993, 18%) in the lower income bracket. It was decided to create a separate middle variable for testing associations to determine if lower levels of income might affect AD completions more so than at the other levels of income. The not stated

variable was created because nearly one fourth of participants (n=228/993, 23%) did not state their income at all.

Country of birth was not analysed for the Baby Boomer analysis as the overwhelming majority (74%, n=730/993) were of self-reported Australian origin with numbers from other individual countries too low (n< 50 per individual country) for comparative sociodemographic analysis.

Statistical analysis

Data for both the main analysis and the secondary analysis were analysed as descriptive and exploratory using SPSS version 19 (SPSS Inc. 2010). Univariate analysis of each of the five questions with demographic information was performed using chi-square tests of association with a two-tailed probability reported.

Multivariate analysis was completed using binary logistic regression to assess the independent associations of non-completions, non-assistance, non-agency, non-computer use, non-online preference and non-interest in ADs with demographic variables. All demographic variables were used in the multivariate model regardless of their statistical significance, except for country of birth in the secondary analysis of age group 47–66 for reasons described previously. Associations for which a two-tailed p-value of <.05 were considered statistically significant.

Please note: The following sections have been deliberately constructed in a manner that reflects the survey results by overall population ages rather than specific generations as survey questions did not directly address generational differences.

To differentiate the studies according to the research objectives, results of the studies are defined as:

- Demographic information for the Main Analysis and Secondary Analysis
- Main Analysis: Overall Population
 - Part 1 - Completion (Primary Outcome), Assistance, Agency
 - Frequency and Prevalence of Completion
 - Frequency and Prevalence of Assistance
 - Frequency and Prevalence of Agency
 - Multivariate analysis of non-completion, non-assistance, non-agency
 - Results of multivariate analysis
 - Non-completion

- Non-assistance
 - Non-agency
 - Summary of results on completion and non-completion, assistance and non-assistance, agency and non-agency
- Part 2 – Comfort with Online Environment and Preferred Mechanism for AD Information
 - Frequency and Prevalence of Computer and Online Comfort and Use
 - Use on Weekly/Daily Basis
 - Use and comfort with online environment for information
 - Multivariate analysis of Non-Use
 - Results of Multivariate analysis on Non-Use
 - Summary of results on computer comfort, use, online devices and non-use
 - Frequency and Prevalence of Preferred Mechanism for AD Knowledge
 - Multivariate analysis of Non-Interest in ADs
 - Results of Multivariate analysis on Non-Interest in ADs
 - Summary of results on preferred online mechanisms for AD knowledge and non-interest.
- Secondary Analysis: 47–66 age group incorporating the Baby Boomer generation
 - Part 1 – Completion, Assistance, Agency
 - Frequency and Prevalence of Completion, Assistance and Agency
 - Multivariate analysis of non-completion, non-assistance and non-agency
 - Results of multivariate analysis for non-completion, non-assistance, non-agency
 - Summary of results on completion and non-completion, assistance and non-assistance, agency and non-agency
 - Part 2 – Comfort with Online Environment and Preferred Online Mechanism for AD Information
 - Frequency and Prevalence of Computer and online comfort and use
 - Multivariate analysis of Non-Use
 - Results of Multivariate analysis on Non-Use
 - Frequency and Prevalence of Preferred Mechanism for AD Knowledge
 - Multivariate analysis of Non-Interest in ADs
 - Results of Multivariate analysis on Non-Interest in ADs

- Summary of results on computer and online comfort, use, preferred mechanisms, non-use and non-interest for AD knowledge.

Results

Demographic Information for Main Analysis and Secondary Analysis

From the 5063 households contacted 3055 interviews were completed representing a 60% response rate and a 64% participation rate. The participation rate for the Baby Boomer population was 33%. It was not possible to ascertain by age the response rate of Baby Boomers from the total households as the sampling method does not have quotas for any age/gender/area splits and no data was provided for population counts in each stratum.

The weighted and non-weighted demographic characteristics for the Overall population can be seen in Table 3.1.

Table 3.1: Demographic variable distribution of participants for Overall population (weighted and unweighted, N=3055)

Demographic Variable	Unweighted Number (N*)	Unweighted Percentage (%*)	Weighted Number (N*)	Weighted Percentage (%*)
Age				
15–24	306	10	487	16
25–44	883	29	977	32
45–64	1011	33	990	32
65 +	855	28	601	20
Sex				
Male	1279	42	1494	49
Female	1776	58	1561	51
Location				
Metropolitan	2241	73	2235	73
Rural	814	27	820	27
Birth Country				
Australia	2262	74	2267	74
Other	793	26	788	26
Marital Status				
Married	1426	47	1573	52
De Facto	293	10	261	9
Separated/Divorced	412	14	333	11
Widowed	343	11	176	6
Never Married	581	18	712	22
Education				
Left School at 15 or less	382	13	310	10
Left School 15+	654	21	617	20
Left school in Year 12 or before (combined category includes Left School at 15 or less and Left School 15 +)	1036	34	927	30
Still at School	77	3	138	5

Demographic Variable	Unweighted Number (N*)	Unweighted Percentage (%*)	Weighted Number (N*)	Weighted Percentage (%*)
Left school +15 but still studying	136	5	189	6
Still Studying (combined cat. includes Still at school and Left school +15 and still studying)	213	8	327	11
Trade/Apprenticeship	349	11	366	12
Certificate/diploma – one year full time or less	360	12	352	12
Certificate/diploma – more than one year full time	436	14	401	13
Cert Dip or Trade Apprentice (weighted combined category includes Trade/Apprenticeship; Certificate/Diploma – one year full time or less; Certificate/Diploma – more than one year full time)	51	38	1119	37
Bachelor degree or higher	655	21	682	22
Occupation ^				
Professional categories (combined)	1008	33	957	31
Clerical and Sales categories (combined)	874	29	824	27
Blue collar categories (combined)	887	29	911	30
Never worked	26	1	16	1
Home Duties	116	4	93	3
Student	50	2	91	3
Never worked, student, home duties categories (combined)	192	6	211	7
Not stated (not included in analyses)	94	3	152	5
Annual Income				
1=Up to \$12,000	94	3	56	2
2=\$12,001–\$20,000	308	10	183	6
3=\$20,001–\$30,000	235	8	195	6
4=\$30,001–\$40,000	183	6	148	5
\$0 – 40,000 (combined 1–4)	820	27	582	19
5=\$40,001–\$50,000	163	5	158	5
6=\$50,001–\$60,000	156	5	145	5
7=\$60,001–\$80,000	284	9	280	9
\$40,001–\$80,000 (combined 5–7)	603	19	583	19
8=\$80,001–\$100,000	208	7	205	7
9=\$100,001–\$120,000	183	7	206	7
10=\$120,001–\$140,000	125	4	141	5
11=\$140,001–\$160,000	102	3	125	4
12=\$160,001–\$180,000	70	2	92	2
13=\$180,001 or more	133	4	173	6
\$80,001 + (combined 8–13)	821	27	942	31
Not stated	811	27	948	31

Categories in bold and italics are groupings used for univariate and bivariate analyses and differ from original SAHOS categories.

*Rounded to nearest whole number

^ Occupation (ANZCO Codes) – only combined data presented except for Never Worked, Home Duties and Student as there are over 300 entries for ANZCO occupations with minimal numbers per occupation, e.g. <75 for any single category)
Source: South Australian Health Omnibus Survey (HOS), Sep-Dec 2012

The weighted and non-weighted demographic characteristics for the for the age group 47–66 incorporating the Baby Boomers can be seen in Table 3.2

Table 3.2: Demographic variable distribution of participants for those aged 47–66 (incorporating the Baby Boomer population, N=993)

Demographic Variable	Unweighted Number (N*)	Unweighted Percentage (%*)	Weighted Number (N*)	Weighted Percentage (%*)
(47–66 years)	1040	34	993	33
Gender				
Male	432	42	495	50
Female	608	58	498	50
Location				
Metropolitan	766	74	701	71
Rural/Regional	274	26	292	30
Marital Status				
Married	532	50	628	63
De Facto	215	21	136	14
Combined Married	747	71	764	77
Separated/Divorced	77	8	80	8
Widow	72	7	41	4
Not Married	88	9	52	5
Not Stated	56	6	56	6
Combined Not Married	293	29	229	23
Education				
Left School in Year 12 or before	384	37	355	35
Still Studying	17	2	17	2
Cert Dip/Trade/Apprentice	421	41	405	41
Combined Cert/Dip/Trade/ Apprentice/Still Studying	438	43	422	43
Bachelor+	218	20	216	22
Occupation^ (ANZCO Codes)				
Professionals	376	36	340	35
Clerical/Sales	324	31	309	31
Blue Collar	291	28	301	30
Combined Clerical/ Sales/Blue Collar	615	59	610	61
Never Worked/Student/ Home Duties	59	5	44	4
Annual Income				
\$0-\$40,000	252	24	179	18
\$40,001-\$80,000	226	21	207	21
\$80,001+	342	33	379	38
Not Stated	220	22	228	23

Categories in italics are groupings used for univariate and bivariate analyses and differ from original HOS categories.

* Rounded to nearest whole number

^ Occupation (ANZCO Codes) – only combined data presented except for Never Worked, Home Duties and Student as there are over 300 entries for ANZCO occupations with minimal numbers per occupation (<75 for any single category)

Source: South Australian Health Omnibus Survey (HOS), Sep-Dec 2012

Part 1 – Main Analysis: Overall population (N=3055) – Completion (Primary Outcome), Assistance and Agency with Advance Directives

Frequency and prevalence of completion by the Overall population (N=3055) – (Q1) for the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Anticipatory Direction/Living Will (LW) and Will

Figure 3.2 illustrates that the Will was the most commonly reported completed instrument (48%) even though it is not an AD.

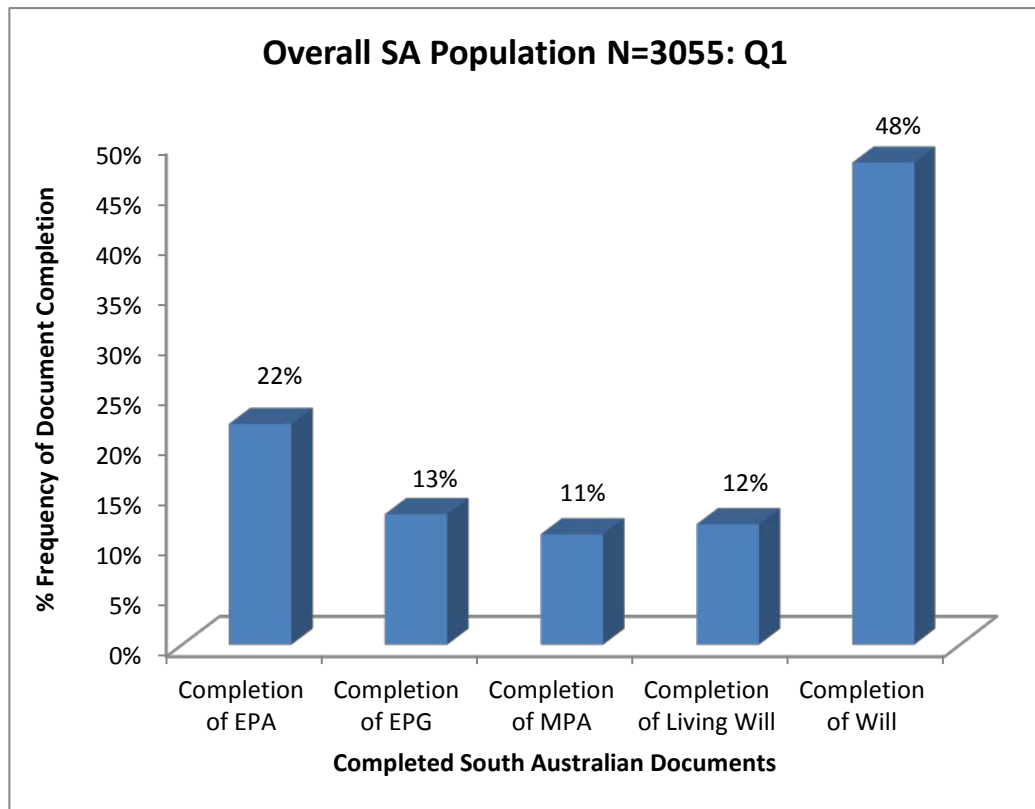


Figure 3.2: Q1 - Frequency of *completion* of individual Advance Directives by the Overall South Australian population (N=3055)

Of the recognised legal ADs in South Australia (EPA, EPG, MPA and Ant Dir/Living Will) more respondents reported having completed the EPA (22%) than any of the healthcare documents EPG (13%), MPA (11%), or Living Will (12%). Approximately half (48%) of the participants reported not completing any of the named documents. The frequency with which 1, 2, 3, 4 or 5 documents were completed is shown in Table 3.3 below:

Table 3.3: Q1 - Frequency of one or more completed documents by the Overall population, N=3055

Type of Document	1 Document Completed (%) N=772 (25% total documents completed)	2 Documents Completed (%) N=334 (11% total documents completed)	3 Documents Completed (%) N=209 (7% total documents completed)	4 Documents Completed (%) N=170 (6% total total documents completed)	5 Documents Completed (%) N=97 (3% total documents completed)
EPA	18 (3)	188 (28)	194 (29)	166 (25)	97 (15)
EPG	7 (2)	21 (5)	115 (29)	154 (39)	97 (25)
MPA	5 (2)	24 (7)	72 (21)	142 (42)	97 (29)
Living Will	61 (17)	113 (31)	44 (12)	46 (13)	97 (27)
Will	681 (46)	324 (22)	202 (14)	168 (11)	97 (7)

Most often only one document was completed (25%), predominantly the Will (N=681/772). When two documents were completed, it was most often the EPA (N=188/334) and Will (N=324/334). Only when three documents were completed did healthcare and lifestyle ADs, particularly the EPG (N=115/209), begin to be completed at rates nearing the financial documents.

Table 3.4 describes the statistically significant sociodemographic associations for *completion* of documents by the Overall population (N=3055).

Table 3.4: Q1 - Univariate analysis of the prevalence of *completion* of individual documents for the Overall population (N=3055)

Demographic	Total N*	EPA			EPG			MPA			Living Will			Will		
		Completion N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value
Age (years)																
15–24	487	2 (0)	(0-1)		4 (1)	(0-2)		2 (0)	(0-1)		19 (4)	(2-6)		11 (2)	(1-3)	
25–44	977	76 (8)	(6-10)		50 (5)	(4-6)		41 (4)	(3-5)		76 (8)	(6-10)		262 (27)	(24-30)	
45–64	990	268 (27)	(24-30)		155 (16)	(13-18)		142 (14)	(12-17)		162 (16)	(14-19)		676 (68)	(65-71)	
65 and over	601	317 (53)	(49-57)	<.001	184 (31)	(27-34)	<.001	154 (26)	(22-29)	<.001	104 (17)	(14-20)	<.001	523 (87)	(84-90)	<.001
Sex																
Male	1494	322 (22)	(19-24)		178 (12)	(10-14)		163 (11)	(9-12)		168 (11)	(10-13)		703 (47)	(45-50)	
Female	1561	341 (22)	(20-24)	.86	216 (14)	(12-16)	.11	177 (11)	(10-13)	.71	194 (12)	(11-14)	.32	768 (49)	(47-52)	.24
Location																
Metropolitan	2235	455 (20)	(19-22)		279 (13)	(11-14)		238 (11)	(9-12)		270 (12)	(11-13)		1041 (47)	(45-49)	
Rural	820	209 (26)	(22-28)	.002	115 (14)	(12-16)	.27	101 (12)	(10-15)	.19	92 (11)	(9-13)	.51	431 (53)	(49-56)	.004
Birth Country																
Australia	2267	531 (23)	(22-25)		323 (14)	(13-16)		276 (12)	(11-14)		275 (12)	(11-13)		1127 (50)	(48-52)	
Other	788	132 (17)	(14-19)	<.001	70 (9)	(7-11)	<.001	64 (8)	(6-10)	.002	87 (11)	(9-13)	.42	345 (44)	(40-47)	.004
Marital Status																
Married	1573	457 (29)	(27-31)		272 (17)	(15-19)		239 (15)	(13-17)		233 (15)	(13-17)		1024 (65)	(63-67)	
Separated/Divorced	333	34 (10)	(7-13)		16 (5)	(3-7)		11 (3)	(1-5)		29 (9)	(6-12)		91 (27)	(23-32)	
De Facto	261	50 (19)	(15-24)		34 (13)	(9-17)		24 (9)	(6-13)		38 (15)	(10-19)		138 (53)	(47-59)	
Widowed	176	97 (54)	(47-62)		56 (32)	(25-38)		50 (28)	(22-35)		33 (19)	(13-24)		143 (81)	(75-87)	
Never Married	712	26 (4)	(2-5)	<.001	15 (2)	(1-3)	<.001	15 (2)	(1-3)	<.001	30 (4)	(3-6)	<.001	76 (11)	(8-13)	<.001
Education																
Left School Year 12 or before	928	223 (24)	(21-27)		136 (15)	(12-17)		107 (12)	(9-14)		96 (10)	(8-12)		521 (56)	(53-59)	
Still Studying	327	15 (5)	(2-7)		10 (3)	(1-5)		9 (3)	(1-5)		19 (6)	(3-8)		32 (10)	(7-13)	
Cert Dip or Trade	1119	274 (25)	(22-27)		170 (15)	(13-17)		145 (13)	(11-15)		165 (15)	(13-17)		600 (54)	(51-57)	
Bachelor or Higher	682	151 (22)	(19-25)	<.001	77 (11)	(9-14)	<.001	78 (12)	(9-14)	<.001	81 (12)	(10-14)	<.001	318 (47)	(43-50)	<.001

Demographic	Total N*	EPA			EPG			MPA			Living Will			Will		
		Completion N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value
Occupation (ANZSCO) codes																
Professionals	957	233 (24)	(22-27)		136 (14)	(12-16)		129 (14)	(11-16)		132 (14)	(12-16)		498 (52)	(49-55)	
Clerical and Sales	824	220 (27)	(24-30)		137 (17)	(14-19)		112 (14)	(11-16)		111 (14)	(11-16)		485 (59)	(55-62)	
Blue Collar	911	174 (19)	(17-22)		98 (11)	(9-13)		84 (9)	(7-11)		96 (11)	(9-13)		422 (46)	(43-50)	
Never Worked/Student/ Home Duties	211	29 (14)	(9-18)	<.001	16 (8)	(4-11)	<.001	11 (5)	(2-8)	<.001	13 (6)	(3-9)	.004	55 (26)	(20-32)	<.001
Annual Income																
\$0-\$40,000	583	174 (30)	(26-34)		105 (18)	(15-21)		85 (15)	(12-17)		69 (12)	(9-14)		354 (61)	(57-65)	
\$40,001-\$80,000	582	130 (22)	(19-26)		80 (14)	(11-17)		69 (12)	(9-15)		67 (12)	(9-14)		265 (46)	(41-50)	
\$80,001+	941	202 (21)	(19-24)		121 (13)	(11-15)		108 (12)	(9-14)		145 (15)	(13-18)		504 (54)	(50-57)	
Not stated	948	157 (17)	(14-19)	<.001	87 (9)	(7-11)	<.001	77 (8)	(6-10)	<.001	80 (8)	(7-10)	<.001	349 (37)	(34-40)	<.001

* Figures in table are for weighted data rounded to whole decimal

Number who responded to question

Source: South Australian Health Omnibus Survey (HOS), Sep-Dec 2012

There was an association between the proportion of completion rates and age across all documents with participants aged 65 years and older completing more documents than participants in younger age categories: EPA χ^2 (3, N=3055)=598, $p<.001$; EPG χ^2 (3, N=3055)=291, $p<.001$; Will χ^2 (3, N=3055)=1114, $p<.001$; MPA χ^2 (3, N=3055)=242, $p<.001$; Living Will χ^2 (3, N=3055)=81, $p<.001$.

Rural participants reported completing the EPA and Will more frequently than did metropolitan participants: EPA χ^2 (1, N=3055) =9.28, $p=.002$; Will χ^2 (1, N=3055) =8.43, $p=.004$.

When considering country of birth, participants whose birth country was Australia completed more of all documents except the Living Will compared to participants who nominated a different country of birth: EPA χ^2 (1, N=3055)=15.32, $p<.001$; EPG χ^2 (1, N=3055)=15.01, $p<.001$; Will χ^2 (1, N=3055)=8.24, $p=.004$; MPA χ^2 (1, N=3055)=9.71, $p=.002$; Living Will χ^2 (1, N=3055)=.67, $p=.42$.

With regard to marital status, participants who were married or widowed reported more completion of documents compared to participants who were separated/divorced, de facto, and never married: EPA χ^2 (4, N=3055)=327, $p<.001$; EPG χ^2 (4, N=3055)=176, $p<.001$; Will χ^2 (4, N=3055)=717, $p<.001$; MPA χ^2 (4, N=3055)=160, $p<.001$; Living Will χ^2 (4, N=3055)=65, $p<0.001$.

Education was an important indicator of completion rates with participants who were still studying least likely to report completing documents: EPA χ^2 (3, N=3055)=65, $p<.001$; EPG χ^2 (3, N=3055)=38, $p<.001$; Will χ^2 (3, N=3055)=231, $p<.001$; MPA χ^2 (3, N=3055)=27, $p<.001$; Living Will χ^2 (3, N=3055)=22, $p<0.001$. The comparison of completion rates of documents of participants *still studying* versus participants who *Left School in Year 12 or before* suggest that these results may be associated with age. It is likely that this result may be due to age because leaving school in Year 12 or before in Australia was standard for people in the age category of 65+ where it is less so today, especially for people under the age of 45. For example, in New South Wales, government schools' retention of students from year 7 to year 10 increased from 13% in 1948 to 48% in 1958 to 72% in 1968 (ABS 2001). The age association was not tested however due to time constraints associated with the thesis.

There were differences in occupational status with participants in the white collar industries (professionals, clerical and sales) associated with more completion of documents compared to participants in blue collar roles or who had never worked,

were students or had home duties: EPA χ^2 (3, N=3055)=25, $p<.001$; EPG χ^2 (3, N=3055)=20, $p<.001$; Will χ^2 (3, N=3055)=81, $p<.001$; MPA χ^2 (3, N=3055)=20, $p<.001$; Living Will χ^2 (3, N=3055)=13, $p=0.004$.

Differences by annual income were associated with significant differences in completion rates: EPA χ^2 (3, N=3055)=38, $p<.001$; EPG χ^2 (3, N=3055)=26, $p<.001$; Will χ^2 (3, N=3055)=98, $p<.001$; MPA χ^2 (3, N=3055)=16, $p<.001$; Living Will χ^2 (3, N= 3055)=22, $p<.001$. However, results from this category were somewhat compromised by only 70% of participants declaring their annual income.

A variable that was statistically non-significant for completion of any document was gender: EPA χ^2 (1, N=3055)=0.03, $p=.86$; EPG χ^2 (1, N=3055)=2.49, $p=.11$; Will χ^2 (1, N=3055)=1.36; $p=.24$, MPA χ^2 (1, N=3055)=0.14, $p=.71$; Living Will χ^2 (1, N= 3055)=1.01, $p=.32$. There was also no association between rural and metropolitan participants for completion of the EPG χ^2 (1, N=3055) =1.24, $p=.27$; MPA χ^2 (1, N=3055) =1.69, $p=.19$; or Living Will χ^2 (1, N=361) =.43, $p=.51$

Frequency and prevalence of assistance for the Overall population (N=3055) (Q2) of EPA, EPG, MPA, Living Will and Will

Once again, of all of the available AD documents, the financial documents of EPA and Will figured prominently when assisting others to complete ADs (Figure 3.3).

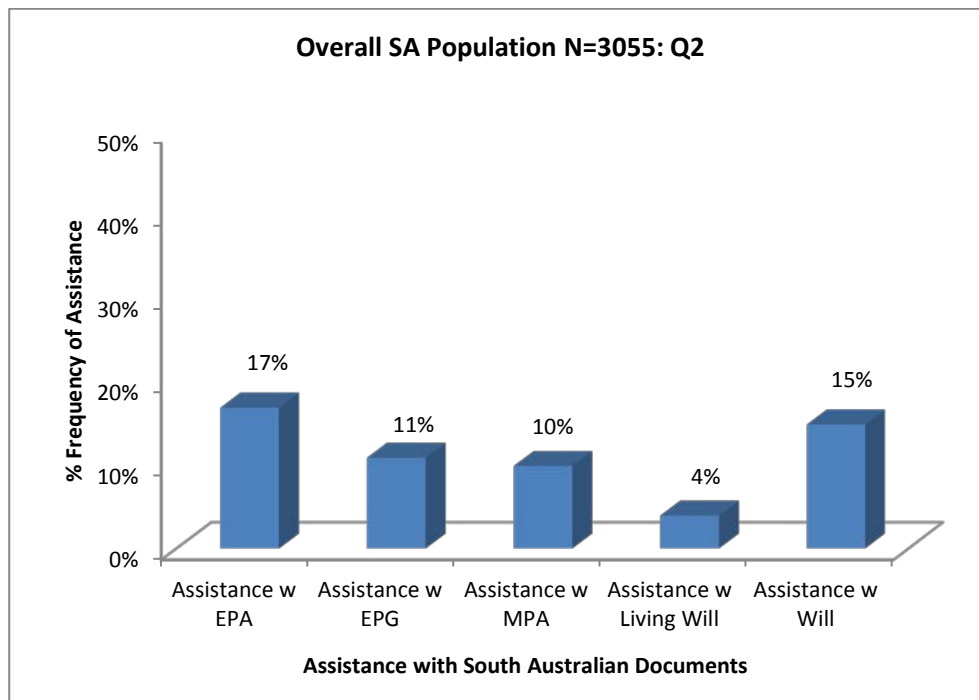


Figure 3.3: Q2 - Frequency of assistance with individual Advance Directives by the Overall population (N=3055)

Of the healthcare documents (EPG, MPA and Living Will), more respondents reported having assisted someone with the EPG (11%) and MPA (10%) than the Living Will (4%). Of the participants, 74% reported not assisting anyone with any of the named documents. Table 3.5 describes the statistically significant sociodemographic associations for *assistance* with ADs for the Overall population.

Table 3.5: Q2 - Univariate analysis of the prevalence of *assistance* with individual documents for the Overall population (N=3055)

Demographic	Total N*	EPA			EPG			MPA			Living Will			Will		
		Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value
Age (years)																
15–24	487	7 (1)	(0-3)		6(1)	(0-3)		7 (1)	(0-3)		3 (1)	(0-2)		11 (2)	(1-4)	
25–44	977	115 (12)	(10-14)		57 (6)	(4-7)		59 (6)	(5-8)		36 (4)	(3-5)		124 (13)	(11-15)	
45–64	990	271 (27)	(24-30)		190 (19)	(16-21)		166 (17)	(14-19)		62 (6)	(5-8)		229 (23)	(20-26)	
65 and over	601	113 (19)	(16-22)	<.001	72 (12)	(9-15)	<.001	60 (10)	(8-13)	<.001	26 (4)	(3-6)	<.001	104 (17)	(14-20)	<.01
Sex																
Male	1494	208 (14)	(12-16)		129 (9)	(7-10)		105 (7)	(6-8)		46 (3)	(2-4)		223 (15)	(14-17)	
Female	1561	298 (19)	(18-22)	<.001	195 (13)	(11-15)	.001	186 (12)	(11-14)	<.001	82 (5)	(4-7)	.003	244 (16)	(14-18)	.60
Location																
Metropolitan	2235	382 (17)	(16-19)		248 (11)	(10-13)		226 (10)	(9-12)		105 (5)	(4-6)		337 (15)	(14-17)	
Rural	820	124 (15)	(13-18)	.19	76 (9)	(8-12)	.15	66 (8)	(6-10)	.09	23 (3)	(2-4)	.02	131 (16)	(14-19)	.55
Birth Country																
Australia	2267	405 (18)	(17-20)		259 (11)	(11-13)		239 (11)	(10-12)		101 (5)	(4-6)		369 (16)	(15-19)	
Other	788	101 (13)	(11-15)	.001	65 (8)	(6-10)	.01	53 (7)	(5-9)	.002	27 (3)	(2-5)	.22	98 (12)	(10-15)	.01
Marital Status																
Married	1573	349 (22)	(20-24)		219 (14)	(12-16)		204 (13)	(11-15)		80 (5)	(4-6)		317 (20)	(18-22)	
Separated/ Divorced	333	48 (14)	(11-18)		26 (8)	(5-11)		29 (9)	(7-12)		12 (4)	(2-6)		38 (11)	(8-15)	
De Facto	261	47 (18)	(13-22)		33 (13)	(8-16)		22 (8)	(5-12)		16 (6)	(3-9)		49 (19)	(14-23)	
Widowed	176	30 (17)	(11-22)		24 (14)	(8-19)		18 (10)	(6-15)		10 (6)	(2-9)		30 (17)	(11-23)	
Never Married	712	32 (5)	(4-7)	<.001	21 (3)	(2-5)	<.001	19 (3)	(2-4)	<.001	9 (1)	(1-3)	<.001	33 (5)	(3-7)	<.001
Education																
Left School Year 12 or before	928	133 (14)	(12-16)		79 (9)	(7-10)		80 (9)	(7-10)		28 (3)	(2-4)		120 (13)	(11-15)	
Still Studying	327	11 (3)	(3-9)		14 (4)	(3-11)		8 (2)	(1-6)		5 (2)	(0-5)		14 (4)	(3-9)	
Cert Dip or Trade	1119	218 (20)	(17-22)		136 (12)	(10-14)		126 (11)	(9-13)		59 (5)	(4-7)		207 (19)	(16-21)	
Bachelor or Higher	682	144 (21)	(18-24)	<.001	95 (14)	(11-17)	<.001	78 (12)	(9-14)	<.001	35 (5)	(3-7)	.003	26 (19)	(15-21)	<.001
Occupation (ANZSCO) codes																
Professionals	957	208(22)	(19-24)		135 (14)	(12-16)		126 (13)	(11-15)		47 (5)	(4-6)		179 (19)	(16-21)	
Clerical and Sales	824	180 (22)	(19-25)		120 (15)	(12-17)		101 (12)	(10-15)		47 (6)	(4-7)		154 (19)	(16-21)	
Blue Collar	911	92 (10)	(8-12)		54 (6)	(4-7)		47 (5)	(4-7)		23 (3)	(2-4)		107 (12)	(10-14)	
Never Worked/ Student/Home Duties	211	19 (9)	(5-13)	<.001	10 (5)	(2-8)	<.001	13 (6)	(3-9)	<.001	9 (4)	(1-7)	.01	21 (10)	(6-14)	<.001

		EPA			EPG			MPA			Living Will			Will		
Demographic	Total N*	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value	Assist N#*(%)	95% CI*	P Value
Annual Income																
\$0-\$40,000	583	90 (15)	(12-18)		64 (11)	(8-13)		46 (8)	(6-10)		26 (5)	(3-6)		90 (15)	(12-18)	
\$40,001-\$80,000	582	81 (14)	(11-17)		60 (10)	(8-13)		54 (9)	(7-12)		16 (3)	(2-4)		87 (15)	(12-18)	
\$80,001+	941	240 (26)	(23-28)		145 (15)	(13-18)		134 (14)	(2-17)		63 (7)	(5-8)		201 (21)	(19-24)	
Not stated	948	95 (10)	(9-13)	<.001	56 (6)	(5-8)	<.001	59 (6)	(5-9)	<.001	22 (2)	(2-4)	<.001	89 (9)	(8-12)	<.001

* Figures in table are for weighted data rounded to whole decimal

Number who responded to question

Source: South Australian Health Omnibus Survey (HOS), Sep-Dec 2012

The percentage of participants that assisted others differed according to age with older people reporting more assistance than younger people: EPA χ^2 (3, N=3055)=182, $p<.001$; EPG χ^2 (3, N=3055)=146, $p<.001$; Will χ^2 (3, N=3055)=117, $p<.001$; MPA χ^2 (3, N=3055)=111, $p<.001$; Living Will χ^2 (3, N=3055)=27, $p<.001$. Participants aged 45-64 more frequently assisted others than any other age group across all of the documents.

In contrast to completion data, there were differences by gender for reported assistance across all documents except the Will with females reporting assistance at a higher percentage than males: EPA χ^2 (1, N=3055)=15, $p<.001$; EPG χ^2 (1, N=3055)=11.90, $p=.001$; Will χ^2 (1, N=3055)=.28, $p=.60$; MPA χ^2 (1, N=3055)=21, $p<.001$; Living Will χ^2 (1, N=3055)=9, $p=.003$.

There was no statistically significant difference for reported assistance between metropolitan and rural participants for any document except the Living Will with participants in the metropolitan area reporting assistance with these documents more often than those in rural areas (χ^2 (1, N=3055)=5, $p=.02$).

Participants born in Australia reported a higher percentage of assistance with all documents than participants born elsewhere except for the Living Will where there was no statistically significant difference: EPA χ^2 (1, N=3055)=11, $p=.001$; EPG χ^2 (1, N=3055)=6, $p=.01$; Will χ^2 (1, N=3055)=7, $p=.01$; MPA χ^2 (1, N=3055)=10, $p=.002$; Living Will χ^2 (1, N=3055)=2, $p=.22$.

For marital status, participants who were married, de facto or widowed had higher percentages of assisting others with all documents compared to participants who had never married or were separated or divorced: EPA χ^2 (4, N=3055)=113, $p=.001$; EPG χ^2 (4, N=3055)=68, $p<.001$; Will χ^2 (4, N=3055)=98, $p<.001$; MPA χ^2 (4, N=3055)=61, $p<.001$; Living Will χ^2 (4, N=3055)=22, $p<.001$.

With regard to education, participants who were still studying were less likely to have reported assisting others with all documents compared to participants with other levels of education: EPA χ^2 (3, N=3055)=61, $p<.001$; EPG χ^2 (3, N=3055)=29, $p<.001$; Will χ^2 (3, N=3055)=49, $p<.001$; MPA χ^2 (3, N=3055)=27, $p<.001$; Living Will χ^2 (3, N=3055)=14, $p=.003$.

Participants in white collar positions (professionals/clerical/sales) were statistically significantly more likely to report assisting others with all documents compared to

blue collar workers or participants who had never worked, were students or had home duties: EPA χ^2 (3, N=3055)=68, $p<.001$; EPG χ^2 (3, N=3055)=52, $p<.001$; Will χ^2 (3, N=3055)=28, $p<.001$; MPA χ^2 (3, N=3055)=43, $p<.001$; Living Will χ^2 (3, N=3055)=12, $p=.01$.

Participants on the highest level of annual income (\$80,001+) reported assisting others with all documents at a greater rate when compared to the other income categories: EPA χ^2 (3, N=3055)=87, $p<.001$; EPG χ^2 (3, N=3055)=45, $p<.001$; Will χ^2 (3, N=3055)=52, $p<.001$; MPA χ^2 (3, N=3055)=38, $p<.001$; Living Will χ^2 (3, N=3055)=26, $p<.001$.

Variables that were non-statistically significant for assistance were: gender for the Will (χ^2 (1, N=3055)=.28, $p=.60$); location for EPA (χ^2 (1, N=3055)=1.68, $p=.19$), EPG (χ^2 (1, N=3055)=2.11, $p=.15$), MPA (χ^2 (1, N=3055)=3, $p=.09$) and Will (χ^2 (1, N=3055)=.36, $p=.55$); and country of birth for the Living Will, χ^2 (1, N=3055)=1.54, $p=.22$.

Frequency and Prevalence of *agency* through the Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG) for the Overall population (N=3055) (Q3)

When asked if they had ever acted as an agent for someone else under the formal EPA or EPG documents, 14% of the Overall population replied “Yes” whilst 86% replied “No” (Figure 3.4).

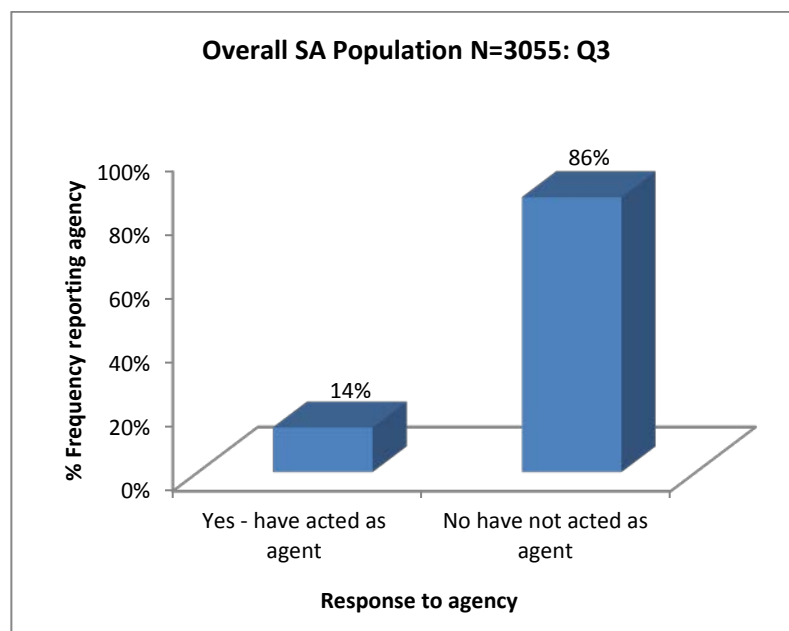


Figure 3.4: Q3 - Frequency of *agency* under the formal Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG) for the Overall population (N=3055)

Table 3.6 describes the statistically significant associations for *agency* for the Overall population (N=3055).

Table 3.6: Q3 - Univariate analysis of the prevalence of agency through EPA or EPG for the Overall population (N=3055)

Yes – I have acted as an agent under EPA or EPG				
Demographic	Total N*	Agency N#*(%)	95% CI*	P value
Age				
15–24	487	5 (1)	(0-3)	
25–44	977	55 (6)	(4-7)	
45–64	990	209 (21)	(18-23)	
65+	601	159 (27)	(23-30)	<.001
Gender				
Male	1494	192 (13)	(11-15)	
Female	1561	237 (15)	(14-18)	0.28
Location				
Metropolitan	2235	322 (14)	(13-16)	
Rural	820	107 (13)	(11-16)	0.16
Birth Country				
Australia	2267	327 (14)	(14-17)	
Other	788	101 (13)	(11-15)	0.24
Marital Status				
Married	1573	282 (18)	(16-20)	
Separated/Divorced	333	41 (12)	(9-16)	
De Facto	261	38 (15)	(10-18)	
Widowed	176	43 (24)	(18-31)	
Never Married	712	24 (3)	(3-6)	<.001
Education				
Left School Year 12 or before	927	135 (15)	(12-17)	
Still Studying	327	11 (3)	(2-9)	
Cert/Dip/Trade/Apprent	1119	192 (17)	(15-19)	
Bachelor +	682	90 (13)	(11-16)	<.001
Occupation				
Professionals	957	152 (16)	(14-18)	
Clerical/Sales	824	148 (18)	(15-21)	
Blue Collar	911	102 (11)	(9-13)	
Never worked/ student/home duties	211	19 (9)	(5-13)	<.001
Annual Income				
\$0–\$40,000	582	117 (20)	(17-23)	
\$40,001–\$80,000	583	72 (12)	(10-15)	
\$80,001+	942	131 (14)	(12-16)	
Not stated	948	108 (11)	(11-15)	<.001

* Figures in table are for weighted data rounded to whole decimal

Number who responded to question

Source: South Australian Health Omnibus Survey (HOS), Sep–Dec 2012

As with completion rates, there was an association with age for acting as an agent with older participants answering yes more frequently compared to younger participants (χ^2 (9, N=3055)=248, $p<.001$) .

The association between marital status and agency showed that participants who were widowed and married were more likely to have answered “yes” compared to participants who had never married (χ^2 (12, N=3055)=110, $p<.001$).

Participants who left school in Year 12 or before, had a Certificate/Diploma/Trade or Apprenticeship, or a Bachelor degree or higher had a greater association with acting as an agent compared to participants who were still studying (χ^2 (9, N=3055)=49, $p<0.001$).

Professional participants and people who worked in the clerical/sales categories had a greater association for agency than participants who had never worked, were students, had home duties or worked in blue collar employment (χ^2 (9, N=3055)=28, $p=.001$).

Interestingly, participants in the lowest annual income category of \$0–\$40,000 had a higher percentage of answering “yes” than participants who had greater income levels (χ^2 (9, N=3055)=34, $p<.001$).

Variables that were statistically non-significant for agency were gender (χ^2 (3, N=3055)=3, $p=.28$); location (χ^2 (3, N=3055)=5, $p=.16$); and country of birth (χ^2 (3, N=3055)=4, $p=.24$).

Multivariate logistic regression analysis of the Overall population (N=3055) comparing *non-completion*, *non-assistance* and *non-agency* (Questions 1-3) with sociodemographic characteristics

Multivariate binary logistic regression analysis of sociodemographic characteristics of *non-completion*, *non-assistance* and *non-agency* are displayed in Table 3.7.

Table 3.7: Multivariate analysis for the Overall population (N=3055), Q1–3: non-completion, non-assistance, non-agency

Demographic	Total N*	Q1: Did Not Complete Any Documents					Q2: Did Not Assist with Any Documents					Q3: Have Not Acted as EPA or EPG				
		N**	% (95% CI)*	Odds Ratio	95% CI	P Value	N**	% (95% CI)*	Odds Ratio	95% CI	P Value	N**	% (95% CI)*	Odds Ratio	95% CI	P Value
Age																
15–24	487	451	93 (88-94)	55.3	[31.29, 97.68]	<.001	461	95 (91-96)	5.0	[2.83, 8.89]	<.001	482	99 (98-100)	.1	[0.02, 0.13]	<.001
25–44	977	670	69 (66-71)	25.9	[17.26, 36.05]	<.001	773	79 (77-82)	2.1	[1.55, 2.75]	<.001	920	94 (93-96)	.2	[0.11, 0.23]	<.001
45–64	990	270	27 (25-30)	4.4	[3.15, 6.27]	<.001	598	60 (58-64)	.8	[0.63, 1.05]	.11	776	78 (77-83)	.7	[0.53, 0.92]	.01
65+ (Reference)	601	60	10 (8-12)	1			424	71 (67-74)	1			439	73 (70-78)	1		
Gender																
Male	1494	727	49 (44-49)	.9	[0.77, 1.16]	.58	1144	77 (74-78)	1.2	[1.02, 1.51]	.03	1295	87 (86-89)	.9	[0.71, 1.16]	.46
Female (Reference)	1561	724	46 (41-46)	1			1112	71 (68-72)	1			1321	85 (82-86)	1		
Location																
Metropolitan (Reference)	2235	1097	49 (45-49)	1			1639	73 (70-74)	1			1908	85 (84-87)	1		
Rural/Regional	820	354	43 (38-45)	.8	[0.63, 0.98]	.03	617	75 (71-77)	1.0	[0.85, 1.28]	.69	714	86 (85-90)	.8	[0.62, 1.05]	.11
Birth Country																
Australia (Reference)	2267	1055	47 (42-46)	1			1641	72 (69-73)	1			1934	85 (84-87)	1		
Other	788	396	50 (45-52)	2.0	[1.57, 2.43]	<.001	615	78 (75-81)	1.6	[1.32, 2.00]	<.001	682	87 (85-90)	.7	[0.53, 0.88]	.003
Marital Status																
Married (Reference)	1573	483	31 (28-33)	1			1034	66 (63-68)	1			1285	82 (81-85)	1		
Separated/Divorced	333	225	68 (63-73)	2.8	[2.09, 3.76]	<.001	264	80 (75-84)	1.5	[1.10, 2.03]	.01	292	88 (84-91)	1.2	[0.85, 1.82]	.26
De Facto	261	109	42 (36-48)	1.8	[1.27, 2.42]	.001	188	72 (67-78)	1.3	[0.98, 1.82]	.07	222	85 (82-91)	.7	[0.45, 0.99]	.05
Widowed	176	24	14 (9-19)	1.0	[0.60, 1.67]	.99	127	72 (65-79)	1.2	[0.85, 1.82]	.26	131	74 (70-84)	.9	[0.62, 1.38]	.69
Never Married	712	609	86 (80-86)	3.1	[2.23, 4.19]	<.001	642	90 (86-91)	1.6	[1.17, 2.31]	.004	687	97 (94-98)	.7	[0.43, 1.17]	.18
Education																
Left School Year 12 or before	927	372	40 (37-43)	1.5	[1.13, 1.85]	.003	708	76 (74-79)	1.5	[1.19, 1.87]	.001	785	85 (84-89)	.6	[0.48, 0.83]	.001
Still Studying	327	277	85 (70-82)	1.2	[0.69, 1.95]	.57	295	90 (79-90)	1.0	[0.64, 1.68]	.89	315	96 (91-98)	.7	[0.35, 1.41]	.32
Cert/Dip/Trade/Apprent (Reference)	1119	467	42 (39-45)	1			788	70 (68-73)	1			926	83 (81-85)	1		
Bachelor+	682	335	49 (45-53)	1.5	[1.13, 1.96]	.01	466	68 (65-72)	1.1	[0.86, 1.43]	.41	589	87 (85-90)	.8	[0.54, 1.04]	.08

		Q1: Did Not Complete Any Documents					Q2: Did Not Assist with Any Documents					Q3: Have Not Acted as EPA or EPG				
Demographic	Total N*	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value
Occupation (ANZSCO Codes)																
Professionals (Reference)	957	410	43 (40-46)	1			647	68 (65-71)	1			803	84 (82-87)	1		
Clerical/Sales	824	315	38 (35-42)	1.0	[0.78, 1.33]	.88	562	68 (65-71)	1.0	[0.79, 1.26]	.96	676	82 (79-85)	1.0	[0.75, 1.35]	.96
Blue Collar	911	446	49 (46-52)	1.6	[1.22, 2.18]	.001	738	81 (78-84)	1.6	[1.24, 2.13]	<.001	803	89 (87-92)	.6	[0.44, 0.86]	.004
Never worked/ Student/ Home Duties	211	146	69 (63-76)	2.2	[1.37, 3.58]	.001	169	80 (74-85)	0.8	[0.55, 1.29]	.43	190	90 (88-96)	.8	[0.43, 1.37]	.37
Annual Income																
\$0-\$40,000	582	210	36 (32-40)	1.2	[0.89, 1.70]	.21	433	74 (71-78)	1.0	[0.78, 1.40]	.79	464	80 (77-84)	1.4	[0.96, 1.96]	.09
\$40,001-\$80,000 (Ref)	583	294	51 (46-54)	1			440	76 (72-79)	1			510	88 (85-91)	1		
\$80,001+	942	397	42 (38-44)	.6	[0.46, 0.79]	<.001	598	64 (60-67)	0.6	[0.49, 0.82]	<.001	810	86 (84-88)	1.1	[0.80, 1.57]	.52
Not Stated	948	550	58 (50-56)	.8	[0.63, 1.11]	.23	784	83 (80-85)	1.2	[0.87, 1.51]	.32	832	88 (86-90)	1.3	[0.90, 1.79]	.18

* Figures in table are for weighted data rounded to whole decimal.

Number who responded to question

Source: South Australian Health Omnibus Survey (HOS), Sep-Dec 2012

Results of multivariate analysis for the Overall population (N=3055) for *non-completion* (Q1) of Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Living Will and Will

Non-completion rates for any of the four AD documents were significantly and independently associated with age, location, country of birth, marital status, education level, occupation and annual income. There was no statistically significant association between non-completion rates and gender.

Associations for *non-completion* (Q1) were seen across all age groups with participants aged 15–24 55 times more likely than those aged 65+ to report non-completion of any of the documents (OR 55.3, 95% CI [31.30, 97.68], $p < .001$).

Participants living in rural areas were slightly less likely to report that they had not completed any of the documents compared to participants living in the metropolitan area (OR 0.8, 95% CI [0.63, 0.98], $p = .03$).

The odds of a person whose birth country was not Australia not completing documents were twice as high compared to those born in Australia (OR 2.0, 95% CI [1.57, 2.43], $p < .001$).

For marital status, participants who were separated/divorced (OR 2.8, 95% CI [2.10, 3.76], $p < .001$), de facto (OR 1.8, 95% CI [1.27, 2.42], $p = .001$) or never married (OR 3.1, 95% CI [2.23, 4.19], $p < .001$) had a stronger association for reporting non-completion of any documents compared to married participants. There was no difference between those married and widowed (OR 1.0, 95% CI [0.60, 1.67], $p = .99$).

Participants who left school in Year 12 or before (OR 1.5, 95% CI [1.14, 1.85], $p = .003$) and those with a Bachelor degree (OR 1.5, 95% CI [1.13, 1.96], $p = .01$) were nearly twice as likely to report not completing any documents compared to participants with a Certificate/Diploma/Trade or Apprenticeship. There was no statistically significant difference between those still studying and those with a Certificate/Diploma/Trade or Apprenticeship with regard to non-completion of documents (OR 1.2, 95% CI [0.69, 1.95], $p = .57$).

Associations of non-completion of documents with regard to occupation found blue collar workers (OR 1.6, 95% CI [1.22, 2.18], $p = .001$) and participants who had never worked, were students, or undertook home duties (OR 2.2, 95% CI [1.37, 3.58], $p = .001$) more likely to report not having completed any of the documents compared to professionals. There was no difference in association between income categories

except for the \$80,001+ income level (OR 0.6, 95%CI [0.45, 0.79], $p<.001$) where fewer respondents reported not completing any documents compared to participants in the \$40,001–\$80,000 level. However, caution should again be taken in interpreting results regarding income categories, as only 70% of respondents reported their income level.

Results of multivariate analysis for the Overall population (N=3055) with *non-assistance* (Q2) to others with the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Living Will and Will

Results of the multivariate regression analysis for *non-assistance* (Q2) to others with these documents showed that age, gender, birth country, marital status, education, occupation and income were significantly and independently associated with non-assistance. Associations for age and non-assistance were again seen across all age groups with younger age groups most often reporting that they had not assisted anyone with documents compared to participants 45 and older (15–24 OR 5.0, 95% CI [2.83, 8.89]; 25–44 OR 2.1, 95% CI [1.55, 2.75], both $p<.001$).

Unlike completions, there was a slight association with gender for non-assistance with males reporting they had not assisted anyone with the documents when compared to females (OR 1.2, 95% CI [1.02, 1.51], $p=.03$).

There was no association for location but, as with non-completions, participants born in another country were nearly twice as likely as participants born in Australia to indicate that they had not assisted others with ADs (OR 1.6, 95% CI [1.32, 2.00], $p<.001$).

For marital status, participants who were separated/divorced (OR 1.5, 95% CI [1.1, 2.03], $p=.01$) or never married (OR 1.6, 95% CI [1.17, 2.31], $p=.004$) were twice as likely to report not having assisted anyone with documents compared to participants who were married.

The model also indicated that participants who left school in Year 12 or before (OR 1.5, 95% CI [1.19, 1.87], $p=.001$) were less likely to assist compared to those with a Certificate/Diploma/Trade or Apprenticeship; whilst blue collar workers (OR 1.6, 95% CI [1.24, 2.13], $p<.001$) were also least likely to assist compared to Professionals.

Participants with incomes over \$80,001+ were approximately half as likely to report not having assisted anyone with documents (OR 0.6, 95% CI [0.49, 0.82], $p<.001$)

compared to those in the middle income category of \$40,001 - \$80,000.

Results of multivariate analysis for the Overall population (N=3055) for *non-agency* (Q3) through the Enduring Power of Attorney (EPA) or Enduring Power of Guardianship (EPG)

Multivariate binary logistic regression analysis for *non-agency* (acting as an agent under the formal EPA and EPG) identified differences with age, birth country, marital status, education, and occupation.

Age was associated with not having acted as an agent with those under 65 much less likely to have acted as an agent compared to those 65 and older (15–24, OR 0.1, 95% CI [0.00, 0.13], $p < .001$; 25–44, OR 0.2, 95% CI [0.11, 0.23], $p < .001$; and 45–64, OR 0.7, 95% CI [0.53, 0.92], $p = .01$).

There was no association for non-agency with gender or location.

Participants born in a country other than Australia were less associated with acting as an agent compared to those born in Australia (OR 0.7, 95% CI [0.53, 0.88], $p = .003$).

The only statistically significant association for not being an agent under marital status was that of de facto (OR 0.7, 95% CI [0.45, 0.99], $p = .05$) when compared against participants who were married.

Participants who left school in Year 12 or before were statistically significantly associated with non-agency (OR 0.6, 95% CI [0.48, 0.83], $p = .001$) when compared to those with a Certificate/Diploma/Trade or Apprenticeship.

Blue collar workers (OR 0.6, 95% CI [0.44, 0.86], $p = .004$) were less often associated with agency when compared to Professionals.

There was no statistically significant difference for non-agency between income groups.

Summary of results on *completion, assistance, agency and non-completion, non-assistance and non-agency* for the Overall population (N=3055) (Q1-3)

In summary, for completion of and assistance with various AD documents, there were significant differences between and within sociodemographic variables.

Positive associations for *completion* included: older age (45 and older); metropolitan location, particularly for the EPA and Will; being born in Australia; being in a

relationship, either married or de facto, or being a widow; having greater than Year 12 education; and working as a professional. Those in the income category of \$80,001+ were more likely to report completing documents than those in the other income categories.

Negative associations for *completion* included: younger age (44 and younger); not being born in Australia; not being in a relationship (separated, divorced or never married); leaving school in Year 12 or before; working in blue collar occupations or having never worked, being a student, or undertaking home duties. Those in lower income categories were less likely to report completing documents compared to those with higher incomes.

Positive associations for *assistance* included: older age (45 and older); being female; being born in Australia; being in a relationship, whether married or de facto, or being widowed; having greater than Year 12 education; and working as a professional. Those in the income category of \$80,001+ were more likely to report assisting others than those in other income categories.

Negative associations for *assistance* included: younger age (44 and younger); being male; not being born in Australia; not being in a relationship (separated, divorced or never married); leaving school in Year 12 or before; and working in blue collar occupations. Those in lower income categories were less likely to report assisting others compared to those in higher income categories.

With regard to agency, the situation followed a similar trend to completion and assistance. Positive associations with *agency* included: older age; being born in Australia; higher levels of education; and working in a professional occupation.

Negative associations with *agency* included: younger age; not being born in Australia; being in a de facto relationship; leaving school in Year 12 or before; and working in blue collar employment.

On the whole, it seemed that age, country of birth, marital status, education, occupation and income were statistically significantly associated with *completion* and *non-completion* as well as *assistance* and *non-assistance*. In contrast, gender was significantly associated with *non-assistance* only while location was statistically significantly associated with *non-completion* only.

Part 2 - Main analysis: Overall population (N=3055) - Comfort and use with computers, online devices and the online environment as well as preferred mechanism for online Advance Directive knowledge

Frequency and prevalence of comfort with computer, online devices and online use by the Overall population (N=3055) (Q4)

In this section, responses are in relation to Question 4 of Figure 3.1. Frequency analysis will describe use, non-use and comfort levels with a computer, online devices and the Internet. Statistically significant association of sociodemographic factor analysis will focus on comfort and use of the computer, online devices and the Internet while multivariate analysis will describe predictors of non-use of computer, online devices or the Internet. Figure 3.5 illustrates the frequency of computer use, online device use and use of the Internet as well as comfort and non-comfort with the online environment for the Overall population (N=3055).

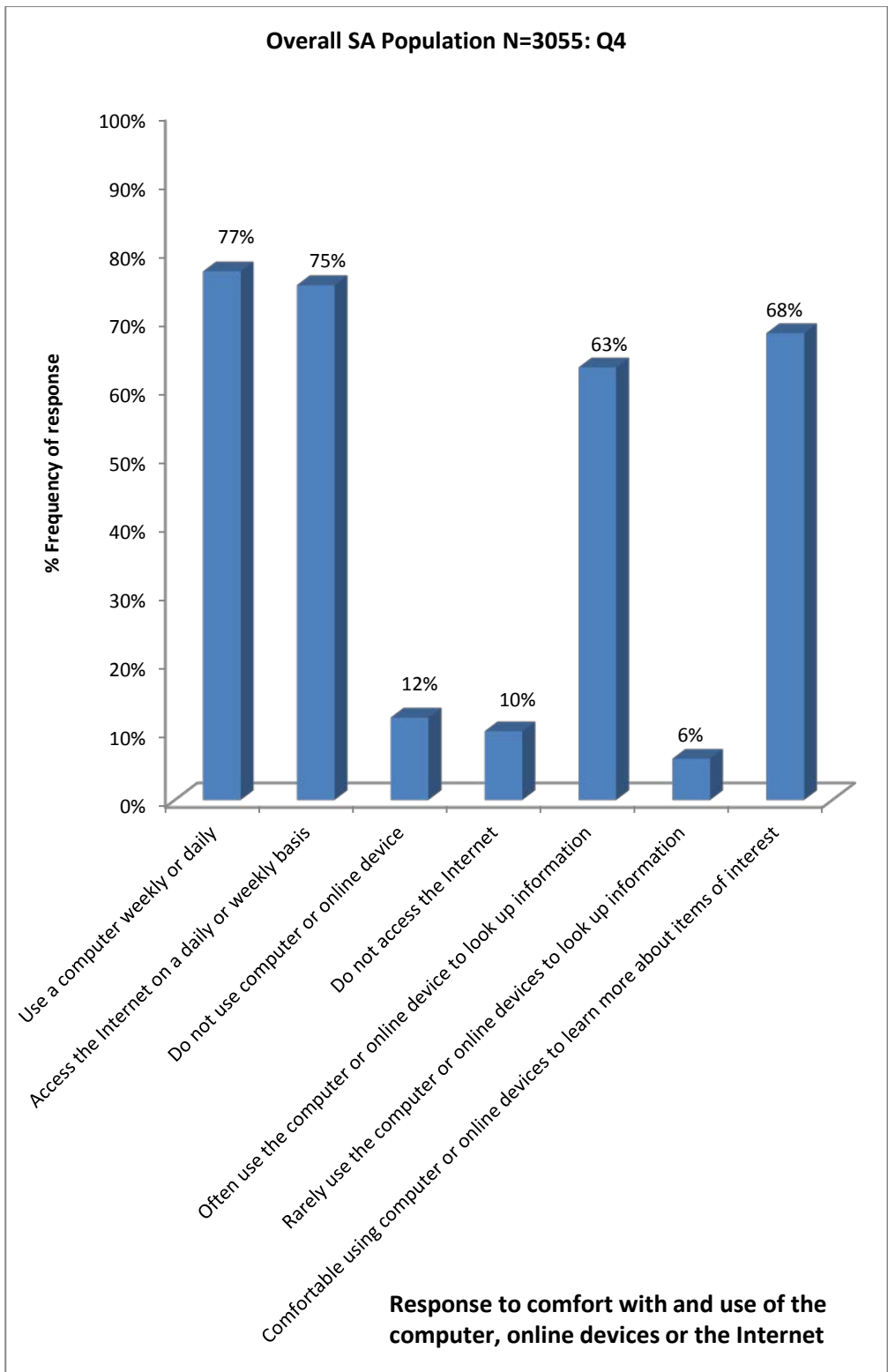


Figure 3.5: Q4 - Frequency of comfort with and use of the computer, online devices or the Internet for the Overall population (N=3055)

A large percentage of the South Australian population use a computer (77%) or the Internet on a daily or weekly basis. Many respondents (68%) reported being comfortable using the computer or online devices to look up information in the online

environment. A very low percentage (12% or less) of the Overall population did not use the computer, online devices, the Internet and were not comfortable with looking up information in the online environment. Table 3.8 describes for the Overall population the statistically significant associations for computer use, online use and comfort in using the online environment for accessing information on ADs.

Discussion of these results will be conducted by combining similar categories for clarity, for example, *Use a computer or online device daily or weekly* with *Access the Internet on daily or weekly basis*. Where there are substantial differences in one category or another, these will be identified in more detail.

Table 3.8: Q4 - Univariate analysis of the prevalence of comfort with and use of the computer and online environment for the Overall population (N=3055)

		Use a computer or online device daily or weekly			Access the Internet on daily or weekly basis			Often use computer or online device to look up information			Comfortable using computer or online device to learn more about items of interest		
Demographic	Total N*	N**(%)	95% CI*	P Value	N**(%)	95% CI*	P Value	N**(%)	95% CI*	P Value	N** (%)	95% CI*	P Value
Age													
15–24	487	448 (92)	(87-94)		415 (85)	(81-89)		374 (77)	(72-81)		390 (80)	(77-85)	
25–44	977	863 (88)	(86-90)		853 (87)	(85-89)		713 (73)	(70-76)		783 (80)	(78-83)	
45–64	990	776 (78)	(76-81)		752 (76)	(73-79)		630 (64)	(60-66)		680 (69)	(66-71)	
65+	601	278 (46)	(42-50)	<.001	262 (44)	(40-48)	<.001	198 (33)	(29-37)	<.001	222 (37)	(33-41)	<.001
Gender													
Male	1494	1165 (78)	(75-79)		1133 (76)	(73-78)		954 (64)	(61-66)		1045 (70)	(67-72)	
Female	1561	1200 (77)	(74-78)	.43	1148 (74)	(71-75)	.14	961 (62)	(58-63)	.18	1030 (66)	(63-68)	.02
Location													
Metropolitan	2235	1789 (80)	(77-81)		1730 (77)	(75-79)		1482 (66)	(64-68)		1604 (72)	(69-73)	
Rural/Regional	820	576 (70)	(66-73)	<.001	551 (67)	(63-70)	<.001	432 (53)	(48-55)	<.001	472 (58)	(54-61)	<.001
Birth Country													
Australia	2267	1777 (78)	(76-79)		1693 (75)	(72-76)		1426 (63)	(60-64)		1561 (69)	(66-70)	
Other	788	589 (75)	(70-77)	.04	589 (75)	(71-77)	.96	489 (62)	(58-65)	.67	514 (65)	(61-68)	.07
Marital Status													
Married	1573	1218 (78)	(75-80)		1183 (75)	(73-77)		968 (62)	(59-64)		1070 (68)	(66-70)	
Separated/Divorced	333	276 (83)	(79-87)		263 (79)	(75-84)		218 (66)	(60-71)		237 (71)	(66-76)	
De Facto	261	186 (71)	(66-77)		184 (71)	(65-76)		154 (59)	(53-65)		158 (61)	(54-66)	
Widowed	176	61 (35)	(27-42)		59 (34)	(26-41)		48 (27)	(20-34)		52 (29)	(22-36)	
Never Married	712	624 (88)	(83-88)	<.001	592 (83)	(80-86)	<.001	526 (74)	(69-77)	<.001	559 (79)	(75-82)	<.001
Education													
Left School Year 12 or before	927	560 (60)	(57-63)		534 (58)	(54-61)		428 (46)	(43-49)		466 (50)	(47-53)	
Still Studying	327	297 (91)	(88-94)		274 (84)	(78-88)		241 (74)	(64-77)		239 (73)	(64-77)	
Cert/Dip/Trade/Apprent	1119	889 (79)	(77-82)		870 (78)	(75-80)		707 (63)	(60-66)		786 (70)	(67-73)	
Bachelor+	682	619 (91)	(89-93)	<.001	604 (89)	(86-91)	<.001	539 (79)	(76-82)	<.001	585 (86)	(83-88)	<.001

Demographic	Total N*	Use a computer or online device daily or weekly			Access the Internet on daily or weekly basis			Often use computer or online device to look up information			Comfortable using computer or online device to learn more about items of interest		
		N#*(%)	95% CI*	P Value	N#*(%)	95% CI*	P Value	N#*(%)	95% CI*	P Value	N#* (%)	95% CI*	P Value
Occupation (ANZSCO Codes)													
Professionals	957	823 (86)	(84-88)		811 (85)	(82-87)		701 (73)	(70-76)		756 (79)	(76-82)	
Clerical/Sales	824	658 (80)	(77-83)		940 (78)	(75-81)		539 (65)	(62-69)		581 (71)	(67-74)	
Blue Collar	911	600 (66)	(63-69)		565 (62)	(59-65)		449 (49)	(46-53)		494 (54)	(51-57)	
Never worked/ Student/Home Duties	211	140 (66)	(60-73)	<.001	138 (65)	(59-72)	<.001	108 (51)	(44-58)	<.001	126 (59)	(53-66)	<.001
Annual Income													
\$0-\$40,000	582	322 (55)	(51-59)		295 (51)	(47-55)		231 (40)	(36-44)		249 (43)	(39-47)	
\$40,001-\$80,000	583	484 (83)	(80-87)		469 (81)	(77-84)		378 (65)	(61-69)		409 (70)	(67-74)	
\$80,001+	942	868 (92)	(90-94)		837 (89)	(87-91)		745 (79)	(76-82)		804 (85)	(83-88)	
Not Stated	948	692 (73)	(67-73)	<.001	681 (72)	(67-73)	<.001	561 (59)	(53-60)	<.001	614 (65)	(60-66)	<.001

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

Source: South Australian Health Omnibus Survey, Sep-Dec 2012

Use of a computer or the Internet on a daily/weekly basis by the Overall population (N=3055) (Q4)

Fewer than half (46%) of participants in the 65 and older age group reported using a computer on a daily or weekly basis compared to other age groups (χ^2 (3, N=3055) =461, $p<.001$). The same trend applied in the reported use of the Internet, with participants aged 65 and older using the Internet less than half of the time (44%) on a daily or weekly basis compared to other age groups (χ^2 (3, N=3055)=420, $p<.001$).

Participants in metropolitan locations were statistically significantly associated with using both the computer (χ^2 (1, N=3055) =32, $p<.001$) and the Internet (χ^2 (1, N=3055) =33, $p<.001$) on a daily or weekly basis compared to participants in rural areas.

Participants born in countries other than Australia reported using the computer less often than those born in Australia (χ^2 (1, N=3055) =4, $p=.04$).

Widowed participants were statistically significantly more likely to be associated with reporting less use of the computer or Internet compared to other marital categories (computer χ^2 (4, N=3055) =238, $p<.001$; Internet χ^2 (4, N=3055) =190, $p<.001$).

Participants who were still studying were equally associated with participants who had a Bachelor degree in using a computer or accessing Internet on a daily or weekly basis (computer χ^2 (3, N=3055) =263, $p<.001$; Internet χ^2 (3, N=3055) =234, $p<.001$).

For occupation, participants in the group who had never worked, were students, or undertook home duties and participants in blue collar employment were equally associated with lower levels of computer and Internet use (computer χ^2 (3, N=3055)=124, $p<.001$; Internet χ^2 (3, N=3055)=140, $p<.001$).

Participants at the income level of \$0-\$40,000 were associated with less computer and Internet use compared to participants in the other income brackets (computer χ^2 (3, N=3055)=303, $p<.001$; Internet χ^2 (3, N=3055)=295, $p<.001$).

Variables that were not statistically significant for association with computer and Internet use included gender (computer χ^2 (1, N=3055) =0.64, $p=.43$; Internet χ^2 (1, N=3055) =2, $p=.14$) and country of birth for Internet access (χ^2 (1, N=3055)=0.00, $p=.96$).

Comfort and use of online devices and environment for seeking information by the Overall population (N=3055) (Q4)

There were differences in comfort and use of online devices and the online environment for seeking information across all sociodemographic categories except country of birth.

Age was associated with reporting less use of online devices for information. Participants 65 or older less often used the online environment for information (33%) and were less comfortable doing so (37%) compared to younger age groups: use – ages 15-24, 77%, ages 25-44, 73%, ages 45-64, 64% χ^2 (3, N=3055)=313, $p<001$; comfort – ages 15-24, 80%, ages 25-44, 80%, ages 45-64, 69% χ^2 (3, N=3055)=365, $p<001$.

There was an association by gender for comfort in using the online environment for information on ADs with males more likely (70%) than females (66%, χ^2 (1, N=3055) =5.6, $p=.02$) to report being comfortable using the online environment for this purpose.

For location, participants in rural areas used online devices less for information (53%) than metropolitan participants (66%, χ^2 (1, N=3055) =47, $p<001$) and had less comfort (58%) than metropolitan participants (72%) using the online environment for information (χ^2 (1, N=3055) =55, $p<001$).

Marital status was associated with use of online devices and comfort in using them for information. Widows and widowers were less likely to report using online devices for information (27%, χ^2 (4, N=3055)=135, $p<001$) or being comfortable using the online environment for information (29%, χ^2 (4, N=3055)=165, $p<001$) compared to participants who were married=62% and 68%, respectively; separated/divorced=66% and 71%, respectively; de facto=59% and 61%, respectively; and never married=74% and 79%, respectively.

In relation to education, participants who left school in Year 12 or before had lower rates of use of online devices for information (46%, χ^2 (3, N=3055)=203, $p<001$) and comfort using the online environment for information (50%, χ^2 (3, N=3055)=240, $p<001$ for comfort) than participants still studying (use – 74%, comfort – 73%); participants with a Cert/Diploma/Trade/Apprenticeship (use – 63%, comfort – 70%) and those with a Bachelor degree or above (use – 79%, comfort- 86%).

Blue collar participants were less likely to report use of online devices for information (49%, χ^2 (3, N=3055) =247, $p<001$) compared to those who had never worked, were students, or undertook home duties (51%), clerical/sales (65%) or professionals (73%). Blue collar workers had less comfort with the online environment for information (54%, χ^2 (3, N=3055) =140, $p<001$) compared to participants who never worked, were students or undertook home duties (59%), clerical/sales (71%) or professionals (79%).

Participants in the lowest income bracket of \$0-\$40,000 used the online environment less for information (40%, χ^2 (3, N=3055)=247, $p<001$) and had the lowest comfort levels in using the online environment for information (43%, χ^2 (3, N=3055)=308, $p<001$) compared to participants in other income brackets (65% for use and 70% for comfort for those in the \$40,000-\$80,000 bracket and 79% for use and 85% for comfort for those in the \$80,001+ bracket).

Variables that were non-significant for use of online devices for information were gender (χ^2 (1, N=3055) =1.8, $p=.18$) and country of birth (χ^2 (1, N=3055) =0.2, $p=.67$). Only country of birth was non-significant for comfort using the online environment for information (χ^2 (1, N=3055) =3.4, $p=.07$).

Multivariate logistic regression analysis of *non-use of a computer or online device* by sociodemographic characteristics for the Overall population (N=3055) (Q4)

Table 3.9 illustrates the multivariate binary logistic regression analysis of sociodemographic characteristics associated with participants who reported not using a computer or online device at all.

Table 3.9: Multivariate analysis for the Overall population (N=3055) Q4:– non-use of a computer or online device

Q4: Do not use a computer or online device					
Demographic	N [#]	% (95% CI) [*]	Odds Ratio	95% CI	P Value
Age					
15–24	8	2 (0-3)	.02	[0.01, 0.06]	<.001
25–44	21	2 (1-3)	.05	[0.03, 0.09]	<.001
45–64	106	11 (9-13)	.26	[0.19, 0.36]	<.001
65+ (Reference)	243	40 (37-44)	1		
Gender					
Male	158	11 (9-13)	.9	[0.62, 1.16]	.31
Female (Reference)	219	14 (13-16)	1		
Location					
Metropolitan (Reference)	240	11 (10-13)	1		
Rural/Regional	137	17 (15-20)	1.1	[0.79, 1.42]	.70
Birth Country					
Australia (Reference)	262	12 (11-13)	1		
Other	116	15 (13-18)	1.1	[0.80, 1.47]	.59
Marital Status					
Married (Reference)	184	12 (10-13)	1		
Separated or Divorced	31	9 (6-12)	2.3	[1.40, 3.76]	.001
De Facto	42	16 (12-20)	1.2	[0.78, 1.88]	.39
Widowed	91	51 (44-59)	2.4	[1.58, 3.54]	<.001
Never Married	31	4 (3-7)	2.0	[1.12, 3.41]	.02
Education					
Left School Year 12 or before	261	28 (25-31)	2.6	[1.93, 3.57]	<.001
Still Studying	8	2 (1-6)	.6	[0.25, 1.56]	.32
Cert/Dip/Trade/Apprent (Reference)	99	9 (7-11)	1		
Bachelor+	10	2 (0-2)	.4	[0.18, 0.73]	.01
Occupation (ANZSCO Codes)					
Professionals (Reference)	48	5 (4-6)	1		
Clerical/Sales	96	12 (9-14)	1.2	[0.76, 1.82]	.46
Blue Collar	187	21 (18-23)	2.8	[1.80, 4.26]	<.001
Never worked/Student/Home Duties	44	21 (15-26)	2.9	[1.63, 5.28]	<.001
Annual Income					
\$0–\$40,000	184	32 (28-35)	2.0	[1.32, 2.99]	.001
\$40,001–\$80,000 (Reference)	45	8 (6-10)	1		
\$80,001+	21	2 (1-3)	.5	[0.29, 0.92]	.02
Not Stated	127	13 (13-17)	1.5	[0.99, 2.25]	.06

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Results of multivariate analysis for non-use of the computer or online devices for the Overall population (N=3055) (Q4)

The trends from the multivariate logistic regression analysis are similar to those of

the univariate analysis.

For the Overall population, there was a statistically significant difference by age for non-computer/device use. Participants in the oldest age category were 50 times more likely to report non-use than those in the youngest age category (OR .02, 95% CI [0.01, 0.06], $p < .001$). As age increased, the reporting of non-use decreased with participants aged 25–44 20 times less likely to report non-use (OR .05, 95% CI [0.03, 0.09]) while participants aged 45–64 were four times less likely to report non-use (OR .26, 95% CI [0.19, 0.36]).

There was a positive association for non-use of computers or the online environment with marital status. Participants who were widowed (OR 2.4, 95% CI [1.58, 3.54], $p < .001$) separated or divorced (OR 2.3, 95% CI [1.40, 3.76], $p = .001$), or never married (OR 2.0, 95% CI [1.12, 3.41], $p = .02$) were more likely to report non-use compared to participants in a married relationship.

With regard to education, participants who left school in Year 12 or before (OR 2.6, 95% CI [1.93, 3.57], $p < .001$) were nearly three times more likely to report non-use compared to participants with a Certificate/Diploma/Trade or Apprenticeship. Participants with a Bachelor degree or higher (OR 0.4, 95% CI [0.18, 0.73], $p = .01$) were least likely to be associated with non-use compared to the Cert/Dip/Trade/Apprentic group.

The regression with employment showed that participants who never worked, were students, or undertook home duties (OR 2.9, 95% CI [1.63, 5.28]) and participants who worked in blue collar employment (OR 2.7, 95% CI [1.80, 4.26]) were positively associated with non-use ($p < .001$ for both) when compared to participants in a professional occupation.

For income, participants in the lowest income bracket of \$0–\$40,000 were twice as likely to report non-use of computers or online devices (OR 2.0, 95% CI [1.32, 3.00], $p = .001$) when compared to participants earning \$40,001–\$80,000. Participants in the highest income bracket of \$80,001+ were least likely to report non-use (OR 0.5, 95% CI [0.29, 0.92], $p = .02$).

Summary of results on comfort and use of the computer and online devices for the Overall population (N=3055) (Q4)

Similar to the results from the multivariate analysis of questions 1–3, comfort with using the computer and online environment is predominantly age-dependent.

Positive associations with *computer, online devices and online use* included younger age, living in a metropolitan location, being in a relationship, having levels of education above Year 12, being employed in a professional occupation, and having an annual income above \$40,000.

Negative associations with *computer, online devices and online use* included: older age; being separated, divorced, widowed or never married; leaving school before Year 12; working in blue collar employment; or not being employed and having an annual income below \$40,000.

As there was no multivariate association for gender, location or country of birth, it is clear that the influence of lower socioeconomic status indicates that not only does lower socioeconomic status influence completion, assistance and agency, but it also influences engagement with the online environment to access knowledge about advance directives.

Frequency and prevalence of the Overall population (N=3055) (Q5) to use various online and offline mechanisms for learning about Advance Directives

This analysis shows frequency and prevalence of preferred online or offline means for engagement with ADs by the Overall population. Figures and tables in this section represent responses to Question 5 of Figure 3.1. In the first instance, frequency analysis will describe online and offline preferences and non-interest in learning about ADs. As with the previous section for computer and online use, analysis of statistically significant association of sociodemographic characteristics will focus on preferred online offline choices. Multivariate analysis will describe predictors of those not interested in learning about advance directives at all.

Figure 3.6 illustrates the frequency with which the Overall population (N=3055) expressed their preference for particular online and offline means for learning about ADs and non-interest in learning about ADs.

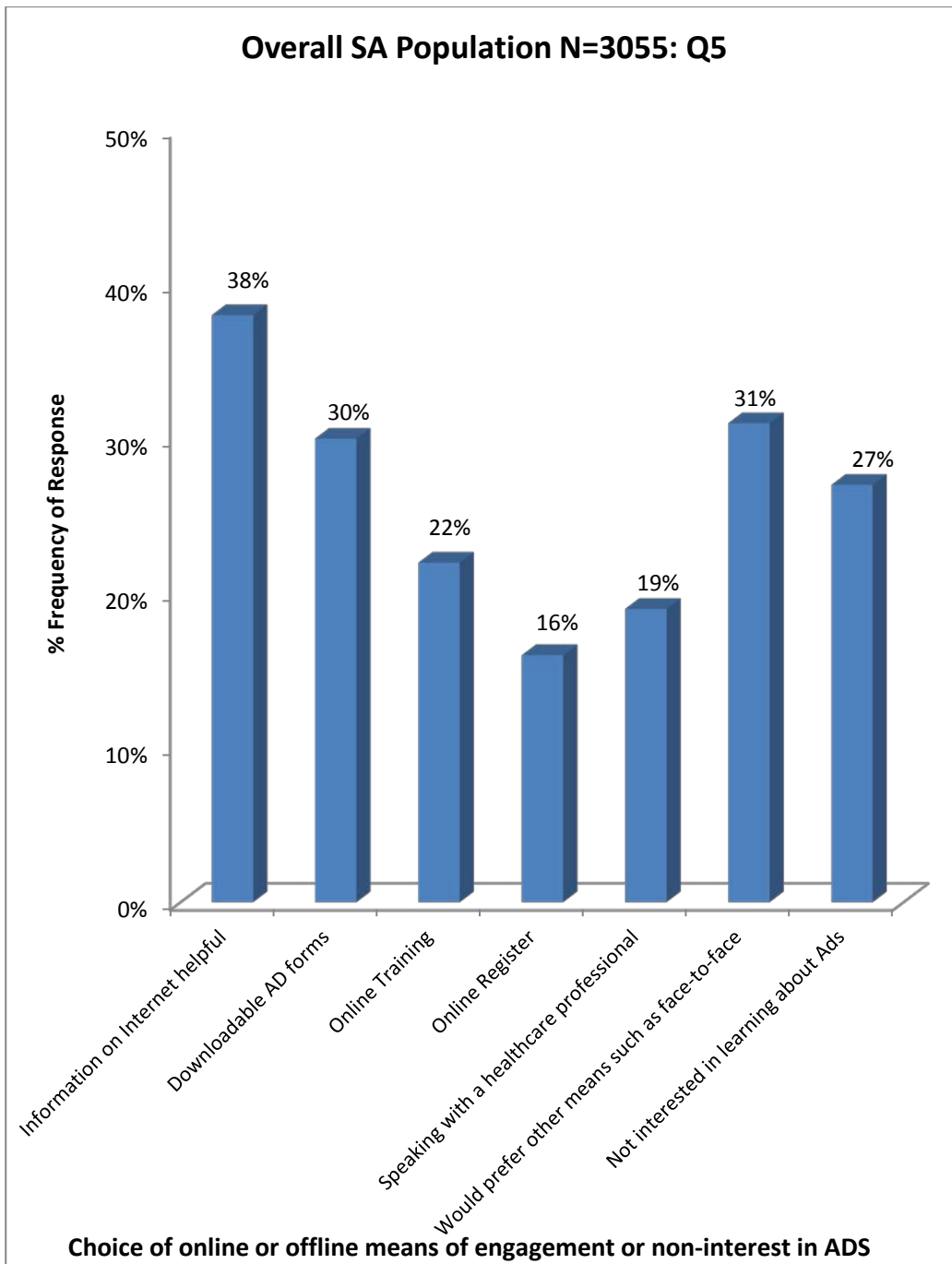


Figure 3.6: Q5 - Frequency of online or offline means of engagement for learning about Advance Directives and non-interest in learning about Advance Directives for the Overall population (N=3055)

Figure 3.6 shows that 38% of people in the Overall population thought information on the Internet about ADs would be helpful while 30% reported a preference for downloadable ADs. There was almost equal representation (31%) of participants who preferred other means for information on ADs such as face-to-face or telephone consultation (known from this point onwards as *other means*). Other online mechanisms of access such as online training on how to complete an advance directive (22%), an online register (16%) or speaking with a healthcare professional

online (19%) were less often chosen as a preference. Respondents had the option of more than one choice so results are not exclusive. The level of non-interest in learning about advance directives at all was 27%. Table 3.10 describes the statistically significant associations of sociodemographic characteristics for different online and offline preferences.

Table 3.10: Q5 - Univariate analysis of the prevalence by the Overall population (N=3055) of preferred online and offline means for learning about Advance Directives

Demographic	Total N*	Information via the Internet would be helpful			AD forms that could be downloaded as a paper copy would be helpful			Online training about how to complete ADs would be helpful			Online register to file ADs would be helpful			Speaking with a legal or healthcare professional online to answer questions would be helpful			I would prefer other means of learning about or completing ADs such as face-to-face or telephone		
		N#*(%)	95% CI*	P value	N#*(%)	95% CI*	P value	N#* (%)	95% CI*	P value	N#* (%)	95% CI*	P value	N#*(%)	95% CI*	P value	N#*(%)	95% CI*	P value
Age																			
15–24	487	168 (35)	(34-44)		116 (24)	(21-31)		103 (21)	(19-28)		56 (12)	(8-15)		67 (14)	(10-17)		86 (18)	(18-26)	
25–44	977	462 (47)	(44-50)		360 (37)	(34-40)		277 (28)	(25-31)		211 (22)	(19-24)		235 (24)	(21-27)		264 (27)	(24-30)	
45–64	990	421 (43)	(39-45)		350 (35)	(32-38)		238 (24)	(21-26)		177 (18)	(15-20)		198 (20)	(18-23)		331 (33)	(30-36)	
65+	601	104 (17)	(14-20)	<.001	86 (14)	(12-17)	<.001	63 (11)	(8-13)	<.001	35 (6)	(4-8)	<.001	65 (11)	(8-13)	<.001	259 (43)	(39-47)	<.001
Gender																			
Male	1494	573 (38)	(37-42)		421 (28)	(27-31)		320 (21)	(20-24)		214 (14)	(13-16)		263 (18)	(16-20)		431 (29)	(28-32)	
Female	1561	582 (37)	(35-40)	.54	491 (31)	(29-34)	.05	362 (23)	(21-25)	.25	265 (17)	(15-19)	.04	302 (19)	(17-21)	.22	509 (33)	(31-36)	.03
Location																			
Metropolitan	2235	937 (42)	(41-45)		712 (32)	(30-34)		567 (25)	(24-27)		404 (18)	(17-20)		459 (21)	(19-23)		693 (31)	(30-34)	
Rural/Regional	820	218 (27)	(24-30)	<.001	200 (24)	(21-28)	<.001	115 (14)	(12-17)	<.001	75 (9)	(7-11)	<.001	105 (13)	(10-15)	<.001	247 (30)	(28-34)	.64
Birth Country																			
Australia	2267	862 (38)	(37-41)		675 (30)	(28-32)		495 (22)	(20-24)		370 (16)	(15-18)		419 (19)	(17-20)		705 (31)	(30-34)	
Other	788	293 (37)	(34-41)	.68	236 (30)	(27-33)	.91	187 (24)	(21-27)	.26	109 (14)	(11-16)	.10	145 (18)	(16-22)	.96	235 (30)	(27-34)	.50
Marital Status																			
Married	1573	671 (43)	(40-45)		527 (34)	(31-36)		382 (24)	(22-26)		270 (17)	(15-19)		325 (21)	(19-23)		525 (33)	(31-36)	
Separated/ Divorced	333	133 (40)	(35-45)		114 (34)	(29-39)		86 (26)	(21-31)		69 (21)	(16-25)		69 (21)	(16-25)		85 (26)	(21-30)	
De Facto	261	87 (33)	(28-39)		78 (30)	(24-36)		56 (22)	(17-27)		47 (18)	(13-23)		45 (17)	(13-22)		96 (37)	(31-42)	
Widowed	176	21 (12)	(7-17)		16 (9)	(5-13)		13 (7)	(3-11)		6 (3)	(1-6)		12 (7)	(3-10)		77 (44)	44 (36-51)	
Never Married	712	243 (34)	(33-41)	<.001	177 (25)	(23-30)	<.001	145 (20)	(18-25)	<.001	88 (12)	(10-16)	<.001	114 (16)	(13-20)	<.001	157 (22)	22 (22-29)	<.001
Education																			
Left School Year 12 or before	927	214 (23)	(20-26)		182 (20)	(17-22)		120 (13)	(11-15)		78 (8)	(7-10)		116 (13)	(10-15)		316 (34)	34 (31-37)	
Still Studying	327	112 (34)	(34-39)		77 (24)	(21-34)		66 (20)	(17-21)		40 (12)	(8-18)		55 (17)	(13-24)		51 (16)	16 (17-28)	

Demographic	Total N*	Information via the Internet would be helpful			AD forms that could be downloaded as a paper copy would be helpful			Online training about how to complete ADs would be helpful			Online register to file ADs would be helpful			Speaking with a legal or healthcare professional online to answer questions would be helpful			I would prefer other means of learning about or completing ADs such as face-to-face or telephone		
		N** (%)	95% CI*	P value	N** (%)	95% CI*	P value	N** (%)	95% CI*	P value	N** (%)	95% CI*	P value	N** (%)	95% CI*	P value	N** (%)	95% CI*	P value
Cert/Dip/Trade/Apprent	1119	443 (40)	(37-42)		353 (32)	(29-34)		270 (24)	(22-27)		192 (17)	(15-19)		201 (18)	(16-20)		378 (34)	34 (31-37)	
Bachelor+	682	387 (57)	(53-61)	<.001	299 (44)	(40-47)	<.001	226 (33)	(29-36)	<.001	169 (25)	(22-28)	<.001	193 (28)	(25-32)	<.001	195 (29)	29 (25-32)	<.001
Occupation (ANZSCO Codes)																			
Professionals	957	476 (50)	(47-53)		374 (39)	(36-42)		276 (29)	(26-32)		205 (21)	(19-24)		226 (24)	(21-26)		302 (32)	32 (29-35)	
Clerical/Sales	824	332 (40)	(37-44)		270 (33)	(30-36)		211 (26)	(23-29)		159 (19)	(17-22)		186 (23)	(20-25)		264 (32)	32 (29-35)	
Blue Collar	911	256 (28)	(25-31)		189 (21)	(18-23)		135 (15)	(13-17)		81 (9)	(7-11)		111 (12)	(10-14)		301 (33)	33 (30-36)	
Never worked/Student/Home Duties	211	52 (25)	(19-30)	<.001	48 (23)	(17-29)	<.001	31 (15)	(10-20)	<.001	17 (8)	(4-12)	<.001	22 (10)	(6-14)	<.001	57 (27)	27 (21-33)	.40
Annual Income																			
\$0-\$40,000	582	124 (21)	(18-25)		102 (18)	(14-21)		79 (14)	(11-16)		37 (6)	(4-8)		76 (13)	(10-16)		231 (40)	40 (35-43)	
\$40,001-\$80,000	583	250 (43)	(39-48)		203 (35)	(31-39)		153 (26)	(23-30)		107 (18)	(15-22)		131 (23)	(19-26)		202 (35)	35 (31-39)	
\$80,001+	942	523 (56)	(53-59)		422 (45)	(42-48)		316 (34)	(31-37)		260 (28)	(25-31)		253 (27)	(24-30)		251 (27)	27 (24-30)	
Not Stated	948	258 (27)	(25-31)	<.001	184 (19)	(17-22)	<.001	134 (14)	(12-16)	<.001	75 (8)	(6-9)	<.001	104 (11)	(9-13)	<.001	257 (27)	27 (26-33)	<.001

* N = figures in table are for weighted data rounded to whole decimal.

Number who responded to question

Source: South Australian Health Omnibus Survey, Sep-Dec 2012

There was a statistically significant association by age in the Overall population for online information assistance with advance directives.

All younger age groups were more likely to prefer information on the Internet when compared to the 65+ age group (17%, χ^2 (3, N=3055) =156, $p<.001$). However, the youngest participants were least likely to prefer information on the Internet (35%) compared to participants in the 25–44 (47%) and 45–64 (43%) age groups. The age trend was also true for downloadable AD forms with participants 65+ least likely to prefer this option (14%, χ^2 (3, N=3055) =115, $p<.001$).

Preference for online training on how to complete ADs showed an association with age as well. Participants 65+ were least likely to prefer this option (11%, χ^2 (3, N=3055)=71, $p<.001$) compared to participants in the 15-24 age group (21%), 25-44 age group (28%) and 45-64 age group (24%).

Preference for the use of an online register for lodging completed ADs was predominantly between the middle age ranges rather than younger ages when compared to participants aged 65+ (15-24, 12%; 25–44, 22%; 45–64, 18%; 65+, 6%, χ^2 (3, N=3055)=79, $p<.001$).

The trend for speaking with a healthcare professional about ADs was similar to that of an online register. Association with this preference was predominantly between the middle range age groups when compared to participants aged 65+ (15-24, 14%; 25-24, 24%; 45-64, 20%; 65+, 11%, χ^2 (3, N=3055) =52, $p<.001$).

The association with a preference for offline means of engagement was the reverse to online preferences with the strongest association for offline preference in the 65+ age group (43%, χ^2 (3, N=3055) =92, $p<.001$) when compared to the other age groups (15-24, 18%, 25-44, 27%; 45-64, 33%).

There was an association between gender for downloadable forms with females (31%) preferring this method more than males (28%, χ^2 (1, N=3055) =3.9, $p=.05$). The same gender association was true for an online register (females 17%, males 14%, χ^2 (1, N=3055) =4.1, $p=.04$) and for offline means of engagement (females 33%, males 29%, χ^2 (1, N=3055) =5, $p=.03$).

There was a statistically significant association for use between all online formats and location. Participants in metropolitan areas had a much stronger association for online means of engagement than those in rural areas: Information on the Internet

(42% metro, 27% rural, χ^2 (1, N=3055)=60, $p<.001$); downloadable forms (32% metro, 24% rural, χ^2 (1, N=3055)=16, $p<.001$); online training (25% metro, 14% rural, χ^2 (1, N=3055)=44, $p<.001$); an online register (18% metro, 9% rural, χ^2 (1, N=3055)=36, $p<.001$); and speaking with a healthcare professional for advice online (21% metro, 13% rural, χ^2 (1, N=3055)=24, $p<.001$).

Similarly, there was a statistically significant association between marital status and online mechanisms as well as preference for offline learning. In general, participants who were widowed were least likely to prefer online mechanisms when compared to other marital groups: information on Internet, χ^2 (4, N=3055)=156, $p<.001$; online forms, χ^2 (4, N=3055)=58, $p<.001$; online training, χ^2 (4, N=3055)=30, $p<.001$; online register, χ^2 (4, N=3055)=36, $p<.001$; online healthcare professional, χ^2 (4, N=3055)=25, $p<.001$). Widows (44%) and participants in de facto relationships (37%) were associated more with preference for offline means of engagement compared to participants who were married (33%), separated/divorced (26%) or never married (22%, χ^2 (3, N=3055)=53, $p<.001$).

There was an association between education and online engagement. Participants who had a Cert/Dip/Trade/Apprenticeship or a Bachelor degree had a greater preference for all online means of engagement. Participants who left school before Year 12 had the least preference for this choice (23%, χ^2 (3, N=3055) =193, $p<.001$). There was a statistically significant association for offline means of engagement with participants who were still studying (16%) favouring this option the least when compared to participants with a Cert/Dip/Trade/Apprenticeship (34%, χ^2 (3, N=3055) =46, $p<.001$).

For occupation, participants who had never worked, were students or undertook home duties were equal to blue collar workers in association for less preference of online options when compared to participants in clerical/sales or professional positions: information on the Internet, χ^2 (3, N=3055)=111, $p<.001$; downloadable forms, χ^2 (3, N=3055)=82, $p<.001$; online training, 15%, χ^2 (3, N=3055)=65, $p<.001$; online register, 8%, χ^2 (3, N=3055)=72, $p<.001$; speaking with a healthcare professional online, 10%, χ^2 (3, N=3055)=58, $p<.001$.

With regard to income, statistically significant association showed that participants in the lowest bracket of income (\$0-\$40,000) had the least preference for online means of engagement: information on the Internet, χ^2 (3, N=3055)=245, $p<.001$;

online forms, χ^2 (3, N=3055)=200, $p<.001$; online training, χ^2 (3, N=3055)=136, $p<.001$; online registration, χ^2 (3, N=3055)=186, $p<.001$; speaking with a healthcare professional online, χ^2 (3, N=3055)=97, $p<.001$. The trend was reversed however for offline means of engagement with participants in the lowest income bracket of \$0–\$40,000 preferring this option more than the other income brackets, χ^2 (3, N=3055)=39, $p<.001$.

There was no statistically significant association between country of birth and any online or offline means of engagement: information on the Internet, χ^2 (3, N=3055)=0.18, $p=.68$; downloadable forms, χ^2 (3, N=3055)=0.01, $p=0.91$; online training χ^2 (3, N=3055)=1.3, $p=.26$; online register, χ^2 (3, N=3055)=2.7, $p=.01$; speaking with a healthcare professional online, χ^2 (3, N=3055)=.003, $p=.96$; offline means of engagement, χ^2 (3, N=3055)=0.45, $p=.50$.

There was also no statistically significant association for preference for offline means of engagement with regard to location, (χ^2 (3, N=3055) =0.22, $p=.64$ or occupation, χ^2 (3, N=3055) =2.9, $p=.40$).

Multivariate logistic regression comparing *non-interest* in learning about ADs with sociodemographic characteristics of the Overall population (N=3055) (Q5)

Multivariate binary logistic regression analysis of sociodemographic characteristics of non-interest in learning about ADs is shown in Table 3.11.

Table 3.11: Multivariate analysis for the Overall population (N=3055) Q5: non-interest in learning about Advance Directives

Q5: Not interested in learning about ADs						
Demographic	N*	N [#] *	% (95% CI)*	Odds Ratio	95% CI	P Value
Age						
15–24	487	201	41 (37-46)	1.1	[0.72, 1.68]	.65
25–44	977	217	22 (20-25)	1.0	[0.74, 1.34]	.98
45–64	990	218	22 (19-25)	.9	[0.71, 1.22]	.62
65+ (Reference)	601	177	30 (26-33)	1		
Gender						
Male	1494	430	29 (26-31)	1.3	[1.03, 1.52]	.03
Female (Reference)	1561	383	25 (22-27)	1		
Location						
Metropolitan (Reference)	2235	549	25 (23-26)	1		
Rural/Regional	820	264	32 (29-35)	1.2	[0.99, 1.48]	.07
Birth Country						
Australia (Reference)	2267	620	27 (25-29)	1		
Other	788	193	25 (22-28)	.9	[0.75, 1.13]	.43
Marital Status						
Married (Reference)	1573	320	20 (18-22)	1		
Separated or Divorced	333	98	29 (24-34)	1.6	[1.16, 2.08]	.003
De Facto	261	66	25 (20-31)	1.2	[0.85, 1.62]	.34
Widowed	176	65	40 (30-44)	1.6	[1.10, 2.29]	.01
Never Married	712	264	37 (33-41)	1.4	[1.02, 1.86]	.40
Education						
Left School Year 12 or before	927	316	34 (31-37)	1.7	[1.34, 2.07]	<.001
Still Studying	327	136	42 (36-47)	1.0	[0.65, 1.47]	.92
Cert/Dip/Trade/Apprent (Reference)	1119	246	22 (20-24)	1		
Bachelor+	682	115	17 (14-20)	1.0	[0.73, 1.30]	.86
Occupation (ANZSCO Codes)						
Professionals (Reference)	957	167	18 (15-20)	1		
Clerical/Sales	824	182	22 (19-25)	1.1	[0.82, 1.38]	.64
Blue Collar	911	304	33 (30-36)	1.6	[1.22, 2.08]	.001
Never worked/Student/Home Duties	211	75	36 (29-42)	1.5	[1.03, 2.16]	.04
Annual Income						
\$0–\$40,000	582	179	31 (27-34)	1.8	[1.31, 2.40]	<.001
\$40,001–\$80,000 (Reference)	583	116	20 (17-23)	1		
\$80,001+	942	165	18 (15-20)	1.2	[0.86, 1.53]	.35
Not Stated	948	353	37 (34-40)	2.2	[1.65, 2.83]	<.001

* N = figures in table are for weighted data rounded to whole decimal.

Number who responded to question

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Results of multivariate analysis for non-interest in ADs for the Overall population (N=3055) (Q5)

There was no statistically significant association with age, location or country of birth in relation to non-interest in advance directives.

There was however a statistically significant association between gender and non-interest in advance directives. The odds of reporting non-interest in ADs were higher for males (29%) than females (25%, OR 1.3, 95% CI [1.03, 1.52], $p=.03$).

With regard to marital status, when compared to the reference group of married, only participants who were separated/divorced (29%, OR 1.6, 95% CI [1.16, 2.08], $p=.003$) and widowed (40%, OR 1.6, 95% CI [1.10, 2.29], $p=.01$) had greater odds of non-interest in ADs.

For education, the only predictor for non-interest was leaving school in Year 12 or before (34%, OR 1.7, 95% CI [1.34, 2.07], $p<.001$) when compared to participants with a Certificate/Diploma/Trade/Apprenticeship.

Participants who had never worked, were students or undertook home duties (36%, OR 1.5, 95% CI [1.03, 2.16], $p=.04$) or worked in blue collar occupation (33%, OR 1.6, 95% CI [1.22, 2.08], $p=.001$) had higher odds of non-interest in ADs when compared to the reference category of Professionals.

Participants in the lowest income bracket of \$0-\$40,000 had higher odds of non-interest in ADs (31%, OR 1.8, 95% CI [1.31, 2.40], $p<.001$) when compared to the middle income bracket of \$40,001-\$80,000.

Summary of results for online and offline preferences for learning about Advance Directives by the Overall population (N=3055) and non-interest in learning about ADs (Q4 and 5)

When considering online preferences for AD engagement, it might be expected that the level of preference for different online mechanisms would reflect the rates of computer and Internet use. As they do not (e.g. 35% preferred information on the Internet compared to an average of 70% of participants using computers and the online environment) then other factors, such as marital status, location or education, may be influencing preferences for using the online environment for AD information. For example, those who are single and/or younger may feel more comfortable using the Internet for online information while those widowed, perhaps with less education, may not.

The fact that 27% of participants had no interest in learning about ADs, reflected mostly by people who were single, had less education, less income, had never worked or worked in blue collar employment, highlights the importance of understanding the relationship between socioeconomic status and effective methods for engagement with AD information in the online environment.

Part 1 – Secondary Analysis: People aged 47–66, incorporating the Baby Boomer generation (N=993) – Completion, Assistance and Agency with Advance Directives

Frequency and prevalence of completion by the Baby Boomer population (N=993) (Q1) for the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Anticipatory Direction/Living Will (LW) and Will

This secondary analysis of the HOS on how those aged 47–66, incorporating the Baby Boomer generation engaged with advance directives (ADs) has been conducted not for the purpose of comparison with any other age group but rather to create baseline knowledge of how this particular cohort may engage with ADs. As the HOS questions were not designed to test generational or age group differences, the data reported in this section is for observational purposes only and to assist in the development of Project 3.

In this analysis, several of the sociodemographic variables within categories have been condensed and for this reason direct comparison with the overall population is not applicable and represents a limitation to this analysis. For example, *still studying* (N=17/993) under the Education category was combined with Cert/Dip/Trade/Apprent (N=355/993) reflecting the fact that participants were engaged in education that might yield a certificate or other graduate document but not a tertiary degree. Conversely, they could have been included with those who had Left School in Year 12 or before but it was found in preliminary testing that this latter group was largely reflective of much older participants (those over 65) whereas the Still Studying group was generally younger in age (15-24 years).

Widowed (N=41) under Marital Status was combined with *Not Married* as this reflected the current status of the participant as not being partnered. It is recognised however that within the literature, widows are a group with a higher level of AD engagement (Carr 2012a, 2012b), therefore combining them with those who had never married, were separated or divorced may not truly reflect the rate of AD completions in a non-marital group.

Finally, the justification for combining Clerical/Sales occupation with Blue Collar occupation rested with preliminary statistical testing that suggested it was better to combine these two groups to represent those in low to middle-income levels of occupation for contrast with professionals (with possibly higher levels of education and income) and participants who had never worked/were students/or had home duties (N=31/993). As the 47 to 66 age-range is usually one of peak employment (Humpel et al. 2009) and has a higher level of education (ABS 2006), the literature shows that those with higher levels of education and income are more likely to complete ADs while those with lower levels of education and income are less likely to engage in AD completion (Carr 2012b; Ko and Lee 2013). Therefore, by grouping the variables in this category in the manner described, testing of association with lower income in this age group could be done.

In future, to create a better reflection of this age group's use of ADs, a national survey providing greater numbers of participants could provide better ability to test sociodemographic variations within this age group, especially the characteristics of income and education the latter of which this Project was not able to test definitively.

Nevertheless, from the 3055 interviews completed, 993 people aged 47–66 form the cohort for this secondary analysis of the HOS. The results are presented as weighted data. There was an even distribution of males and females in the cohort.

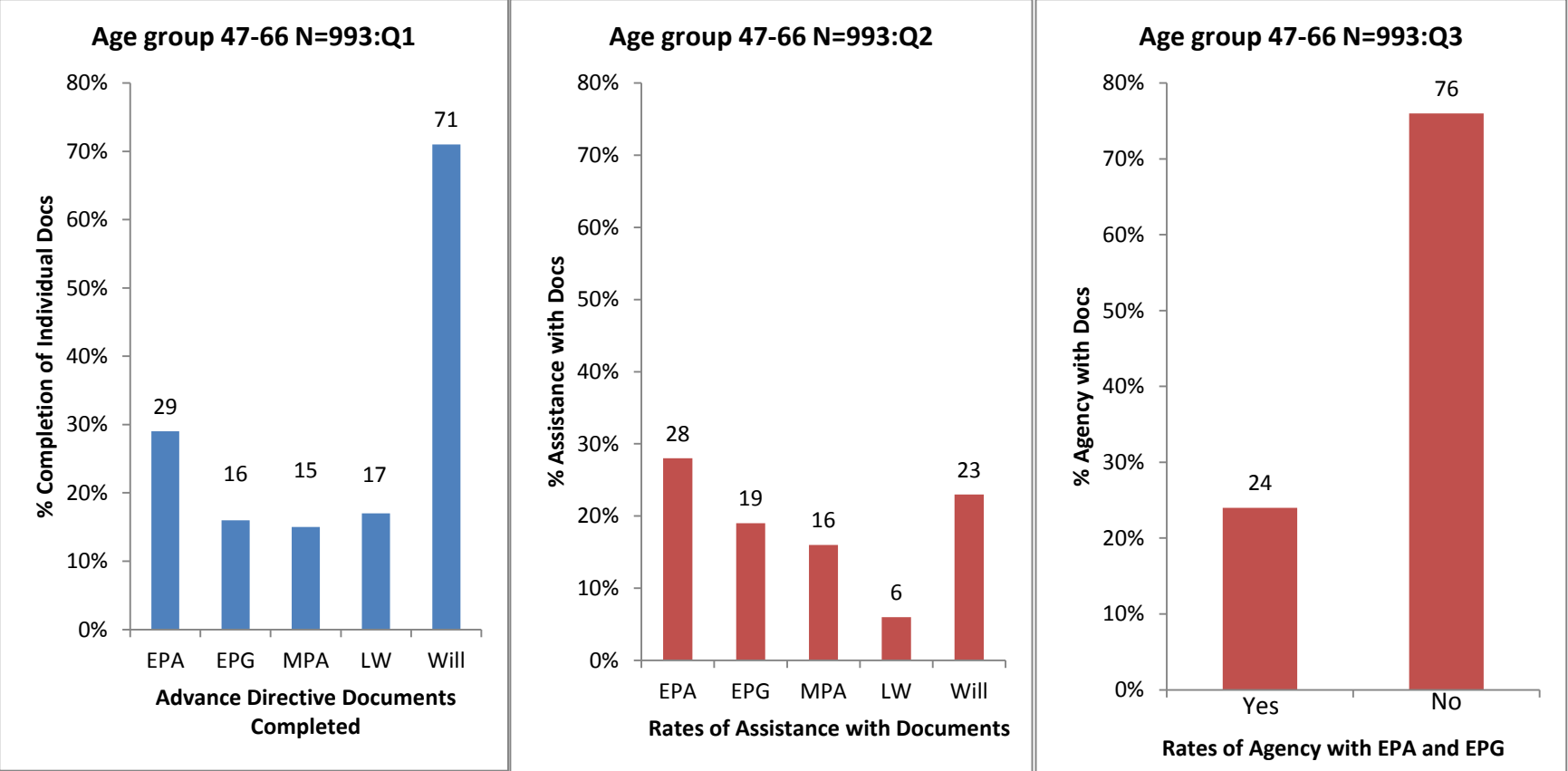


Figure 3.7: Q1-3 - Frequency of completion, assistance and agency of individual Advance Directives by people aged 47–66 incorporating the Baby Boomer generation, (N=993)

For completion of ADs, this group most commonly reported completion of the Will (71%) even though it is not an AD (Figure 3.7).

Of the recognised legal ADs in South Australia (EPA, EPG, MPA and Ant Dir/Living Will), the 47–66 age group reported completing the EPA (29%) more often than any of the healthcare documents: EPG (16%), MPA (15%), and Living Will (17%). Of note is the somewhat high level of engagement with the Living Will in this age group and the fact that nearly two-thirds of this age group reported completing any one of the named documents.

Tables 3.12–3.14 describe the univariate analysis of sociodemographic characteristics against *completion*, *assistance* and *agency* of ADs for people aged 47–66 (N=993) within the HOS.

Table 3.12: Q1 - Univariate analysis of the prevalence of *completion* of individual documents by the age group 47–66 incorporating the Baby Boomers (N=993)

Demographic	Total N*	EPA			EPG			MPA			Living Will			Will		
		Completion N#*(%)	95% CI*	P Value	N#* (%)	95% CI*	P Value	N#*	95% CI*	P Value	N#* (%)	95% CI*	P Value	N#* (%)	95% CI*	P Value
Sex																
Male	494	157(32)	(28-36)		91 (18)	(15-22)		80 (16)	(13-19)		88 (18)	(14-21)		357 (72)	(68-76)	
Female	498	130 (26)	(22-30)	.05	72 (15)	(11-18)	.01	65 (13)	(10-16)	.17	81 (16)	(13-20)	.52	350 (70)	(66-74)	.46
Location																
Metropolitan	700	199 (28)	(25-32)		117 (17)	(14-19)		103 (15)	(12-17)		124 (18)	(15-20)		504 (72)	(69-75)	
Rural	292	88 (30)	(25-35)	.59	46 (16)	(11-20)	.69	42 (14)	(10-19)	.89	45 (15)	(11-20)	.38	203 (70)	(64-75)	.43
Marital Status																
Married†	764	237 (31)	(28-34)		135 (18)	(15-20)		120 (16)	(13-18)		136 (18)	(15-21)		572 (75)	(72-78)	
Not Married†	229	51 (22)	(17-28)	.01	28 (12)	(8-16)	.05	26 (11)	(7-15)	.10	33 (14)	(10-19)	.23	135 (59)	(53-65)	<.001
Education																
Left School in Year 12 or before	355	71 (20)	(16-24)		44 (12)	(9-16)		34 (10)	(7-13)		49 (14)	(10-17)		238 (67)	(62-72)	
Still Study/Cert/Dip/Trade/Apprent†	423	14 (34)	(29-39)		85 (20)	(16-24)		79 (19)	(15-22)		81 (19)	(15-23)		313 (74)	(70-78)	
Bachelor or Higher	214	73 (34)	(28-40)	<.001	33 (15)	(11-20)	.01	32 (15)	(10-20)	.002	39 (18)	(13-24)	.12	156 (73)	(67-79)	.08
Occupation (ANZSCO) codes																
Professionals	340	114 (34)	(29-39)		62 (18)	(14-22)		58 (17)	(13-21)		60 (18)	(14-22)		249 (73)	(68-78)	
Clerical/ Sales/ Blue Collar†	611	160 (26)	(23-30)		92 (15)	(12-18)		81 (13)	(11-16)		97 (16)	(13-19)		430 (70)	(67-74)	
Never Worked/ Student/ Home Duties	31	7 (23)	(8-40)	.04	3 (10)	(-1-22)	.28	2 (7)	(-2-17)	.12	6 (19)	(4-33)	.71	19 (61)	(44-80)	.31
Annual Income																
\$0–\$40,000	179	45 (25)	(19-32)		25 (14)	(9-19)		22 (12)	(7-17)		24 (13)	(8-18)		110 (62)	(54-59)	
\$40,001–\$80,000	207	60 (29)	(23-35)		36 (17)	(12-23)		34 (17)	(12-22)		36 (17)	(12-23)		136 (66)	(59-72)	
\$80,001+	379	122 (32)	(28-37)		71 (19)	(15-23)		62 (16)	(13-20)		79 (21)	(17-25)		300 (79)	(75-83)	
Not stated	228	60 (26)	(20-32)	.27	30 (13)	(9-18)	.25	27 (12)	(8-16)	.30	31 (14)	(9-18)	.06	162 (71)	(65-77)	<.001

* N = figures in table are for weighted data rounded to whole decimal

N = number who responded to question

† Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Table 3.13: Q2 - Univariate analysis of the prevalence of assistance with individual documents by the age group 47–66 incorporating the Baby Boomers (N=993)

Demographic	Total N*	EPA			EPG			MPA			Living Will			Will		
		Assistance N#* (%)	95% CI*	P Value	N#* (%)	95% CI*	P Value	N#*	95% CI*	P Value	N#* (%)	95% CI*	P Value	N#* (%)	95% CI*	P Value
Sex																
Male	494	125 (25)	(22-29)		82 (17)	(13-20)		64 (13)	(10-16)		26 (5)	(3-7)		108 (25)	(21-29)	
Female	498	152 (31)	(27-35)	.07	109 (22)	(18-25)	.04	97 (20)	(16-23)	.01	35(7)	(5-9)	.25	124 (22)	(18-25)	.21
Location																
Metropolitan	700	219 (31)	(28-35)		147 (21)	(18-24)		124 (18)	(15-21)		51 (7)	(5-9)		169 (24)	(21-27)	
Rural	292	59 (20)	(16-25)	<.001	44 (15)	(11-19)	.03	36 (12)	(9-16)	.04	10 (3)	(1-6)	.02	63 (22)	(17-26)	.37
Marital Status																
Married†	764	231 (30)	(27-34)		156 (20)	(18-23)		131 (17)	(14-20)		48 (6)	(5-8)		186 (24)	(21-27)	
Not Married†	229	47 (21)	(15-26)	.004	35 (15)	(11-20)	.08	30 (13)	(9-18)	.15	13 (6)	(3-9)	.74	46 (20)	(15-25)	.18
Education																
Left School in Year 12 or before	355	78 (22)	(18-26)		53 (15)	(11-19)		48 (14)	(10-17)		15 (4)	(2-6)		61 (17)	(13-21)	
Still Study/Cert/Dip/Trade /Apprent†	423	125 (30)	(25-34)		85 (20)	(16-24)		74 (18)	(14-21)		30 (7)	(5-10)		108 (26)	(21-30)	
Bachelor or Higher	214	75 (35)	(28-41)	.003	53 (25)	(19-30)	.01	39 (18)	(13-23)	.22	16 (8)	(4-11)	.17	66 (31)	(23-36)	.001
Occupation (ANZSCO codes)																
Professionals	340	110 (32)	(27-38)		81 (24)	(19-29)		66 (19)	(15-24)		23 (7)	(4-10)		93 (27)	(23-32)	
Clerical/ Sales/ Blue Collar†	611	153 (25)	(22-28)		101 (17)	(14-20)		85 (14)	(11-17)		34 (6)	(4-7)		131 (21)	(18-25)	
Never Worked/ Student/ Home Duties	31	8 (25)	(8-40)	.05	3 (10)	(-1-23)	.01	6 (19)	(4-32)	.08	2 (7)	(-2-17)	.75	5 (16)	(2-30)	.07
Annual Income																
\$0–\$40,000	179	37 (21)	(15-27)		28 (16)	(10-21)		20 (11)	(7-16)		8 (5)	(1-7)		33 (19)	(13-24)	
\$40,001–\$80,000	207	42 (20)	(15-26)		35 (17)	(12-22)		30 (15)	(10-19)		8 (4)	(1-7)		40 (19)	(14-25)	
\$80,001+	379	146 (39)	(34-43)		94 (25)	(20-29)		75 (20)	(16-24)		37 (10)	(7-13)		113 (30)	(25-34)	
Not stated	228	53 (23)	(18-29)	<.001	34 (15)	(10-19)	.01	36 (16)	(11-20)	.06	8 (4)	(1-6)	.003	46 (20)	(15-25)	.003

* N = figures in table are for weighted data rounded to whole decimal

N = number who responded to question

† Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Table 3.14: Q3 - Univariate analysis of the prevalence of agency through the Enduring Power of Attorney or Enduring Power of Guardianship (EPG) by the age group 47–66 incorporating the Baby Boomers (N=993)

Yes – I have acted as an agent under EPA or EPG				
Demographic	Total N*	Agency N [#] (%)	95% CI*	P Value
Sex				
Male	494	113 (23)	(18-26)	.59
Female	498	121 (24)	(21-28)	
Location				
Metropolitan	700	176 (25)	(21-28)	.07
Rural	292	58 (20)	(15-24)	
Marital Status				
Married [†]	764	189 (25)	(21-27)	.11
Not Married [†]	229	45 (20)	(14-24)	
Education				
Left School in Year 12 or before	355	66 (19)	(14-22)	.01
Still Study/Cert/Dip/Trade/Apprent [†]	423	118 (28)	(23-32)	
Bachelor or Higher	214	50 (23)	(17-28)	
Occupation (ANZSCO) codes				
Professionals	340	86 (25)	(21-30)	.13
Clerical/ Sales/ Blue Collar [†]	611	138 (23)	(19-26)	
Never Worked/ Student/ Home Duties	31	3 (10)	(-1-22)	
Annual Income				
\$0–\$40,000	179	49 (27)	(20-34)	.32
\$40,001–\$80,000	207	40 (19)	(16-24)	
\$80,001+	379	92 (24)	(20-28)	
Not stated	228	53 (23)	(18-29)	

* N = figures in table are for weighted data rounded to whole decimal

[#] N = number who responded to question

[†] Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Prevalence of *completion*, *assistance* and *agency* of the Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Medical Power of Attorney (MPA), Living Will and Will by those aged 47-66 incorporating the Baby Boomers (N=993) (Q1-3)

There was no association between gender and *completion* of documents, however there was an association for *assistance*. Females reported greater rates of assistance for the EPG (22%) than males (17%, χ^2 (1, N=993) =4.4, $p=.04$) as well as greater rates of assistance with the MPA (20% females vs 13% males, χ^2 (1, N=993) =7.8, $p=.01$). Gender was not statistically significantly associated with assistance for the: EPA (χ^2 (1, N=993)=3.4, $p=.07$), Living Will (χ^2 (1, N=993)=1.4, $p=.25$) or Will (χ^2 (1, N=993)=1.6, $p=.21$).

There was no association between location and *completion* of documents, however there was an association between location and *assistance* with all documents except the Will. Participants living in metropolitan locations reported greater rates of assistance for the EPA (31% v rural 20%, χ^2 (1, N=993)=13, $p<.001$); the EPG (21% metro v 15% rural, χ^2 (1, N=993)=4.8, $p=.03$); the MPA (18% metro v 12% rural, χ^2 (1, N=993)=4.4, $p=.04$) and the Living Will (7% metro v 3% rural, χ^2 (1, N=993)=5.3, $p=.02$). There was no statistically significant association between location and assistance with the Will (χ^2 (1, N=993) =0.8, $p=.37$).

There was an association between marital status and *completion* of documents with participants who were married reporting greater rates of completion of the EPA (31%) than those not married (22%, χ^2 (1, N=993)=6.6 $p=.01$); and greater rates of completion of the EPG (18% married v 12% not married, χ^2 (1, N=993)=3.8, $p=.05$); as well as the Will (75% married vs. 59% not married, χ^2 (1, N=993)=22, $p<.001$). Marital status was not statistically significantly associated with *completion* of the MPA (χ^2 (1, N=993) =2.7, $p=.10$) or the Living Will (χ^2 (1, N=993) =1.5, $p=.23$).

With regard to *assistance*, there was an association between marital status and only the EPA with married participants reporting greater rates of assistance (30%) than not married (21%, χ^2 (1, N=993)=8.2, $p=.004$). There was no statistically significant association between marital status and *assistance* for the: EPG (χ^2 (1, N=993)=3.0, $p=.08$; MPA, χ^2 (1, N=993)=2.1, $p=.15$; Living Will, χ^2 (1, N=993)=.11, $p=.74$; or Will, χ^2 (1, N=993)=1.8, $p=.18$).

There was no consistent association between levels of education and the completion of different AD documents. For example, participants with a Cert etc.,

(34%) and participants with a Bachelor degree (34%) were equally likely to report more completion of the EPA than participants who had Left school in Year 12 or before (20%, $\chi^2 (2, N=993)=22, p<.001$). For the EPG and MPA documents, participants with a Cert etc., reported higher rates of completion (20% for EPG, 19% MPA) when compared to participants with a Bachelor degree (15% for EPG, 15% for MPA) or who Left school in Year 12 or before (12% EPG, $\chi^2 (2, N=993) =8.5, p=.01$, 10% MPA, $\chi^2 (2, N=993) =13, p=.002$). Education was not statistically significantly associated with *completion* for the Living Will ($\chi^2 (2, N=993) =4.2, p=.12$) or the Will ($\chi^2 (2, N=993) =5.2, p=.08$).

There was an association between education and *assistance* for 2 of the same AD documents as *completion* (EPA and EPG) but not the MPA ($\chi^2 (2, N=993) =3.1, p=.22$). There was an association with assistance, however, between education and the non-AD document, the Will. Participants who Left school in Year 12 or before reported lower rates of *assistance* for the EPA (22%, $\chi^2 (2, N=993)=12, p=.003$), EPG (15%, $\chi^2 (2, N=993)=8.5, p=.01$) and Will (17%, $\chi^2 (2, N=993)=13, p=.001$) when compared to the other education levels (Cert etc., 30% EPA, 20% EPG, 26% Will; Bachelor or higher, 35% EPA, 25% EPG, 29% Will). There was no statistically significant association between education and assistance for the: MPA ($\chi^2 (2, N=993) =3.1, p=.22$) and the Living Will ($\chi^2 (2, N=993) =3.6, p=.17$). Education was the only category associated with *agency* (assisting someone with the EPA or EPG) with participants who Left school in Year 12 or before reporting lower rates of agency (19%) when compared to those with a Cert etc. (28%) or Bachelor (23%, $\chi^2 (2, N=993)=9.3, p=.01$).

There was an association between occupation and *completion* with only one document, the EPA. For this document, participants who had never worked etc., reported lesser rates of completion (23%) when compared with participants who worked in clerical/sales/blue collar (26%) or were in a professional occupation (34%, $\chi^2 (2, N=993)=6.5, p=.04$). There was no statistically significant association between occupation and completion of the EPG ($\chi^2 (2, N=993)=2.6, p=.28$), MPA ($\chi^2 (2, N=993)=4.2, p=.12$), Living Will ($\chi^2 (2, N=993)=0.7, p=.71$) and Will ($\chi^2 (2, N=993)=2.4, p=.31$).

With regard to *assistance*, there was an association between occupation and assisting others with the EPA and EPG documents in this age group. For *assistance* with the EPA document, participants who never worked, etc. reported

equal rates of assistance to participants with a clerical/sales/blue collar occupation (25%) but this rate was less than that of professionals (32%, $\chi^2 (2, N=993)=6.1, p=.05$). For the EPG document, participants who never worked, etc. reported lesser rates of assistance with this document (10%) compared to participants in clerical/sales/blue collar professions (17%) or professionals (24%, $\chi^2 (2, N=993)=9.5, p=.01$). There was no statistically significant association between occupation and *assistance* for the MPA ($\chi^2 (2, N=993) =5.1, p=.08$), Living Will ($\chi^2 (2, N=993) =.59, p=.75$) and Will ($\chi^2 (2, N=993) =5.2, p=.07$) With regard to the category of income, the only association between income and *completion* was for the Will. Participants in the highest income bracket of \$80,001+ reported completion of this document at a greater rate (79%) than those in the middle income level of \$40,001–\$80,000 (66%) and lowest income level of \$0–\$40,000 (62%, $\chi^2 (3, N=993)=23, p<.001$). There was no statistically significant association between income and completion for the: EPA, $\chi^2 (3, N=993) =3.9, p=.27$; EPG, $\chi^2 (3, N=993) =4.1, p=.25$; MPA, $\chi^2 (3, N=993)=3.7, p=.30$; and Living Will, $\chi^2 (3, N=993)=7.4, p=.06$.

In relation to *assistance*, participants in the highest income bracket of \$80,001+ consistently reported greater rates of assistance for the: EPA (39%), EPG (25%), Living Will (10%) and Will (30%) when compared to participants in the middle income bracket (20% EPA, 17% EPG, 15% MPA, 4% Living Will, 19% Will) and participants in the lowest income bracket of \$0–\$40,000 (EPA 21%, $\chi^2 (3, N=993)=34, p<.001$; EPG 16%, $\chi^2 (3, N=993)=12, p=.01$; Living Will 5%, $\chi^2 (3, N=993)=14, p=.003$; Will 19%, $\chi^2 (2, N=993)=14, p=.003$). There was no association between income and *assistance* with the MPA ($\chi^2 (3, N=993) =7.3, p=.06$).

Gender ($\chi^2 (1, N=993)=.30, p=.59$); location ($\chi^2 (1, N=993)=3.2, p=.07$); marital status ($\chi^2 (1, N=993)=2.6, p=.11$); occupation ($\chi^2 (2, N=993)=4.2, p=.13$); and income ($\chi^2 (3, N=993)=3.6, p=.32$) were not statistically significantly associated with agency.

Multivariate logistic regression analysis of the 47-66 age group incorporating the Baby Boomers (N=993) (Q1-3) comparing *non-completion, non-assistance and non-agency* with sociodemographic characteristics

Table 3.15 displays the results of the multivariate logistic regression analysis for *non-completion, non-assistance and non-agency* (Q1-3) by those aged 47–66 incorporating the Baby Boomer generation.

Table 3.15: Multivariate analysis for people aged 47-66 incorporating the Baby Boomers (N=993) in the HOS - Q1-3: non-completion, non-assistance, non-agency

Demographic	Total N*	Q1: Did Not Complete Any Documents					Q2: Did Not Assist with Any Documents					Q3: Have not Acted as EPA or EPG				
		Response N#*	% (95% CI)*	Odds Ratio	95% CI	P Value	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value
Gender																
Male	495	113	23 (19-26)	.9	[0.69, 1.29]	.70	311	63 (59-67)	1.4	[1.04, 1.81]	.03	121	76 (74-82)	1.2	[0.90, 1.70]	.19
Female (Reference)	498	132	27 (23-30)	1			286	57 (53-62)	1			375	76 (72-79)	1		
Location																
Metropolitan (Reference)	701	167	24 (21-27)	1			409	58 (55-62)	1			523	75 (72-79)	1		
Rural/Regional	292	77	26 (21-31)	1	[0.70, 1.36]	.86	189	65 (59-70)	1.1	[0.81, 1.48]	.55	230	79 (76-85)	1.3	[0.93, 1.89]	.12
Marital Status																
Married [†] (Reference)	764	159	21 (18-24)	1			441	58 (54-61)	1			571	75(73-79)	1		
Not Married [†]	229	85	37 (31-44)	1.9	[1.34, 2.68]	<.001	157	69 (62-74)	1.4	[1.02, 2.02]	.04	182	80(76-86)	1.6	[1.07, 2.42]	.02
Education																
Left School Year 12 or before	355	106	30 (25-35)	1.3	[0.93, 1.91]	.11	233	65 (60-70)	1.2	[0.89, 1.70]	.21	285	80(78-86)	1.7	[1.15, 2.45]	.01
Study/Cert/Dip/ [†] Trade/Apprent (Reference)	422	93	22 (18-26)	1			246	58 (53-63)	1			305	72(68-77)	1		
Bachelor+	216	45	21 (16-26)	1.2	[0.77, 1.94]	.40	119	56 (49-62)	1.2	[0.83, 1.79]	.32	163	76(72-83)	1.4	[0.88, 2.13]	.16
Occupation (ANZSCO Codes)																
Professionals	340	75	22 (18-26)	1			186	55 (50-60)	1			252	74 (70-79)	1		
Clerical/Sales/ [†] Blue Collar (Reference)	610	158	26 (22-29)	1.2	[0.80, 1.73]	.42	389	64 (60-68)	1.3	[0.92, 1.78]	.15	13	77 (74-81)	1.1	[0.77, 1.65]	.53
Never worked/ Student/Home Duties	44	10	32 (16-51)	1.3	[0.55, 3.04]	.56	18	58(41-77)	1.0	[0.45, 2.20]	.98	468	90 (78-100)	3.0	[0.87, 10.10]	.08
Annual Income																
\$0-\$40,000	179	66	37 (30-44)	1.1	[0.70, 1.74]	.66	118	66 (59-73)	0.8	[0.53, 1.30]	.42	130	73 (66-80)	0.5	[0.30, 0.83]	.01
\$40,001-\$80,000 (Reference)	207	60	29 (23-35)	1			140	68 (61-74)	1			166	81 (76-87)	1		
\$80,001+	379	66	17 (14-21)	0.6	[0.37,0.87]	.01	190	50 (45-55)	0.5	[0.35, 0.74]	<.001	287	76 (72-80)	0.9	[0.54, 1.33]	.47
Not Stated	228	52	23 (17-28)	0.7	[0.43, 1.03]	.07	149	65 (59-72)	0.9	[0.57, 1.28]	.44	170	75 (71-82)	0.7	[0.44, 1.14]	.15

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

[†] Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep-Dec 2012

For participants aged 47–66 there was a statistically significant association between *non-completion* of ADs (Q1) and marital status as well as income.

Participants who were not married were twice as likely to report *non-completion* of any AD document (37%, OR 1.9, 95%CI [1.34, 2.68], $p < .001$) when compared to participants who were married (reference variable). Participants in the highest income bracket of \$80,001+ were half as likely (17%, OR 0.6, 95%CI [0.37, 0.87], $p = .01$) as those in the middle income bracket of \$40,000-\$80,000 (reference variable) to report not completing any ADs.

With regard to *not assisting* others with AD documents (Q2), gender, marital status and annual income were all predictors of *non-assistance* in this 47–66 age cohort.

Males had higher odds of *non-assistance* than females (reference category) (63%, OR 1.4, 95%CI [1.04, 1.81], $p = .03$). Non-married participants were more likely to report *non-assistance* (69%, OR 1.4, 95% CI [1.02, 2.02], $p = .04$) than married participants; while participants in the highest income bracket of \$80,001+ were half as likely to report *non-assistance* (50%, OR 0.5, 95%CI [0.35, 0.74], $p < .001$) when compared to participants in the middle income bracket of \$40,000-\$80,000. For non-agency (Q3) that is not having acted as an agent under the EPA or EPG, marital status, education and income were statistically significantly associated with *non-agency* in this age group.

Participants who were not married had higher odds of reporting *non-agency* (80%, OR 1.6, 95% CI [1.07, 2.42], $p = .02$) when compared to married participants.

Participants who Left school in Year 12 or before (80%, OR 1.4, 95%CI [1.15, 2.45], $p = .01$) were statistically significantly associated with *non-agency* when compared to those with a Cert etc., (reference variable). For income, participants in the lowest income bracket of \$0–\$40,000 were less likely to report *non-agency* (73%, OR 0.5, 95%CI [0.30, 0.83], $p = .01$) when compared to participants in the \$40,001–\$80,000 income bracket (reference variable).

Summary of results on *completion, assistance, agency and non-completion, non-assistance and non-agency* for the age group 47-66 incorporating the Baby Boomers (N=993) (Q1-3)

The results from this secondary analysis of Questions 1 – 3 for participants aged 47–66 clearly identify specificity in relation to sociodemographic characteristics that influence their engagement with ADs.

Although gender and location were generally not significant predictors of *completion* or *agency*, they were for *assistance* to others with AD documents.

Marital status had limited association in univariate analysis for *completion* and *assistance*, but had statistically significant association in multivariate analysis for *non-completion*, *non-assistance* and *non-agency* with participants who were not married less likely to complete, assist or act as agents.

Univariate analysis of education indicated differences between participants with less schooling and participants with more schooling with regard to *completion*, *assistance* and *agency* of AD documents while multivariate analysis found that the only predictor for *non-agency* in this category was for participants who Left school in Year 12 or before.

Univariate analysis of occupation for *completion* of any AD document showed statistically significant association of this category with only one document, the EPA. There was however, more association between occupation and *assistance*. Multivariate analysis revealed no statistically significant association between occupation and *non-completion*, *non-assistance* and *non-agency* in this age group.

With regard to income, univariate analysis showed association with *completion* of the Will; however, the association between income and *assistance* was much stronger incorporating almost all of the AD documents. Multivariate analysis for *non-completion*, *non-assistance* and *non-agency* revealed a strong association between income and these elements, however, the results were mixed with participants in the highest income category least likely to say they had not completed or assisted with documents while participants in the lowest income category were most likely to report acting as an agent.

Positive sociodemographic characteristics influencing overall engagement with ADs in this age group were: female gender, being married, higher levels of education, and either higher or lower levels of income when compared to the middle income bracket.

Negative sociodemographic characteristics influencing engagement with ADs in this age group were: male gender, not being married, having left school in Year 12 or before, and again either higher or lower income levels when compared to the middle income bracket.

Part 2 - Secondary Analysis: People aged 47–66, incorporating the Baby Boomer generation (N=993) – Comfort with the online environment and preferred online mechanism for engagement with advance directives (ADs)

Secondary analysis of those aged 47-66 incorporating the Baby Boomers (N=993) (Q4) for frequency and prevalence of of comfort with computer, online devices and online use

In this section, responses are in relation to Question 4 of Figure 3.1 which focuses on daily or weekly use of computers and the Internet as well as comfort in seeking information using the online environment. Frequency analysis will describe use, non-use and comfort levels. Univariate analysis will focus on comfort and use while multivariate analysis will describe predictors of non-use.

Figure 3.8 illustrates the frequency of computer and Internet use, non-use and levels of comfort and non-comfort with the online environment for those aged 47–66 incorporating the Baby Boomers (N=993).

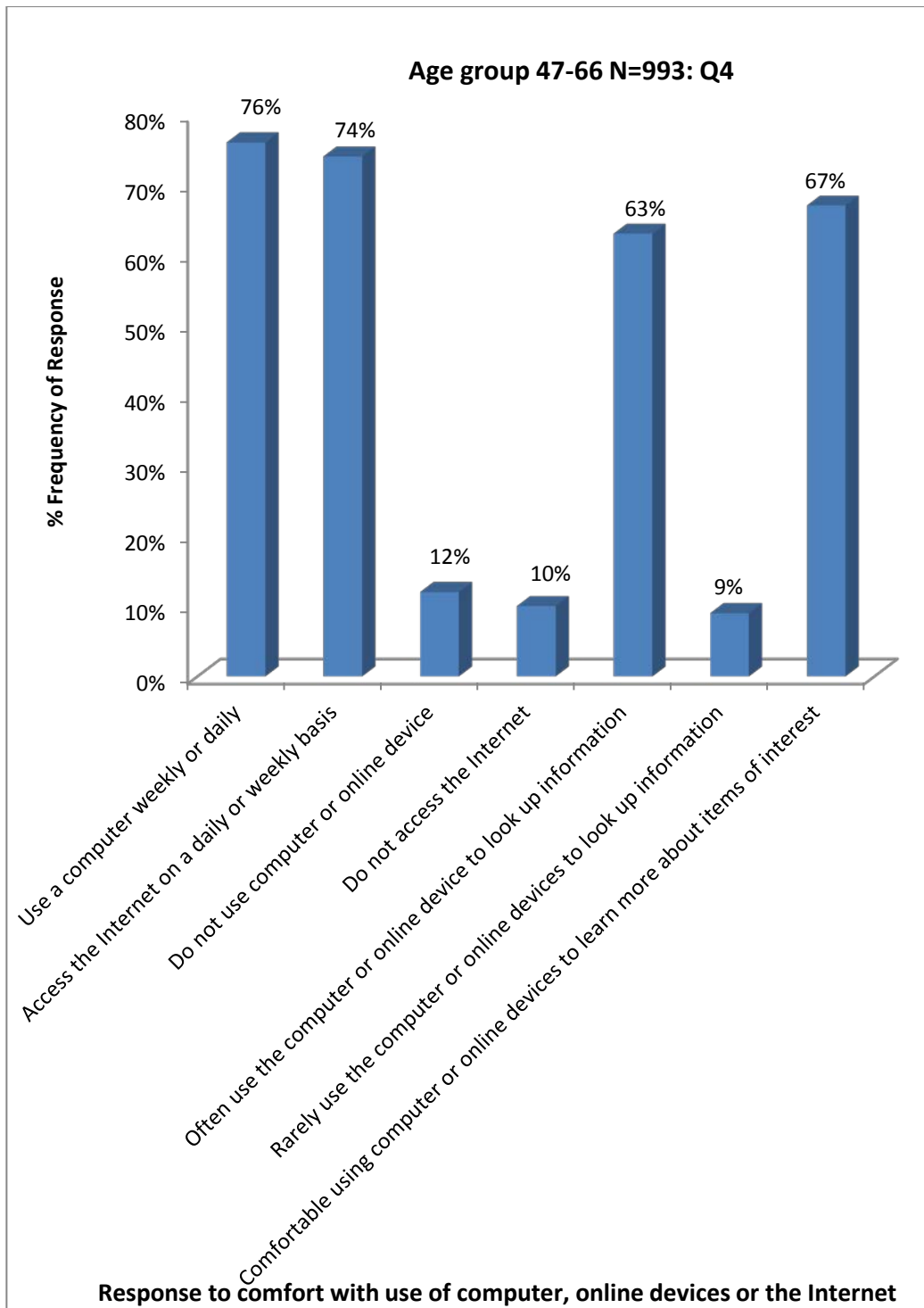


Figure 3.8: Q4 - Frequency of comfort with and use of the computer, online devices or the Internet for people aged 47–66 incorporating the Baby Boomer Population, (N=993)

As can be seen from Figure 3.8, those aged 47–66 in the HOS had high rates of use of the computer and Internet (76% and 74%, respectively) as well as high levels of comfort using computers and online devices to look up information (63% and 67%, respectively).

Table 3.16: Q4 - Univariate analysis of the prevalence of comfort with and use of the computer and online environment by the age group 47–66 incorporating the Baby Boomers (N=993)

Demographic	Total N*	Use a computer or online device daily or weekly			Access the Internet on daily or weekly basis			Often use computer or online device to look up information			Comfortable using computer or online device to learn more about items of interest		
		Response N** (%)	95% CI*	P Value	N** (%)	95% CI*	P Value	N** (%)	95%CI*	P Value	N** (%)	95% CI*	P Value
Gender													
Male	495	384 (78)	(74-81)		367 (74)	(70-78)		305 (62)	(57-66)		327 (66)	(62-70)	
Female	498	371 (75)	(71-78)	.26	370 (74)	(70-78)	.96	316 (63)	(59-68)	.61	341 (68)	(64-72)	.47
Location													
Metropolitan	701	555 (79)	(76-82)		546 (78)	(75-81)		460 (66)	(62-69)		495 (71)	(67-74)	
Rural/Regional	292	200 (69)	(63-74)	<.001	190 (65)	(60-71)	<.001	160 (55)	(49-61)	.001	173 (59)	(53-65)	<.001
Marital Status													
Married†	764	602 (79)	(76-82)		587 (77)	(74-80)		500 (65)	(62-69)		539 (71)	(67-74)	
Not Married†	229	152 (66)	(60-73)	<.001	149 (65)	(59-71)	<.001	121 (53)	(46-59)	.001	129 (56)	(50-63)	<.001
Education													
Left School Year 12 or before	355	222 (63)	(58-68)		214 (60)	(55-65)		178 (50)	(45-55)		190 (54)	(48-59)	
Still Study/Cert/Dip/Trade/Apprent†	422	344 (81)	(78-85)		334 (79)	(75-83)		272 (64)	(60-69)		296 (70)	(66-74)	
Bachelor+	216	188 (88)	(83-92)	<.001	189 (88)	(84-92)	<.001	171 (80)	(74-85)	<.001	181 (85)	(80-89)	<.001
Occupation (ANZSCO Codes)													
Professionals	340	292 (86)	(82-90)		294 (87)	(83-90)		251 (74)	(69-79)		267 (79)	(74-83)	
Clerical/Sales/Blue Collar†	610	438 (72)	(68-75)		421 (69)	(65-73)		354 (58)	(54-62)		381 (62)	(58-66)	
Never worked/Student/Home Duties	44	14 (45)	(27-64)	<.001	13 (42)	(23-60)	<.001	7 (23)	(8-40)	<.001	11 (34)	(16-52)	<.001
Annual Income													
\$0–\$40,000	179	99 (55)	(48-63)		93 (52)	(45-60)		72 (40)	(33-48)		81 (45)	(38-52)	
\$40,001–\$80,000	207	160 (77)	(72-83)		151 (73)	(67-79)		124 (60)	(53-67)		129 (63)	(56-69)	
\$80,001+	379	350 (92)	(90-95)		340 (90)	(87-93)		303 (80)	(76-84)		332 (85)	(81-89)	
Not Stated	228	146 (64)	(58-70)	<.001	152 (67)	(61-73)	<.001	121 (53)	(46-60)	<.001	136 (60)	(53-66)	<.001

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

† Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Prevalence of use of a computer or the Internet on a daily/weekly basis by the Baby Boomer population (N=993) (Q4)

There was no association between gender and use of a computer or online device ($\chi^2 (1, N=993) = 1.3, p=.26$). However, all other sociodemographic categories did show statistically significant associations with computer and online device use.

Participants in the metropolitan area reported more use of the computer or other online devices (79%) more than rural participants (69%, $\chi^2 (1, N=993) = 18, p<.001$).

This was also true for participants who were married (79%) when compared to participants who were not married (66%, $\chi^2 (1, N=993) = 15, p<.001$).

With regard to education, participants who Left school in Year or before less often reported computer use (63%, $\chi^2 (2, N=993) = 58, p<.001$) than participants with a Cert etc., (81%) or a Bachelor degree (88%).

Participants who had never worked, were students or undertook home duties reported least amount of use of the computer or online devices less (45%, $\chi^2 (2, N=993) = 41, p<.001$) compared to participants who worked in clerical/sales/blue collar occupations (72%) or professional occupations (86%).

With regard to income, participants at the lowest annual income level of \$0–\$40,000 reported less use of computers or online devices (55%, $\chi^2 (3, N=993) = 116, p<.001$) when compared to participants in the middle income bracket of \$40,000–\$80,000 (77%) or upper income bracket of \$80,000+ (92%).

The only variable that was statistically non-significantly associated for computer and Internet use was gender ($p=.26$ for computer, $p=.96$ for Internet use).

Prevalence of accessing a computer or the Internet on a daily or weekly basis by those aged 47-66, incorporating the Baby Boomers (N=993) (Q4)

As with computer and online device use, there was no association between gender and use of the Internet on a daily or weekly basis ($\chi^2 (1, N=993) = 0.00, p=.96$). However, there was a statistically significant difference between variables for all of the other sociodemographic categories.

Participants from metropolitan areas reported accessing the Internet more often (78%, $\chi^2 (1, N=993) = 18, p<.001$) than participants from rural areas (65%).

Participants who were married reported accessing the computer and Internet more

often (77%, χ^2 (1, N=993) =13, $p<.001$) than participants who were not married (65%).

Similarly to the use of a computer or online device, participants who Left school in Year 12 or before reported less use of the Internet (60%, χ^2 (2, N=993)=62, $p<.001$) than participants who had a Cert etc., (79%) or who had a Bachelor degree (88%).

For occupation, participants who never worked/students or had home duties reported less use of the Internet (42%, χ^2 (2, N=993)=53, $p<.001$) than participants who worked in clerical/sales/blue collar (69%) or professional (87%) occupations.

Also similarly to the use of a computer or online device, participants in the lowest income bracket of \$0-\$40,000 reported less use of the Internet (52%, χ^2 (3, N=993)=99, $p<.001$) than participants in the middle level (73%) or highest (90%) income brackets.

Prevalence for comfort and use of online devices and environment for seeking information by the Baby Boomer population (N=993) (Q4)

The results from these two choices mirrored the results of computer and Internet use.

There was no statistically significant association between gender and use or comfort with using a computer or the online environment for information on ADs (χ^2 (1, N=993) =0.3, $p=.61$ for use; χ^2 (1, N=993) =0.5, $p=.47$ for comfort). There were, however, statistically significant differences between variables within categories similar to those seen for use of a computer and access to the Internet. Metropolitan participants had a higher percentage (66%, χ^2 (1, N=993) =10, $p=.001$) and more comfort (71%, χ^2 (1, N=993) =13, $p<.001$) of use of the online environment than participants from rural areas (55% for use; 59% for comfort).

Married participants reported more use (65%, χ^2 (1, N=993) =12, $p<.001$) and comfort (71%, χ^2 (1, N=993) =16, $p<.001$) than participants who were not married (53% for use; 56% for comfort).

Participants who Left school in Year 12 or before reported less use (54%, χ^2 (2, N=993) =61, $p<.001$) and less comfort (50%, χ^2 (2, N=993) =50, $p<.001$) with using the online environment for information about ADs than participants with higher levels of education (Cert etc., 64% for use, 70% for comfort; Bachelor+ 80% for use, 85% for comfort).

With regard to occupation, participants who had never worked, were students or undertook home duties were less likely to report use (23%, χ^2 (2, N=993)=44, $p<.001$) or comfort (34%, χ^2 (2, N=993)=42, $p<.001$) with the online environment for AD information in comparison to participants in clerical/sales/blue collar occupations (58% use; 62% comfort) or professionals (74% use; 79%, comfort). Similar to computer and Internet use, participants in the lowest income bracket of \$0–\$40,000 reported less use (40%, χ^2 (3, N=993)=96, $p<.001$) and less comfort (45%, χ^2 (3, N=993)=101, $p<.001$) with the online environment for AD information than participants in the middle income bracket (60% use; 63% comfort) or highest income bracket (80% use; 85% comfort).

Multivariate logistic regression analysis by sociodemographic characteristics of *non-computer* and *non-online device* use by those aged 47–66 incorporating the Baby Boomer generation, (N=993) (Q4)

Table 3.17 illustrates the multivariate binary logistic regression analysis of sociodemographic characteristics associated with those who reported not using a computer or online device at all.

Table 3.17: Multivariate analysis for participants aged 47–66 incorporating the Baby Boomer generation, (N=993) - Q4: Non-use of computer or any online device

Q4: Do not use a computer or online device						
Demographic	Total N*	N#*	% (95% CI)*	Odds Ratio	95%CI	P Value
Gender						
Male	495	48	10 (7-13)	.9	[0.57, 1.42]	.65
Female (Reference)	498	69	14 (11-17)	1		
Location						
Metropolitan (Reference)	701	66	9 (7-12)	1		
Rural/Regional	292	52	18 (13-22)	1.2	[0.75, 1.84]	.46
Marital Status						
Married [†] (Reference)	764	70	9 (7-11)	1		
Not Married [†]	229	48	21 (16-27)	1.9	[1.20, 3.05]	.01
Education						
Left School Year 12 or before	355	82	23 (19-28)	2.4	[1.46, 3.84]	<.001
Still Study/ Cert/Dip/Trade/ Apprent [†] (Reference)	422	32	8 (5-10)	1		
Bachelor+	216	3	1 (0-3)	0.5	[0.14, 1.90]	.32
Occupation (ANZSCO Codes)						
Professionals (Reference)	340	10	3 (1-5)	1		
Clerical/Sales/ Blue Collar [†]	610	96	16 (13-19)	3.6	[1.69, 7.52]	.001
Never worked/ Student/Home Duties	44	11	34 (16-52)	5.0	[1.71, 14.48]	.003
Annual Income						
\$0–\$40,000	179	53	30 (22-36)	2.6	[1.41, 4.64]	.002
\$40,001–\$80,000 (Reference)	207	21	10 (6-14)	1		
\$80,001+	379	9	2 (1-4)	0.3	[0.15, 0.78]	.01
Not Stated	228	35	15 (11-20)	1.3	[0.73, 2.43]	.35

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

[†] Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Results of multivariate analysis for *non-use of the computer or any online device* by participants aged 47-66 years incorporating the Baby Boomer generation (N=993) (Q4)

The trends from the multivariate logistic regression analysis follow that of the univariate analysis. There was a strong association for non-use of a computer or online device for marital status, education, occupation and income. Only gender (OR 0.9, 95% CI [0.57, 1.42], $p=.65$) and location (OR 1.2, 95% CI [0.75, 1.84], $p=.46$) had no statistically significant association for non-use of computer or online devices.

Participants who were not married were more likely to report non-use (21%, OR 1.9,

95%CI [1.20, 3.05], $p=.01$) than participants who were married.

For education, participants who Left school in Year 12 or before were twice as likely to report non-use (23%, OR 2.4, 95% CI [1.46, 3.84], $p<.001$) when compared with participants with a Cert. etc.

There was a stronger association between non-use and occupation for participants who were not professionals. Participants in clerical/sale/blue collar occupation were four times more likely to report non-use (16%, OR 3.6, 95% CI [1.69, 7.52], $p=.001$) than professionals while participants who had never worked, were students or had home duties were five times more likely to report non-use (34%, OR 5, 95% CI, [1.71, 14.48], $p=.003$).

With regard to income, there was a two-way shift in the odds of reporting non-use with participants in the lowest income bracket of \$0–\$40,000 three times more likely to report non-use (30%, OR 2.6, 95% CI [1.41, 4.64], $p=.002$) when compared to the middle income bracket (reference) while participants in the highest income bracket of \$80,001+ were far less likely to report non-use (2%, OR 0.3, 95%CI, [0.15, 0.78], $p=.01$).

Summary of results on comfort and use of the computer and online devices for the Baby Boomer population (N=993) (Q4)

Positive associations with comfort with online devices and online use for those aged 47–66 in this secondary analysis included: living in a metropolitan location; being married; having higher levels of education; working in blue collar or white collar employment; and having an income of \$40,001 or more per year.

Negative associations with computer and online use included: living in rural/regional locations; not being married; leaving school in Year 12 or before; having never worked, being a student or undertaking home duties; and having an income less than \$40,001 per year.

These results indicate that people in the Baby Boomer age group with lower socioeconomic status may have a harder time accessing or obtaining information about ADs via the online environment at a time when they may be likely to consider them, such as when planning retirement or being diagnosed with a chronic or terminal illness.

Of particular concern is that the online environment may not assist those who have

less income, are single, or who have never worked. These people may need more targeted and offline approaches for providing information about ADs if they wish to protect their individual choices for future healthcare. For people in this age group who are comfortable with and do use the online environment however the next section describes their preferred mechanism of online engagement for information about ADs.

Frequency and prevalence of participants aged 47–66 incorporating the Baby Boomer generation (N=993) (Q5) to use various online and offline mechanisms for learning about Advance Directives

This analysis shows the frequency and prevalence for the choice of different online and offline mechanisms for engagement with AD information by participants aged 47–66 in the HOS. Figures and tables in this section represent responses to Question 5. As with the previous section for computer and online use, univariate analysis by sociodemographic factor will focus on preference for different online choices as well as preference for offline means of engagement, while multivariate analysis will describe predictors for no interest in learning about ADs at all.

Figure 3.9 illustrates the frequency with which participants aged 47–66 in the HOS expressed their preference for different online means of engagement with ADs.

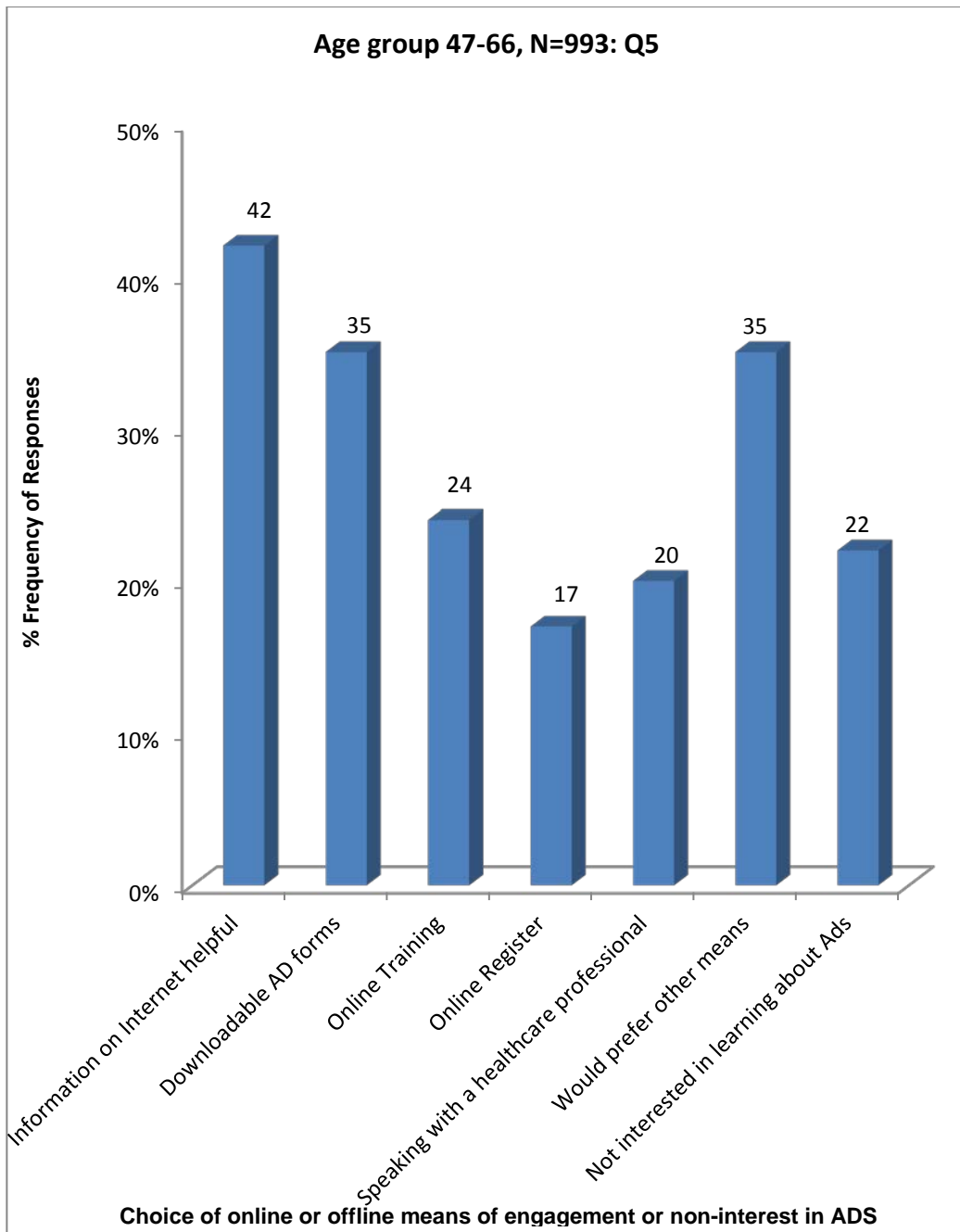


Figure 3.9: Q5 - Frequency of online or offline means of engagement for learning about Advance Directives and non-interest in learning about Advance Directives for those aged 47–66 incorporating the Baby Boomer generation, (N=993)

Figure 3.9 illustrates that 42% of people in this age group thought information on the Internet about ADs would be helpful while 35% reported a preference for downloadable ADs. There was almost equal representation (35%) of a preference for offline means for information on ADs such as face-to-face or telephone consultation (known as *other means*). Other online mechanisms such as online training for completing an AD (24%), an online register (17%) or speaking with a healthcare professional online about ADs (20%) were less often chosen as a preference. Respondents had the option for more than one choice so results are not exclusive. The level of non-interest in learning about ADs at all was 22%. Table 3.18 describes the associations for different online and offline preferences.

Table 3.18: Q5 - Univariate analysis of the prevalence by those aged 47-66, incorporating the Baby Boomers (N=993) of preferred online and offline means for learning about Advance Directives

Demographic	Total N*	Information via the Internet would be helpful			AD forms that could be downloaded as a paper copy would be helpful			Online training about how to complete ADs would be helpful			Online register to file ADs would be helpful			Speaking with a legal or healthcare professional online to answer questions would be helpful			I would prefer other means of learning about or completing ADs such as face-to-face or telephone		
		N#* (%)	95%CI*	P Value	N#*	95%CI*	P Value	N#*	95%CI*	P Value	N#*	95%CI*	P Value	N#*	95%CI*	P Value	N#*	95%CI*	P Value
Gender																			
Male	495	212 (43)	(38-47)		170 (34)	(30-38)		115 (23)	(19-27)		85 (17)	(14-21)		87 (18)	(14-21)		164 (33)	(29-37)	
Female	498	198 (40)	(35-44)	.31	175 (35)	(31-39)	.79	119 (24)	(20-27)	.81	82 (17)	(13-20)	.76	106 (21)	(18-25)	.14	182 (37)	(32-41)	.27
Location																			
Metropolitan	701	306 (44)	(40-47)		246 (35)	(31-38)		184 (26)	(23-29)		139 (20)	(17-23)		153 (22)	(19-25)		252 (36)	(32-40)	
Rural/Regional	292	104 (36)	(30-41)	.02	99 (34)	(29-40)	.71	50 (17)	(13-21)	.002	28 (10)	(6-13)	<.001	41 (14)	(10-18)	.004	94 (32)	(26-37)	.24
Marital Status																			
Married	764	345 (45)	(41-48)		294 (39)	(35-42)		193 (25)	(22-28)		137 (18)	(15-21)		153 (20)	(17-23)		254 (33)	(30-37)	
Never Married	229	65 (28)	(23-35)	<.001	51 (22)	(17-28)	<.001	40 (18)	(13-23)	.01	30 (13)	(9-18)	.09	40 (18)	(12-23)	.39	92 (40)	(34-46)	.05
Education																			
Left School Year 12 or before	355	98 (28)	(23-32)		93 (26)	(21-31)		56 (16)	(12-19)		45 (13)	(9-16)		51 (14)	(11-18)		130 (37)	(31-41)	
Still Study/Cert/Dip/Trade/Apprent†	422	196 (46)	(41-51)		148 (35)	(30-40)		110 (26)	(22-30)		73 (17)	(14-21)		82 (19)	(16-23)		154 (36)	(32-41)	
Bachelor+	216	116 (54)	(47-60)	<.001	105 (49)	(41-55)	<.001	68 (32)	(24-37)	<.001	49 (23)	(18-29)	.01	60 (28)	(22-34)	<.001	61 (29)	(23-35)	.09
Occupation (ANZSCO Codes)																			
Professionals	340	172 (51)	(45-56)		153 (45)	(40-50)		101 (30)	(25-34)		75 (22)	(18-27)		87 (26)	(21-30)		113 (33)	(28-38)	
Clerical/Sales/Blue Collar	610	226(347)	(33-41)		182 (30)	(26-33)		124 (20)	(17-24)		88 (14)	(12-17)		105 (17)	(14-20)		213 (35)	(31-39)	
Never worked/Student/Home Duties	44	5 (16)	(3-31)	<.001	5 (16)	(2-28)	<.001	3 (10)	(-1-23)	.001	3 (9)	(-2-18)	.01	1 (3)	(-3-11)	.001	15 (48)	(29-67)	.24
Annual Income																			
\$0-\$40,000	179	42 (24)	(17-30)		33 (18)	(13-24)		20 (11)	(6-16)		7 (4)	(1-7)		23 (13)	(8-18)		75 (42)	(34-49)	
\$40,001-\$80,000	207	82 (40)	(32-46)		66 (32)	(25-38)		50 (24)	(18-30)		36 (17)	(12-23)		42 (20)	(15-26)		86 (42)	(34-48)	
\$80,001+	379	217 (57)	(52-62)		188 (50)	(44-54)		126 (33)	(28-37)		100 (26)	(22-31)		102 (27)	(23-32)		103 (27)	(23-32)	
Not Stated	228	69 (30)	(24-36)	<.001	58 (25)	(20-31)	<.001	39 (17)	(12-22)	<.001	24 (11)	(6-14)	<.001	26 (11)	(7-16)	<.001	82 (36)	(30-42)	<.001

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

† Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep-Dec 2012

There was no association between gender and choice of online mechanism or other means of engagement with advance directives.

There was a statistically significant association between location and choice however. Metropolitan participants showed a stronger preference for all online options except for AD downloadable forms (χ^2 (1, N=993)=.1, $p=.79$) when compared with rural participants: info on the Internet (44% metro v 36% rural, χ^2 (1, N=993)=6, $p=.02$); online training (26% metro v 17% rural, χ^2 (1, N=993)=10, $p=.002$); online register (20% metro v 10% rural, χ^2 (1, N=993)=16, $p<.001$); speaking with a healthcare professional (22% metro v 14% rural, χ^2 (1, N=993)=8, $p=.004$). There was no association between location and preference for other means of gaining information on ADs (36% metro v 32% rural, χ^2 (1, N=993) =1.3, $p=.24$).

For marital status, participants who were married had a greater association of preference for: info on the Internet (45% married v 28% not married, χ^2 (1, N=993)=20, $p<.001$); AD downloadable forms (39% married v 22% not married, χ^2 (1, N=993)=20, $p<.001$); and online training (25% married v 18% not married, χ^2 (1, N=993)=6, $p=.01$). Participants who were not married had a preference for other means of gaining information on ADs (40% married v 33% not married, χ^2 (1, N=993) =3.8, $p=.05$). There was no association between marital status and preference for an online register (χ^2 (1, N=993) =3, $p=.09$) or speaking with a healthcare professional (χ^2 (1, N=993) =.8, $p=.39$).

Education had a statistically significant association for all categories of online mechanisms with participants who Left school in Year 12 or before reporting less preference for online options: info on the Internet (28% Left school, χ^2 (2, N=993)=47, $p<.001$) compared to Cert. etc., (46%) and Bachelor + (54%)); AD downloadable forms (26% Left school, χ^2 (2, N=993)=31, $p<.001$) compared to Cert. etc., (35%) and Bachelor + (49%)); online training (16% Left school, χ^2 (2, N=993)=21, $p<.001$) compared to Cert. etc., (26%) and Bachelor + (32%)); online register (13% Left school, χ^2 (2, N=993)=10, $p=.01$) compared to Cert. etc., (17%) and Bachelor + (23%)); and, speaking with a healthcare professional (14% Left school, χ^2 (2, N=993)=16, $p<.001$) compared to Cert. etc., (19%) and Bachelor + (26%)). There was no association between education and preference for other means of learning about advance directives (χ^2 (2, N=993) = 5, $p<.09$).

The trend in association for occupation mirrored that of education. Participants who had never worked, were students or had home duties had statistically significantly less preference for all online mechanisms for learning about ADs when compared to participants in clerical/sales/blue collar or professional employment: info on Internet (16% never worked, etc., v 37% clerical etc., v 51% professional, χ^2 (2, N=993)=25, $p<.001$); AD downloadable forms (16% never worked, etc., v 30% clerical etc. v 45% professional, χ^2 (2, N=993)=28, $p<.001$); online training (10% never worked, etc., v 20% clerical etc. v 30% professional, χ^2 (2, N=993)=14, $p=.001$); online register (9% never worked, etc., v 14% clerical etc. v 22% professional, χ^2 (2, N=993)=11, $p=.01$); and, speaking with a healthcare professional (3% never worked, etc., v 17% clerical etc. v 26% professional, χ^2 (2, N=993)=16, $p=.001$). There was no association between occupation and preference for other means of learning about advance directives (χ^2 (2, N=993) =3, $p=.24$).

For income, there was a statistically significant association between income and all online preferences as well as other means of learning about ADs. Participants in the lowest income bracket of \$0-\$40,000 were consistently less likely to prefer online means of engagement when compared to participants in the other income brackets: info on (24%, \$0-\$40,000, v 40% \$40,001-\$80,000 v 57% \$80,000+, χ^2 (3, N=993)=74, $p<.001$); AD downloadable forms (18%, \$0-\$40,000, v 32% \$40,001-\$80,000 v 50% \$80,000+, χ^2 (3, N=993)=67, $p<.001$); online training (11%, \$0-\$40,000, v 24% \$40,001-\$80,000 v 33% \$80,000+, χ^2 (3, N=993)=40, $p<.001$); online register (4%, \$0-\$40,000, v 17% \$40,001-\$80,000 v 26% \$80,000+, χ^2 (3, N=993)=53, $p<.001$); and, speaking with a healthcare professional (13%, \$0-\$40,000, v 20% \$40,001-\$80,000 v 27% \$80,000+, χ^2 (3, N=993)=28, $p<.001$). The association between other means and income was the opposite with participants in the lowest and middle income brackets showing a statistically significant preference for this form of engagement with ADs (42%, χ^2 (3, N=993)=18, $p<.001$) compared to those in the \$80,000+ income bracket (27%). A variable that was not significant for choice of either online or offline means was gender across all options. All variables were non-significant for offline means except for income level.

Multivariate logistic regression analysis of participants aged 47–66 incorporating the Baby Boomers (N=993) (Q5) comparing *non-interest in learning about ADs with sociodemographic characteristics*

Multivariate binary logistic regression analysis of sociodemographic characteristics statistically associated with non-interest in learning about ADs is shown in Table

3.19.

Table 3.19: Multivariate analysis for participants aged 47–66 incorporating the Baby Boomer generation (N=993) Q5: non-interest in learning about Advance Directives

Q5: Not interested in learning about ADs						
Demographic	N*	N#*	% (95% CI)*	Odds Ratio	95% CI	P Value
Gender						
Male	495	117	24 (20-28)	1.3	[1.0, 1.83]	.10
Female (Reference)	498	102	21 (17-24)	1		
Location						
Metropolitan (Reference)	701	151	22 (19-25)	1		
Rural/Regional	292	68	23 (18-28)	0.9	[0.63, 1.26]	.50
Marital Status						
Married [†] (Reference)	764	157	21 (18-23)	1		
Not Married [†]	229	62	27 (21-33)	1.3	[0.88, 1.86]	.19
Education						
Left School Year 12 or before	355	103	29 (24-34)	1.7	[1.17, 2.43]	.01
Still Study/Cert/Dip/Trade/ Appren [†] (Reference)	422	80	19 (15-23)	1		
Bachelor+	216	36	17 (12-22)	1.2	[0.74, 2.01]	.44
Occupation (ANZSCO Codes)						
Professionals (Reference)	340	54	16 (12-20)	1		
Clerical/Sales/ Blue Collar [†]	610	156	26 (22-29)	1.5	[1.00, 2.32]	.05
Never worked/ Student/Home Duties	44	8	26 (10-42)	1.3	[0.51, 3.19]	.60
Annual Income						
\$0–\$40,000	179	52	29 (22-36)	1.6	[0.98, 2.64]	.06
\$40,001–\$80,000 (Reference)	207	40	19 (14-25)	1		
\$80,001+	379	66	17 (14-21)	1.0	[0.64, 1.60]	.96
Not Stated	228	61	27 (21-33)	1.5	[0.92, 2.30]	.11

* N = figures in table are for weighted data rounded to whole decimal

Number who responded to question

[†] Collapsed groups: Marital = married + defacto; Not Married = widowed, separated, divorced, never married; Cert/Dip/Trade/Apprent includes Still Studying; Clerical/Sales/Blue Collar combined

Source: South Australian Health Omnibus Survey, Sep–Dec 2012

Results of multivariate analysis for *non-interest in learning about ADs* for participants aged 47–66 incorporating the Baby Boomers (N=993) (Q5)

The only variable to act as a predictor for non-interest was education with participants who Left school in Year 12 or before twice as likely (29%, OR 1.7, 95% CI [1.17, 2.43], $p=.01$) to report non-interest in learning about ADs compared to those with a Cert. etc., (reference variable).

Summary of results for online and offline preferences for learning about Advance Directives by those aged 47-66 incorporating the Baby Boomers (N=993) (Q5) and *non-interest in learning about ADs*

When considering online preferences for AD engagement, the 47-66 year old age

group (N=993) in this secondary analysis reflects preferences and interest similar to those of the Overall population (N=3055). Where univariate analysis showed differences across all categories for the majority of choices for online engagement with ADs, multivariate analysis was statistically significantly associated only with education and non-interest in learning about ADs. Participants with lower levels of education may have poor health literacy so engagement in an e-Health environment may provide multiple barriers for learning about ADs in this environment. Such factors may include, but are not limited to: online reading skills; comprehension of the information provided; and the ability to understand intuitively how to use and gain access to online devices and training.

The fact that 22% of people in this secondary analysis had no interest in learning about ADs at all suggests that there are still other factors that may impact on engagement with these documents beyond age and indicates the importance of exploring how external factors, such as divorce or income, may influence engagement with ADs.

Discussion

The aim of the research contained within this section was to identify: the level of engagement by the Overall South Australian population with the four legal ADs in this state; rates of assisting others with these documents; agency rates; and comfort, use and preferences for learning about ADs using the online environment. The results from this research clearly indicate that engagement with legal ADs in South Australia is minimal, especially with healthcare ADs. Where ADs are completed, they are more likely to be financial documents such as the EPA and non-ADs such as the Will. The survey clearly indicates the level of comfort and use of the online environment by participants in this study as well as their preferred online means of engagement with ADs. Factors associated with AD and online engagement were defined by demographic variables which identified that those with lower socioeconomic status may be less able, as well as less willing, to access or obtain information about ADs. This could impact upon uptake and use of these documents at the appropriate time of need for people with lower socioeconomic status.

The online environment, in particular, may not be able to assist with AD engagement if people have low levels of income, are single, aged, or have never worked. These people may need more targeted and offline approaches for AD information if they

wish to protect their individual choices for future healthcare. For those who are comfortable with and do use the online environment however, the mechanism of preference for online engagement was that of information on the Internet and downloadable forms. Specific sociodemographic characteristics affecting AD and online engagement are discussed under the sub- headings that follow.

The effect of age

On the whole, there were relatively few differences between the Overall population and those aged 47–66, incorporating the Baby Boomer population. What the results from this survey indicate is that older age is a dominant and predictive factor for AD completions. The completion of ADs at age 65 or older may reflect retirement or estate planning arrangements wherein lawyers and financial planners may encourage completion of healthcare and lifestyle ADs such as the EPG at the same time as the EPA. This supposition has as evidence the much higher rate of completions of Wills to AD documents by those 45 and older in the Overall population compared to those under 45. What is unclear, however, is why Wills are completed at far greater rates than documents for healthcare decision-making while a person is still alive. Does this reflect our reticence with engaging with the idea of our own mortality, or is it a reflection of media messages that medicine offers cures for all that ails us?

Unique evidence from this study in relation to age is that engagement with ADs may begin from age 45 onwards rather than, as previously reported, engagement predominantly being by those aged 65 and over. The engagement with ADs from 45 onwards, as evidenced in the rates of completion of documents by those aged 47–66, may be indicative of experience and knowledge about ADs gained through older relatives completing ADs. For example, becoming the substitute decision-maker for parents, friends or relatives entering residential aged care may have exposed people aged 47–66 in this study to these documents earlier in life than was the case for their older relatives or friends. Evidence for this assertion was hinted at with the slightly increased rates of assistance to others by those 45 and older in the Overall population.

The age effect also clearly illustrates that AD completion is relatively rare for those under the age of 45, even though these documents can be completed by anyone aged 18 and older at any time. Less completion of documents by people in younger age groups may be symptomatic of a perspective whereby death is seen to be quite distant and any need to contemplate arrangements for ill health are not compatible

with the vibrancy of youth. On the other hand, less completion of documents by younger people may also be a result of these documents not being targeted to younger age groups. Younger people do have times in their life however when they may consider making advance arrangements to ensure future security, such as taking out life insurance at a time of marriage or child-bearing and mortgage insurance at a time of house-buying. Could they or should they also be made aware of ADs at the same time? If they are not being made aware of ADs at these times, then they are not being provided with an association or need for ADs at times of marriage, birth of children or other occasions when consideration of future healthcare and financial arrangements may be prudent and timely.

The effect of gender

In contrast to Carr (2012b), I rarely found evidence of a difference between genders in completion or agency of ADs. Does this reflect the fact that in 2012, the decreased age gap between males and female at death (AIHW 2015) means that both genders are reaching ages whereby they are equally as likely to complete ADs or act as an agent? For example, those aged 65 and over may reflect similar numbers of males and females reaching the stage of life where ADs are completed as part of either retirement planning or residential aged care admission. If they are ageing together, then it may be likely that they are creating AD documents together neutralising any difference between genders in completion rates. Therefore, literature, which in the past showed differences between genders in AD engagement (Carr, Moorman & Boerner 2013, Carr 2012b, Lin & Brown 2012), may no longer be relevant to South Australia as both genders age, retire, live longer, suffer illnesses and enter residential aged care at similar rates. Of interest in the Baby Boomer analysis however was the difference between genders for some documents (EPA, EPG) over others. Is this a reflection of marital status such as Lin and Brown (2012) discovered for this age group? Further research to confirm how gender features across age groups for AD completions would illuminate at what time gender may play a more prominent role in AD creation.

Gender did, however, have an influence in assisting others with these documents. Females more often reported assisting others with the healthcare documents while males more often reported assisting with financial documents. This trend was seen in both the Overall population and in those aged 47–66. While this may reflect traditional gender roles associated with responsibility for finances and health, it also provides a clear indicator of which gender is more likely to assist others with

particular documents, especially the healthcare documents. Further research exploring whether female assistance with ADs reflects care arrangements, e.g. at the time that increased care is required for a spouse, partner or parent would provide further clarification about the effect of experience and knowledge on AD completions regarding care provision.

Additional research in this area may also expose more complicated familial expectations of care arrangements and the impact this has on completion of particular documents. Results regarding assistance with ADs in this study provide the evidence for targeting each of the sexes through promotional activities to different professional groups, such as using financial planners for males considering retirement or financial care arrangements for others, and using healthcare specialists to target women assisting in the healthcare of others.

The only other difference between genders in my study was revealed in online engagement with ADs. In the Overall population, females reported being less comfortable than males with the use of the online environment to learn about items of interest. This may be a reflection of age, with women who are older having less confidence in the online environment overall (ABS 2011b). When it came to registering or downloading ADs online, however, more females reported a preference for these options than males. The reasons behind this preference are unclear.

Females also reported a greater preference for face-to-face or telephone discussion on ADs while males reported higher rates of non-interest in learning about ADs. The preference for a more personal interaction in relationship to ADs may reflect differing communication styles of the different genders. Male non-interest in ADs, on the other hand, may be another reflection of “gendered care” arrangements whereby males may feel that someone, usually a female, will provide care at the time of need, therefore engagement with ADs is not required. In these areas of online and offline engagement with ADs, further research could unpack hidden expectations of future care. The online environment could then be used for educating both males and females in the likelihood and choice of future carer and care arrangements such that open discussion and shared decision-making can take place including the need for or use of ADs.

The effect of location

The metropolitan/rural divide was clearly evident in both populations. For the Overall

population completion of financial instruments was preferred by those in the rural area over healthcare ADs. Perhaps this reflects the need to protect financial resources more in rural areas where healthcare resources for ageing may be less available or estate planning has been normalised.

In contrast, there was a greater trend by those aged 47–66 in the metropolitan area reporting assistance to others with all documents except a Will. This may be because metropolitan participants have more access to healthcare resources in which AD discussion might arise. For example, in metropolitan areas there may be easier access to general practitioners, lawyers or financial planners when seeking advice about these documents for others. Alternatively, it could be that metropolitan participants have greater access to and preference for learning about ADs online, thus being able to provide assistance to those who do not.

Impedance to rural and regional participant access to information about ADs online may inhibit their ability to complete or assist others with completing these documents. Future research could explore the link between online access, location and availability to resources online and offline which might influence AD engagement by different age groups in different locations.

The effect of race or country of birth

The effect of race was not measured in this study. Comparisons between non-indigenous and indigenous races residing in Australia could not be made as the Australian Indigenous population in this study represented less than 2% of the overall sample and could not be statistically compared as a separate variable. Mortality within the Australian Indigenous population occurs at younger ages than in the non-Indigenous population (ABS 2012b) so if sufficient numbers of participants with this background had been available, it would have been helpful to assess the use of ADs by this group within a younger age range.

On the other hand, country of birth was measured with the majority of participants from Australia (74%) and the United Kingdom/Ireland (11%). The method of the HOS was such that the sample accurately represented the characteristics of the South Australian population (Harrison Health Research 2012) therefore conclusions about AD use contrasting Australians with a variable combining all other countries of birth were deemed relevant.

This research found that people who were born in Australia reported more

completion, assistance and agency for others on ADs than people who were born in other countries combined. Cultural influences of AD engagement are increasingly being explored as there is mixed evidence in the literature about the effect of culture on AD completions (Allen et al. 2008; Bayer et al. 2006; Braun, Onaka & Horiuchi 2001). In a society as culturally diverse as Australia (ABS 2011a), promotion or engagement of ADs to newly arrived migrants may be required with attention paid to cultural attitudes that may affect engagement with these documents.

Future research could also explore whether cultural factors dissipate for migrants who live in Australia over a long period of time such that other Australian influences, e.g. healthcare systems and services or different family and generational expectations, influence participation in ADs more than culture.

There were no significant differences for online or offline preferences in computer engagement between participants born in Australia and participants born elsewhere. This may indicate that the use of the online environment is becoming more entrenched such that there were no substantial differences between those who had a different country of birth to Australia. This finding suggests that in future the online environment may be an effective means for communicating information about ADs across cultures but will need to be tested for preferred mechanisms and context.

The effect of marital status

Marital status was a key factor in both populations for completion and assistance of all documents, with those widowed reporting equal rates of completion and assistance to those married and in de facto relationships. These rates of completion and assistance may also reflect age-related experience and knowledge of ADs through retirement planning and the death of a partner or spouse in the later years of marriage necessitating financial and healthcare protection arrangements for the surviving partner or spouse. It would be interesting to understand whether this experience/knowledge of ADs at these times reflected positively or negatively on future AD use. For example, were AD completions by participants who were married, widowed and de facto a reaction to exposure to others with or without an AD?

The fact that these three categories of marital status were equally likely to report assisting others with these documents suggests that there may be interactions occurring during assistance which influence completion. Future qualitative research exploring this link may provide greater insight into the factors which influence these

marital groups to protect their individual autonomy with ADs.

What this study did not report upon was the naming of substitute decision-maker by participants who were widowed, married or de facto in these categories. Moorman and Inoue (2013) found that partners did not necessarily influence the decisions made within an individual AD even though they may be named as a substitute decision-maker. Understanding who is likely to be named a substitute decision-maker and how they engage with the instructions of their spouse may provide an opportunity to better inform substitute decision-makers, when named, of their responsibilities in this role at the time formal EPA, EPG and other documents are completed.

It would also be informative to know why substitute decision-makers may not be named. Is the choice not to name a substitute decision-maker, as inferred by the limited completion of proxy documents such as the EPG and MPA, an indication of familial conflict or of an age when no family members are left? If this is so, what third-party candidates might fill the gap?

Within the aged 47–66 group, people who were married reported completing the EPA and Will at a greater rate than participants who were not married although there was no difference seen in this group for the healthcare documents. For this age group, completing financial documents may be the first indicator that retirement or estate planning plays a key role in access to knowledge about and willingness to complete ADs as part of the planning process at this age. Policy and practice measures for ADs may need to shift focus from ADs for people who are suffering from chronic or terminal illness and introduce these ADs to people who are still generally healthy at a time of retirement or estate planning so discussions about healthcare preferences can take place earlier and more often well before they are needed.

In Lin and Brown's (2012) study, they found that unmarried Boomers faced greater financial and social disadvantage than married Boomers. How might this play out with ADs? In this HOS both the Overall and 47-66 age group populations showed that people who were separated, divorced or never married reported completing and assisting with AD documents much less than people who were widowed, married or de facto. Two areas for consideration in future promotion of ADs present themselves then for these marital groups.

The first area of consideration involves lawyers and GPs attending to the needs of clients who are not married to introduce the topic of ADs rather than these people having to wait for retirement or estate planning opportunities. The second area of consideration for people who are not currently married is around the issue of who they may choose as the substitute decision-maker. Although they may gain knowledge and/or experience through assisting others with these documents at some point in their lives, when considering completion for themselves, not having a partner or spouse with whom to engage in such decision-making may make people who are not married feel that completion of proxy ADs, such as the EPG and MPA, is not worthwhile.

To counter this perspective, there may be an opportunity to create a new category of substitute decision-maker, such as a professional third party SDM, who can act as financial and/or healthcare decision-maker for individuals who don't have anyone to name as substitute decision-maker. The EPG provides the opportunity for such naming but has not generally been used as an instrument to name an agreed and employed professional to act as substitute decision-maker for an unmarried individual without a partner, spouse or children. If an EPG has not been completed, guardianship orders at a time of medical crisis may be granted to those named by the court (who may or may not know the individual to any great extent) without the guardian necessarily having knowledge of the individual's preferred arrangements (Office of the Public Advocate 2015).

Of interest when analysing computer use between people who were married and not married was that participants who were married, de facto, separated, divorced and not married were more comfortable with and more often used the online environment for information compared to participants who were widowed. This distinction in marital status with online engagement may be related to age and experience if as is likely, the widows within this study are of older age. There were insufficient numbers of widows in this study, however, to test the association between widowhood and age with AD use.

Preference for learning about ADs in the online environment did not show any differences in the Overall population for different marital categories except for people who were widowed who consistently reported not being interested in the use of the online environment for knowledge about ADs. People who were never married however did prefer the online environment. These differences may be a reflection of age with older widows having less experience with the online environment, while

people who have never married may be in younger age groups with much more comfort and use in the online environment for gathering information. It may also mean that those who are not married are using the online environment more for information and social engagement and so are more comfortable with this mechanism for gaining information and knowledge. Significantly, what these results indicate is that marital status not only plays a key role in current completions of and use of the online environment for AD engagement but also that age may influence the use of the online environment for AD engagement especially when widowhood is added to the mix.

Intriguingly, choices for use of the online environment to gain knowledge of ADs did not match rates of comfort with using the online environment, whether married or unmarried. Is this an indicator that within marital groupings there are factors at play for communication with and on ADs other than just the means of access for information? Further exploration of other factors that may influence the use of the computer environment for information on ADs by those married or not married will enhance knowledge about how to target specific groups and the kinds of information that may be pertinent to them in relation to ADs.

The effect of education

Education was a factor in completion and assistance for both population groups. Specifically, participants who were still studying had the lowest rates of completion and assistance, indicating that age may yet again be a confounding effect. This could be because those still studying may have been in the younger age groups which are not prone to consider ADs.

For computer comfort, use and preference, in both populations, participants who Left school in Year 12 or before were least likely to report comfort and preference for online engagement with AD use. Age may again be a factor with many people who Left school in Year 12 or before probably being of older age with less experience and comfort in the online environment. Including a larger sample size in future surveys exploring AD use in South Australia may provide better clarity on the effect of age and education on AD use.

Overall, higher levels of education yielded higher rates of completion, assistance, and agency with ADs as well as comfort, use and preference for the online environment. Along with age and marital status, education was a dominant independent predictor for AD engagement.

The effect of occupation

Similar patterns to that seen for education were seen with occupation. Those in both populations who never worked, were students, undertook home duties, or were in blue collar employment were least likely to report completing or assisting ADs. It is unclear whether age is an effect here as well. However, as is evident from the statistical analysis conducted, age may play a particular role in relation to occupation with younger participants in the HOS still studying while older participants may incorporate people who have traditionally never worked, e.g. females within older marriages.

As blue collar employment was also an indicator for lower rates of completion and assistance, this variable may be influenced by less education. The evidence in this study shows clearly that participants with professional occupations were more likely to report completing and assisting with ADs.

The same trend was true for association of occupation with comfort, use and preference for the online environment to learn about ADs. This may be reflective of people in professional occupations (clerical and above) having greater access to and experience with the online environment than people in blue collar occupations or who have never worked or have home duties. Investigating these differences further could provide more evidence of the effect of occupation and access to the online environment for information on ADs. For example, if professionals use computers on a daily basis while people in blue collar occupations do not, then the natural inclination to seek information in the online environment may be stronger for professionals than for people in blue collar occupations, who have never worked or are homemakers.

There is little in the literature to indicate how occupation may play a role in AD engagement.

The effect of income

Ko and Lee (2013) found a definite association between lower incomes and less engagement with ADs, however the variable of income in this HOS showed mixed results because one third of respondents did not answer the question therefore the influence this variable has on AD engagement in this study should be considered with caution. Nevertheless, similar to Ko and Lee's (2013) study, participants in the HOS with higher income levels reported completing more documents (specifically the EPA and Will). In this HOS, participants at lower income levels reported

completion of more of the healthcare directives even though these completion rates were small. Do the results in this HOS reflect people with higher incomes having more of a legacy to bequeath and administer thereby feeling the necessity to complete EPAs and Wills while people on lower incomes do not feel the same because they have less to bequeath? Or is it about people on lower incomes having less resources with which to engage lawyers/solicitors or others?

On the other hand, is the association between low income and completion of healthcare directives reflective of poorer health states by those in lower income categories? This study would have benefitted from questions about individual self-reported health status such that the association between income and healthcare directives could be further examined.

With regard to an association between assistance and income, participants in higher income categories were more likely to assist others with ADs than participants in lower income categories. Does this indicate that age yet again is operating as a factor, with younger people who have higher levels of education, occupation and income assisting older relatives with AD completions? Or is it reflective of those aged 47–66 having more experience with substitute decision-making as caretakers for older relatives and thus have familiarity with ADs? When trying to tease out the interplay of these variables on each other for AD completion, this research found that participants in the 47–66 age group showed no difference in rates of completion or assistance for any document other than the Will suggesting perhaps that assistance becomes more prominent when estate planning is being conducted.

There was an overwhelming trend of comfort with and use of the online environment by participants with incomes greater than \$40,000 per year in both the Overall and Baby Boomer populations. This may indicate that participants earning this level of income have increased access to the online environment either professionally (through education and occupation) or personally. The trend was similar for online preferences for gaining information on ADs, but like marital status the rates of preference for use of the online environment were not as high as the rates of comfort and use. This result again suggests that there may be other factors at play when investigating and choosing to access information on ADs using the online environment.

Agency

With regard to agency, very few participants (14% of the Overall population)

responded in the affirmative to having acted as an agent for others though the rate of agency was highest in the 65 and over age group and comparable to levels of assistance reported. To prove that experience and knowledge through agency may lead to AD completion, future research should continue to monitor the rates of assistance and agency with completion rates, particularly in the Baby Boomer age and younger age groups, as this will provide longitudinal data that could provide evidence of association between experience and knowledge affecting AD and online engagement.

Independent predictors of non-completion, non-assistance and non-agency

Independent predictors for non-completion and non-assistance with ADs in the Overall population were age, country of birth, education and income, while marital status was statistically significantly associated for non-completion but not non-assistance in both population groups. Further research is required to understand how these factors influence non-completion and more evidence of the effect that non-assistance and non-agency may have on non-completion. For marital status, these results suggest that experience and knowledge of ADs through assistance to others may not necessarily lead to completion of formal documents if people have a partner or spouse whom they will depend upon to make the right decisions without the necessity of putting this in a written document.

Education was not found to be highly indicative of non-completion or non-assistance in both population groups but occupation was found to be significant for non-assistance. The occupation results may be reflective of the male gender dominating less professional occupations through blue collar work or higher levels of female participants identifying as professionals as a result of recruitment for the study through academic and other professional organisation venues. Nevertheless, professionals were shown to have lower rates of non-assistance when compared to the other occupation variables.

The interplay of occupation, education and gender requires further exploration to understand the mechanisms involved in non-engagement with ADs. Income levels in both population groups were found to be of significance in non-completion and non-assistance similar to Ko and Lee's (2013) findings and this may relate to high income professionals being less likely to report non-completion and non-assistance than those at lower income levels. Finally, rates of non-agency were significantly and independently associated with age, with participants under the age of 45 up to ten times more likely to report not having acted as an agent than participants aged

over 45.

Independent predictors of non-computer use and non-interest in ADs

When looking at predictors for non-computer use, age, marital status, education, and occupation were significantly and independently associated with non-computer use in the Overall population but only education was associated with non-computer use in participants aged 47–66. The association of education with non-computer use for participants aged 47–66 may be the result of older people having less history and experience of computer and online use. This association should become negligible as future generations become totally online proficient.

In both populations, education was predictive of non-interest as was income in the Overall population. It may be that people with less education and income do not see the relevance of ADs for their circumstances. This may have ramifications from a health literacy perspective as well as from a healthcare management perspective for the chronically ill, who are more likely to be from poorer and less educated socioeconomic backgrounds (ABS 2012b). It is quite clear that in both the Overall and Baby Boomer populations in this HOS a lack of socioeconomic support, whether based on social support (marital status), education, occupation or financial support, may make availability and use of a computer difficult. This, in turn, may put people in rural/regional or poorer metropolitan locations at a distinct disadvantage when trying to learn about or engage with AD information in the online environment.

Recommendations from this research

This thesis, within the timeframe and parameters of its genesis, has not looked at the effect of age as a confounder for the other sociodemographic categories as the overall purpose of this chapter and the HOS was to identify use of ADs and the online environment in the general public. Nevertheless, the results from this research suggest that AD and online engagement in the general South Australian public reflect levels similar to that previously reported in other research and are subject to variability within sociodemographic characteristics such as age, marital status, education, occupation and income. Implications of these research findings are as follows:

1. The online environment has a place for AD information dissemination and engagement especially for people with higher levels of comfort with and use of the online environment. The fact that completions of ADs remained low in this study even though comfort and use of the online environment was high, may

mean that that people will use the online environment to access information and download forms but not extend this to completion of ADs. Nevertheless, providing information and forms online is a good start for people who prefer to use this means of engagement with ADs.

2. The place of e-Health in AD contemplation and completion may be more important as future generations who have grown up in an e-Health environment age and are increasingly computer literate and comfortable with the online environment.
3. The population is heterogeneous so when creating online or offline information on ADs, a universal format may not satisfy targeted or particular groups such as the very young, very old, widows, blue collar workers and less computer or healthcare literate people. This would mean that information specific to particular groups may need to continue to be made available in both online and offline formats as well as provision of opportunities for face-to-face consultation for some time to come.
4. In relation to stages of behaviour change, if ADs are completed at greater rates by people who are aged 45 and older, it may be important to prepare people who are younger than 45 to experience this phenomenon with parents, grandparents or older relatives and friends. This would prepare them to contemplate and action AD completion earlier in their lives as a normal part of future planning arrangements.

To engage more people who are 45 and older in AD completion, it may be more prudent to develop engagement with healthcare ADs at the same time as engagement with financial and retirement planning rather than end-of-life care. This research revealed that financial ADs were more commonly engaged with than healthcare directives in older age groups. These results may relate to the normalisation of protecting financial assets that has occurred over generations. If so, this offers the opportunity to translate knowledge on healthcare planning through channels in which healthcare directives can be offered and discussed at the same time as financial directives possibly leading to greater completions of healthcare directives. This would facilitate changing the behaviour of contemplation of ADs based on experience of normalised financial planning into the next stages of preparation and action for healthcare planning.

5. Knowledge translation requires understanding how knowledge occurs, how it is interpreted, the best method for dissemination, and expected outcomes. What this HOS study has revealed is that knowledge about ADs can be disseminated through the online environment but will only capture that portion of the

population that is comfortable with and is happy to use the online environment for accessing this information in this way. Others, who may be influenced by factors such as gender, location, education, occupation and income, may still require different approaches. Regardless of the mechanism of dissemination however there will be a portion of the population who will not be interested in engaging with ADs at all due to factors that this study hints at but did not clearly reveal involving socioeconomic circumstances around marriage, education and income. Policy makers will need to decide if the choice not to engage with ADs by those who feel they do not have a vested interest in these documents will be supported. The acceptance that some people may not choose to engage with ADs will affect healthcare practice and the outcomes this choice engenders, such as higher rates of hospitalisation and medical resource use, undecided substitute decision-makers, and default mechanisms of care at the end of life.

This study has also confirmed that rates of computer use and comfort are highest in the youngest age groups, supporting evidence that people in younger age ranges are likely to be comfortable with digitised information and healthcare information conveyance through e-Health mechanisms. However, although people may wish to engage in ADs in the online environment, low completion rates of ADs suggest that there is not a particular event or time that will initiate completion of ADs other than possibly experience and knowledge of the need for financial ADs, such as EPAs and Wills. Therefore, just providing information or documents in the online environment on ADs may not be enough to change contemplation into an action for completion of these documents.

Future research should consider tracking the process and use of ADs which have been uploaded into e-Health systems to identify success or failure of the documents and the barriers and facilitators for their use in the e-Health environment.

6. Grounded theory provides the opportunity to match initial understanding of AD experience and knowledge with larger and more diverse populations as well as others in the same population. Results from this study have affirmed that age is a significant factor for completion and assistance with ADs and that the ages at which completion and assistance increase is that of 45 years and above, which includes people in the Baby Boomer generation cohort. These results suggest that research about AD engagement within this generational cohort is worthwhile to pursue, especially to identify whether other socioeconomic factors, such as marital status change the rates of completion, assistance and agency with ADs

as this generational group ages and experiences healthcare and lifestyles that may be quite different to the ones their parents are currently experiencing.

Significantly, people in the age range of the Baby Boomers had, in this study, proclivities for completion and assistance with ADs at rates nearing that of people in older age ranges. Whether this is due to factors associated with ageing itself or with factors that may be unique to this generation, this study was unable to identify. Of particular interest will be how financial planning differs between the Baby Boomer generation and younger cohorts as economic circumstances change in Australia. If those younger than the current Baby Boomers are not able to accumulate financial wealth to the same or greater extent as the Baby Boomers, will they engage in retirement and financial planning to the same extent? If they do not, how then will they be exposed to future planning regimes that use this mechanism to incorporate education on healthcare directives?

7. People who may be without access to computers or the Internet due to location, income or other socioeconomic factors may struggle to gain online access to information on ADs as opposed to people with higher rates of income, white collar employment, more education and in a metropolitan location who may use the online environment more regularly to access information on ADs. Interestingly, although participants in this HOS who had never married were least likely to complete ADs, they had higher rates of using the online environment compared to other marital categories. Widows, on the other hand, who had the highest completion rates of ADs, were least likely to use the online environment for information on ADs. Therefore, it seems under these conditions that targeting of AD information in the online environment may need to place a special emphasis on those who are not married while policy makers' understand that widows and other sociodemographic groups may still prefer face-to-face or other means of engagement.

Future research evaluating ADs and computer/online engagement with ADs by different generations at the same age that the Baby Boomers are now may be able to provide more evidence on whether there are any differences identifiable by generational cohort rather than age itself. This would identify the influence of personal autonomy in healthcare decision-making in different generational groups and possibly provide clearer evidence that ADs may be useful for only those generational groups which have a strong preference for personal autonomy in healthcare decision-making.

Implications of this research study

Longitudinal studies investigating whether AD and computer engagement shifts with time, age and generation as these documents become part of normal healthcare planning will also indicate whether there are differences between the generations in their understanding of, willingness and need to protect their healthcare using ADs.

Results from this survey suggest that people born in the Baby Boomer age range are comfortable with and happy to use the online environment for accessing information and AD forms; but will this yield increased completion of these documents? This survey suggests that the answer to this question may only be known as the Baby Boomers reach older age and gain more experience assisting others with these documents or find a reason to complete them, e.g. completion with a Will. While this study did not show great variation between the genders with regard to completion or agency, it did show that females were more likely to assist others with healthcare documents whilst males were more likely to assist others with financial documents, thus providing evidence for targeting the different genders with different messages regarding financial and healthcare planning. For example, males engaging in financial planning can be targeted with messages for healthcare planning, while females engaging in healthcare planning should also be made aware of the need for financial planning. However, will this assistance eventually translate into more healthcare AD completions by females with experience in healthcare provision to others whilst males lag behind because of concentrating on financial documents?

This study also showed that females preferred more offline means of learning about ADs while males were more likely not to be interested in learning about ADs at all. It would be interesting to explore this relationship further as it may reflect traditional gender care patterns and provide additional opportunities for exploring the decision-making that is occurring between people who are married or in relationships where males may need care.

In addition, there is still a large proportion of people aged 65 and over not completing healthcare and lifestyle ADs (approximately 68%). This may be because they are not aware of the documents, may not accept the role or value of these documents, or may choose not to complete them. For GPs and other HCPs working with a high proportion of older, married, non-married and/or non-working individuals, they may find it useful to promote ADs to these patients, especially by promoting the value of identifying a trusted substitute decision-maker who can assist with future

healthcare decision-making.

Using e-Health engagement while waiting in GP offices may provide the opportunity for promoting the message of advance care planning, including ADs, in a neutral and respected environment such that both males and females can be engaged in this messaging without entering into relationship dynamics. Providing opportunities for discussion of ADs with this cohort when they are in relatively good health may increase trust in healthcare and personal relationships and better understanding of the extent of healthcare required by each individual in the future.

E-Health mechanisms to promote messaging about ADs at times of GP engagement may also assist in easier promotion of ADs. For example, use of immediate interactive or passive online applications such as tablets, “apps” and healthcare television in the GP office may provide earlier opportunities for discussion of ADs with HCPs such that medical decisions for future treatment are acknowledged, respected and able to be acted upon at the appropriate time. Such online applications may also enable extension of training in the use of computers and the online environment to access healthcare information.

The fact that many people under the age of 45 did not complete these documents indicates an opportunity to target these populations with health promotion campaigns similar to organ donation such that awareness of and the benefits of having these documents in place any time after the age of 18 can be made. On the other hand, it may be that concentrating efforts on age groups where the likelihood of completion of ADs at what is considered to be an appropriate time of life will serve to gradually normalise these documents such that future generations are prepared to engage with these documents at earlier ages for later use.

People with higher incomes, in white collar occupations and higher education levels in this study were more likely to prefer online access to AD information over participants in lower socioeconomic categories. This means that we still have a decade or more to go before the transition to the paperless society occurs for most members of the community such that computer-based, interactive online mechanisms of knowledge translation in this area become the default access choice of engagement.

Overall, the HOS survey demonstrated that we are still in the early days of AD acceptance and the means of disseminating information on the importance of these

documents will need to continue to be conducted on a continuous basis in a variety of ways until age is no longer a factor in the use of the online environment for disseminating such information.

Strengths and limitations of the study

Strengths and limitations of this study include the following:

1. The use of self-reporting without validation which may be less reliable than use of validation through document review. However, this study tried to account for this by having participants make specific choices about the actual AD documents they completed, such as EPA, EPG, etc. rather than just asking if they had completed an AD.
2. Only studying this population at one point in time is a limitation. Asking the same questions in this HOS in future surveys consistently over a period of years may provide details of events initiating AD contemplation and those events which move this behaviour from contemplation to preparation and action. Nevertheless, results from this study indicate that older age is a significant predictor for engagement. At what specific older age this may be more likely is not able to be determined within this study as other factors, such as location, occupation and education, create additional influences on engagement. Whether these influences act consequentially or collectively require further investigation. For example, when reaching the age of 65 is occupation an initiator for specifically engaging in AD contemplation through questions of retirement planning alternatives, or is the driver chronic illness management within employment?
3. Not testing for health status was a limitation in this study. By not asking about health status in the HOS, this study lacks comparability to other studies investigating completion rates of ADs with people who have particular disease states. However, the intent of this study was to measure the completion rates of ADs in the general population such that the wellness rather than just the illness base of ADs could be part of the composition of completion rates.
4. Not testing statistically significant associations for confounding effects of age is a limitation of this study. This was not able to be done due to the time constraints for production of this thesis but will be done for future publications on this data.
5. The inability to create causal association or correlation specific to the Baby Boomer generation is a limitation of the study. In this chapter, as the HOS is a general, population-based survey, any results for the age group 47 to 66 that incorporates people in the Baby Boomer generation are not specific to any direct

or homogenous features this generation may have. This is because the correlation between age in this age cohort with AD and computer engagement may be affiliated with factors that are specific to this generation but have not been defined in the question design of the survey. To create direct associations between AD and online use and a particular generation, the HOS survey questions should have included questions specifically targeted to factors that uniquely influence the Baby Boomer generation in comparison to other generations, such as preferences for autonomy in healthcare decision-making or experience through others with ADs. Additionally, Baby Boomer experience with the use of ADs may also be a result of retirement planning rather than a result of other sociodemographic factors. The fact that AD use was not positioned within questions of retirement planning is a limitation of the secondary analysis of this age cohort in this study.

6. Another limitation with regard to the Baby Boomer generation analysis is the combining of different sociodemographic variables. These combinations were made for pragmatic reasons associated with the number of participants in variables within the categories as well as evidence suggesting that different variables may be more influential than others. For example, the Overall population results and the literature show that being married is a strong predictor for AD completion and engagement. Because the secondary analysis was done with a population sample of less than one third of the original population sample, it was decided to compare those who were married to those who were not married without delineating into particular states of marriage or non-marriage. Results derived, therefore, may not be a true reflection of the use of ADs by people who are currently not married because the literature has identified that widowhood, which was included in the non-married variable, is a strong predictor for AD engagement; however, this variable also included participants who registered as separated, divorced and never married who may have had different reasons for not completing ADs, such as having a relationship that has broken down or never having had a partnered relationship at all.
7. The low level of use of ADs in older ages (65 and older) even though these documents have been available since 1995 also begs investigation into whether healthcare services or policy have influenced engagement with these documents in this age range. The effect of actual healthcare services or policy for implementation and use of ADs was not investigated in this survey beyond identified legal documents and limits the findings with regard to their influence on completion of ADs and acceptance of ADs by HCPs at the time of need.

8. There are other types of e-Health mechanisms that were not specifically addressed in this survey, such as social media (e.g. Facebook) sites, preference for particular e-Health devices (e.g. iPads), and other issues specific to computer and online use, such as Internet access at home, school or other locations. This information may have enabled a better understanding of the influence of factors such as location on the choices reported for online and offline preferences for engagement with ADs.

Consequently, identification of these strengths and limitations in this research project assisted in the format and design for the third project in this thesis by incorporating more detailed survey questions and choices, as well as fine-tuning the form of computer-based, interactive online mechanisms used for exploring specifically Baby Boomer interest and use of ADs in the e-Health environment.

Conclusion

In conclusion, this study is the first to examine differences in the completion of individual advance directive documents in South Australia as well as age group differences in the Overall South Australian population. The results of this research have identified population groups in South Australia who may have more or less propensity for completing ADs. To be effective, ADs need to be accessible and written in a manner that recognises different levels of understanding and access such that people of any age can complete them in a manner they prefer, whether online or offline.

General practitioners and other healthcare professionals are likely to have increasing and ongoing patient encounters with generational groups such as the Baby Boomers as these groups age and provide care to others. Measuring completion rates of engagement with ADs and computer use across generations may provide better understanding of the type of ADs more likely to be completed by different generations as they age and how socioeconomic or health status may impact on this decision-making and the use of the online environment for engagement with ADs. Further research in this area through replication of these and additional questions in future HOS surveys conducted every three to five years will provide longitudinal data that may identify specific generational and sociodemographic effects impacting on the use of both ADs and e-Health information.

The fact that there was a significant minority of people (22% – 27%) not interested in

learning about ADs at all may indicate that there is complexity in consideration of these documents, or that people are willing to relinquish their autonomy to a healthcare system which they feel serves them well. This may indicate that the purpose of ADs and what they are trying to achieve from the healthcare system perspective, such as uncomplicated decision-making and support of personal choice, will not be straightforward for healthcare professionals. To delineate whether non-interest in ADs is an age issue or related to digital or healthcare literacy, the next chapter investigates the effectiveness of two different types of e-Health formats for enhancing AD completions by South Australian Baby Boomers.

CHAPTER 4 – PROJECT 3 – RANDOMISED CONTROLLED TRIAL OF TWO COMPUTER-BASED, INTERACTIVE ONLINE FORMATS TO ENHANCE COMPLETION OF ADVANCE DIRECTIVES BY A SAMPLE OF SOUTH AUSTRALIAN BABY BOOMERS

Introduction

When the results of SUPPORT (1995) did not find the outcome anticipated, that is, increased use of ADs with dedicated education and policy support, Teno et al. (1998) called for more empirical evidence to determine the usefulness of ADs in promoting and protecting future personal autonomy in healthcare. Many heeded the call, as evidenced in the systematic reviews of Patel, Sinuff & Cook (2004), Wilkinson et al. (2007), and Tamayo-Velazquez et al. (2010). However, inconsistent and narrowly focused research studies have been unable to adequately address the question of completion rates by the general public or a specific generational group.

This chapter describes the purpose, method and results of the third project that encompasses this thesis. The study is a randomised controlled trial (RCT) of two computer-based, interactive online interventions to actuate completion of advance directives (ADs) by South Australian Baby Boomers. It will be reported according to the CONSORT (Moher et al. 2001) recommendations. The intervention study was developed with knowledge arising from Project 2 on preferences nominated by the Baby Boomer population in SA regarding computer-based, interactive online environments.

Background

For the first intervention in this RCT, the research design was influenced by Project 1 and particularly the work of Dexter et al. (1998). Dexter et al. (1998)'s work was the basis for the use of an electronic prompting mechanism to facilitate consideration and completion of ADs in this study. The difference between the RCT used in this project and research by Dexter et al. (1998) or other similar studies is that the population in this RCT is the general lay population rather than healthcare professionals, patients or healthcare systems.

The second intervention in this RCT has been influenced by knowledge translation and the use of various formats for educating people about ADs as described in the work of Tamayo-Velasquez et al.'s systematic review (2010). This review highlighted

that targeted education and information about ADs to an audience of the right age and time for completion may assist AD uptake and completion. To apply this knowledge in practice, the second intervention to be trialed in this RCT involved the creation of an online education module about ADs specific to South Australia with links to supporting information, documentation and forms in the online environment. The intent was to understand if providing knowledge in the online environment was enough, in and of itself, to facilitate completion of an AD.

The design of the second intervention was constrained due to the emergence during the course of Project 3 of the new SA *Advance Care Directive Act 2013*, a new ACD form and new guidelines for completion. The intended release of this new form during the course of the trial complicated the context, delivery and content of the education module and precluded ability to have all legitimate AD forms available to complete within the online education module. As a result, to prevent confusion about which SA forms were valid at the time of the RCT, only information and links to the SA forms as they existed at the time of the trial (older forms such as the EPA, EPG, MPA and Anticipatory Direction or Living Will) were provided.

The specific age group under focus for the second intervention was the Baby Boomer generation as my previous research (Bradley 2012) indicated that this generation was not only interested in ADs but also would be amenable to provision of information about them in the online environment.

Rationale

The rationale for testing these two interventions (to be known as *prompting* and *AD education module*) with the Baby Boomer generation in the manner described consists of two reasons.

The first reason was that evidence from the Systematic Review conducted in Chapter 2 of this thesis illustrated that the most effective computer-based, interactive online mechanisms facilitating actual AD completion are electronic prompting and online education. For this RCT therefore, these two online mechanisms were chosen to assess the effectiveness of either or both interventions to actuate a completed AD. Measuring the effectiveness of both interventions through comparison of pre-and post-survey responses provided a means not only for determining which intervention was better but also to provide empirical evidence of the online intervention successfully able to directly initiate the action of AD

completion.

The second reason for conducting the RCT in the manner described was to test whether this particular generational group was more likely to engage in AD completion if engagement was provided in an online environment. In my previous study (Bradley 2012), Baby Boomer participants suggested the online environment could provide ease of use and access to information about ADs such that those Baby Boomers contemplating creation of ADs would receive enough information at the right time to actuate a completed AD. Research from the HOS (Chapter 3) illustrated that the Baby Boomer age group was computer literate and showed a level of acceptance of engaging with AD information and facilitation through the online environment. Therefore, it was hypothesised when constructing this RCT that by choosing the Baby Boomer cohort as the population sample to be tested, the confounding effect of age or computer literacy shown in the HOS might be negated.

If neither intervention proved to be effective to a determined level of clinical effect, then this would suggest that in this Baby Boomer cohort AD completions may be subject to factors beyond simple accessibility. These factors could be similar to those associated with sociodemographic variables identified in the HOS for non-engagement with ADs.

It should be noted that all of the systematic reviews on factors that are most effective in enhancing AD completions found that face-to-face or some form of personal guidance was most effective in addition to the mechanism under investigation (Patel, Sinuff & Cook 2004, Wilkinson et al. 2007, Tamayo-Velasquez, 2010). However, as the cost of human labour is currently under assessment in the context of an ageing Australian healthcare environment (Productivity Commission 2011), it has been covertly suggested in studies such as those of Aronsky et al. (2004) that providing sufficient information about healthcare preferences such as Do-Not-Resuscitate (DNR) orders through a means requiring less labour costs, such as the online environment, could enable or replace the need for face-to-face or personal assistance in healthcare promotion for subject areas such as ADs . Nevertheless, as long as the rate of completions of ADs remains low (Morhaim & Pollock, 2013; White et al. 2014), the online environment is not yet proven to be a more effective means for enhancing completion rates of ADs over that of other mechanisms, e.g. face-to-face assistance.

In summary, this project seeks to provide evidence on the effectiveness of

computer-based, interactive online mechanisms to facilitate AD completions with a group of participants who are computer literate, of a generation at the right time for AD consideration, and who may be more conducive to seeking out information in the online environment such that they are willing to complete these documents without the need for personal assistance.

Aim

The aim of this project was to examine the effect of two computer-based, interactive online mechanisms to enact AD completions by South Australian Baby Boomers.

Research question

The research questions for this project were:

1. "How effective are email prompting and an online AD education module for enacting completions of the four legal AD documents in South Australia (EPA, EPG, MPA, Anticipatory Direction or Living Will) in a particular generational cohort, namely South Australian Baby Boomers, compared to no information or prompting?", and
2. "Which of two interventions (email prompting or an online education module) are more effective for completing AD documents in this group?"

The effect being explored is the number of individuals who complete documents (to measure the change of behaviour stage from contemplation to action), not the number or type of documents completed, although these have also been measured and commented upon as a secondary outcome. To be able to separately determine the effectiveness of both email prompting and education module interventions, I used a 2 x 2 factorial design. Participants were randomly assigned to four distinct groups comprising prompting, online education, both, or none. For evaluation of the prompting, I compared participants in those groups which received a computer-based, electronic prompt through email (Prompt) against those groups which did not receive a prompt (Non-Prompt). To determine the effect of the education module, I compared those groups which received the education module (AD module) to those groups which did not (Non-AD module). To determine the primary outcome of increased individual completion of any AD document, individuals from intervention groups were compared to the Control group, which had neither prompting nor education information.

Objectives

Objectives of the research were to:

- provide evidence of the effectiveness of a purposively designed computer-based, interactive online AD education module to effect completion of at least one of the four legal ADs in South Australia by members of the Baby Boomer cohort (Objective 1)
- provide evidence of the effectiveness of email prompts to effect completion of at least one of the four legal ADs in South Australia by this cohort (Objective 2)
- investigate any secondary effects of email prompts and the AD education module on actuating completion of the four legal ADs by this cohort (Objective 3)
- provide evidence of rates of assistance from others with any AD completions, discussion about ADs with others at any time during the study, acting as a substitute decision-maker (SDM) for others whilst a participant in the study, and assisting others to complete ADs during the study (Objective 4)
- provide evidence of the acceptance and willingness to use computer-based, interactive online formats for provision of AD information (Objective 5)
- provide evidence of facilitators and barriers to AD completions by this cohort when using computer-based, interactive online formats (Objective 6)
- establish elements of knowledge translation which facilitate contemplation of ADs even though they may not yield a completed AD (Objective 7)

Randomised Controlled Trial (RCT) as an empirical method for meeting the objectives of this study

The National Health and Medical Research Council (NHMRC) lists randomised controlled trials (RCTs) as one of the highest levels of research design (Level I/II) for providing evidence of the effectiveness of an intervention (NHMRC 2005).

Randomised controlled trials may be exploratory or definitive depending on population size, objectives of the study and designated outcomes (NHMRC 2005).

Project 3 provides exploratory, descriptive and statistical evidence of the effect of two computer-based, interactive online interventions to enact completion of any of four legal ADs available in South Australia for a sub-group of the population (i.e. self-selected South Australian Baby Boomers who met the eligibility criteria and chose to participate in the study).

Ethics

This study was approved by the Flinders University Social and Behavioural Research Ethics Committee in June 2013 under Project Number 6069.

Research study method

Research study design

A two-by-two factorial design was used meaning that two independent interventions (email prompting and an online AD education module) were evaluated using one design (Stampfer et al. 1985) to test for enhancing completions by individuals of the four legal ADs in South Australia as demonstrated in Figure 4.1.

2 x 2 factorial design for RCT testing 2 online interventions to actuate AD completions			
		Intervention A – AD Module	
		No	Yes
Intervention B – Email Prompt	No	No AD Module No Email Prompt (Group A)	AD Module Only (Group B)
	Yes	Email Prompt Only (Group C)	Email Prompt AD Module (Control Group D)

Figure 4.1: Diagram of 2 x 2 factorial design of Project 3

When describing the various intervention groups, the following key was used:

- Group A – Control (No AD module, No prompt)
- Group B – AD module only
- Group C – Email Prompts only (Prompt)
- Group D – AD module + Prompts

Trial design

The 2 x 2 factorial research design investigates which of two effects, when compared to a control group, may be responsible for the primary outcome intended (Boyd 2014, Field 2011, Stampfer et al. 1985). It is used as a means for effectively conducting multiple randomised controlled trials at one time comparing more than one intervention with more than one group through the use of half the number of participants that would normally be required to measure the interventions in separate randomised control trials (Boyd 2014, Field 2011, Stampfer et al. 1985). In this study, the effect of two computer-based, interactive online interventions (intervention group) was compared to determine the rate of individuals completing ADs without the comparable intervention. This design assumes that neither intervention interacts with the other. This assumption was verified before the final analysis. Measurements of completion were performed at baseline and after a minimum period of three months for some participants and a maximum period of six months for others through self-reporting of completion. No analysis was made for length of time or time points at which completion occurred and no effort was made to confirm completion by witnessing completed documents, as the purpose of this study was to understand the effectiveness of the online environment to assist the general public with completion of these documents, not to learn about particular details contained therein or to make sure the documents had been completed correctly. Participants in the study were divided equally between four groups (Prompt, AD module, Prompt + AD module, Control) using a randomisation technique to minimise differences between groups with regard to gender, location and age.

In essence, the use of a 2 x 2 factorial design enabled the measurement of the effect of the two factors, email prompt or AD education module, between two or more different groups of participants for completion of any or all of the four legal ADs. This provided the ability to assess the separate effect of each intervention compared to a control group as well as the effect of the interventions (main effects or factors) on two different groups of participants which is the purpose of such a design (Boyd 2014, Field 2011, Stampfer et al. 1985). If the effect of the two factors (i.e. email prompts and AD education module) were different depending on whether they were combined with the other factor or not (called an interaction effect (Boyd 2014, Stampfer 1985)) the research design would have needed to incorporate sufficient sample size and design to see such an effect.

However, to detect these kind of interaction effects requires sample sizes that are four times as large as those to detect main effects alone (based on having four groups of participants) which I was not able to do within the logistics and time constraints of this thesis. Therefore, I did not power the study to detect an interaction effect. In addition, given that there was no reason why the effect of each factor could not be additive when the factors were applied together, the 2 x 2 factorial research study design provided the ability to contrast averages such that statistical power for the effect could be estimated. This made use of this research design an efficient method for understanding not only single intervention effects but also the effect of combining otherwise independent interventions into and through one research study as it was designed to do (Anderson & Whitcomb 2014).

Eligibility criteria and participant sample

Participants for this RCT were members of the South Australian general public born in the years 1946–1965 known as the Baby Boomer generation in Australia. The size of the total population of this group in South Australia as at 2011 was approximately 440,000 (ABS 2011c). The online nature of the study provided capacity to enroll as many people as wished to participate providing they met the inclusion criteria. Information and Consent Forms for the project can be seen in Appendices 4.3 and 4.4.

Inclusion criteria for the study involved the following:

- The person had to be a South Australian resident at the time of and throughout the study period (because the documents to be completed were South Australian documents)
- The person had to be born between 1946–1965 (the definition of the Baby Boomer generation according to the ABS 2003)
- The person had to be able to understand written English well enough to understand the documents involved (as the documents must be written in English in South Australia)
- The person needed to have access to a computer, email address and Internet access (for correspondence and receipt of surveys)
- The person must *not* have completed any of the four legal SA ADs (being the Enduring Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney, or Anticipatory Direction, otherwise known as a Living Will). Potential participants were allowed to have completed an estate Will, a

Power of Attorney (which is of limited duration) or an Organ Donation Card. The reason for not permitting anyone who had completed any one of the four legal AD documents from participating in the study was due to logistical and statistical considerations. Although this has affected generalisability of the results through restricting the analysis to specific and not all documents, nevertheless, not having completed *any* of the four legal documents meant that statistical analysis could take place from a basis of 0 and reflect the main effect of the interventions without confounding effects based on other, additional documents already created

- Finally, the person had to be willing to participate for the duration of the study (approximately 12 months) (See Advertisement, Appendix 4.1).

Exclusion Criteria were predicated on not having met all of the inclusion criteria above. If it was found that participants did not meet the study criteria, they were politely thanked for their interest and linked to publicly available material on South Australian ADs for their knowledge and benefit. Their email details were then removed from the database.

Method of recruitment

So as to extend the reach of communication of the project as widely as possible to as broad an audience as possible, four methods were used to recruit participants in the study:

1. In the first instance, participants from Project 2 (HOS study) who volunteered to participate in additional future research by Harrison Health Research and were of the appropriate age group were contacted via an email address provided by Harrison Health Research. No individual details were provided other than email addresses. Participants from this source were primed with knowledge about ADs from participation in the HOS but their choice to participate in this RCT was self-selected without any specific knowledge about ADs from this RCT study at the time of recruitment.
2. Concurrently, existing networks of contacts that support populations of people in the Baby Boomer age range, such as Flinders University, Seniors Information Centre, Council of the Ageing (COTA); or, who may have been exposed to ADs in some form such as the Australian Nursing and Midwifery Federation, SA Health and The Legal Services Commission, were asked for permission to advertise this project on their websites, in their newsletters and/or via their email networks (Appendix 4.2). The form of request can be seen in Appendix 4.5.

3. To recruit more generally, local media was used. Newspapers including the local suburban Messenger and affiliate newspapers, The Advertiser and The Sunday Mail (both statewide newspapers) as well as other magazines associated with Baby Boomers (SA Lifestyle) had advertisements placed for the study. As there is no single means of engagement with the whole of the general public, free local newspapers circulating throughout most communities in South Australia (i.e. Messenger Newspapers) provided a mechanism for engaging with a wider Baby Boomer audience. Messenger Newspapers and their affiliates also cover regional and rural South Australia. Examples of these advertisements can be seen in Appendix 4.6. In addition to newspaper advertisements, mention of the study was made on local programs of the Australian Broadcasting Corporation (891) and one of the top commercial radio stations, 5AA. Broadcasters read on air the same advertisements as those placed in the newspapers.
4. In addition, the primary researcher also conducted occasional seminars on ADs for nurses and community groups such as Neighbourhood Watch[®], a community organisation whose mission is to assist people to look after each other in their own neighbourhoods. Hard copy fliers similar to those in Appendix 4.1 were left at these seminars and also in public spaces at local libraries and shopping centres.
5. A major form of recruitment as the study progressed was snowballing or word of mouth, and via electronic social messaging networks such as Facebook. Often, those who felt family or friends would be interested would forward the email advertisement either in whole or in part. This meant the researcher had lost control of the expression of request, necessitating clarification with enquirers to the study who required more information for assessing participation.

Though there was a possibility of bias in this RCT due to self-selection of participants for this study, this bias was negated through the many more enquiries to participate in the study than participants who were eligible. The criteria for eligibility to the study meant that only people who met strict criteria could participate regardless of their interest in ADs. The bias that self-selection may have brought to the study was also countered through randomisation such that the primary outcome of completion was not dependent on the willingness of the participants to engage in a nominated activity as such but rather the primary outcome was dependent on the way in which they used any information received to engage in a specific element of the activity, that is completion of an AD. In other words, participants were not selected for their intention to complete an AD but rather they were selected for their consideration, interest in and contemplation of the documents. Though this may

have resulted in bias in the RCT due to self-selection, this bias was minimised by the objective being completion rather than contemplation.

Costs for recruitment through the various means listed above were substantial. Fortunately, these costs were able to be met through sequestered monies by CareSearch to augment the PhD scholarship. Additional funding came from the consultancy fund of Professor Paddy Phillips and the Flinders University Research Higher Degree (RHD) Student Maintenance Fund, a fund which provides up to \$2000 per RHD year for resourcing RHD studies.

Setting

The setting for this study was the participant's own computer and Internet service. Through this online environment, participants received email information about the study, surveys if they were eligible to participate, and access to the online AD education module or any other web-based information on ADs.

Material used in Project 3

Intervention (Prompt Group): Email prompts

For the email prompts a survey which repeated the first seven questions of the Pre-survey was asked at each prompt time point (Appendix 4.8). These surveys were designed to be minimally intrusive yet act as a 'prompt' to bring the subject forward in the participant's mind from pre-contemplation to action stage. The concept for this design emerged from the work of Dexter et al. (1998) and Murphy, et al. (1997) as well as more recent health promotion strategies for breast and prostate screening whereby age-related prompting for testing occurs. It was also hoped that by answering the surveys, I would be able to determine when during the study period the ADs may have been completed and the number of prompts required for completion before completion took place. Unfortunately, due to logistical and time constraints within the design of the study, it was not possible to ascertain this secondary outcome from the prompt surveys completed.

There was one additional question asked in the prompt surveys regarding information gained from any website on ADs through the user's own initiative. Finally, there were some modifications made to the seven questions to adjust for present or future tense or other items that may have been relevant to only Group C or Group D.

Intervention (AD Module Group): AD education module

The other intervention in this study was a uniquely designed computer-based, interactive online education module with information relevant to ADs in South Australia. The design of this module incorporated information from the literature review (Project 1) on successful methods of knowledge translation about ADs both offline and online. The AD module could be viewed via an online link during the course of the study:

<https://checkbox.caresearch.com.au/Survey.aspx?s=6c3f8c889a924453ab3f8d97e3e8fb60&u=a159467b-4c17-4779-9581-aa58c308487d&forceNew=true&test=true>

Once the study and thesis examination process was complete, the link to the module was inactivated.

Briefly, the module contained 56 Powerpoint slides which addressed the following information:

- What ADs are all about
- Why people might choose to create an AD
- Who should create an AD
- How ADs work with detailed information about the 4 South Australian documents and substitute decision-making
- When ADs should be completed
- What can be done with this new knowledge about ADs
- What information should be included in an AD
- Information about the upcoming new SA ACD Act, form and guidelines
- Finally links to websites where forms could be obtained and other information sought

The AD module was created with the assistance of CareSearch staff, especially Ms Ruth Murton, the website manager for CareSearch. It was placed on a webpage within the CareSearch web space that could only be accessed by participants via specific links provided to them. The links to the education module were created for both Apple MacIntosh (including iPad) and PC versions since participants may have used one or the other type of systems for viewing the module. There were multiple iterations of the module designed and tested with Ms Murton and also with Ms Kathy

Williams, Policy and Ethics Analyst from SA Health, who assisted with the correct terminology and conditions of the four legal South Australian ADs and the new ACD (which was not tested in this trial). Because participants were free to access whatever information they wanted from other online facilities during the course of the study, it was necessary to provide not only information on South Australian ADs relevant to older documents in use, but also to alert participants to the fact that the ADs would change during the course of the study and where they might be able to find information on this when the new information became available. Participants received basic knowledge on the four AD documents and sufficient information about when and how the new South Australian ACD would come into effect and what it would contain.

Testing of information of the AD module was conducted from both within the CareSearch space as well as externally with a small group of people with expertise on the subject who were outside the parameters for participation (i.e. not Baby Boomers or otherwise ineligible to participate). Those who tested the module were asked to assess useability, readability and relevancy of the knowledge presented for the purpose intended.

Participants receiving the online AD education module intervention were able to access the module as often as they liked throughout the term of the study but received this intervention only at one time point, December 2013. Additional participants who entered the study after this time received the AD module at the time of their randomisation into groups B or D. No surveys were done in connection with receipt of the AD module email or information and participants were alerted to the fact that there were no surveys affiliated with the AD module at the time they received this intervention.

At the conclusion of the study (June 2014), all participants were provided access to the AD module through links in emails generated in the Post-survey and subsequent email reminders to complete the Post-survey. This was done to make sure no participants were disadvantaged by not having had information that could be found in the AD module.

Outcome Measure Instruments: Pre-Survey

People who enquired to participate in the study, completed and then returned a Consent Form were all sent a Pre-survey for completion prior to randomisation into the trial. The Pre-survey was designed to understand the participant's knowledge of

and previous engagement with different types of all ADs, not just the four legal ones. The Pre-survey (Appendix 4.7) consisted of three sets of questions, a brief version of which is below.

Set 1 (main questions about AD use)

- Q2: Have you completed any of the forms listed? – *Primary Outcome Question*
- Q4: If you did complete any documents, did you receive assistance from someone to complete the document (a number of options provided)?
- Q5: Since participating in this study, have you discussed ADs with anyone (a list of people provided)?
- Q6: Thinking about your family and friends, have you helped someone learn about or complete any of the forms listed (same list of people as in Question 3)?
- Q7: Since the commencement of the study, have you acted as the power of attorney or guardianship for someone (combination or singly of EPA, EPG and MPA)?

Set 2 (main questions about the online environment)

- Q7A: How comfortable are you using a computer and/or the Internet?
- Q8A: How often do you use a computer and/or Internet?
- Q14A: Which form of assistance (online or offline) would be helpful to you for learning about ADs?
- Q13A: Which type of assistance (online or offline) would be helpful to you for learning about ADs?
- Q11A: Do you currently use social media (list of different types provided)?

Set 3 (main demographic information)

- Q15: Gender
- Q16: Age based on year of birth
- Q18: Country in which person was born
- Q19: Marital status
- Q20: Household Income
- Q21: Occupation
- Q17: Aboriginal or Torres Strait Islander

- Q22: Location of Residence (Metropolitan, Rural/Regional)

The questions for the Pre-survey were based on those from the HOS in Chapter 3 except for education level which was omitted through one of the pre-survey design iterations due to an oversight.

Modifications to the original range of choices available in the HOS were also made for the Pre-survey. These modifications were generally around different types of hardware or software that people may be using to access information, e.g. Facebook, iPads. The RCT allowed for more choices to be offered for each question in contrast to the HOS where each choice provided incurred an additional cost.

Pilot testing of all of the surveys in this RCT (Pre-, Prompts-, and Post-) and the AD education module in the RCT was conducted with a select group of work colleagues, friends and family members with various levels of knowledge about ADs and online environments but were not eligible to participate in the study due to age, relationship or conflict of interest. Surveys were tested by a small group of experts from CareSearch, SA Health, statisticians, supervisors and lay people who also tested the AD education module. Those who tested the materials were asked to assess useability, readability and relevancy of the knowledge presented for the purpose intended. Feedback provided was incorporated iteratively into multiple versions until consensus was achieved on the final versions of both surveys and AD module used.

It should be noted that the purpose of the AD education module was not to create an independent entity that could be used outside of the RCT so more prescribed measurements of useability, readability and relevancy (Tieman and Bradley 2013) were not conducted. Rather the education module was created to provide the requisite information required for participants in the study to contemplate creation of an AD.

The sample size was not conducive to association or correlation analysis with sociodemographic characteristics as many individual sociodemographic characteristics yielded sample sizes of less than 50 which is felt to be the minimum number required to prove statistical association between demographic variables and factors being tested (Field 2011).

Outcome Measure Instruments: Post survey

All participants who concluded the study were sent the Post-survey for completion at

the same time. Questions asked in the post surveys were segregated for relevancy to each of the four groups (Appendix 4.9). For example, the first eight Post-survey questions were the same for each group and comprised a repeat of the first seven questions from the Pre-survey plus an additional question asking for reasons why they did not complete any documents if they had not completed them. Additional questions were asked on items that may have been relevant to individual groups, such as questions about the AD module for Groups B and D or email prompts for Groups C and D. Based on feedback from some participants to the Pre-survey and Prompt-surveys during the course of the study, the Post-survey was also modified in an iterative process to avoid frustration and confusion for participants, especially those in Control Group A who did not have any prior exposure to the AD module or email prompt surveys. Post-survey responses for the first eight questions were used for comparison to Pre-survey responses to measure the primary outcome of individuals completing ADs.

All of the surveys contained opportunities for open-ended comments based on the section completed, e.g. AD education module questions had an open-ended comment section for participants to provide their own commentary about the module apart from the specific module questions asked. Open-ended commentary was also available in the Post-survey to comment on the study as a whole. The surveys were uniquely designed for this project but reflect parameters assessed in other studies on AD completion as found in the literature review in Project 1 (Chapter 2) and the HOS study in Project 2 (Chapter 3).

Sample size

Sample sizes were calculated according to Dupont and Plummer (1990) using their logistic regression calculator (Dupont & Plummer 1998). To determine sample size for Project 3, the following variables were considered:

- Effect size = 10% for each factor
- Power = .80
- Prospective
- Uncorrected chi-square test
- Two sided Type 1 error rate: alpha = .05

- Sample size for uncorrected chi-square test = 101 cases per group to detect a 10% difference. There were 4 factors (independent variables) so total sample size was based on 4 parallel groups = 404.

To adjust for a 2 x 2 design which increases the power of the study by assessing the main effects of the two groups with the same factor together, a variance inflation factor as described by Hsieh et al. (2011) was applied. This halved the initial total sample size required from 404 to 202 which it was felt was more achievable within the time constraints available to conduct the study. The sample size of 202 was then multiplied x 35% (to allow for refusals and attrition) which necessitated a minimum sample size of 272 participants (i.e. 68 participants per group) required for the study.

Randomisation

Randomisation in this project involved randomising the study population (SA Baby Boomers interested in ADs) into one of four different interventions and/or controls to ensure a balance in both known and unknown confounders between groups. After completed Consent Forms were received, participants were provided with the Pre-survey (Appendix 4.7). The Pre-survey was designed to: make sure participants had not completed any of the four legal ADs; make sure they understood the level of engagement with ADs experienced; make sure they understood participant comfort with and use of the online environment; and to document demographic characteristics. When the Pre-survey was returned, randomisation was conducted using a block randomisation generator in blocks of four with stratification based on three factors: age (first or second decade of Baby Boomers); gender (male/female); and location (metropolitan or rural). As the Pre-survey was submitted, the Research Data Management System (RDMS) of CareSearch generated an email to the researcher with details of the three factors, namely birth year (older decade 1946–1955, younger decade 1956–1965), gender, location (metropolitan or rural). These factors allowed stratification of the sample such that equal numbers of each type of stratification would be placed in randomised groups. In total there were eight different stratification categories as shown in Figure 4.2:

Stratified categories for randomisation of participants in RCT			
1	Male	Young	Rural
2	Male	Young	Metro
3	Male	Old	Rural
4	Male	Old	Metro
5	Female	Young	Rural
6	Female	Young	Metro
7	Female	Old	Rural
8	Female	Old	Metro

Figure 4.2: Stratified categories for randomisation

Each Pre-survey had a researcher-generated UID (Unique Identifier). An example of the email received by the researcher at the completion of a Pre-survey is shown in Figure 4.3.

Example of computer-generated email when Pre-survey was submitted in RCT

Hi Sandy,

Just letting you know that a Pre-survey entry has been submitted to the system for

UID 2062013

Survey Submission Date: 2/09/2013 9:51:26 AM

*Gender: **Female***

*Year you were born: **1964***

Identify as ATSI: No

I was born in: Australia and New Zealand

Marital Status: Married

Income: \$100,001 - 120,000

Employment: Health Professional (all types)

*I live in: **Rural or Regional** (Adelaide Hills, Barossa, Eyre Peninsula, Western South Australia, Far North, Fleurieu Peninsula, Kangaroo Island, Limestone Coast, Murray Mallee, Yorke Peninsula and Mid North)*

I learned about this study: Work or School Colleague

Figure 4.3: Computer generated email from submitted Pre-survey

The UID number was then placed in one of the stratification group spreadsheets where a previously computer-generated randomised group number was lodged, as shown in Figure 4.4.

Example of randomisation groupings for RCT				
group	gendergrp	agegrp	areagr	UID
B	Male	Young	Rural	123456
D	Male	Young	Rural	789101
C	Male	Young	Rural	234567
A	Male	Young	Rural	345678
C	Male	Young	Rural	456789
D	Male	Young	Rural	567891

Figure 4.4: Example of randomisation spreadsheets*

*If details of person were that they were male, in younger decade, and rural, then their UID was placed in the empty cell next to the first group with subsequent UIDs following continuously from the first.

At the conclusion of recruitment, the different groups were then formed, for example all of those from the stratification tables in Group A were put together as Group A. These then formed the groups for the interventions as follows:

- Group A – Control
- Group B – AD Module only
- Group C – Email Prompt only
- Group D – AD Module + Prompt.

Data collection and analysis

Data for the study were collected from the Pre-, Prompt- and Post-surveys. Responses to questions for all surveys were collated in the Research Data Management System (RDMS) of CareSearch. The RDMS is an integral part of the CareSearch palliative care knowledge network and is covered by a user agreement with Flinders Partners, Flinders University. Survey responses went directly to the RDMS, bypassing the researcher in order to provide anonymity and confidentiality of survey responses.

Only the researcher and her supervisors had access to individual details linked to UIDs with such details kept in a secure and locked location accessible only to the researcher. Data analysis was done solely by UID to prevent bias on the part of the researcher that may have occurred through knowledge gained by email communications prior to Pre-survey distribution. If problems arose for participants during the course of the study, the RDMS Manager would forward individual emails

to the researcher for follow-up such that UID confidentiality could be maintained, for example, the email contained the name of the participant but not the UID. So as not to pre-empt or inadvertently influence survey designs or answers, data from all surveys was not analysed until the conclusion of the study.

Once a week, the researcher screened the RDMS files for duplicate survey responses or at the request of a participant who did not know if they had completed a survey. If a UID recorded the same survey more than once, these duplicate surveys and those with incomplete responses were deleted from the database before importing the data into Excel for data analysis. If the participant did not know if they had completed a survey, then the researcher requested the RDMS manager to access the database to check for completion or duplication so as to avoid, as much as possible, revealing any association between UID and individual names or details.

Once survey information was uploaded to Excel for analysis, the questions from all surveys were sorted and matched by UID such that Pre-, Prompt- and Post-survey responses to Questions 1 through 7 could be linked together to form the package of information to be analysed. In the first instance, this created two separate datasets:

1. Pre-survey vs. Post-survey (for those not in Prompt groups); and
2. Pre – Prompt – Post- surveys (for those in Prompt groups).

The second dataset Pre – Prompt – Post- surveys was thought to be able to provide some information on timing or effect of individual email prompts for Questions 1 through 8. The number of participants in the Prompt group who completed all five surveys (Pre-survey, Prompt-surveys 1 to 3, Post-survey) was 90 from the two groups (C and D) subjected to Prompting. However, insufficient numbers of totally completed responses, especially of individual document completions in Prompt-surveys made this information redundant and the effect of the email prompting could be seen more clearly through the Pre-survey vs. Post-survey analysis for each of the Prompt participants. If a participant completed the Pre-survey and any Prompt-survey, but not the Post-survey, they were excluded from the final analysis as the analysis was conducted on Pre- and Post-survey completions only.

Outcomes

Figure 4.5 is from the Cochrane Handbook of Systematic Reviews for Interventions (Higgins & Green 2011) and describes the types of outcomes that should be

considered when conducting healthcare research with outcome-based measures as well as the different levels of outcomes that may occur.

- Main outcomes, for inclusion in the “Summary of findings” table, are those that are essential for decision-making, and should usually have an emphasis on patient-important outcomes.
- Primary outcomes are the two or three outcomes from among the main outcomes that the review would be likely to be able to address if sufficient studies are identified, in order to reach a conclusion about the effects (beneficial and adverse) of the intervention(s).
- Secondary outcomes include the remaining main outcomes (other than primary outcomes) plus additional outcomes useful for explaining effects.
- Ensure that outcomes cover potential as well as actual adverse effects.
- Consider outcomes relevant to all potential decision makers, including economic data.
- Consider the type and timing of outcome measurements.

*Higgins, J & Green S 2011, 'General methods for Cochrane reviews: Cochrane Handbook for Systematic Reviews of Interventions, Version 5.1.0', The Cochrane Collaboration, Canberra.

Figure 4.5: Factors to consider when developing criteria for “types of outcomes”*

Based on the criteria from the Cochrane Handbook for Systematic Reviews of Interventions illustrated in Figure 4.5, the primary or main outcome for this study is the increase in the number of individuals completing any of the four legal South Australian AD documents when the person has been subjected to one of two computer-based, interactive online interventions known as email prompting and an AD education module.

To determine the primary outcome of individuals' completion rates, a comparison was made between Pre-survey where none of the four legal documents should have been completed, and Post-survey where one or more of the four legal ADs could have been completed.

The primary outcome of total number of individuals completing documents by intervention was first calculated by summing up the number of individuals who completed any of the four legal ADs (Enduring Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction or Living Will) per group.

Prevalence, univariate and multivariate analysis for both overall document completion and the individual document completions by intervention and non-intervention will be shown in tables which compare each of the above named documents against:

- Combined Prompt/Non-Prompt Group
- Combined AD module/Non-AD module Group.

Secondary outcomes that were analysed included assistance from anyone during the study to complete the documents (Question 4), discussion with anyone about ADs during the time of the study (Question 5), helping someone with any ADs during the time of the study (Question 6) and acting as a substitute decision-maker during the time of the study (Question 7). Questions 4 through 7 were not asked for comparative purposes against completion rates. Rather, they were asked to develop context and understanding of how this participant group may have engaged in other activities related to AD completion based upon one or the other of the interventions or no intervention at all.

A number of other questions were also asked in the Post-survey to provide information about computer and online use, other elements associated with email prompting and the AD education module, and satisfaction with the format and participation in the study.

Finally, thematic analysis was conducted on open-ended commentary about factors influencing participation in the study. Participants were able to make open comments either as a choice within each question of the survey or at the end of the study in the Post-survey.

Of particular focus were factors such as the ease of use of the AD module and online surveys or barriers and facilitators identified by participants during the study as assisting or not assisting completion of ADs. Thematic analysis from open comments was guided by classical grounded theory wherein participants were provided the opportunity to comment about particular issues from their own perspective and what was important to them about and within each issue, e.g. why weren't ADs completed (Q3)? For those comments provided as an open comment from within each question (e.g., Q3), the number of comments provided from within the question across all groups (A-D) was combined recorded as well as a general description of the overall comments and examples under each question sub-heading.

Within the open commentary section provided at the end of the study (Post-survey), the comments were open coded across the groups. The codes often referred to elements of the post-survey questions but not necessarily within a particular question's open comments section, so the Post-survey codes were then categorised to reflect additional detail for particular aspects of AD engagement.

For example, if the Post-survey codes referred to barriers for completion of the ADs, then all comments referring to barriers for completion across groups A to D were grouped under the category *barriers for completion*. These were then assessed for themes. The themes are described at the end of Chapter 4 in the open commentary section. An example of the method of coding, categorisation and themes can be seen in Appendix 4.10. I conducted the thematic analysis in this fashion without a formal template as I had used classical grounded theory in a Masters on this subject (Bradley 2012) and this process was familiar to me.

Statistical methods

Once the data were compiled and arranged for statistical analysis, datasets were uploaded to SPSS version 19 for exploratory, descriptive statistical analysis.

All analyses were conducted on an intention-to-treat basis; a two-sided probability value of .05 constituted statistical significance. Categorical variables were compared using chi-square in the first instance to determine any significant effect between documents for any group. Main effects and any interaction effects of the intervention and between group differences were assessed using binary logistic regression.

Participants

Figure 4.6 illustrates the participants who were enrolled, allocated, randomised and analysed in this study. Please note that there were a number of people (29) who were randomised and participated in the study prior to their Pre-survey results being analysed. This occurred because of the way that randomisation took place. Prior evidence of *no* document completion was not assessed prior to the randomisation process as it was presumed none would be completed between time of Consent and Pre-survey completion. However, these 29 participants had a delay in receipt of Pre-survey from the time of their Consent wherein they had indicated that they had not completed any of the 4 documents and thus were eligible for the study. As the Pre-survey analysis was not conducted until the conclusion of the study, the completion of ADs by these 29 participants between time of Consent and the time of

the Pre-survey submission was not discovered until after the study had been completed. Therefore, the data from these 29 participants were eliminated from the final analysis as they did not represent a baseline of 0 completions at the time of Pre-survey.

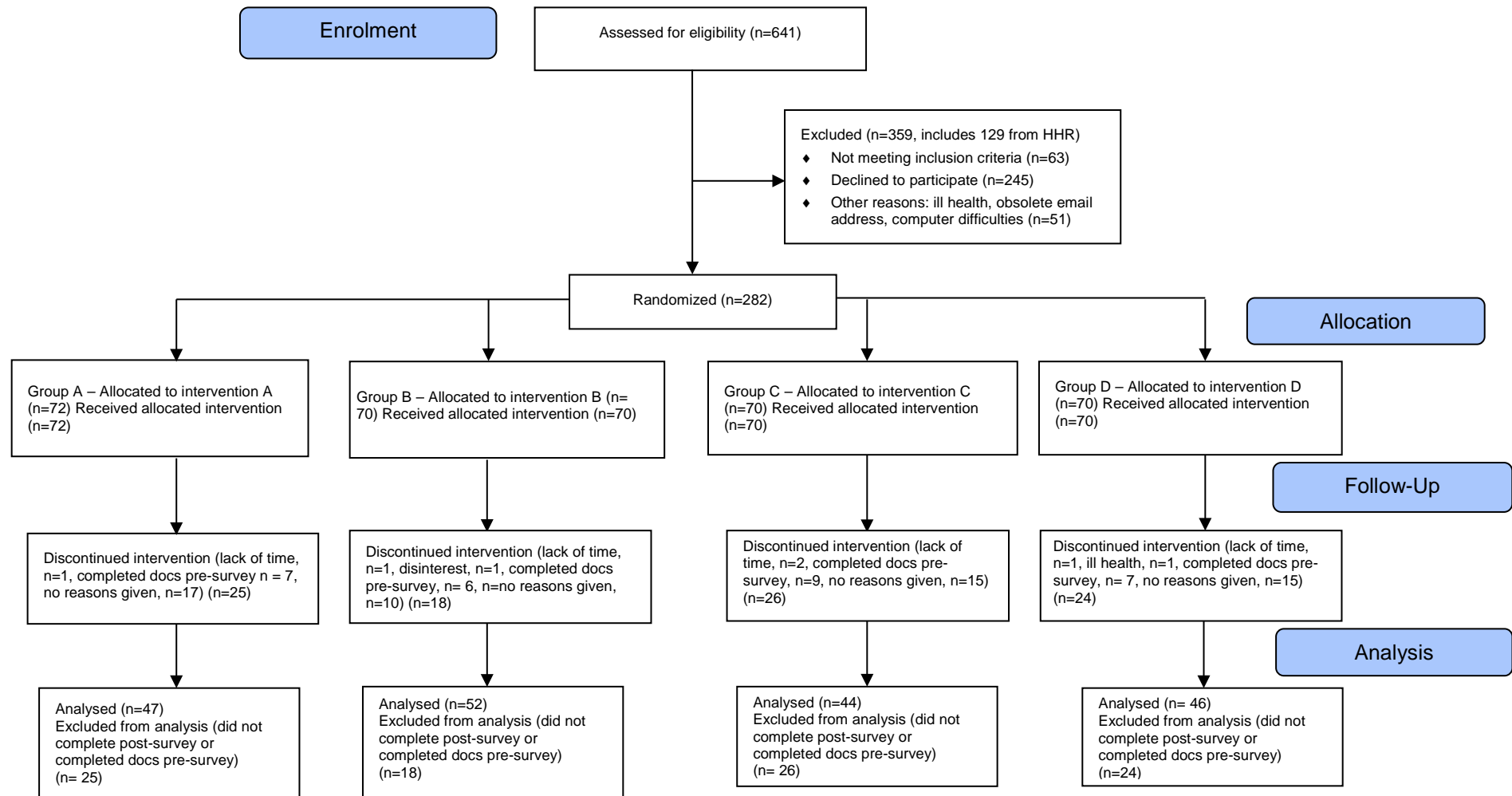


Figure 4.6: Flow diagram of inclusions and exclusions based on CONSORT recommendations*

*Moher D, Schulz K, Altman D (2001).

Timelines and final recruitment to study

It was determined that the project should be conducted over a 12 month period based on recommendations in systematic reviews of ADs by Wilkinson et al. (2007) and Tamayo-Velazquez et al. (2010) which found that many educational interventions tested hadn't been tested long enough for conclusive information about their effectiveness in increasing AD completion rates. Therefore, both the AD module and email prompts were targeted to be released at strategic time points over 12 months such that some interval for contemplation of completion of ADs could occur that would lead to preparation and action to complete an AD. Within this RCT, the anticipated timeline of 12 months for contemplation was only partially met with one half of the participants who had sent in Consents (n=150) by June 2013 receiving the Pre-survey by July–August 2013 such that they had nearly 12 months to contemplate creation of ADs. Some of these participants had been enrolled in the study early on in the recruitment process (April/May 2013) and form part of the 29 participants who completed AD documents between Consent and distribution of Pre-survey. For the other half of participants, those recruited after June 2013 and/or as soon as their Consent arrived, they received the Pre-survey promptly but the amount of time they had to contemplate completing an AD through the study varied from 3 months (when the final recruitment of participants concluded in February 2014 with the number required reached) to 9 months.

Interventions were not released until the majority of Pre-surveys (260) had been received such that sufficient numbers of participants were likely to be achieved for the study. This did not occur until December 2013 for the bulk of participants. The AD Module was released to Groups B and D once only in early December with continuing access to the module throughout the rest of the time period of the project. This access was made available through a link in the initial email informing them of this intervention and its availability. Email prompts were targeted to three time points: early December 2013, at the same time that the AD module was released so those receiving both interventions of prompt and AD education module were exposed to both at the same time: January 2014: and April 2014.

The time points for prompting were based on suggestions by previous participants in a study by Bradley (2012) that ideal times for prompts to occur would be around birthdays, driver's licence renewals or holidays. As this study was not resourced to follow up participants based on individual characteristics such as birthdays or driver's licence renewals, the nominated times for prompting centred on holiday

break periods in the South Australian calendar, especially the primary holiday break periods of December/January (Christmas/New Year) and April (Easter) which also coincided with school holiday periods. These times were chosen as it was predicted that many people take personal leave during this time and would likely have more time to deal with personal matters and/or reflect on what is needed in the year ahead; and also it was felt that this would be a more conducive time to think about ADs when participants who were prompted to do so may have had more time to act on the prompt. The additional time points of the end of January and beginning of April were also chosen as they represented timepoints that were both closer to and further from the initial event. A Gantt chart of timelines is presented in Table 4.1.

Table 4.1: Gantt chart of timeline interventions

Group A = Control Group B = AD Module Group C = Prompt Group D = AD Module + Prompt	2013				2014			
	June	July–Aug	Sept–Oct	Nov–Dec	Jan–Feb	Mar–Apr	May–June	July–Aug
Recruitment								
Pre-Survey								
Sent to first 150 participants		150						
Sent to remaining 132 (282 total)		151 +			Final 282			
First Reminder to Complete Pre-Survey*				8 Nov				
Second Reminder to Complete Pre-Survey*				20 Nov				
Interventions								
<i>Group A – Control[†] (72 participants)</i>				26 Nov	After 26 Nov			
<i>Group B – AD Module[^] (70 participants)</i>				2 Dec	After 2 Dec			
<i>Group C – Email Prompt No. 1[^] (70 participants)</i>				2 Dec	After 2 Dec			
<i>Group D – AD Module+ Email Prompt No. 1[^] (70 participants)</i>				2 Dec	After 2 Dec			
Email Prompt No. 1 Reminder								
<i>Group C</i>				16 Dec	7 Feb			
<i>Group D</i>				16 Dec	7 Feb			
Email Prompt No. 2								
<i>Group C</i>					24 Jan	28 Feb		
<i>Group D</i>					24 Jan			
Email Prompt No. 2 Reminder								
<i>Group C</i>					10 Feb	14 Mar		
<i>Group D</i>					10 Feb	14 Mar		

Group A = Control Group B = AD Module Group C = Prompt Group D = AD Module + Prompt	2013				2014			
	June	July–Aug	Sept–Oct	Nov–Dec	Jan–Feb	Mar–Apr	May–June	July–Aug
Email Prompt No. 3 [#]								
<i>Group C</i>						2 Apr		
<i>Group D</i>						2 Apr		
Email Prompt No. 3 Reminder								
<i>Group C</i>						15 Apr		
<i>Group D</i>						15 Apr		
Post Survey								
<i>Group A</i>							30 May	
<i>Group B</i>							30 May	
<i>Group C</i>							30 May	
<i>Group D</i>							30 May	
Post-Survey Reminder								
<i>All Groups</i>							15 June	
Close of Data Collection All Groups							30 June	

[#] All 140 participants in these groups received at same time

* Reminders to Blue group sent 2 weeks after Pre-Survey sent: ongoing basis after first 150 recruited

+ Control received email alerting them to the fact that the study had begun and they may or may not receive other emails up to June 2014

^ For first 150 – all sent at same time. For 150+ sent within 2 weeks of Pre-survey completion.

Reminders to complete surveys for all groups except the Control group were initiated two weeks after whichever survey had been sent. Initially, it was anticipated to send more than one reminder for each survey but after the first reminder was sent for completion of the Pre-survey, subsequent reminders confused participants and led to duplications of survey completions and email enquiries asking whether recorded entries had been accepted by the system.

Enquiries to the researcher made during this time were engaged with through the Survey Manager (an independent person resourced through CareSearch) to determine whether an individual survey had been received. Correspondence was then sent from the researcher back to the participant acknowledging that they either had or had not completed the Pre-survey. To alleviate such confusion for future surveys, it was decided to send only one reminder two weeks after any survey had been sent. Although this limited the opportunity to gain more completed surveys, it was a risk deemed necessary to avoid duplication and confusing participants. In addition, the system was modified such that any subsequent reminders were reconfigured to contain a message to participants telling them they had completed the survey and it had been lodged. After this was done, there were no more enquiries regarding whether surveys had been completed with duplications dropping off as well.

Results

From 641 enquiries, 359 people were excluded from participation either because of completed documents (primarily the EPA), technical computer issues, sudden ill health, not being able to participate in the project for the length of time required, or having second thoughts about participation (Figure 4.6). This left 282 people eligible to participate in the study (10 more than the minimum required). From these 282 eligible participants, 189 completed both the Pre- and Post-surveys. Of the 282 people originally sent a Pre-survey, 64 participants did not complete a Post-survey and were removed from the Pre vs. Post dataset leaving a total of 218 completed Pre- and Post-surveys. Reasons provided for dropping out of the study by those who indicated that they were dropping out prior to Post-survey distribution included lack of time (5), ill health (1) and disinterest in participating further (1). The remaining number of people did not provide any reason for not completing the Post-survey and were not followed up as ethical considerations concluded that participants may have felt this intrusive and it had not been made part of the initial conditions for participation in the study.

Twenty-nine of the 218 participants remaining had completed one of the four ADs (Enduring Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney or Anticipatory Direction/Living Will) between the time of Consent and the completion of the Pre-survey. These 29 participants were excluded from the final dataset as analysis could not be made of Pre-survey to Post-survey completion from a baseline of zero. The excluded participants from each group (from the 29 participants) were similarly distributed across the 4 randomisation groups as illustrated in Figure 4.7:

Participants per group excluded from Pre- Post Analysis			
Group A (Control - No intervention)	Group B (AD module only)	Group C (Prompt only)	Group D (AD module + Prompt)
7	6	9	7

Figure 4.7: Number of participants excluded due to completion of documents at Pre-survey

These 29 individuals completed 45 individual documents (EPA, EPG, MPA, Ant Dir or Living Will) either singly or in combination according to their Pre-surveys. Testing of whether inclusion of these individuals led to 10% clinical effect was not conducted as the primary outcome was based on an increase in individual completions from zero at Pre-survey to any number at Post-survey for a direct link to the interventions for completion of documents. Otherwise, it may have been that other factors influenced completion of the documents external to the study.

In the final analysis, the total percentage of returned and completed Pre- and Post-surveys analysed was 67% (n=189/282). Data analysis was then continued as an intention to treat analysis on the 189 UID matched participants who completed both the Pre- and Post-surveys as described in Figure 4.6.

Demographics

Table 4.2 illustrates the demographic composition of the 189 participants by group and by intervention.

Table 4.2: Demographics of 189 participants with Pre-and Post-survey responses in RCT who have been included in analysis

	Total N*=189 (%)	Group A N=47 N#* (%)	Group B N=52 N#* (%)	Group C N=44 N#* (%)	Group D N=46 N#* (%)	P value	Combined Group Prompt (C+D=90) N#* (%)	Combined Group Non- Prompt (A+B=99) N#* (%)	P value	Combined Group AD Module (B+D=98) N#* (%)	Combined Non-AD Module (A+C=91) N#* (%)	P value
Birth Decade												
1946–1955	103 (46)	28 (60)	28 (54)	25 (57)	22 (48)		47 (52)	56 (57)		50 (51)	53 (58)	
1956–1965	86 (39)	19 (40)	24 (46)	19 (43)	24 (52)	.70	43 (48)	43 (43)	.55	48 (49)	38 (42)	.32
Gender												
Male	48 (22)	10 (21)	14 (27)	13 (30)	11 (24)		24 (27)	24 (24)		25 (26)	23 (25)	
Female	141 (64)	37 (79)	38 (73)	31 (71)	35 (76)	.82	66 (73)	75 (76)	.70	73 (75)	68 (75)	.97
Location												
Metropolitan	143 (64)	38 (81)	36 (69)	34 (77)	35 (76)		69 (77)	74 (75)		71 (72)	72 (79)	
Rural	46 (21)	9 (19)	16 (31)	10 (23)	11 (24)	.59	21 (23)	25 (25)	.76	27 (28)	19 (21)	.29
Country of Birth												
Australia and New Zealand	136 (61)	30 (64)	39 (75)	35 (80)	32 (70)		67 (74)	69 (70)		71 (72)	65 (71)	
Other Country	53 (24)	17 (36)	13 (25)	9 (21)	14 (30)	.37	23 (26)	30 (30)	.47	27 (28)	26 (29)	.88
Marital Status												
Married/De Facto	114 (51)	24 (51)	37 (71)	27 (61)	26 (57)		53 (59)	61 (62)		63 (64)	51 (56)	
Sep/Divorced/Widow/Single	73 (33)	23 (49)	15 (29)	16 (36)	19 (41)	.35	35 (39)	38 (38)	.32	34 (35)	39 (43)	.51
Occupation												
Professionals	74 (33)	23 (49)	19 (37)	13 (30)	19 (41)		32 (36)	42 (42)		38 (39)	36 (40)	
Clerical/Sales	40 (18)	9 (19)	12 (23)	12 (27)	7 (15)		19 (21)	21 (21)		19 (19)	21 (23)	
Blue Collar	6 (3)	0 (0)	2 (4)	0 (0)	4 (9)		4 (4)	2 (2)		6 (6)	0 (0)	
Never Worked/Student/Home Duties/Retired	68 (31)	15 (32)	18 (35)	19 (43)	16 (35)	.24	35 (39)	33 (33)	.60	34 (35)	34 (37)	.14
Annual Income												
\$80,001+	73 (33)	11 (23)	11 (21)	13 (30)	9 (20)		31 (34)	42 (42)		35 (39)	38 (42)	
\$40,001–\$80,000	48 (22)	13 (28)	11 (21)	6 (14)	18 (39)		24 (26)	24 (24)		29 (32)	19 (21)	
\$0–\$40,000	44 (20)	19 (40)	23 (44)	19 (43)	12 (26)	.28	22 (24)	22 (22)	.71	20 (22)	24 (26)	.40

*N=rounded to whole number
#Number who responded

There were no significant differences in characteristics between the individual groups and different demographic variables. This was also true for the combined groupings of Prompt/Non-Prompt and AD Module/Non-AD Module.

Primary analysis

Main effects of one of two interventions on completion rates of four legal ADs compared to no intervention

The primary outcome for analysis was the number of individuals who completed any one of the 4 legal AD documents per intervention and non-intervention. Prevalence and univariate analysis of the primary outcomes for each group are illustrated in Table 4.3.

Table 4.3: Q1 - Primary outcome - Post-survey results of individuals per group completing any of the 4 legal Advance Directive documents as a result of one or more interventions[§]. Analysis also includes which individual documents were completed per group.

Individuals who completed one or more documents N* (%) /Types of Documents completed	Total from N*=189 Pre and Post surveys		Total Individuals Completing Any Document Prompt Group (N=90 Groups C+D) N [#] (%)	Type of Documents completed Prompt Group (Groups C + D) N*=5		Total Individuals Completing Any Document Non-Prompt Group (N=99 Groups A+B) N [#] (%)	Types of Documents completed Non-Prompt Group (Groups A+B) N*=8		Total Individuals Completing Any Document AD Module Group (N=98 Groups B+D) N [#] (%)	Types of Documents completed AD Module Group (Groups B+D) N*=9		Total Individuals Completing Any Document Non-AD Module Group (N=91 Groups A+C) N [#] (%)	Types of Documents completed Non-AD Module Group (Groups A+C) N*=4	
	Pre	Post		Pre	Post		Pre	Post		Pre	Post		Pre	Post
13 (7%)			6 (6%)			7 (7%)			9 (9%)			4 (4%)		
EPA	0	7		0	3		0	4		0	6		0	1
EPG	0	6		0	2		0	4		0	4		0	2
MPA	0	5		0	1		0	4		0	2		0	3
Ant Dir	0	2		0	0		0	2		0	1		0	1
LW	0	2		0	1		0	1		0	1		0	1
Total Individual Docs	0	22		0	7		0	15		0	14		0	8

*N=rounded to whole number

#Number who responded

§ At pre-survey, none of these documents were allowed to be completed

What Table 4.3 illustrates is that the number of individuals who completed any of the four legal ADs between Pre- to Post-survey was minimal (N=13) and less than the 10% predicted (for 10% clinical effect, the number of individuals should have been a minimum of 19). This was consistent for each intervention and non-intervention group. Univariate analysis described in Table 4.4 shows that there was no significant difference between the intervention and non-intervention groups for individuals completing documents ($p=.48$ for Prompt vs Non-Prompt; $p=.44$ for AD Module vs Non-AD Module).

Table 4.4: Q2A - Univariate analysis of Post-survey completion of any of four legal Advance Directives comparing Prompt/Non-Prompt groups v AD module /non-AD module groups § (N=189)

Q2A: Completion of any of 4 Individual AD documents							
	Total of Individuals who completed any AD document (N=189) n ^{#*} (%)	Prompt Group (C+D, N=90) n ^{#*} (%)	Non-Prompt Group (A+B, N=99) n ^{#*} (%)	P Value	AD Module Group (B+D, N=98) n ^{#*} (%)	Non-AD Module Group (A+C, N=91) n ^{#*} (%)	P Value
Any AD Document (+)	13 (7%)	6 (6%)	7 (7%)		9 (9%)	4 (4%)	
No AD Document (-)	176 (93%)	84 (94%)	92 (93%)	.48	89 (91%)	87 (96%)	.44

*N=rounded to whole number

#Number who responded

§ At pre-survey, none of these documents were allowed to be completed

This result proves the null hypothesis false: that without any intervention, ADs won't be completed, as those in the non-intervention groups completed documents. This result may illustrate that other effects impacting on completion beyond email prompting or AD online education facilitate completion above the use of the online environment.

Combinations of the four legal documents done by the 13 individuals as illustrated in Table 4.3 seem to suggest that of the groups exposed to either intervention (Prompt or AD module), those exposed to the AD module (Groups B and D) completed more documents. However, as will be illustrated in multivariate analysis, these differences were not significant.

Secondary analysis

In this section, multivariate analysis of Question 2A (completion of any of the four legal documents) was conducted using binary logistic regression. Effects of the combined 2 interventions were assessed as follows:

1. Combined Prompt Group (C and D) compared against Non-Prompt Group (A and B)
2. Combined AD Module group (B and D) – compared against Non-AD Group (A and C)

The purpose of conducting the analysis in this fashion was to test for main effects of either intervention (prompt or AD module) to facilitate AD completion. Table 4.5 illustrates the main effects from Post-survey responses for completion of any of any of the four legal documents individually based on intervention or non-intervention groups.

Table 4.5 Multivariate analysis Q2A: Post-survey completion of the four legal Advance Directives comparing Prompt/Non-Prompt groups v AD module /non-AD module groups § (N=189)

Post-survey Q2A: Completion rates of any of the 4 legal ADs (EPA, EPG, MPA, Anticipatory Direction and Living Will same document but treated separately)							
		Prompt groups (Groups C+D) versus Non-Prompt groups (Groups A+B)			AD Module groups (B+D) versus Non-AD module groups (A+C)		
Document Name	Number of individual documents completed N ^{#*} =22	Odds Ratio	95% CI	P Value	Odds Ratio	95% CI	P Value
EPA	7	.8	[.18, 3.76]	.82	5.9	[0.69, 49.63]	.11
EPG	6	.5	[0.10, 3.02]	.49	1.9	[0.33, 10.55]	.47
MPA	5	.3	[0.03, 2.42]	.24	.6	[0.10, 3.70]	.58
Ant Dir	2	0	0	1	.9	[0.06, 14.84]	.94
LW	2	1.1	[0.68, -17.85]	.95	.9	[0.57, -15.08]	.96

*N=rounded to whole number

#Number who responded

§ At pre-survey, none of these documents were allowed to be completed

In Table 4.5, analysing only the single document completions, the results show that there was no effect for either intervention over non-intervention groups to yield an increase in completion rates of any document to a statistically significant association. The greatest rate of increase of completion from Pre-survey to Post-survey for a single individual document was the EPA (Pre=0 to Post=7). The EPG (Pre=0 to Post=6) and MPA (Pre=0 to post =5) were the next two most frequently completed single documents across the groups. The end-of-life care documents, the Anticipatory Direction and Living Will were completed less often (Pre=0 to Post=2 for both).

Other variables relating to AD completion but not dependent on it are described as secondary outcomes in the next section.

Secondary outcomes

Prevalence for Question 2B (other document completions)

In Question 2 of the Post-survey, there were other document choices provided to capture the range of instructional and proxy making documents familiar to the public. These choices included:

- Power of Attorney (POA – of limited duration)
- Will (testamentary document)
- Advance Care Plan (clinically focused care plans)
- Statement of Choices (clinically focused end-of-life document based on the Respecting Patient Choices program)
- Life Values Statement (end-of-life document based on the Voluntary Euthanasia Society)
- Organ Donation Card
- Psychiatric Advance Directive (otherwise known as Ulysses documents for episodes of acute mental illness).

From these other documents, 29 separate individuals (not including the 13 who completed any of the four legal ADs) completed a total of 42 other named documents. Figure 4.8 includes the total number of registered completions of individual documents Post-survey.

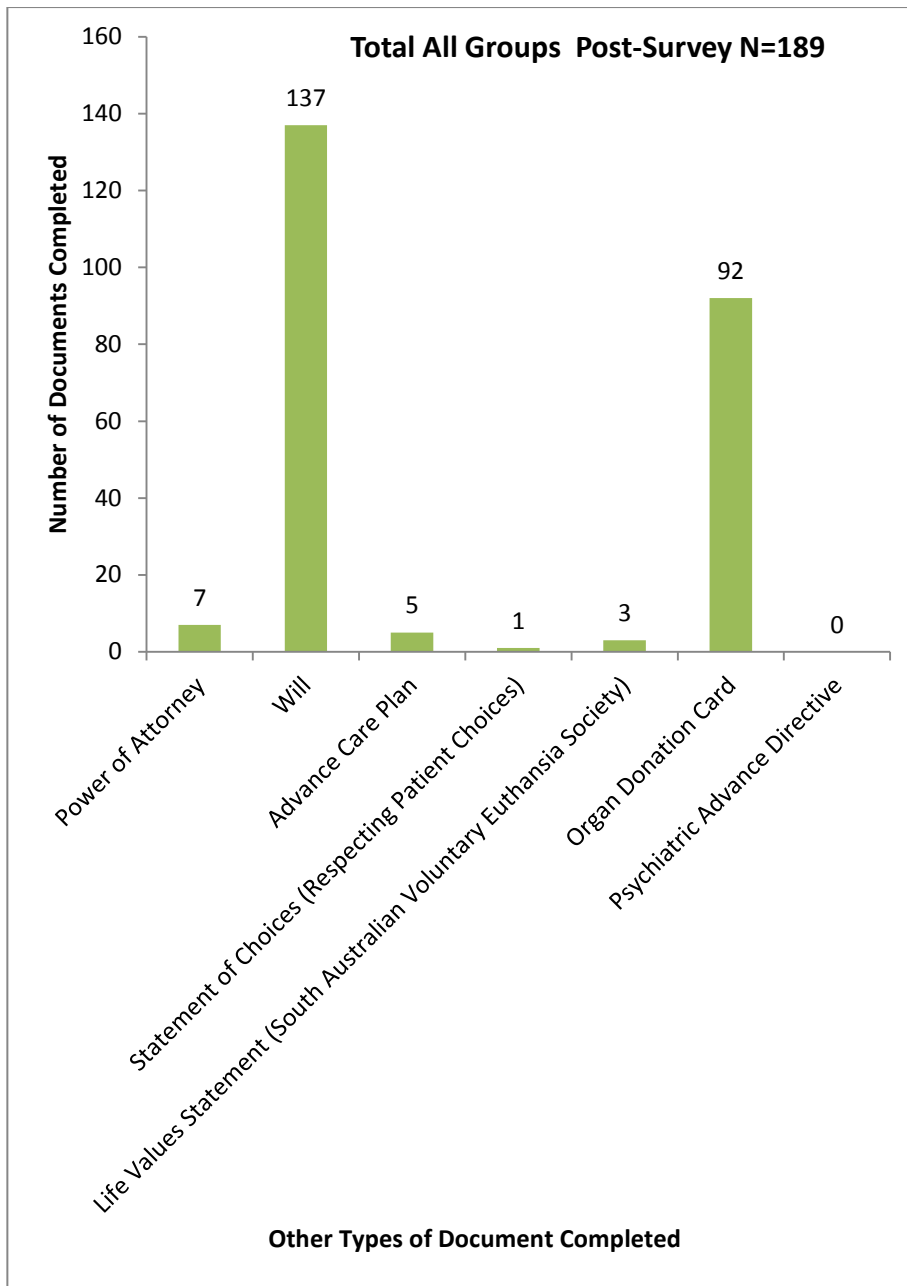


Figure 4.8: Q2B - (completion of other documents). Number and type of other documents completed - Post -Survey

Overall, approximately 75% (n=137/189) of the Baby Boomer participants had completed a Will and 54% (n=92/189) had completed an Organ Donation Card. The rates of Will completion were equivalent to those seen for the age group 47-66 in the HOS (Project 2, Chapter 3, Figure 3.2).

Table 4.6 describes multivariate analysis of any intervention effects for these other documents.

Table 4.6 Multivariate analysis Q2B: Pre-survey to Post-survey completion of other documents comparing Prompt/Non-Prompt groups v AD module/non-AD module groups (N=189)

Pre- and Post-survey Q2B: Completion rates of other documents (other planning documents were allowed to be completed prior to participation in the study [§])															
		Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)					Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)		
Name of Document	Number of individual documents completed <u>Pre-survey</u> N [#] * (%)	Pre Odds Ratio	Pre 95% CI	Pre P Value	Pre Odds Ratio	Pre 95% CI	Pre P Value	Number of individual documents completed <u>Post-survey</u> N [#] * (%)	Post Odds Ratio	Post 95% CI	Post P Value	Post Odds Ratio	Post 95% CI	Post P Value	
POA [§]	5 (3%)	4.6	[0.52, 41.86]	.18	1.4	[0.23, 8.90]	.70	7 (4%)	.8	[0.18, 3.82]	.81	2.4	[0.45, 12.62]	.31	
Will [^]	146 (77%)	1.5	[0.77, 3.05]	.23	.9	[0.47, 1.83]	.82	137 (73%)	1	[0.51, 1.84]	.93	.7	[0.38, 1.38]	.32	
ACP	0 (0%)	N/A	N/A	N/A	N/A	N/A	N/A	5 (3%)	.7	[0.12, 4.48]	.73	1.4	[0.23, 8.58]	.72	
SoC	0 (0%)	N/A	N/A	N/A	N/A	N/A	N/A	1 (1%)	0	0	0	0	0	0	
LVS	0 (0%)	N/A	N/A	N/A	N/A	N/A	N/A	3 (2%)	0	0	0	0	0	0	
ODC [†]	109 (58%)	.9	[0.48, 1.52]	.58	1.2	[0.69, 2.21]	.47	92 (58%)	.7	[0.41, 1.29]	.27	1.1	[0.63, 1.97]	.72	
PAD	0 (0%)	N/A	N/A	N/A	N/A	N/A	N/A	0	0	0	0	0	0	0	

*N=rounded to whole number

#Number who responded

§ At pre-survey completions of the POA were allowed. The numbers in the Post-survey number column represent Post-survey responses only without accounting for Pre-survey responses.

[^] The Will decreased from Pre-survey completions (pre-146 to post-137).

[†] The ODC decreased from Pre-survey completions (pre-109 to post-102).

The Power of Attorney, Will and Organ Donor Card were allowed to be completed and recorded in both the Pre- and Post-survey as they were not part of the exclusion criteria for participation in the study. All results for this question (Q2B) are based on Post-survey responses only and no analysis was conducted on differences between Pre- and Post- survey completion rates for these documents. No explanation is offered for the decrease in rates of recorded Wills and Organ Donation Cards.

As with the completion of the four legal ADs, there was no effect of either intervention to yield a statistically significant association for completion of any of these other documents.

Prevalence for Question 4 (receiving assistance with ADs)

In Question 4 (assistance), there were a number of categories provided to capture the range of people that may have assisted the participant with either learning about or completing any named document in the study. These choices included:

- family
- friend
- lawyer
- financial planner
- justice of the peace
- doctor
- nurse
- allied health worker
- pharmacist
- personal care worker
- social worker
- chaplain
- complementary therapist
- work colleague
- website
- Facebook contact.

Figure 4.9 shows the prevalence of assistance from the different categories of people named.

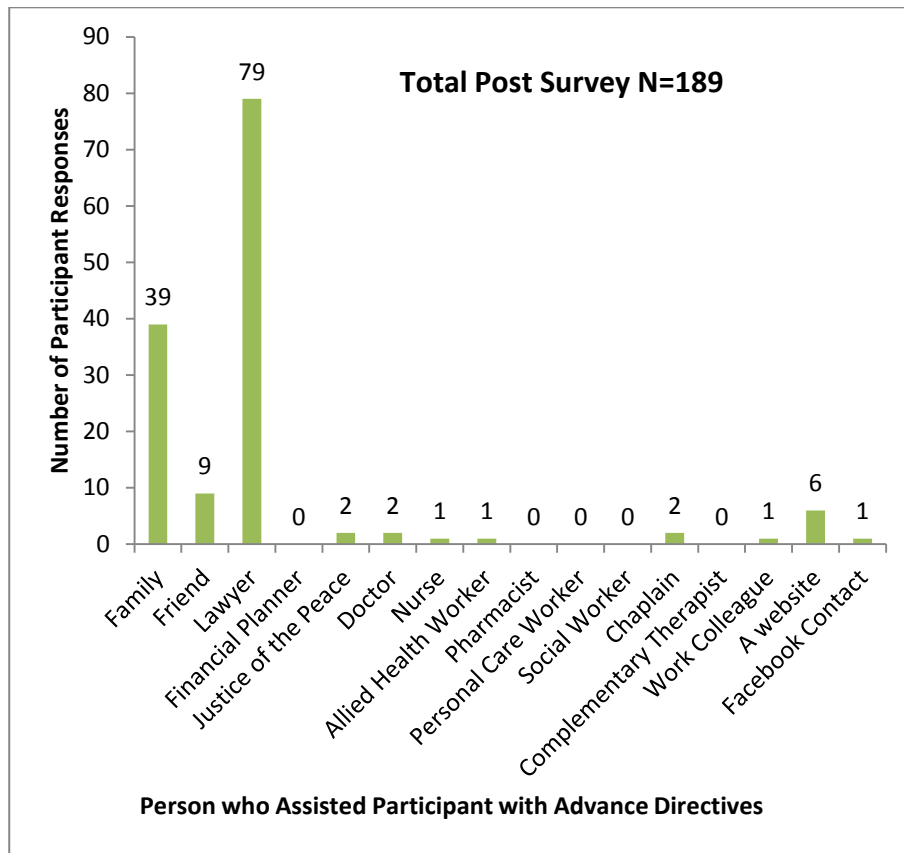


Figure 4.9: Q4 (assistance from others). Number and type of person providing assistance to participant with any Advance Directive document – Post Survey

As can be seen in Figure 4.9, the type of person most often used by participants in the study for assistance with these documents was a lawyer (n=79) followed by family (n=39) and friends (n=9). The numbers are not directly correlated with the number of individuals in the study as participants were free to choose more than one option in these and other secondary outcome questions.

Univariate analysis using chi-square tests was conducted on Question 4 (assistance from others) to explore whether there were any differences between the groups for assistance with individual documents (Table 4.7). For this analysis, categories for the variable of “any assistance” were combined for all categories where there was a positive response (family, friend, lawyer, justice of the peace, doctor, nurse, allied health worker, chaplain, work colleague, website, or Facebook contact).

Table 4.7: Q4 - Univariate analysis of post-survey response of assistance from others with any document - comparison between Prompt/Non-Prompt groups and AD Module /non-AD Module groups (N=189)

Q4: Assistance from someone with any Advance Directive document							
	Total N [*] =189 n [#] * (%)	Prompt Group N=90 n [#] * (%)	Non- Prompt Group N=99 n [#] * (%)	P Value	AD Module Group N=98 n [#] * (%)	Non-AD Module Group N=91 n [#] * (%)	P Value
Any assistance (+)	106 (56)	54 (60)	52 (53)		49 (50)	57 (63)	
No assistance (-)	83 (44)	36 (40)	47 (47)	.37	49 (50)	34 (37)	.62

*N=rounded to whole number

#Number who responded

Table 4.7 illustrates that there was no difference between the groupings with regard to assistance from others with documents ($p=.37$ Prompt vs Non-Prompt and $p=.62$ for AD Module vs Non-AD Module groups). For Question 4, the overall rate of recorded assistance from others with AD documents was 56% with 106 instances of assistance recorded.

Table 4.8 describes multivariate analysis of any intervention effects for assistance from others with these documents.

Table 4.8: Multivariate analysis Q4 - Pre- to Post-survey assistance provided by others with any documents comparing Prompt/Non-Prompt groups and AD Module /non-AD Module groups (N=189)

Pre-survey and Post-survey Q4: Assistance from others with advance directive documents (were allowed to get assistance prior to participation in study) [§]															
		Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)					Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)		
Type of Person	Number of Participant Responses <u>Pre-survey</u> N ^{#*^}	Pre Odds Ratio	Pre 95% CI	Pre P Value	Pre Odds Ratio	Pre 95% CI	Pre P Value	Number of Participant Responses <u>Post-survey</u> N ^{#*^}	Post Odds Ratio	Post 95% CI	Post P Value	Post Odds Ratio	Post 95% CI	Post P Value	
Family	25	.6	[0.24, 1.37]	.21	.6	[0.24, 1.37]	.20	39	.8	[0.40, 1.65]	.56	.6	[0.28, 1.18]	.13	
Friend	6	.5	[0.09, 2.97]	.47	.2	[0.02, 1.53]	.12	9	1.4	[0.36, 5.34]	.63	.7	[0.19, 2.83]	.65	
Lawyer	89	.8	[0.46, 1.45]	.49	1	[0.56, 1.75]	.96	79	1.1	[0.63, 2.01]	.70	.7	[0.40, 1.27]	.25	
Financial Planner	2	0	0	0	0	0	0	0	0	0	N/A	0	0	N/A	
Justice of the Peace	1	0	0	0	0	0	0	2	1.1	[0.68, 17.85]	.95	.9	[0.06, 15.08]	.96	
Doctor	1	0	0	0	0	0	0	2	0	0	0	0	0	0	
Nurse	1	0	0	0	0	0	0	1	0	0	0	0	0	0	
Allied Health Worker	0	0	0	.0	0	0	0	1	0	0	0	0	0	0	
Pharmacist	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
Personal Care Worker	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
Social Worker	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
Chaplain	0	0	0	0	0	0	0	2	0	0	0	0	0	0	
Complementary Therapist	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
Work Colleague	2	0	0	0	0.9	[0.06, 14.84]	.94	1	0	0	0	0	0	0	
A website	3	2.2	[0.20, 25.28]	.51	1.9	[0.17, 21.36]	.60	6	2.3	[0.41, 12.80]	.35	1.9	[0.34, 10.79]	.46	
Facebook Contact	0	0	0	N/A	0	0	N/A	1	0	0	0	0	0	0	

*N=rounded to whole number

#Number who responded

§ At pre-survey participants may have already had some assistance. The numbers in the Post-survey column represent Post-survey responses only without accounting for Pre-survey responses.

^No percentage is provided as participants may have had assistance from multiple people so is not reflective of per person response.

All multivariate analysis results are based on Post-survey responses only, so no analysis has been conducted on differences between Pre- and Post- survey for assistance by particular categories of people. Multivariate analysis showed that there were no statistically significant associations between intervention over non-intervention for assistance from others.

Prevalence for Question 5 (discussion about ADs)

In Question 5 (discussion), there were a number of categories provided to capture the range of people that the participant may have discussed ADs with throughout the study period. These categories were the same as those in Question 4 (assistance from others) except for the category of website (as it was assumed that you cannot really discuss documents with a website):

- family
- friend
- lawyer
- financial planner
- justice of the peace
- doctor
- nurse
- allied health worker
- pharmacist
- personal care worker
- social worker
- chaplain
- complementary therapist
- work colleague
- Facebook contact.

Figure 4.10 shows the prevalence of discussion with others from the different categories of people named.

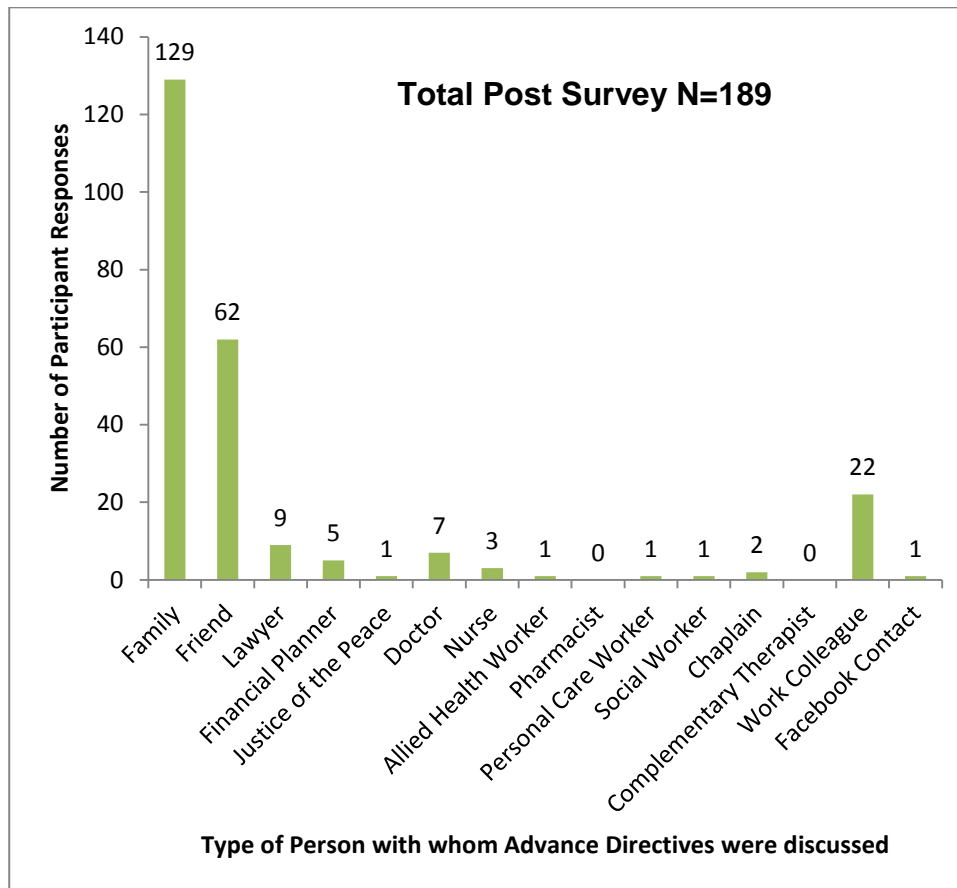


Figure 4.10: Q5 (discussion with others). Prevalence of person chosen - Post-survey

As can be seen in Figure 4.10, the type of person most often used for discussion about ADs was the family (n=129) followed by friends (n=62) and then work colleagues (n=22). Lawyers (n=9) and doctors (n=7) were chosen far less often to discuss these documents with than others identified.

Univariate analysis using chi-square was conducted on Question 5 (discussion) Post-survey to explore, in the first instance, whether there was any difference between the groups for rates of discussion by intervention (Table 4.9). For this analysis, categories for the variable “Did discuss with someone (+)” combined all categories where there was a positive response (family, friend, lawyer, financial planner, justice of the peace, doctor, nurse, allied health worker, personal care worker, social worker, chaplain, work colleague, Facebook contact).

Table 4.9: Q5 - Univariate analysis post-survey of number of participants who discussed Advance Directives with someone comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)

Q5: Total of individuals with whom Advance Directive documents were discussed							
	Individuals who did or did not discuss ADs with someone N=189 n ^{#*} (%)	Prompt Group (C+D) N=90 n ^{#*} (%)	Non-Prompt Group (A+B) N=99 n ^{#*} (%)	P Value	AD Module Group (B+D) N=98 n ^{#*} (%)	Non-AD Module Group (A+C) N=91 n ^{#*} (%)	P Value
Did discuss with someone (+)	147 (78%)	75 (83%)	72 (73%)		81 (83%)	66 (73%)	
Did not discuss with someone (-)	42 (22%)	15 (17%)	27 (27%)	.54	17 (17%)	25 (27%)	.23

*n=rounded to whole number
#Number who responded

Table 4.9 above illustrates that there was no statistically significant difference between the intervention and non-intervention groups with regard to discussion with others of ADs ($p=.54$ for Prompt/Non-prompt group v $p=.23$ for AD/Non-AD group). Participants were able to choose multiple responses to reflect different people they may have had discussions with so answers are not exclusive to just one category. For Question 5, the rate of reported discussion was 78% with 147 responses of discussions recorded.

Table 4.10 below describes multivariate analysis of intervention or non-intervention effects for discussion of these documents.

Table 4.10: Multivariate analysis Q5: Post-survey of number of participants who discussed Advance Directives with someone comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)

Pre-survey and Post-survey Q5: Type of person and number of participants who discussed ADs with others (were allowed to discuss with others beforehand)*														
Type of Person	Number of Participant Responses Pre-survey N ^{#*^}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)			Number of Participant Responses Post-survey N ^{#*^}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)		
		Pre Odds Ratio	Pre 95% CI	Pre P Value	Pre Odds Ratio	Pre 95% CI	Pre P Value		Post Odds Ratio	Post 95% CI	Post P Value	Post Odds Ratio	Post 95% CI	Post P Value
Family	99	.9	[0.51, 1.60]	.72	.6	[0.35, -1.13]	.12	129	.9	[0.47, 1.61]	.66	1.4	[0.73, 2.50]	.33
Friend	35	1.2	[.0.58, 2.51]	.63	.7	[0.36, 1.55]	.43	62	.8	[0.43, 1.44]	.43	1	[0.53, 1.81]	.95
Lawyer	4	1.1	[.0.15, 7.99]	.92	.9	[0.13, 6.73]	.94	9	.5	[0.13, 2.21]	.39	1.2	[0.30, 4.47]	.83
Financial Planner	3	2.2	[0.20, 24.83]	.52	.5	[0.04, 5.21]	.53	5	1.7	[0.27, 10.31]	.57	1.4	[0.23, 8.69]	.71
Justice of the Peace	0	0	0	N/A	0	0	N/A	1	0	0	.0	0	0	0
Doctor	0	0	0	N/A	0	0	N/A	7	1.5	[0.33, 6.87]	.61	1.3	[0.27, 5.78]	.77
Nurse	2	0	0	0	.9	[0.06, 14.84]	.94	3	.6	[0.05, 6.34]	.64	0	0	0
Allied Health Worker	0	0	0	N/A	0	0	N/A	1	0	0	0	0	0	0
Pharmacist	0	0	0	N/A	0	0	N/A	0	0	0	0	0	0	0
Personal Care Worker	0	0	0	N/A	0	0	N/A	1	0	0	0	0	0	0
Social Worker	0	0	0	N/A	0	0	N/A	1	0	0	0	0	0	0
Chaplain	1	0	0	N/A	0	0	N/A	2	0	0	0	0	0	0
Complementary Therapist	0	0	0	N/A	0	0	N/A	0	0	0	0	0	0	0
Work Colleague	14	2.2	[0.69, 6.96]	.18	6.4	[1.38, 29.46]	.02	22	1.1	[0.46, 2.81]	.78	3.6	[1.28, 10.26]	.02
Facebook Contact	0	0	0	N/A	0	0	N/A	0	0	0	0	0	0	0

*N=rounded to whole number

#Number who responded

§ At pre-survey participants may have already had discussions and this was allowed. The numbers in the Post-survey column represent Post-survey responses only without accounting for Pre-survey responses.

^No percentage is provided as participants may have had assistance from multiple people so is not reflective of per person response.

All multivariate analysis results are based on Post-survey responses only, so no analysis has been conducted on differences between Pre- and Post- survey for discussion with particular categories of people. Multivariate analysis showed that there was no statistically significant association between intervention or non-intervention groups for discussion with others except for the variable of work colleague with the Combined AD Module group 3 to 6 times more likely to discuss ADs with work colleagues than those in the Prompt group. As this study was heavily reliant on snowballing and other methods which involved work colleagues, this finding is not unexpected.

Prevalence for Question 6 (helping others complete documents)

In Question 6 (helping), participants were asked to choose which documents they had helped other people with. The document choices provided captured the complete range of instructional and proxy making documents familiar to the public and included the four legal ADs. These choices were as follows:

- Enduring Power of Attorney (EPA – enduring instructional and proxy)
- Power of Attorney (POA – of limited duration)
- Enduring Power of Guardianship (EPG – instructional and proxy)
- Will (testamentary document)
- Medical Power of Attorney (MPA – instructional and proxy)
- Anticipatory Direction (instructional – end-of-life)
- Living Will (instructional – end-of-life)
- Advance Care Plan (clinically focused care plans)
- Statement of Choices (clinically focused end-of-life document based on the Respecting Patient Choices program)
- Life Values Statement (end-of-life document based on the Voluntary Euthanasia Society)
- Organ Donation Card
- Psychiatric Advance Directive (otherwise known as Ulysses documents for episodes of acute mental illness).

Figure 4.11 includes the total number of documents that participants helped others with according to Post-survey responses. Participants could choose as many documents as relevant. There was no comparison made of Pre- vs. Post-survey responses.

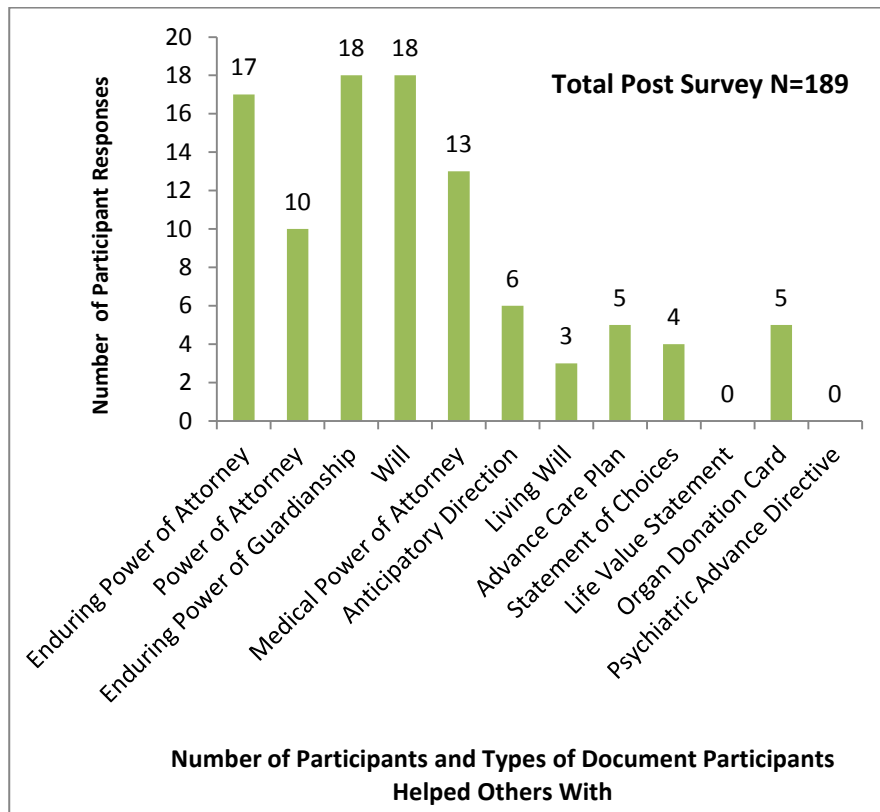


Figure 4.11: Q6 (helped others). Type of documents and number of participants who helped others during course of study – Post Survey

Overall, according to the Post-survey the Enduring Power of Attorney (n=17), Enduring Power of Guardianship (n=18) and Will (n=18) were the documents participants helped others with the most. Of the healthcare and end-of-life documents, the Medical Power of Attorney had the next highest rate of response in relation to helping someone else with this document (n=13).

Univariate analysis using chi-square was conducted on Question 6 (helping) Post-survey to explore whether there was any difference between the intervention and non-intervention groups for helping others with individual documents (Table 4.11). For this analysis, categories for the variable “Did help someone” were combined into one category consisting of the four legal documents Enduring Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney, Anticipatory Direction and Living Will singly or in combination.

Table 4.11 describes univariate analysis of the intervention groups for helping others with these documents.

Table 4.11: Q6 - Univariate analysis Q6 of post-survey responses of helping someone with any document during the course of the study comparing Prompt/non-Prompt groups and AD/non-AD Module groups (n=189)

Q6: Helped someone with a Document							
	Total of individuals who helped someone with any planning document during course of study N=189 n [#] (%)	Prompt Group (C+D) N=90 n [#] (%)	Non-Prompt Group (A+B) N=99 n [#] (%)	P Value	AD Module Group (B+D) N=98 n [#] (%)	Non-AD Module Group (A+C) N=91 n [#] (%)	P Value
Did help someone (+)	32 (17%)	21 (23%)	11 (11%)		19 (19%)	13 (14%)	
Did not help someone (-)	157 (83%)	69 (77%)	88 (89%)	.76	79 (81%)	78 (86%)	.59

*n=rounded to whole number
#Number who responded

Table 4.11 illustrates that there was no difference between the groupings with regard to helping others with documents ($p=.76$ Prompt/Non-Prompt; $p=.59$ AD Module/Non-AD Module). For Question 6, the rate of participants recording helping someone was 17% overall. Thirty-two individuals responded in the Post-survey that they had helped others with different documents.

Table 4.12 describes multivariate analysis of any effects of the intervention over non-intervention for helping others with these documents. Participants were able to choose multiple responses to reflect different documents they may have helped others with.

Table 4.12 Multivariate analysis of Q6: Post-survey of number of participants who helped others with planning documents or Advance Directives during study comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)

Pre-survey and Post-survey Q6: Helped with documents														
Type of Document	Number of Participant Responses Pre-survey N ^{#*}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)			Number of Participant Responses Post-survey N ^{#*}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)		
		Pre Odds Ratio	Pre 95% CI	Pre P Value	Pre Odds Ratio	Pre 95% CI	Pre P Value		Post Odds Ratio	Post 95% CI	Post P Value	Post Odds Ratio	Post 95% CI	Post P Value
EPA	60	1.7	[0.93, 3.22]	.09	1.7	[0.88, 3.08]	.12	17	.6	[0.20, 1.61]	.29	.8	[0.30, 2.19]	.67
POA	28	2.3	[0.98, 5.24]	.06	1.9	[0.81, 4.33]	.15	10	1.7	[0.46, 6.21]	.43	.9	[0.26, 3.34]	.91
EPG	37	1.6	[0.77, 3.27]	.22	1.1	[0.55, 2.32]	.75	18	.7	[0.25, 1.82]	.44	.9	[0.35, 2.42]	.86
Will	47	1.2	[0.62, 2.33]	.58	1.1	[0.56, 2.09]	.83	18	1.4	[0.54, 3.77]	.48	.9	[0.35, 2.45]	.88
MPA	29	2	[0.90, 4.62]	.09	2	[0.87, 4.57]	.11	13	.5	[0.14, 1.58]	.22	1.5	[0.48, 4.85]	.48
Ant Dir	7	2.8	[0.54, 15.04]	.22	.7	[0.15, 3.21]	.64	6	.5	[0.10, 3.02]	.48	.9	[0.18, 4.68]	.92
LW	4	1.1	[0.15, 8.14]	.91	2.9	[0.29, 27.88]	.37	3	2.3	[0.20, 26.44]	.50	0	0	0
ACP	1	0	0	0	0	0	0	5	1.7	[0.27, 10.21]	.59	.2	[0.02, 2.06]	.19
SoC	1	0	0	0	0	0	0	4	.4	[0.04, 3.47]	.37	.3	[0.03, 2.92]	.30
LVS	0	0	0	0	0	0	0	0	0	0	N/A	0	0	N/A
ODC	22	1.7	[0.67, 4.17]	.26	.5	[0.20, 1.23]	.13	5	.3	[0.03, 2.47]	.25	3.8	[0.42, 34.90]	.24
PAD	0	0	0	N/A	0	0	N/A	0	0	0	N/A	0	0	N/A

*N=rounded to whole number

#Number who responded

§ At pre-survey participants may have already helped others and this was allowed. The numbers in the Post-survey column represent Post-survey responses only without accounting for Pre-survey responses.

^No percentage is provided as participants may have helped with more than one document from multiple people so is not reflective of per person response.

All results are based on Post-survey responses only, so no analysis has been conducted on differences between Pre- and Post- survey for any document. Multivariate analysis showed that there were no main effects for any intervention over non-intervention for helping others with any AD documents.

Prevalence for Question 7 (acted as substitute decision-maker under the particular proxy documents)

In Question 7 (acted), participants were asked to choose the documents under which they had acted as substitute decision-maker for others. There are only certain documents that allow proxy or substitute decision-making nomination so these were the focus of this question. The documents provided for choice were provided as standalone or combined as follows:

- Enduring Power of Attorney (EPA – enduring instructional and proxy)
- Power of Attorney (POA – of limited duration)
- Enduring Power of Guardianship (EPG – instructional and proxy)
- Power of Attorney + Enduring Power of Guardianship (POA + EPG)
- Enduring Power of Attorney + Enduring Power of Guardianship (EPA + EPG)
- Medical Power of Attorney (MPA)
- Enduring Power of Attorney + Medical Power of Attorney (EPA + MPA)
- Power of Attorney + Medical Power of Attorney (POA + MPA)
- Enduring Power of Guardianship + Medical Power of Attorney (EPG + MPA)
- Power of Attorney + Enduring Power of Guardianship + Medical Power of Attorney (PA + EPG + MPA)
- Enduring Power of Attorney + Enduring Power of Guardianship + Medical Power of Attorney (EPA + EPG + MPA)
- Guardianship Order (GO)
- Psychiatric Advance Directive (otherwise known as Ulysses documents for episodes of acute mental illness).

Figure 4.12 includes the total number of documents that participants helped others with according to Post-survey responses. Participants could choose as many documents as were relevant. As participants were asked this question in the Pre-survey also there has been no comparison made of Pre- vs. Post-survey responses.

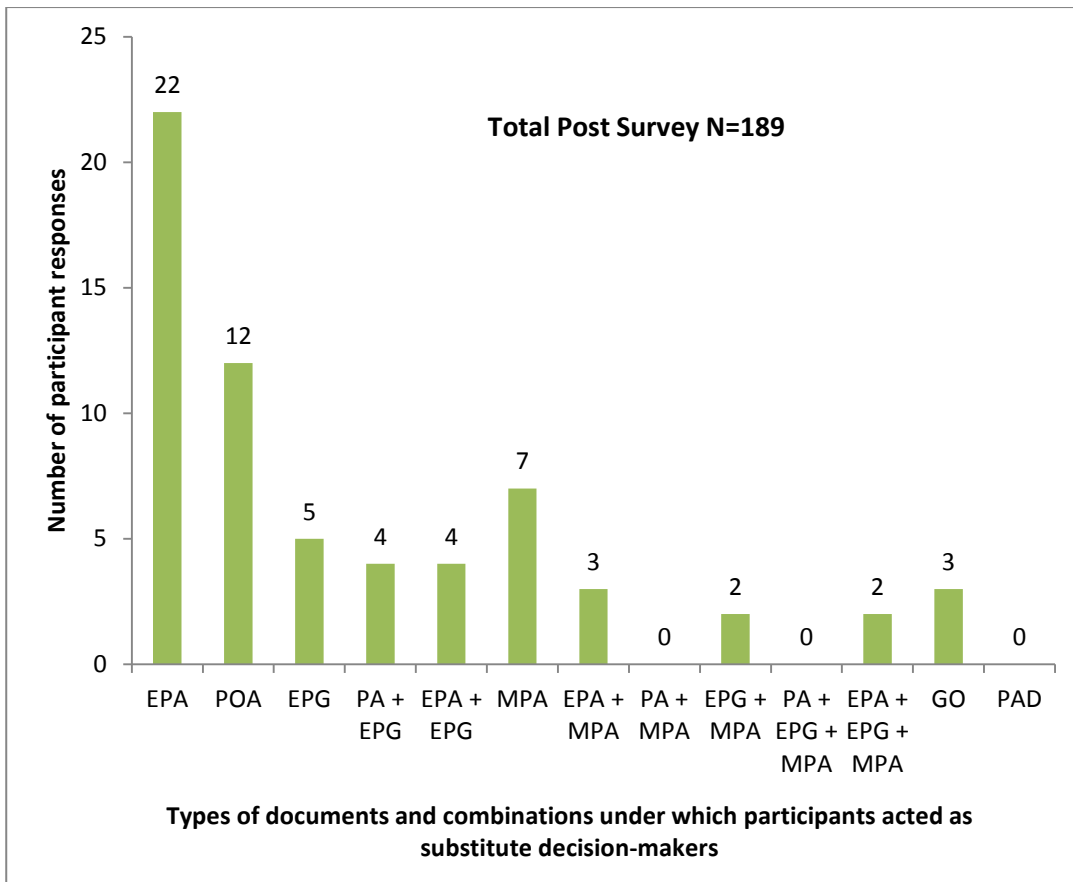


Figure 4.12: Q7 (acted as substitute decision-maker).Number of responses and types of documents participants acted under as substitute decision-maker for others – Post survey

Overall, Figure 4.12 illustrates that according to the Post-survey, the most common of any of the 4 legal ADs under which people acted as a substitute decision-maker was the Enduring Power of Attorney (n=22), followed by the Enduring Power of Guardianship (n=5) then the Medical Power of Attorney (n=7). As participants may have responded more than once to different categories, the responses are not exclusive to just one category.

This question was asked to explore whether there was prevalence of single use documents over combinations of documents. The results indicate that although the EPA is the dominant document under which people act as SDM, there are also combinations of documents that people may act under.

Univariate analysis using chi-square was conducted on Question 7 (acting as substitute decision-maker) Post-survey to explore whether there was any difference between the intervention groups for acting as substitute decision-makers under individual or combinations of documents (Table 4.13). For this analysis categories for the variable “Did Act” were combined and included those of the four legal documents Enduring Power of Attorney, Enduring Power of Guardianship, Medical

Power of Attorney, Anticipatory Direction and Living Will, either separately or together:

- EPA
- EPG
- EPA + EPG
- MPA
- EPA + MPA
- EPG + MPA
- EPA + EPG + MPA.

Table 4.13 describes univariate analysis of any interaction effects between prompt/not prompt and AD/Non-AD groups for the completion of these documents:

Table 4.13: Q7 - Univariate analysis - post-survey responses of individuals who acted as a substitute decision-maker during the course of the study comparing Prompt/non-Prompt groups and AD/non-AD Module groups (n=189)

Category Q7: Acted as substitute decision-maker (SDM)							
	Total of individuals who acted as SDM N=189 n ^{#*} (%)	Prompt Group (C+D, N=90) n ^{#*} (%)	Non-Prompt Group (A+B, N=99) n ^{#*} (%)	P Value	AD Module Group (B+D, N=98) n ^{#*} (%)	Non-AD Module Group (A+C, N=91) n ^{#*} (%)	P Value
Did Act (+)	35 (19%)	22 (24%)	13 (13)		21 (21%)	14 (15%)	
Did not Act (-)	154 (81%)	68 (76%)	86 (87%)	.42	77 (79%)	77 (85%)	.54

*n=rounded to whole number

#Number who responded

Table 4.13 illustrates that there was no statistical difference between the groupings with regard to helping others with documents ($p=.42$ for Prompt vs Non-Prompt; $p=.54$ for AD Module vs Non-AD Module). For Question 7 (acting as substitute decision-maker) the overall rate of response of acting for someone as a substitute decision-maker was 19%. Thirty-five individuals responded in the Post-survey that they had acted for others under different documents.

Table 4.14 describes multivariate analysis of any intervention effects for acting as a SDM under any of the proxy documents. Participants were able to choose multiple responses to reflect different documents they may have acted under.

Table 4.14: Multivariate analysis Q7 - Post-survey of number of participants who acted as substitute decision-makers during study comparing Prompt/non-Prompt groups and AD Module/non-AD Module groups (n=189)

Pre-survey and Post-survey Q7: Acted as substitute decision-maker for others (Pre-survey responses were allowed for this question)														
Type of Document or Combination	Number of Participant Responses Pre-survey N ^{#*^}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)			Number of Participant Responses Post-survey N ^{#*^}	Prompt (N=90) versus Non-Prompt (N=99)			AD Module (N=98) versus Non-AD Module (N=91)		
		Pre Odds Ratio	Pre 95% CI	Pre P Value	Pre Odds Ratio	Pre 95% CI	Pre P Value		Post Odds Ratio	Post 95% CI	Post P Value	Post Odds Ratio	Post 95% CI	Post P Value
EPA	17	1.7	[0.60, 4.59]	.33	1.8	[0.64, 5.13]	.26	22	.6	[0.24, 1.50]	.27	2.2	[0.84, 5.59]	.11
POA	12	1.6	[0.49, 5.34]	.43	3	[0.78, 11.46]	.11	12	1.1	[0.35, 3.58]	.86	1.3	[0.41, 4.34]	.64
EPG	8	.7	[0.15, 2.87]	.58	6.9	[0.83, 57.28]	.07	5	0	0	0	3.8	[0.41, 35.59]	.24
PA + EPG	2	1.1	[0.07, 17.85]	.95	.9	[0.06, 15.08]	.96	4	.4	[0.04, 3.52]	.38	.9	[0.13, 6.66]	.93
EPA + EPG	3	2.2	[0.20, 25.28]	.51	1.9	[0.17, 21.36]	.60	4	0	0	0	.9	[0.12, 6.66]	.92
MPA	3	.6	[0.05, 6.40]	.64	0	0	0	7	.8	[0.18, 3.78]	.80	1.3	[0.27, 5.72]	.78
EPA + MPA	2	1.1	[0.07, 18.65]	.93	0	0	0	3	2.3	[0.20, 25.28]	.51	1.9	[0.17, 21.36]	.60
PA + MPA	2	0	0	0	1	[0.06, 15.78]	.98	0	0	0	N/A	0	0	N/A
EPG + MPA	2	1.1	[0.07, 18.65]	.93	0	0	0	2	1	[0.07, 17.64]	.96	0	0	0
PA + EPG + MPA	0	0	0	0	0	0	0	0	0	0	N/A	0	0	0
EPA + EPG + MPA	2	0	0	0	0	0	0	2	1.1	[0.07, 18.65]	.93	0	0	N/A
GO	1	0	0	0	0	0	0	3	.6	[0.05, 6.17]	.63	1.9	[0.17, 20.91]	.62
PAD	0	0	0	N/A	0	0	N/A	0	0	0	N/A	0	0	N/A

*N=rounded to whole number

#Number who responded

§ At pre-survey participants may have already been a substitute decision-maker and this was allowed. The numbers in the Post-survey column represent Post-survey responses only without accounting for Pre-survey responses.

^No percentage is provided as participants may have been substitute decision-maker under more than one document so is not reflective of per person response.

All results are based on Post-survey responses only, so no analysis has been conducted on differences between Pre- and Post- survey for any document. Multivariate analysis showed that there were no statistically significant differences between intervention and non-intervention groups for acting as SDM under any of the four legal documents or combination thereof.

Other outcomes

Outcomes for the other questions asked in the Post-survey will be described using only frequency analysis as they were designed for exploratory purposes only and are not directly related to testing for primary outcome, intervention, main or interaction effects.

Supporting questions on AD use (Q3, Q8, Q31–32 Post-survey)

Question 3 (Figure 4.13) illustrates the reasons why participants chose not to complete documents during the course of the survey.

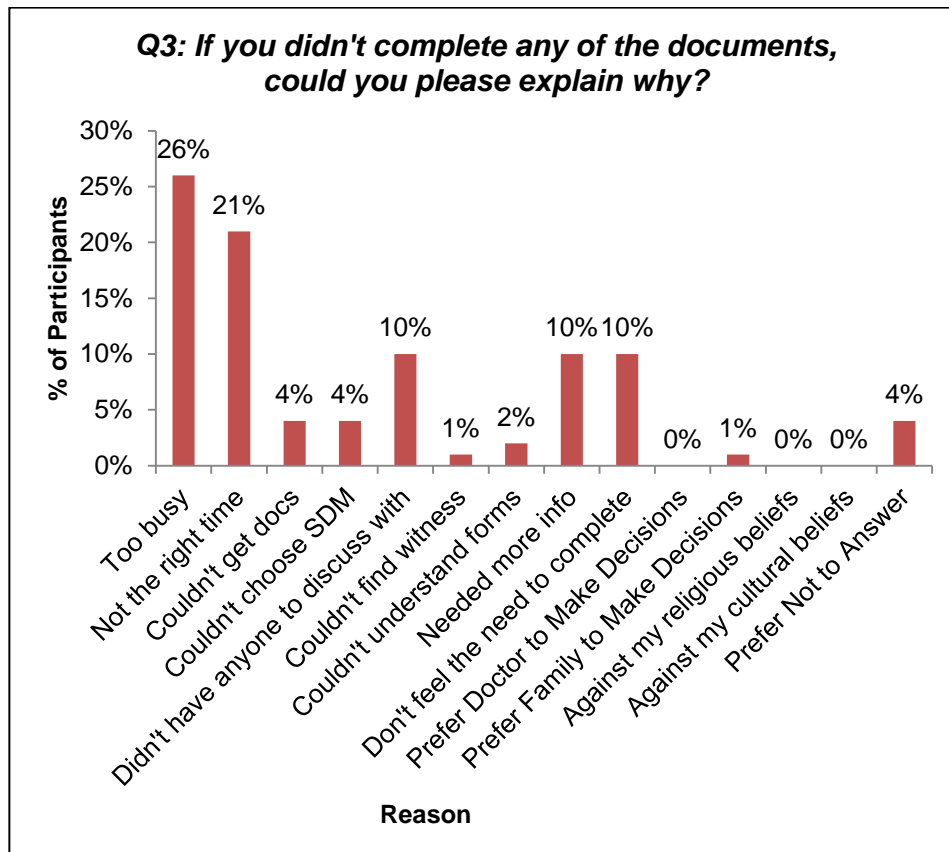


Figure 4.13: Q3 (why didn't you complete?). Prevalence of responses and reasons - Post-survey

The majority of responses (47%) indicated that respondents who didn't complete ADs were either too busy (26%) or it wasn't the right time for them to complete

documents (21%). Also important were: not having anyone to discuss ADs with (10%), needing more information (10%) and not feeling the need to complete the forms (10%). All of these answers indicated that factors other than the computer-based, interactive online interventions affected the rate of completions.

Question 8 explored whether the participant would be willing to act as a SDM. Figure 4.14 illustrates that 53% of participants would be willing to act as a SDM.

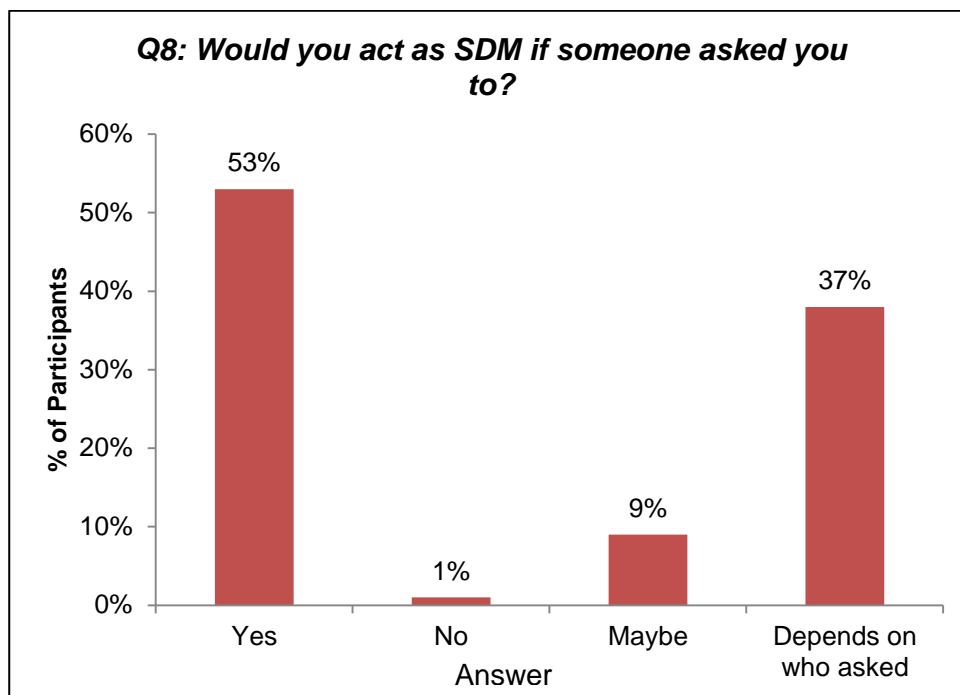


Figure 4.14: Q8 (would you act as a substitute decision-maker?). Prevalence of responses and reasons - Post-survey

Although the majority responded in the affirmative, 37% indicated that it depended upon who asked and combining this with those who chose “maybe”, nearly an equal number of responses (46%) were not sure if they would.

Question 32 (Figure 4.15 below) investigated the likelihood of participants completing documents in the next three months.

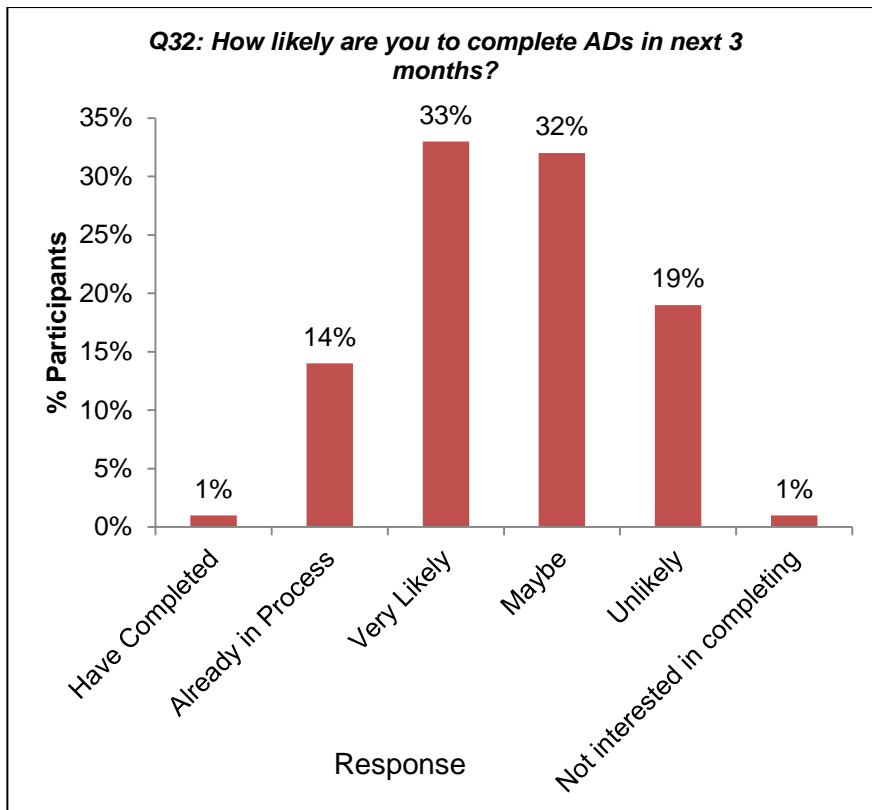


Figure 4.15: Q32 (likelihood of completing an AD in the next 3 months). Prevalence of responses and reasons - Post-survey

As Figure 4.15 illustrates, 15% of participants had already completed or were in the process of completing documents while another 65% were possibly going to complete documents. As was similar to the HOS Survey (Table 3.11, Chapter 3), over 20% of participants were unlikely or had no interest in completing AD documents (combined Unlikely and Not Interested categories).

Finally, Question 31 asked whether participants felt they now knew more about ADs. Figure 4.16 below indicates that although the majority felt they knew more, almost half either did not know more about ADs (17%) or were unsure (29%). The study could not control for information provision about ADs from statewide sources as promotion of the new SA Advance Care Directive was taking place at the same time as the trial. Therefore, those in the non-intervention group may have had some information about ADs but did not know exactly what they were about or how they might apply. Others may have been confused about the differences between old and new forms.

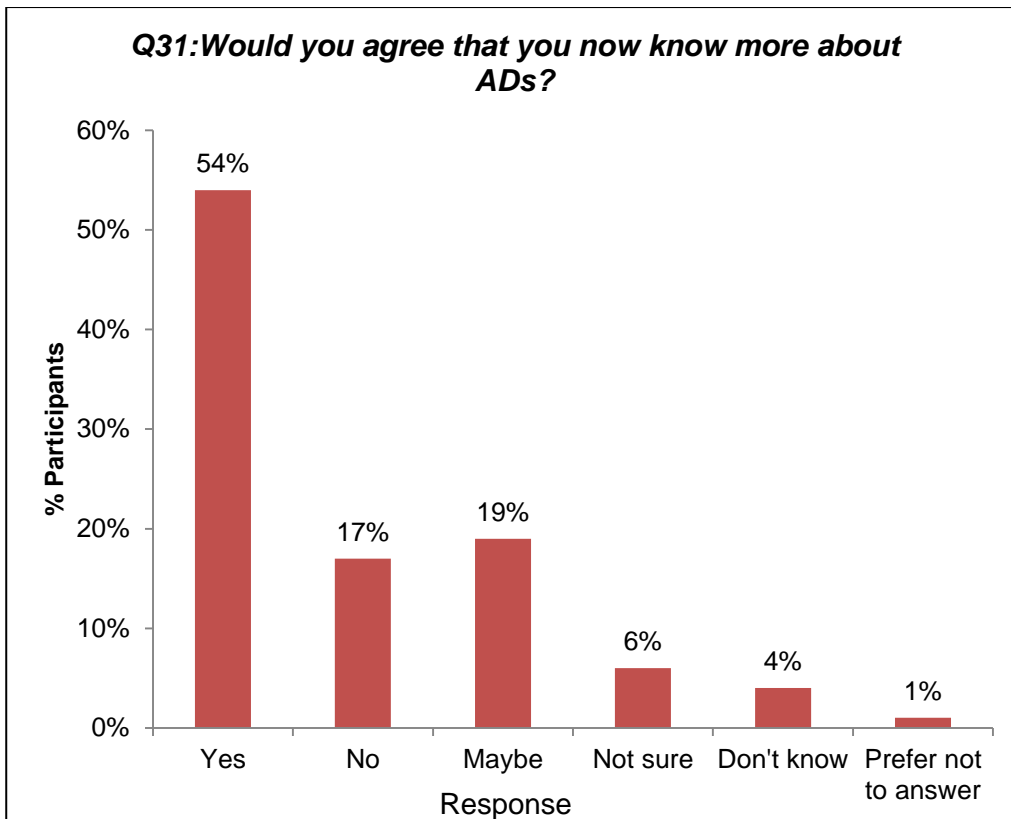


Figure 4.16: Q31 (do you know more about ADs now?). Prevalence of responses and reasons - Post-survey

Other Pre- and Post- question responses not directly related to the interventions

The remaining questions asked in the survey (Q7A–Q30) will be described through frequency or thematically because: firstly, many provide supporting information about preferences and use of ADs and computer-based interactive online formats rather than a direct correlation between interventions and use; and secondly, some are open commentary on satisfaction with the research design and participation in the study. These questions have been segregated into the following sub-sections:

- supporting questions of use of the online environment (Q7A–Q14 – Pre-survey questions)
- use of the online environment, including the AD module in this study, for AD assistance (Q9–12, Q17, Q19, Q21, Q24–Q25, Q29 Post-survey questions); and
- questions about the effectiveness of surveys, prompts and other dimensions of the survey itself (Q13–16, Q23, Q27 Post-survey questions).

This analysis of these responses assists in building characteristics of this participant group that may shed further light on factors other than the e-Health environment that

may impact on AD decision-making.

Supporting questions on use of the online environment (Q7A–Q14A – Pre-survey questions only)

Question 7A (Pre-survey, Figure 4.17) asked about level of comfort using computers.

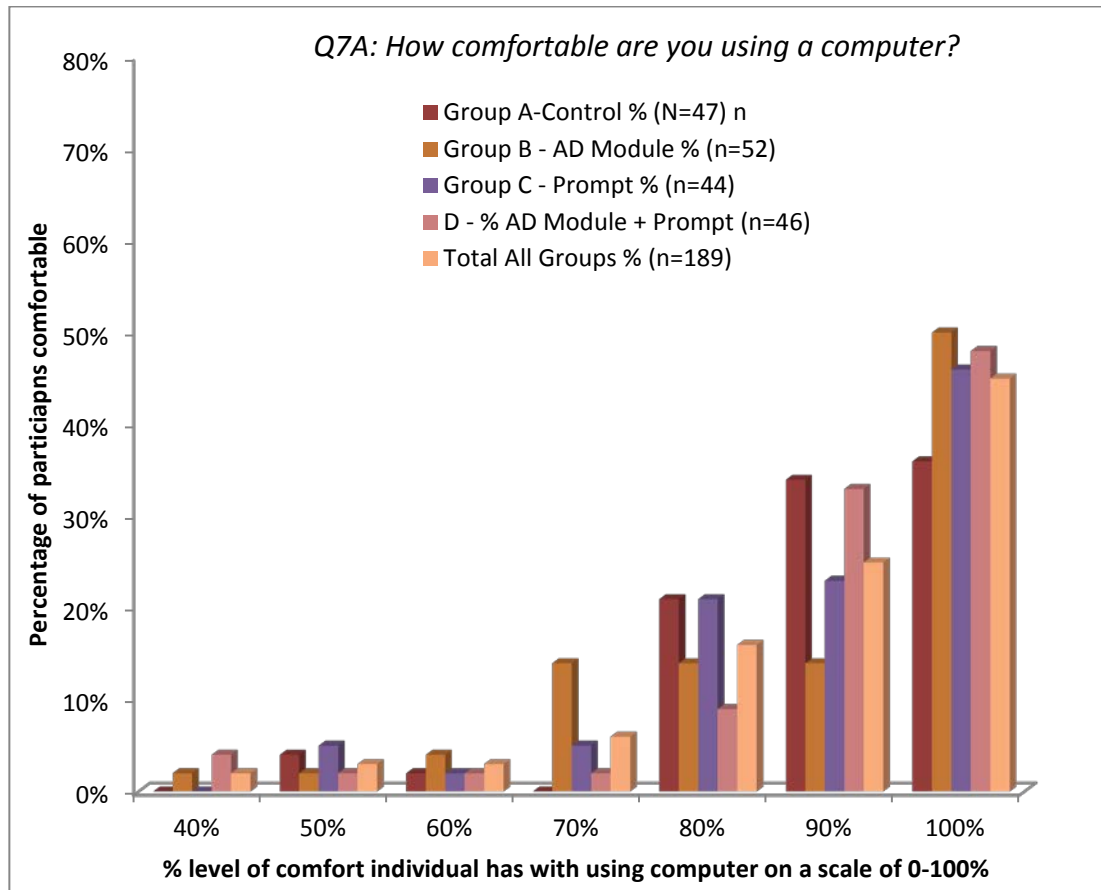


Figure 4.17: Q7A (comfort with computer use). Percentage of participants comfortable with computer and particular level of comfort - Pre-survey

There was no difference between groups with the majority indicating they had levels of comfort ranging predominantly between 70–100%. As a corollary, participants were asked about their level of comfort using the Internet (Q9A). The majority indicated even higher comfort levels with using the Internet with rates ranging predominantly between 80–100% (Figure 4.18).

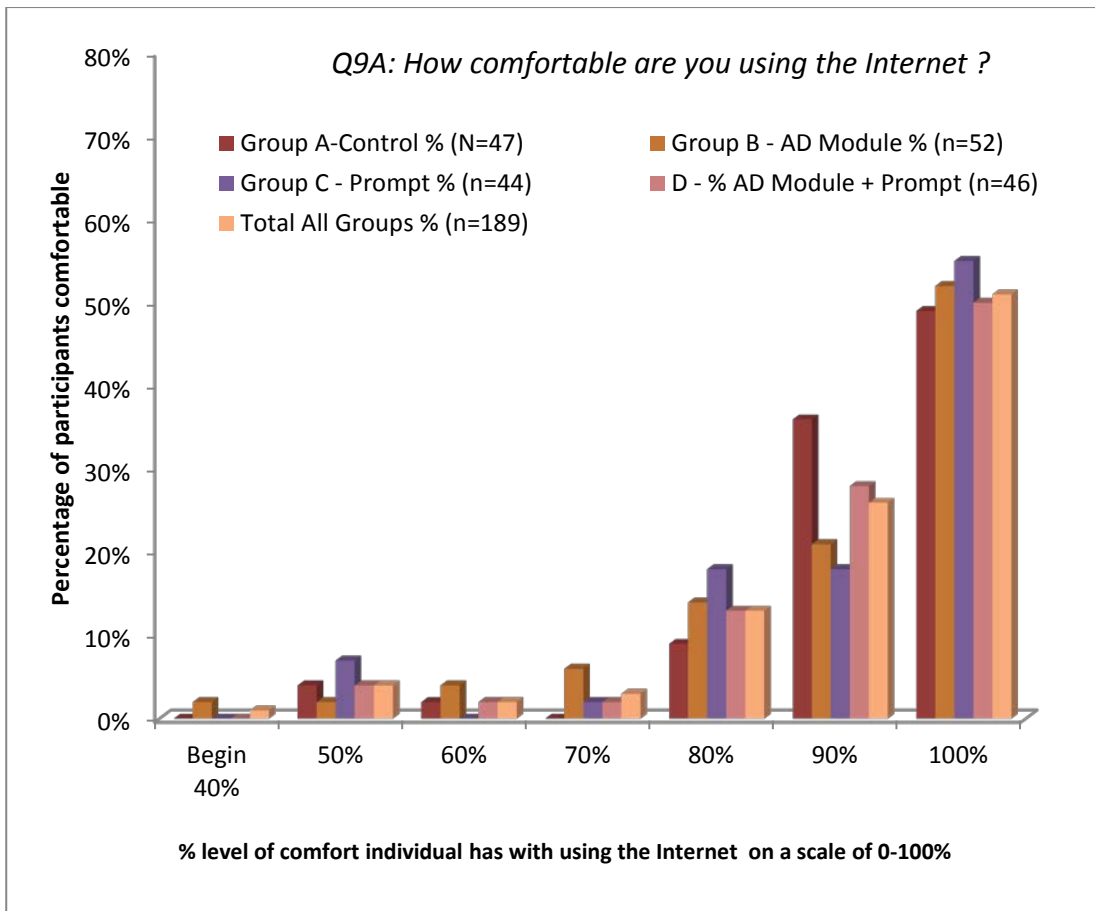


Figure 4.18: Q9A (comfort with the Internet). Percentage of participants comfortable with computer and particular level of comfort - Pre-survey

For both Questions 8A and 10A (levels of daily or weekly use of the computer and Internet) responses across all groups for both questions were 95% or higher with regard to using the computer and Internet three times or more a week (data not shown). Therefore, the characteristics of this population sample demonstrate a high level of comfort and use with the online environment on a regular basis such that non-familiarity with this environment would not have been a reason for lack of completion of ADs using this environment.

When looking at the types of hardware and software in use by participants, Figure 4.19 (Q12A) illustrates that the majority of participants used both computer-based and mobile hardware on a regular basis.

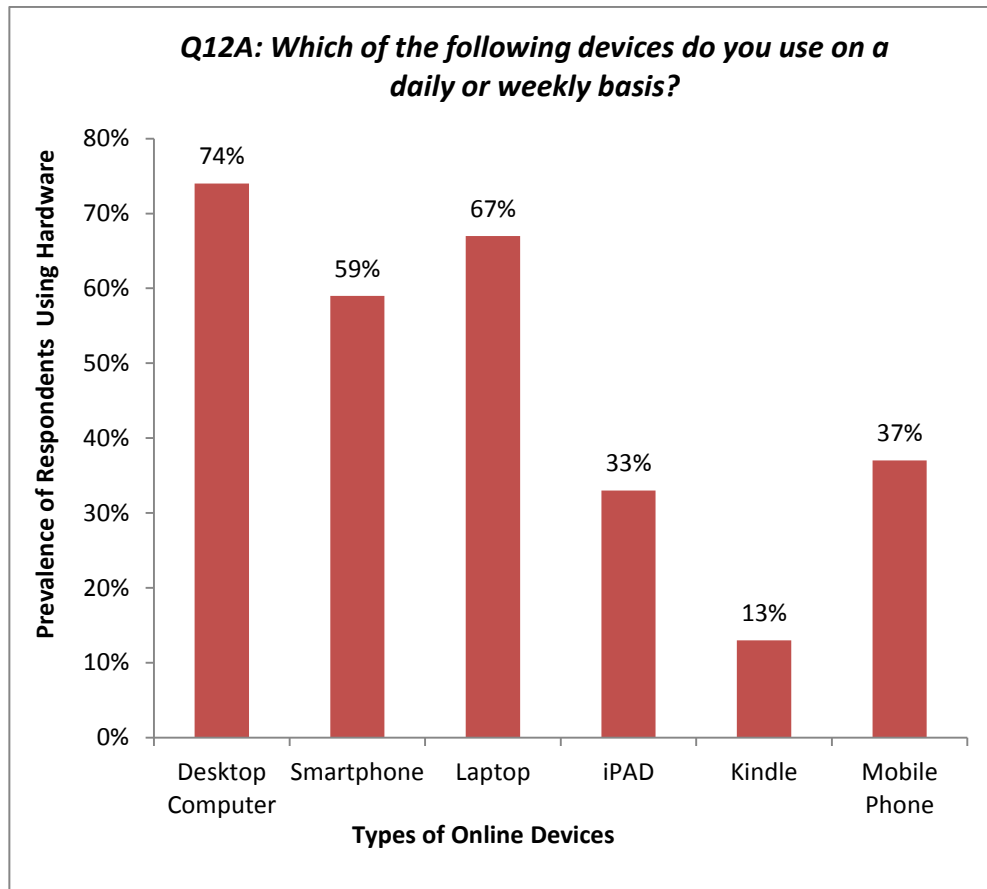


Figure 4.19: Q12A (type of online devices being used). Prevalence of response - Pre-survey

Figure 4.20 (Q13A) that follows indicates that most of the participants also used a variety of software on a regular basis.

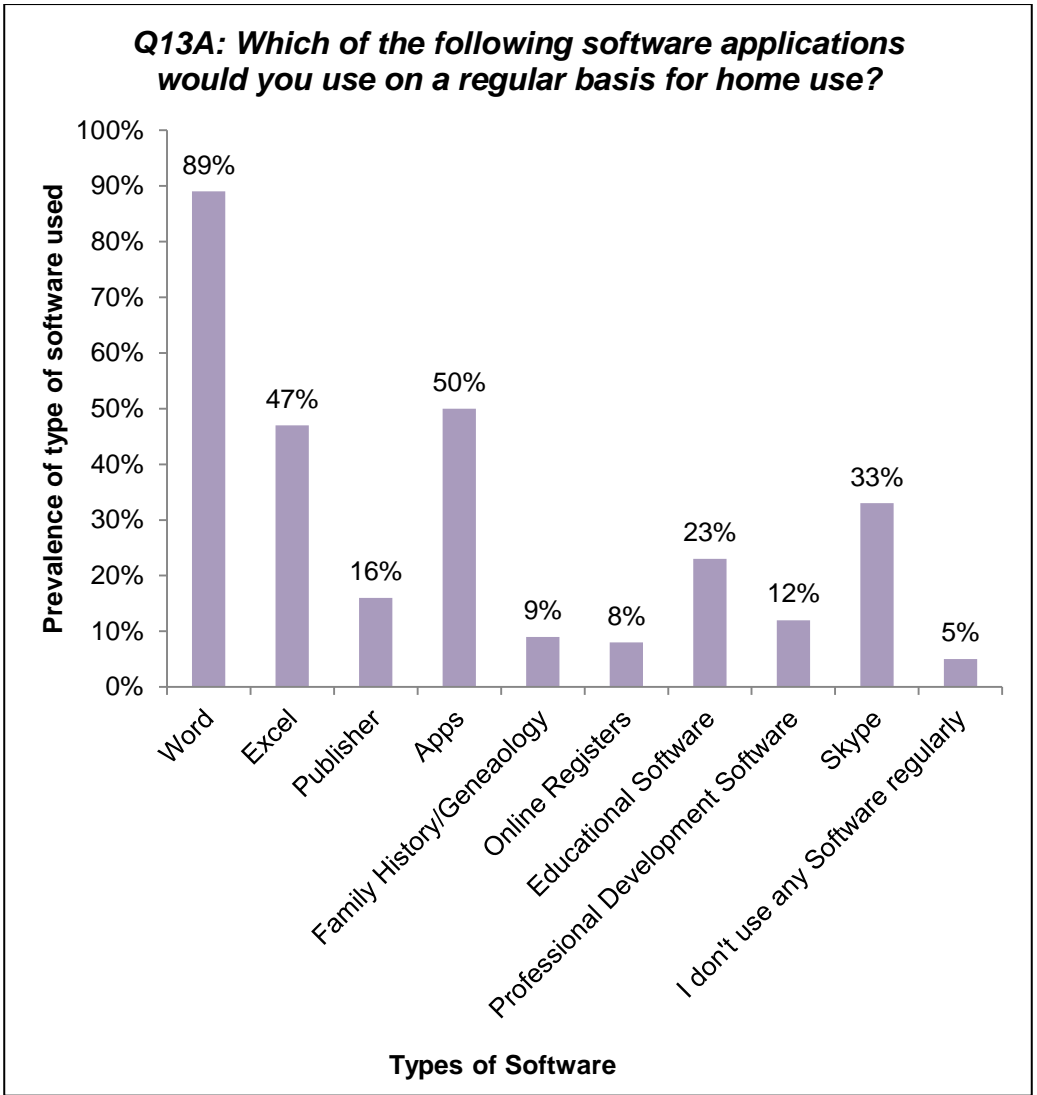


Figure 4.20: Q13A (software applications used and type of software used). Prevalence of response - Pre-survey

Question 14A asked participants in the survey which online or offline mechanisms they would find most helpful in learning about ADs. Figure 4.21 illustrates the method of AD information participants would have found most helpful prior to participating in the survey.

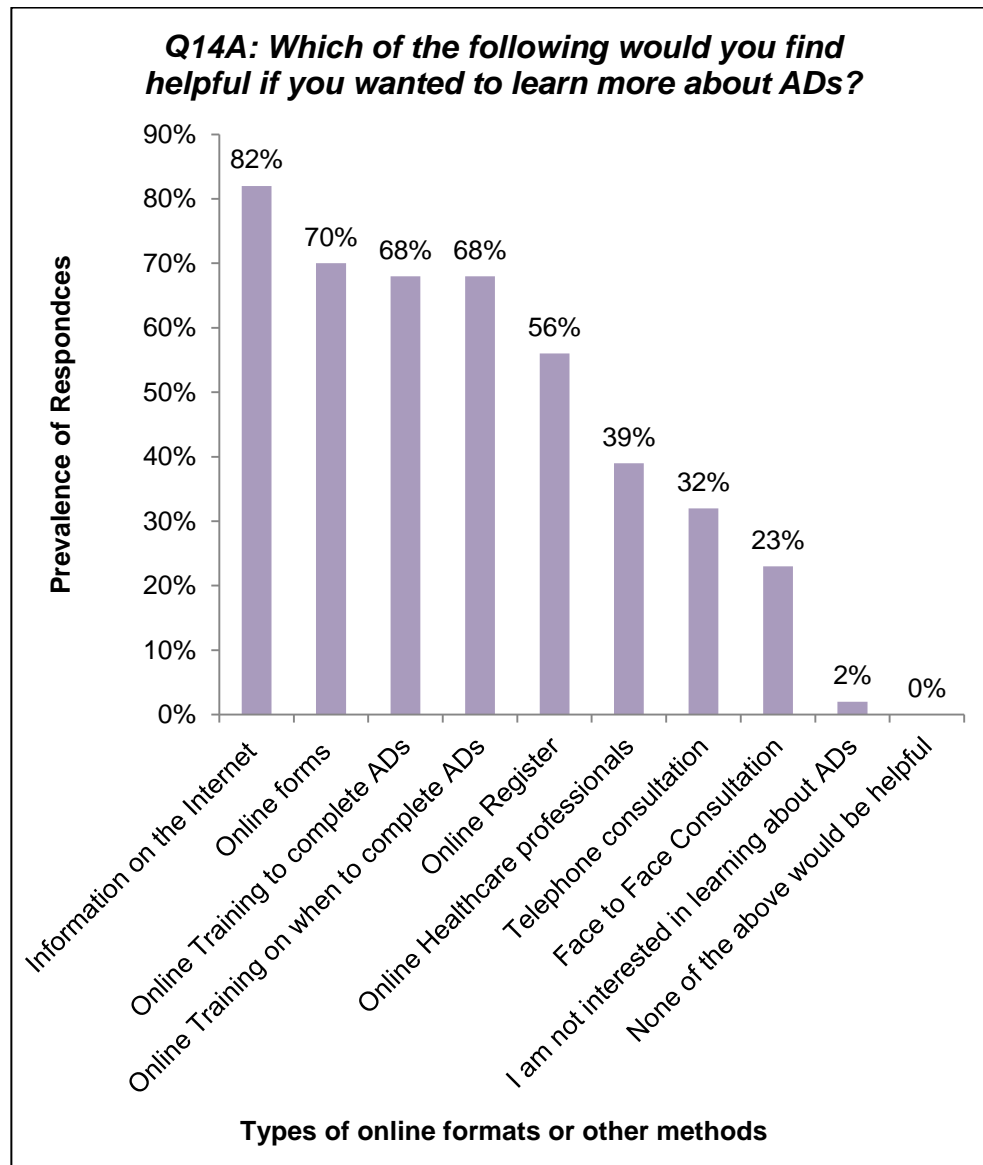


Figure 4.21: Q14A (what form of online or other method would you have found helpful?). Prevalence of response - Pre-survey

As this was a self-selected group of participants with a high proclivity towards use of the online environment, it is not surprising to see that the majority would find interactive online methods more helpful than other methods such as telephone or face to face. This is in contrast to those in the HOS study (Project 2, Chapter 3, Table 3.16) where 45% of that population sample preferred the online environment and approximately 35% preferred other means.

Supporting questions on use of the online environment, including the AD module in this study for AD assistance (Q9–12, Q17, Q19, Q21, Q24–25, Q29 Post-survey questions only)

Questions 9 (Figure 4.22) and 10 (Figure 4.23) repeated the question on preferred method for accessing AD information by splitting the question into the components for preference for learning and preference for completing ADs using computer-based, interactive online or other methods. Figure 4.22 illustrates both online and offline formats assisted with learning more about ADs.

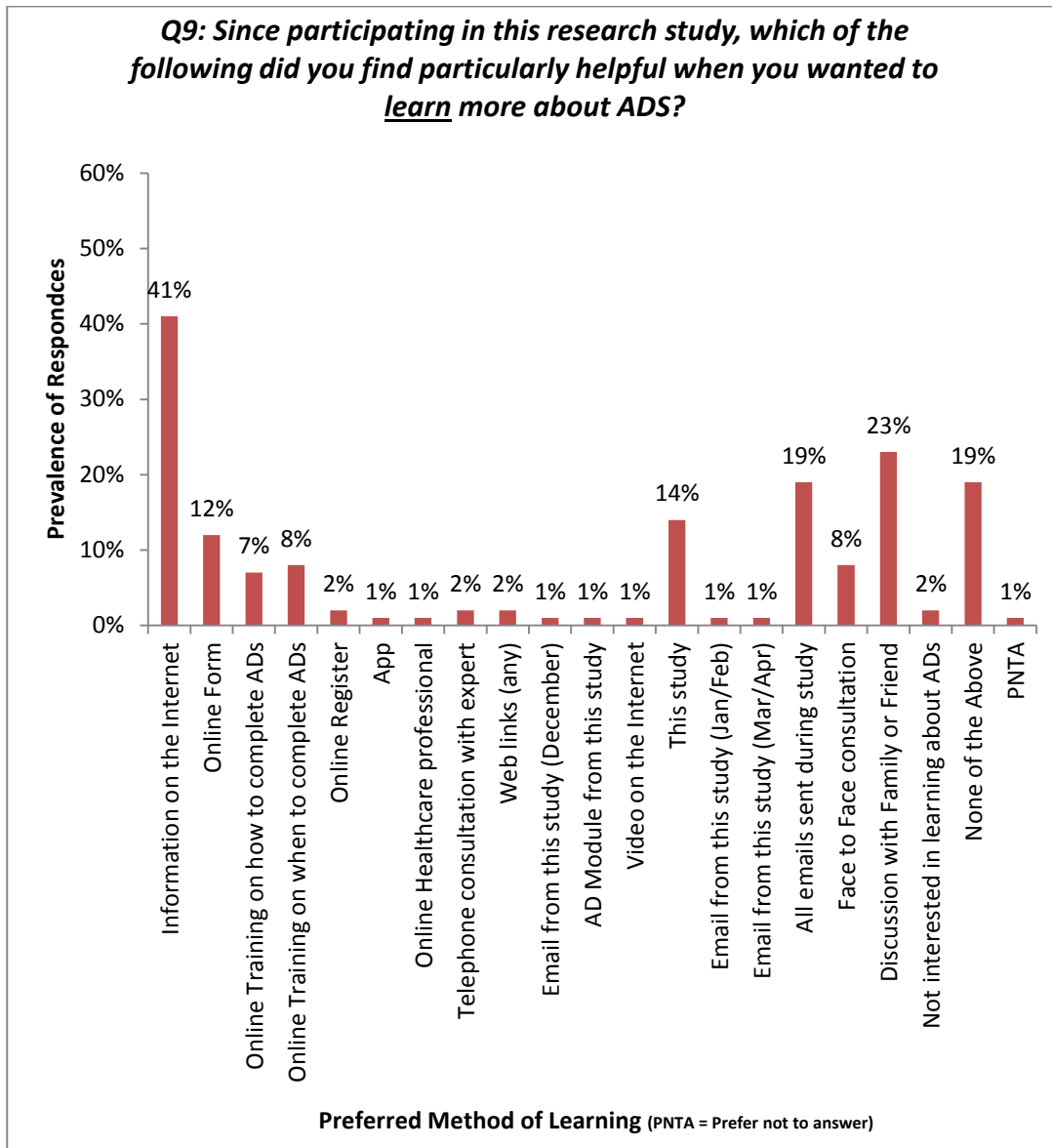


Figure 4.22: Q9 (which online or offline format assisted learning of ADs). Prevalence of response - Post-survey

In both questions (Q9 and Q10A), participants preferred information on the Internet (41%, Figure 4.22, 28% Figure 4.23) to other methods, with discussion with family or

friends ranking second (23% Figure 4.22, 21% Figure 4.23).

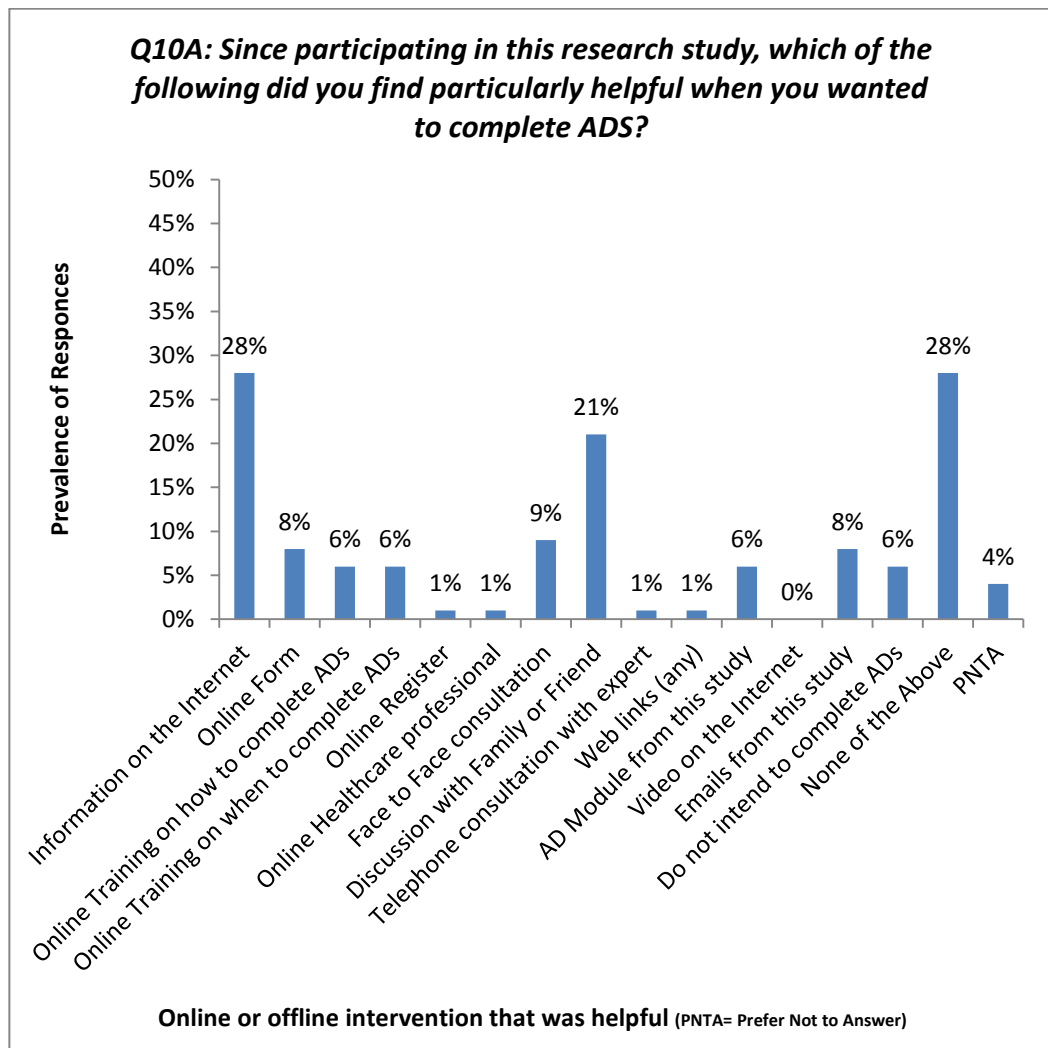


Figure 4.23: Q10A (which was helpful for completing ADS prevalence of response?). Prevalence of response - Post-survey

Over 20% of participants both did not prefer any of the methods mentioned for either learning or completing ADS.

The next set of questions considered whether any particular software, websites or online facilities assisted with AD knowledge or translation. Figure 4.24 (Q12) shows that the only software programs to assist participants for ADS were those of *CareSearch* and *Word* (both 15%).

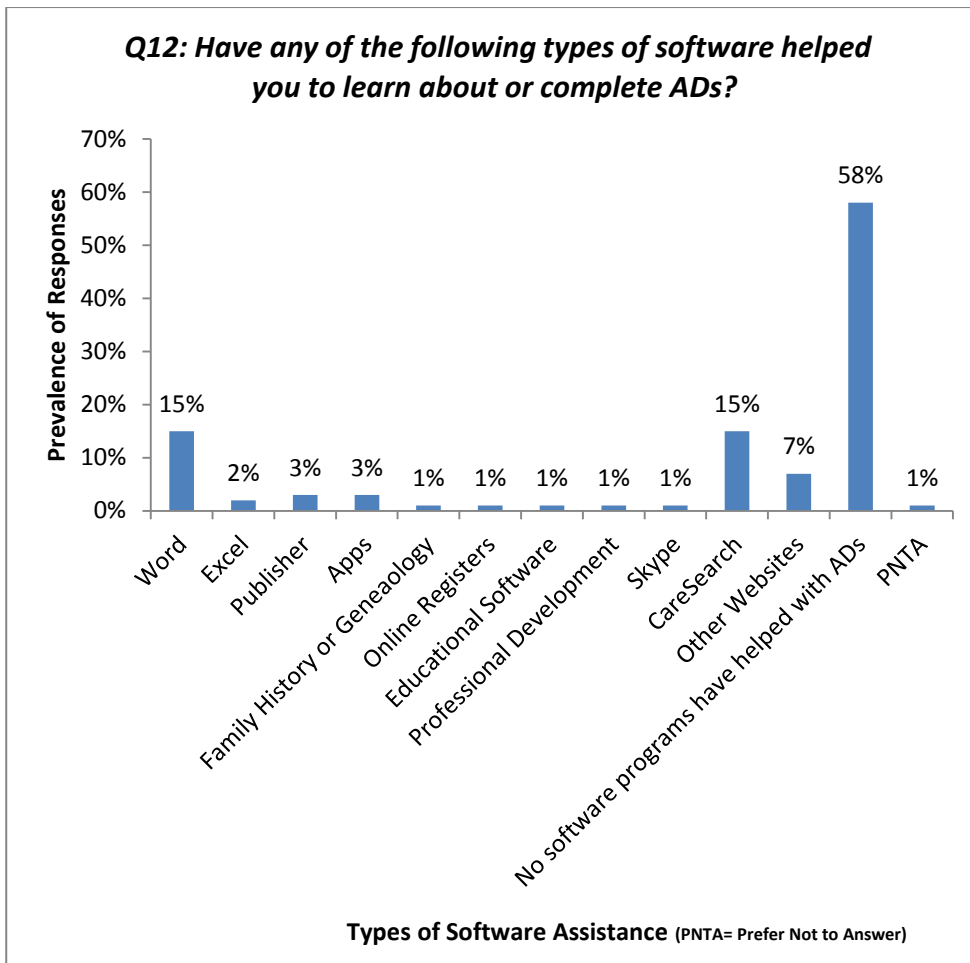


Figure 4.24: Q12 (which type of software was helpful for completing ADs). Prevalence of response - Post-survey

It is not unexpected that CareSearch figures prominently as the study was conducted under CareSearch through the PhD scholarship so advertising of the research study incorporated advertising of CareSearch. The fact that the majority of people (58%) indicated that no software assisted them suggests that many people may prefer to learn about or complete ADs using hard copy resources, such as pamphlets, brochures or hard copy AD documents, or through discussion with others.

For hardware devices, Question 11 (Figure 4.25) revisited the use of hardware in learning or completing ADs and illustrates that the most prolific hardware device that assisted was the desktop computer followed by a laptop.

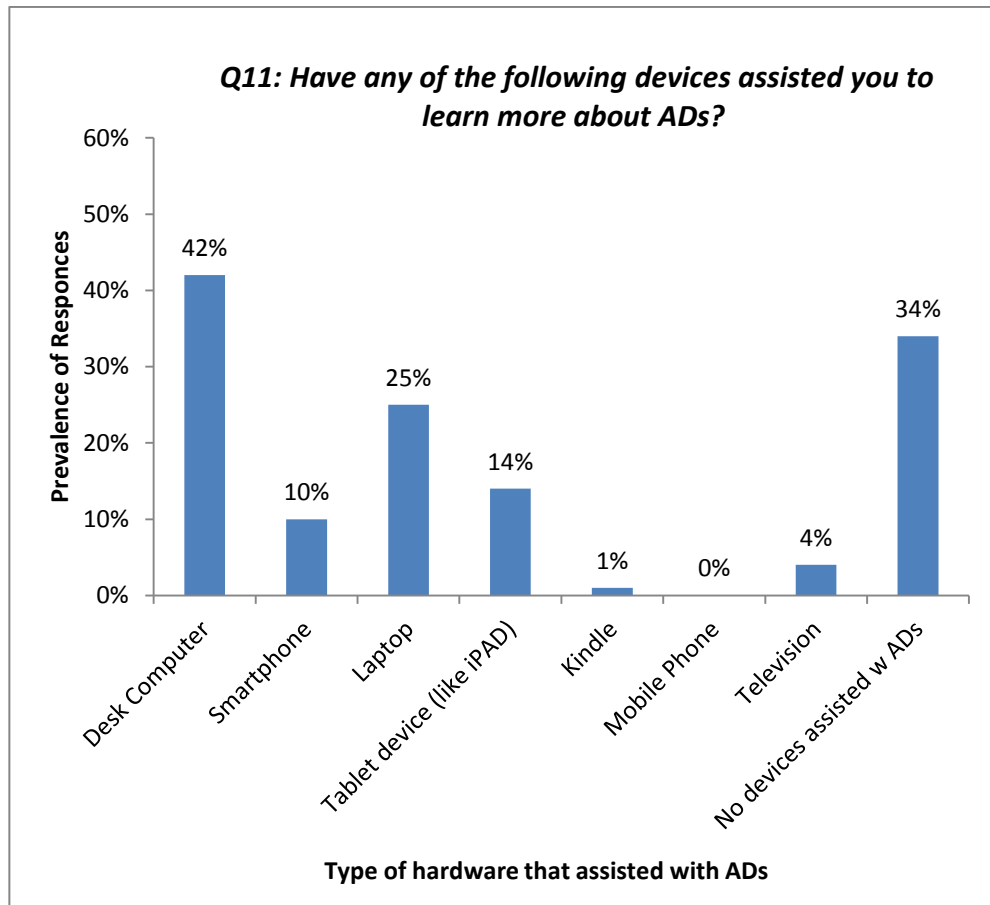


Figure 4.25: Q11 (which hardware devices assisted with learning about ADs). Prevalence of responses - Post-survey

These results provide a baseline for measurement of this population's use of newer technologies as they age and may wish to learn more about these documents. Of interest is that no one used their mobile phone.

The next set of questions specifically looks at the way the AD Module assisted with learning or completing ADs and some barriers or facilitators to its use. Question 17 (Figure 4.26) asked if the AD module assisted people to complete particular AD documents.

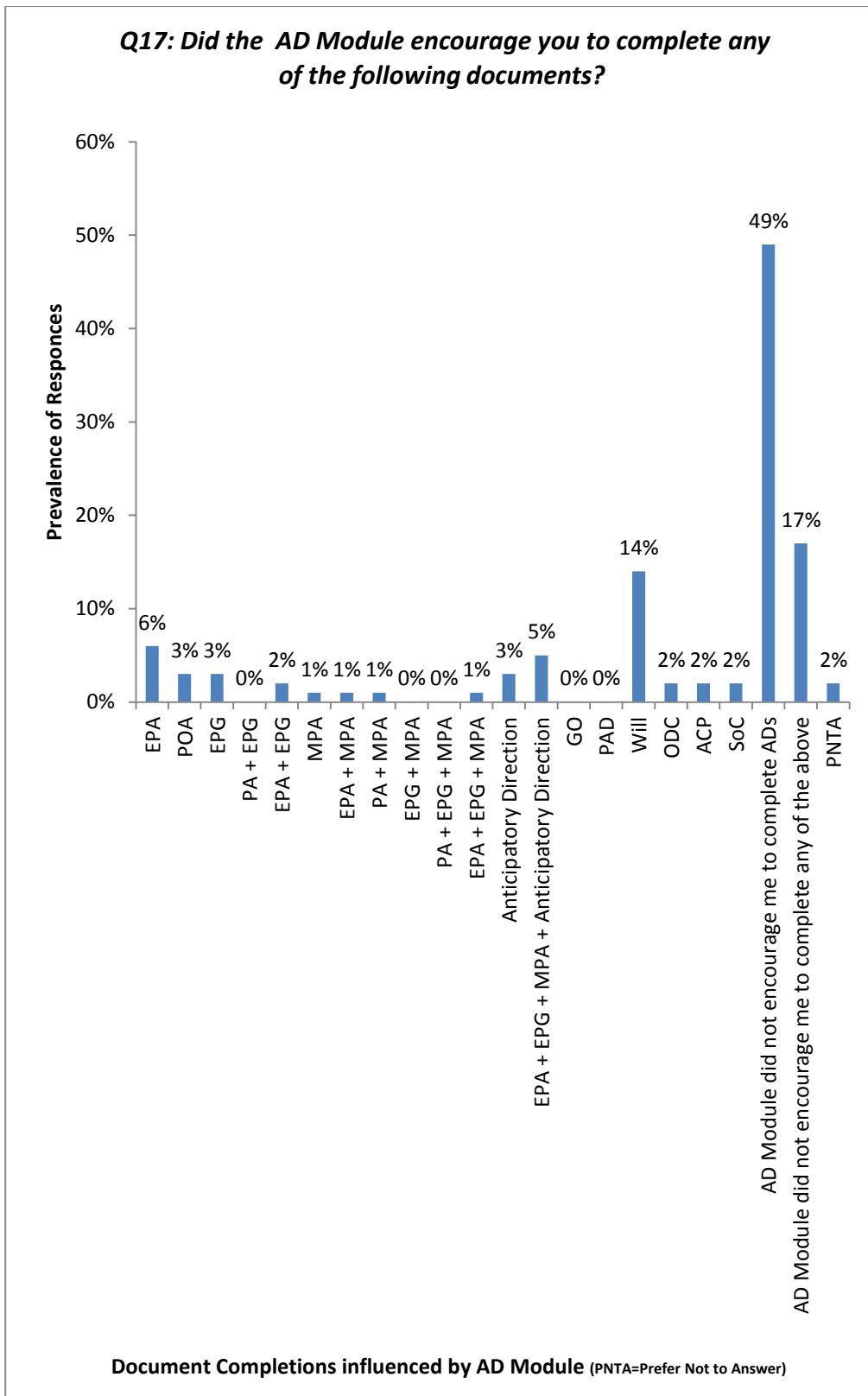


Figure 4.26: Q17 (did AD module encourage completion of any documents?). Prevalence of response - Post-survey

As can be seen in Figure 4.26, information in the online module encouraged completion of the Will (14%) more than any other document although the majority of

respondents (49%) said the module did not act as an incentive for completing ADs. Figure 4.27 (Q21) shows that the language in the module did not provide a barrier to AD knowledge for the majority of participants but there was still a significant minority (29%) who did not find the module easy to understand with the percentage of those preferring not to answer (13%) possibly adding to this response (by not wanting to appear to not having understood).

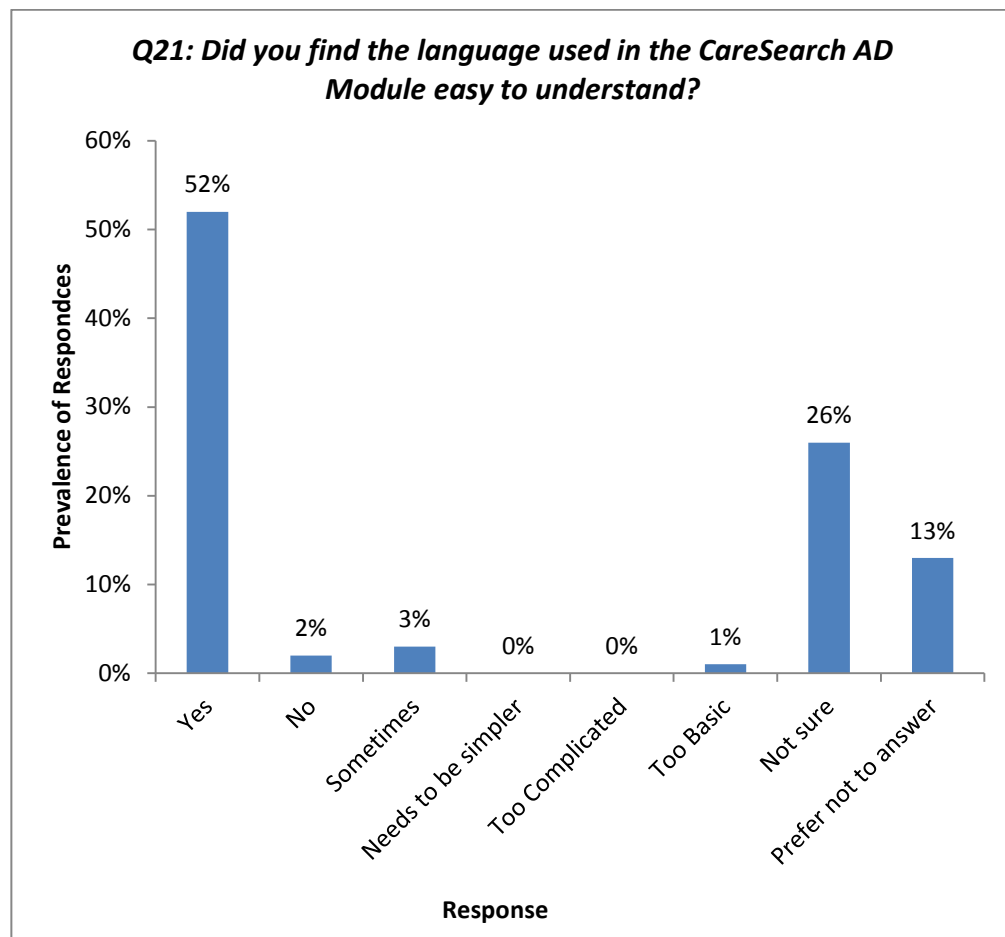


Figure 4.27: Q21 (was language in AD module easy to understand?). Prevalence of response - Post-survey

Question 24 (Figure 4.28) explored improvements that could be made to the AD module to better facilitate AD completions. As can be seen in Figure 4.28, a large minority of respondents found the information met their needs but an equal minority preferred not to answer.

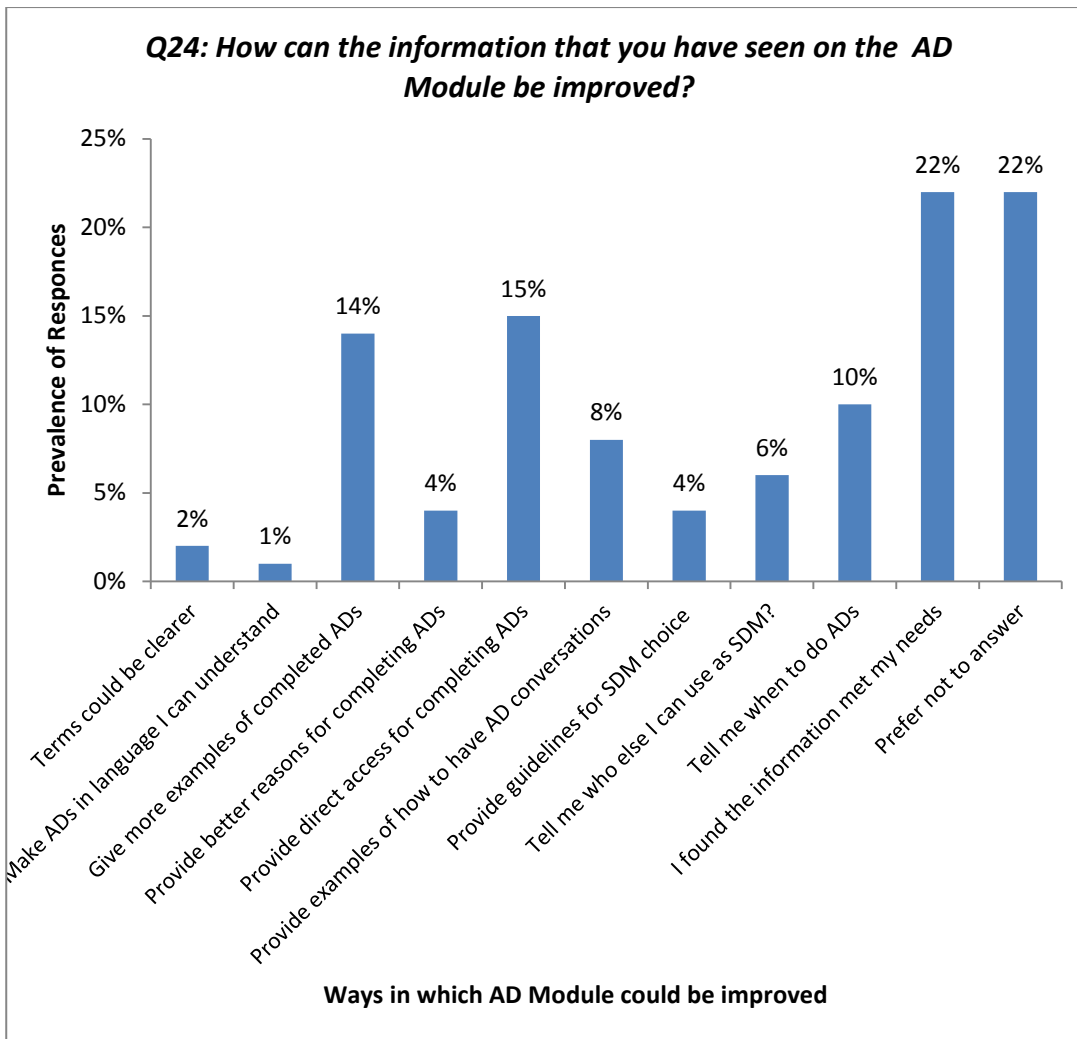


Figure 4.28: Q24 (choices for improvement of AD module). Prevalence of response - Post-survey

Responses to Question 24 (Figure 4.28) indicated that the greatest percentage of responses centred on improvements that could be made on access to AD documents (15%) and examples of what might be put in them (14%) indicating that accessibility and relativity on a practical basis to information about the documents in the AD module were areas for improvement. It was encouraging to see that for a number of participants however (22%), the information in the AD module met their needs.

To gauge the effectiveness of the AD module from the perspective of sharing or linking others to this educational instrument, in Question 25 participants were asked if they would recommend the AD module to family or friends (Figure 4.29).

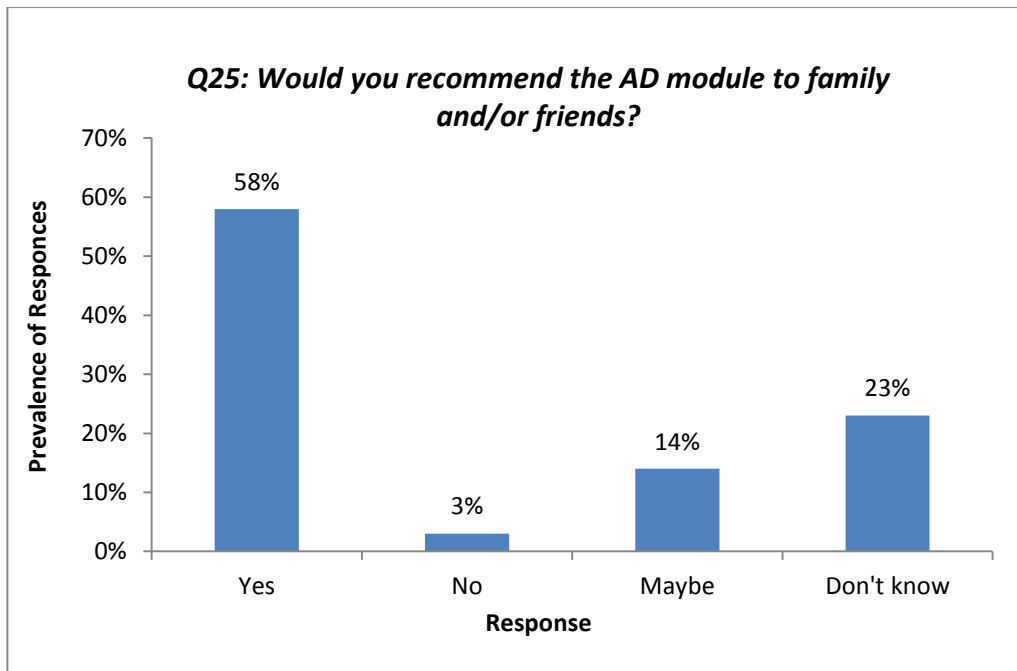


Figure 4.29: Q25 (would you recommend AD module?). Prevalence of response – Post-survey

Figure 4.29 illustrates that the majority would recommend the AD module as it stands although a significant minority (37% - Maybe and Don't Know categories combined) were unsure.

When exploring how any form of online information about ADs could be improved, participants were much more forthcoming, as demonstrated in Figure 4.30 (Q29).

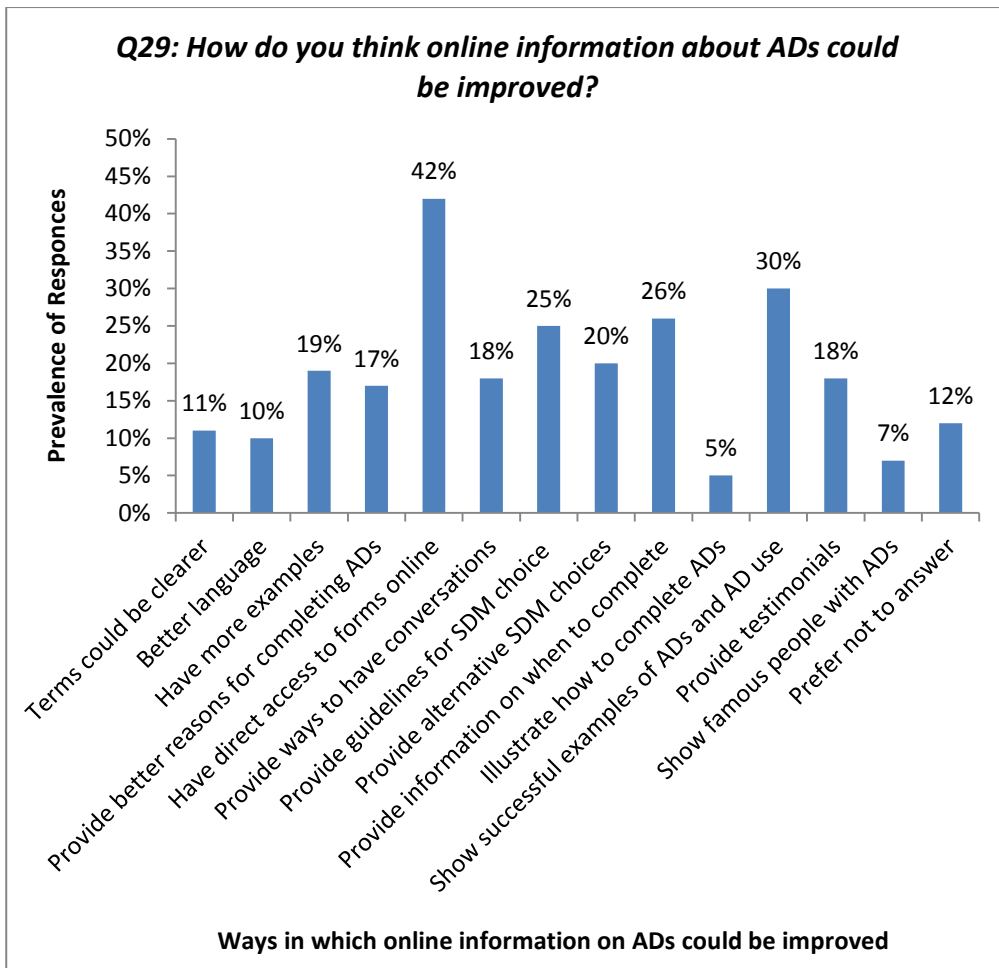


Figure 4.30: Q29 (how online information about ADs can be improved). Prevalence and type of response - Post- survey

Figure 4.30 (Q29) indicates the importance of providing the AD forms online when information is being accessed as indicated by the 42% who chose this option more than any other. Participants could choose more than one response so the choices representing the need to see examples (examples of what to put into ADs, 30%) and further guidance on SDM choices (25% guidelines, 20% SDM choices) seem to need to be made more explicit for online educational AD modules to be more effective.

The choice of timing of when the documents should be completed (26%) indicates that timeliness is not intuitive and that the information in the module emphasising time points at which AD completion could be considered were not succinct enough to be applicable or acceptable. The language used in both the AD module and other online information services appears to meet the reading level of most participants in this study as few (10%) indicated that language was a barrier to their understanding of the information provided. This may however be indicative of a higher level of

educational achievement within this cohort and it was unfortunate that education level was not measured.

Supporting questions about the effectiveness of surveys, prompts and other dimensions of study design (Q13-Q16, Q23, Q27 Post-survey questions only)

Questions 14, 15 and 27 asked whether the surveys themselves assisted people to complete ADs. Results for these questions are illustrated in Figure 4.31.

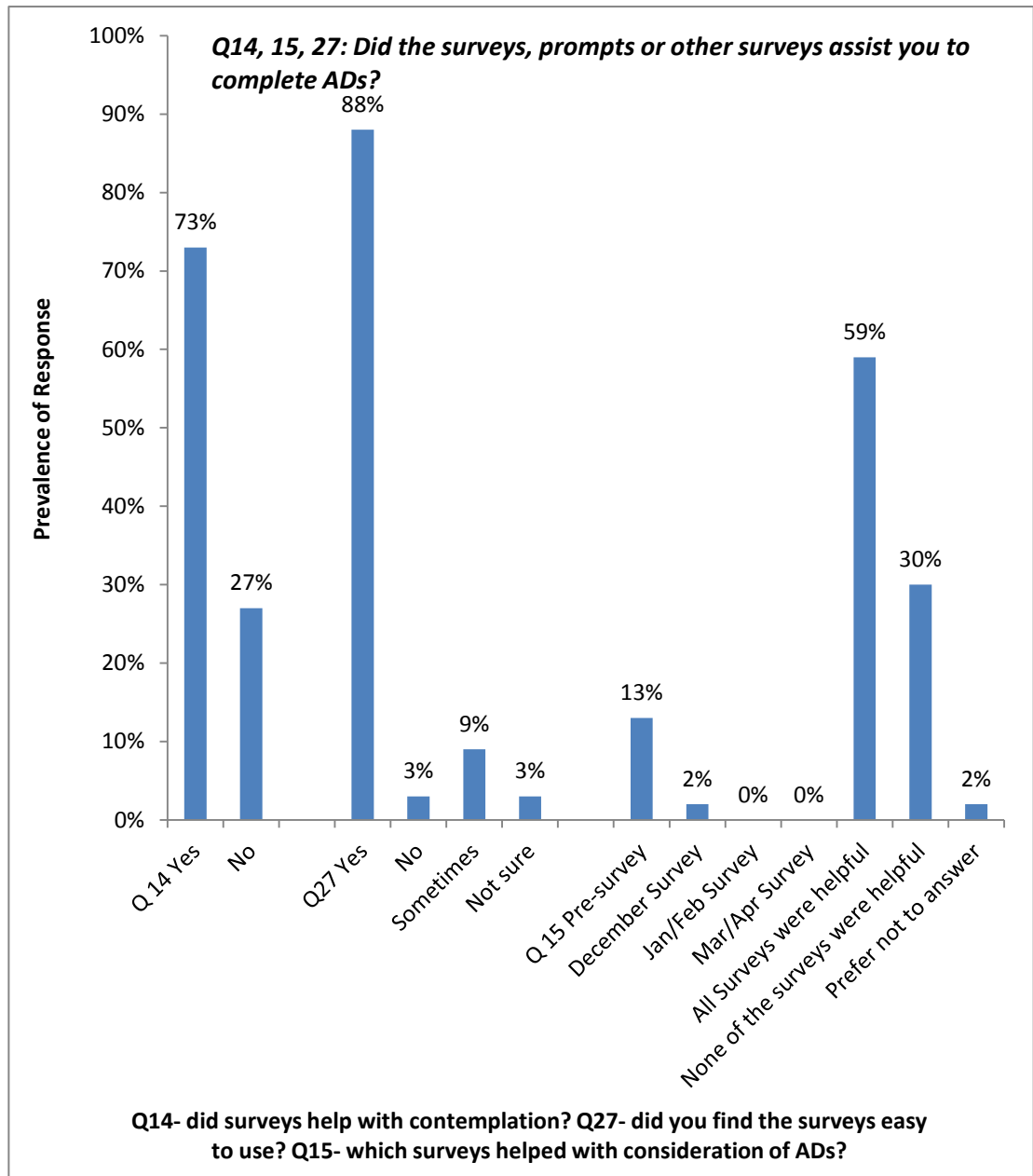


Figure 4.31: Prevalence of response to Q14 (did surveys help you to contemplate doing an AD?). Prevalence of response to Q15 (if surveys were helpful, which ones were most helpful?). Prevalence of response to Q27 (did you find the surveys easy to use?) - Post-survey

As Figure 4.31 (Q14) demonstrates, 73% of participants found the surveys during the course of the study were helpful for thinking about ADs. With regard to ease of

use (Q27), 88% had no difficulty in using the online surveys. The majority (59%) found all of the surveys were helpful (Q15) with the Pre-survey being identified as most helpful (13%), possibly because more information about ADs was provided in the Information Sheet that accompanied recruitment materials. A significant minority found none of the surveys were useful (30%) with open commentary providing more information in this regard.

As the surveys acted as a prompt, participants were asked their preferred online mechanism for receiving future reminders to complete ADs (Figure 4.32, Q13).

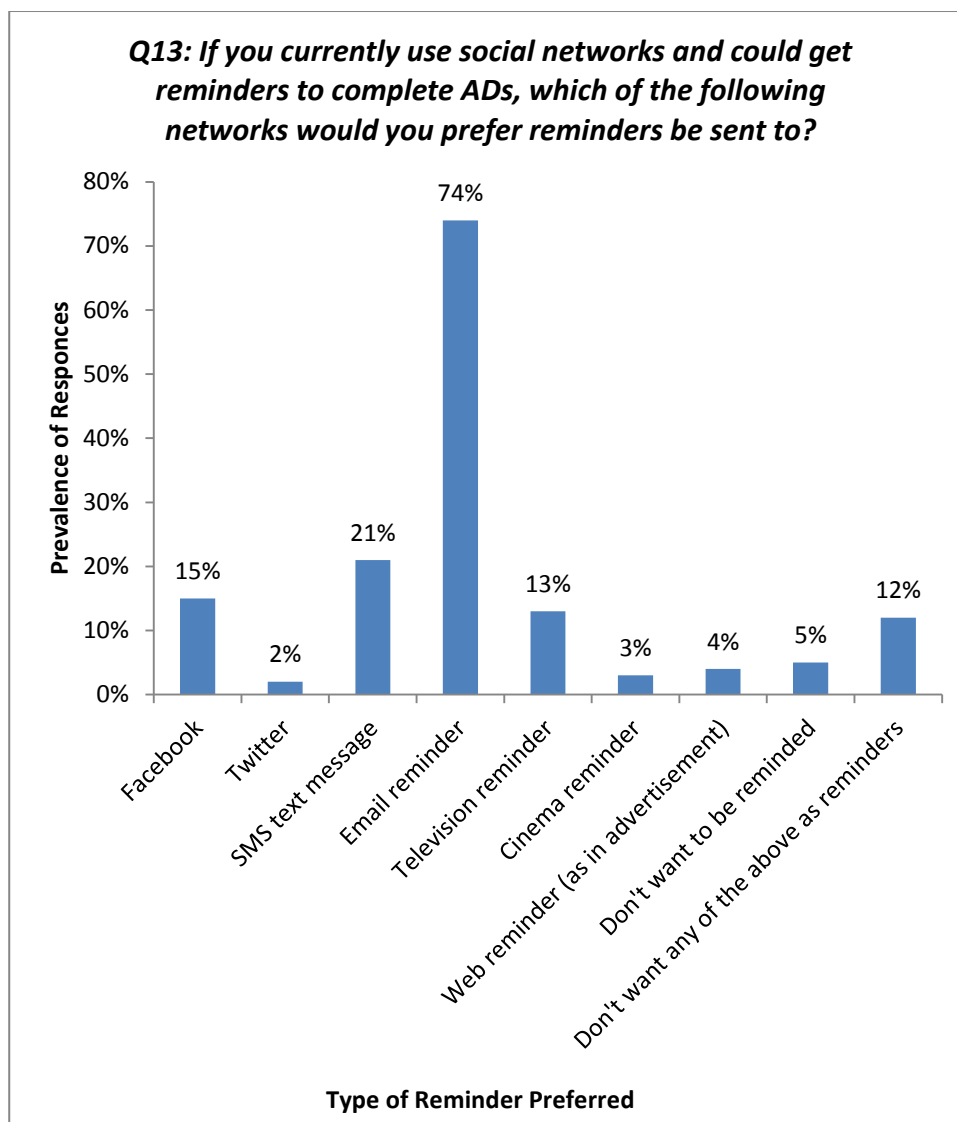


Figure 4.32: Q13 (type of social media for reminders about completing ADs). Prevalence of responses - Post-survey

Figure 4.32 (Q13) shows that the majority (74%) preferred reminders via email over other social networking formats. When asked when they would prefer to receive such reminders, Figure 4.33 (Q16) shows that most participants preferred reminders

on their birthday or whenever they completed financial or other such instruments (e.g. Will). Travel was also seen to be an opportune time to be reminded about completing ADs.

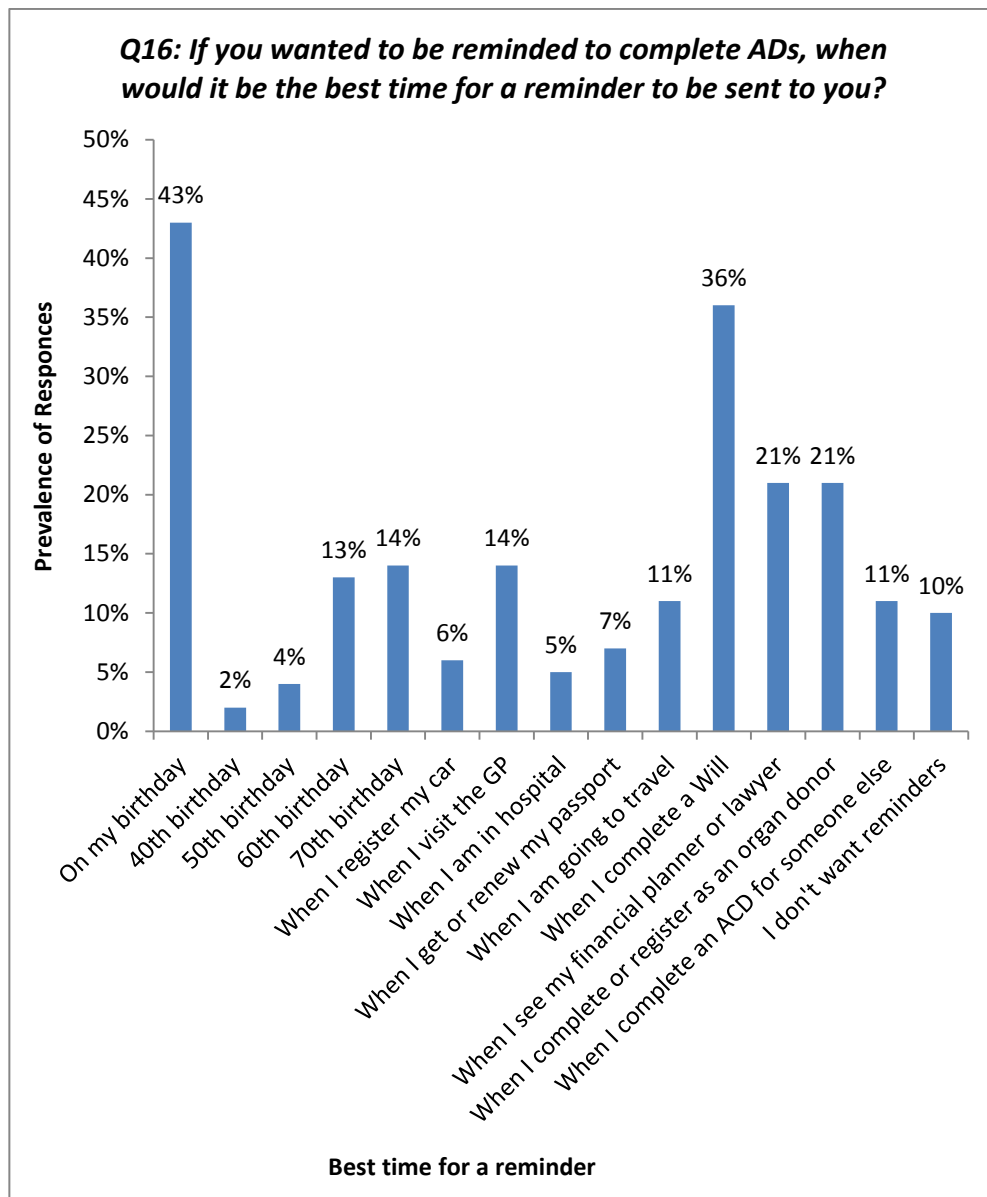


Figure 4.33: Q16 (when is the best time for a reminder to complete an AD?). Prevalence of responses - Post-survey

When people did want to be reminded on their birthday, they chose later birthdays (60th and 70th) rather than earlier ones. Those wanting reminders to complete ADs at the time of completing a Will (36%) and when seeing a financial planner or lawyer (21%, respectively) provide evidence that supports previous information from the HOS on financial documents being reported as the ADs most often completed. Far fewer participants wanted to be reminded when visiting their GP (14%) or when in hospital (5%) which is normally where ADs and advance care planning would be

promoted.

Open commentary

Question 2 (completions of ADs): No. of comments received Pre-, Post- and Prompt-surveys = 7

Participants often provided commentary clarifying the documents completed and the reason for their interest in the study – mostly the fact that their Wills were out of date. One participant indicated that it was very difficult to complete the Power of Attorney when people live in different states. One participant had completed a Memorandum of Wishes while another couldn't remember if they had completed a Power of Attorney or Enduring Power of Attorney. The number of different documents available and the terminology related to them can create difficulty in knowing which documents have been completed in relation to healthcare planning as opposed to financial planning.

Question 3 (why weren't ADs completed?): No. of Post-survey comments received = 18

The majority of comments described difficulty in completing documents. Difficulties alluded to included sickness or ill health, lack of transportation, difficulty negotiating documents between different states, lack of reminders, the need for time and commitment, as well as the complexity in completing forms and the process. Cost was mentioned although no specifics regarding cost were given. One participant wrote "*it would be an advantage to know where these forms are available and some info regarding help to complete if on lower income. Lawyers' fees are prohibitive on a pension*".

One person was waiting for the new Advance Care Directive form. One person still could not understand the documents even after participation in the study. Another person mentioned that they were trying to decide which child to name as SDM and this had led to the delay in completion of their document.

Question 4 (who did you receive assistance from?): No. of Pre- and Post-survey comments received = 28

Of those with specific information about receiving assistance from someone when completing an AD, most people named the Public Trustee. Other people named included *accountant, advisor in UK, conveyancer, family members*. Two people mentioned using a Will kit. The document most often referred to with regard to assistance was the Will.

Question 5 (who did you discuss ADs with?): No. of Pre- and Post-survey comments received = 4

Individual family members were named as those engaged in discussion. One person had memory problems and couldn't remember who they had discussed ADs with.

Question 6 (did you help anyone with an AD?): No. of Pre- and Post-survey comments received = 3

Question 6 asked whether or not participants had helped anyone complete any of the named documents. Pre-survey results indicated that overall, most participants had helped family or friends. One person had assisted a relative in another country with AD documents. One person helped someone with an Organ Donation Card. Another person said they had created a Word document with their personal effects and beneficiaries.

Question 7 (did you act as a substitute decision-maker?): No. of Pre- and Post-survey comments received = 4

The final question for the dataset comprising Q2–Q7 was Question 7 “Have you ever acted as the Substitute Decision-maker (SDM) for someone using any of the named documents”? Pre-survey analysis found that very few participants had acted as a SDM for any particular document.

One person was unsure if they acted as SDM under POA or EPA. Another person was named as SDM by parents but documents had not yet been signed. One person had acted as guardian for an intellectually disabled person. One person had acted as SDM while working in a residential aged care facility.

Prompt Question 7 (since Pre-survey have you used any of the following for information about ADs?): No. of comments received = 3

One person specifically mentioned the Powerpoint sent by CareSearch (AD module for this study) while another participant said they were a Respecting Patient Choices consultant and had previous knowledge that assisted them with AD assessment.

Other websites mentioned in Open Comments that were used to learn or complete ADs were:

Table 4.15: Websites participants visited during study

Name	Link
Google	None
Not named (N/N)	www.lsc.sa.gov.au
N/N	www.lawhandbook.sa.gov.au
CareSearch	Link for AD module
Dept of Health	Not provided
Office of Public Advocate	N/P
SA Govt website, OPA, Guardianship Board	N/P
N/N	http://www.sa.gov.au/subject/seniors/legal+issues/Power+of+attorney+and+advance+directives
Maybe one on euthanasia	Can't remember
Tindall Gask Bentley lawyers 2 state	http://www.tgb.com.au/menu/wills-estates
ABC radio law report	N/P
State Probate Registrar	N/P
Legal Services Commission	N/P
N/N	http://www.smh.com.au/money/planning/triumph-of-the-homemade-will-20130625
N/N	http://online.slatergordon.com.au/sgo/uploadedFiles/eCommiLegal_Web_Site/Wills/Sample%20Will.pdf
N/N	http://tinyurl.com/luwgcwd (shortened SA Health link)
Advance Directive draft kit currently in discussion	N/P
N/N	http://www.unisuper.com.au/grow-your-super/nominating-beneficiaries
Comlaw website	N/P
N/N	www.nlm.nih.gov/medlineplus/advancedirective.htm
General browsing	N/P
N/N	Directcare.com.au/2012/05/advance-care-planning
N/N	http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+Internet/health+topics/legal+matters/medical+power+of+attorney+and+anticipatory+direction
SA and NSW Health Departments	N/P
General search engine	N/P

Question 12 (other types of devices that helped person learn about ADs): No. of Post-survey comments received = 6

Other types of devices used on a daily basis included Photoshop, Excel, Word, audio and e-books, and online newspapers. Collaborate and Blackboard software were also named. Also used were Internet browsers, no specific description, and

one person said banking.

Question 13A (which software applications were used?): No. of Post-survey comments received = 12

Many listed LinkedIn as a software application they used at home. Skype and Google Plus were also mentioned as well as Spiceworks. Two people mentioned they were taking online courses and researching topics using online software but did not provide brand names.

Question 14 (what would you find helpful for learning about ADs?): No. of Post-survey comments received = 2

One person said a lawyer or friend would be helpful for learning more about ADs while another said there was already information online but it could be improved.

Other comments received

At the conclusion of the Post-survey, participants could make further comment about their experience in the study. Additional comments have been analysed thematically using a classical grounded theory approach under the following themes:

Theme: Need to get my act together

Most participants suggested they found the study reminded them to engage in ADs but they just lacked the impetus to do so: *“I found the study useful in learning more about advance directives. These are important and I need to get my act together to get them completed.”* (UID No.49062013)

Theme: Having the discussion

Two participants described how the survey gave them the opportunity to discuss ADs with their husbands: *“Partly because of this research, I have been having increased chats with my husband about getting these things done.”* (UID No. 74062013)

“My husband is now more aware of the reasoning behind the directives.” (UID No. 70062013)

Another participant (UID No. 381072013) described that as a Baby Boomer she should be *“doing something sooner than later and if my only child (34 year old with 2 children and busy career) was more interested, I might have done more about it by now”*. Participant UID No. 232062013 said that *“Just the fact of taking part in the whole process was an eye opener. It encouraged me to discuss it with partner and*

family.”

Other participants were not quite so successful in engaging loved ones with discussion on ADs however: *“Well done and should be made available to the general public. Tried to talk to my parents (who are in denial) and this (AD Module) would have helped immensely”* (UID No. 551102013).

“It was thought-provoking to participate in this study and even if I don’t do anything soon, it is much more in my mind. It is good to stimulate the discussion and provide sources of information on why and how, as I have found that many people do not really want to talk about it in any detail when it comes up in conversation.” (UID No. 316072013)

Theme: Mixed Feelings about ADs and Self-reflection

One participant declared that they *“could make their own decisions on how they would like to live”* (UID No.360072013), while another participant (UID No. 136062013) acknowledged that *“they had all of the information they needed about ADs”* and queried whether their incompletion was due to reticence in thinking about death and disability: *“We keep saying we have all the information but still haven’t done it. I don’t know if this is because we don’t like to think about death and disability when we still feel fit?”*

Another participant was quite reflective about his/her experience with the study including reconsideration of organ donation. *“The surveys made me aware of the options I have to properly organise events in case of sudden, unexpected death or expected death. I had thought before the surveys that having a Will drawn-up by a lawyer and naming a power of attorney was enough. I now realise that having advance medical directives in place plus medical power of attorney would make processes after my death easier for my remaining family members and therefore lessen the trauma of their decision making regarding my wishes. This study has also reminded me of my reluctance to become an organ donor of which I am ashamed. I think if articles reassuring me of the benefit of becoming an organ donor was linked to the site for becoming an organ donor (reassurance about the actual removal process) I and others would become organ donors as I wish to contribute to society as a whole.”* (UID No. 505082013). Another participant, UID No. 339072013 reflected that they *“should have done it years ago, perhaps at aged 40 when my kids were young.”*

However, not everyone felt that participating in the study assisted them with AD decision-making. UID No. 377072013 *“felt pretty disengaged from this study. I may be more prone to pay attention to it when I have retired in a few months’ time, and having a bit of time on my hands might have prompted me to look for information on the Internet. As it was, I was fitting it into working days and would forget it the moment I had completed the survey.”* His/her comments reflect those of other participants who found they were too busy to seek the information required to complete advance directives during the time of the study.

Theme: Reminders

A number of participants when questioned about the frequency and form of being reminded to complete ADs were keen to provide suggestions. UID No. 49062013 suggested an opt-in reminder via email with appropriate links to AD information as a way of reminding people to complete the forms, while UID No. 101062013 felt that more publicity would heighten general public awareness. For one participant, just participating in the study was *“my nudge to myself to DO it. It kept me on task, reminded me to continue and meet my goal”* (UID No. 552102013). Whereas UID No. 98062013 suggested he/she required reminders *“probably weekly because as soon as I close an email and go to act on something, something else takes it’s place”*.

Experiences with the AD message through other methods of communication reinforced the reminders received in the study. UID No. 494082013 wrote that although the reminders *“did heighten my awareness of advanced care directives. Just need more time to do the directives. It did provide a good opportunity to talk to others about these directives. There was a really good article in the ‘Australian’ and also a good discussion on the ‘Insight’ program on the ABC.”*

It is recognised that participating in studies is often a means through which participants act upon things they have considered and this was demonstrated by UID No. 565102013 who said *“The reminder emails kept the topic front of mind and promoted conversations with family and friends about the documents and this survey.”* UID No. 565112013 had a similar experience: *“I think being part of the survey group and receiving emails has made me think about ADs for me and family members in a way that would not have happened otherwise. I still have some follow up work to do but the process has started!”*

Nevertheless, participation in the study alone wasn’t enough to actuate completion

of ADs: *“Each survey makes me think I need to prioritise this. I have discussed what I want but have not recorded it in a formal way. The questionnaires reminded me but I need more powerful prompts and information to actually DO it! Thank you and good luck with the rest of this project.”* (UID No. 623122013)

Theme: Dissatisfaction with survey design

A number of participants throughout the study had difficulty with the survey design, accessing the AD module, or understanding the parameters of the research study. These critiques of the study design provided valuable insight for the researcher into the expectations of people when using the online environment for surveys and how to improve this for future studies. There were quite a few complaints about the poor design of the survey questions as participants had to nominate an answer on the screen before they could progress. This was a deliberate design strategy by the researcher to avoid skipped questions. Most complainants felt some of the choices made available were not relevant.

For example, UID No. 505082013 said *“I felt the surveys push participants in certain directions and therefore the results of the survey may not reflect the true feelings of the participants”*. These sentiments indicated the person may have wanted to get more out of the study than the study intended. As this was a research study designed to establish the effectiveness of one or both of two interventions, it is possible that this participant was looking for information outside the scope of the study that could better have assisted them with their perspective on ADs.

Another participant found the survey boring (UID No. 559102013). Other participants, particularly in Group A which didn't receive any intervention were frustrated with not being given information and materials as demonstrated by this comment: *“too much time elapsed between the first and last survey-the only 2 I got. I kept waiting for something to prompt me to go ahead and look up the advanced directive on the Internet. But I will do that in the next few weeks.”* (UID NO. 294072013). UID No. 600112013 said *“I only received the first and the last questionnaires so don't feel any more enlightened. I am disappointed as I was looking forward to some real information.”* Another participant, UID No. 353072013 felt similarly: *“As I have only been required to complete a couple of surveys and have not received any other information I do not feel that I have learnt anything during the study. This is a little disappointing”*, as did UID No. 430072013: *“I found it most frustrating that I received no information or online links to further information. I'd like it to have been much easier for me to complete these directives. Maybe the*

info was provided but I missed it??”

For those participants in Groups B and D, a link was provided to the AD module with information on ADs at the beginning of the study. This link was accessible throughout the study. At the conclusion of the study, the link to the AD module was provided to all participants at the end of the Post-survey and again in a separate email invitation but it is possible that participants did not see or read this information prior to commenting on the survey.

Several participants wanted to be able to elaborate on their responses such as UID No. 299072013, who said *“sometimes the opportunity to comment or clarify would be useful”*, while others, like UID No. 419072013, would have liked for some questions to have an “unsure” option even though every question was provided with the ability to put additional comments in or to click on *Prefer not to answer, Other, or None of the Above*. It is recognised however that these options may not have been sufficient and/or the *Unsure* response may have been more appropriate.

Theme: AD Education Module

Participant comments on the AD module were generally of three categories: 1) they did not access the education module (even though they were in the AD Module Group); 2) they thought the module was excellent and informative; or 3) they could not remember receiving the AD Module or what it had said (and didn’t know how to access it again even though instructions were given on how to do so). What this has demonstrated is that it may be necessary to provide simpler and clearer instructions as to how to access material online such that it can readily be used. The constraints of the research study and the website where the AD Module was housed made this less straightforward than it could have been.

Theme: Additional suggestions

Participants had valuable suggestions for future modifications to AD documents, such as UID No. 585102013 who suggested: *“perhaps provide a step by step guide for completing each of the documents such that filling in multiple choice questions along the way to narrow down how you feel about the things needed to be decided would help me.”* UID No. 484082013 said *“I want advance directives (or clear patient decision not to make directives) to be required by health services – they are too important to be left to patient initiative – most people are probably a little like me and don’t prioritise this task even though they should.”*

UID No. 82602013 suggested “*(The study) certainly made me more acutely aware of the importance of the need to complete advance directives in order to ensure that my wishes, should I become incapacitated, are acted upon. Really must get my act together ... Maybe it would be worth having lunchtime ‘info workshops’ onsite at employment sites.*”

Theme: Further actions as a result of participation in the study

Almost all of the participants were gracious and appreciative of the opportunity to participate in the study. UID No. 552102013’s comment encompassed many of similar refrains from other participants “*I wish you well in this important area. Everyone would benefit from this project and I see it (an AD) like a Will, that it can be updated as needed as life progresses. I will promote the completion of the important advance directive document with every opportunity I get.*”

On a personal level, UID No. 144062013 wrote that the experience of participating in the study “*provided me with a better understanding of what I should be doing prior to it being too late. I will focus on the relevant documents/instructions closer to my 60th birthday*”; while UID No. 502082013 confirmed that the study “*reinforced my awareness that I need to complete these forms. I have placed a reminder in my calendar to complete the forms as soon as my study load has eased.*”

Theme: Personal Experiences of AD use or non-use

As an indication of their experience with ADs, a number of participants provided information about personal experiences with loved ones who did or did not have ADs, such as UID No. 379072013 who wrote: “*My brother died in hospital and he didn’t have this in place because he didn’t want to do it. I became the one to make decisions for him. It was ok as we had talked about what he wanted but would have been more settling for me had it been written down by him.*”

UID No. 518092013 indicated that “*My main knowledge had come from family members in QLD [sic], where it is a legal document. Since then I have asked other friends if they knew of it. I like that everything you want when you are no longer able to [sic]. Your website just confirmed what I learnt from my relatives in Qld. With more information that I will keep investigating, I now feel much more empowered to know exactly what I want and my family are happy with my decision.*”

Some experiences with other people who were included in AD discussions with the participant were not quite successful. UID No. 407072013 wrote “*The concept & the*

need for advance directives is difficult to explain to older people – e.g. if in their 80's. In my experience (with my late father) he did not want to be bothered with all this complicated stuff (it may not be complicated to those putting forward these ideas but many people don't want to come to grips with these issues). Older people just want to be left in peace, and let the 'kids' sort out the difficult issues when the time comes! Also my understanding is that ADs are a 'state issue' only i.e. if someone who has made 'directives' in SA suddenly becomes seriously ill whilst on holidays interstate, then these 'directives' do not apply in VIC. Uniformity across all states is needed. Also I have experienced 'Enduring Powers of Attorney' being manipulated by family members to their own financial advantage in the case of a person with dementia – the whole issue of ensuring the wishes of older people are carried out correctly are frequently problematic."

Abuse of advance directives was also noted by UID NO. 432072013 "Yes, my mother passed away with a will which my brother proceeded to change at his will as he was the power of attorney". UID No. 368072013's story illustrates the additional emotional burden that many Baby Boomers face as their relatives age and require care: "90 year old mother just gone into aged care and is not happy – willing herself to die – can understand this as there is no quality of life – she is rapidly becoming more confused on a daily basis – it is hard to watch someone who was very switched on become so despondent with life."

Nevertheless, there were those such as UID No. 430072013 who have had reinforced motivation for supporting ADs from personal experience: "I've had a stroke and have had difficulty getting hospital staff to treat me respectfully and listen to/take notice of what I'm saying. Fortunately my 3 children have stepped forward and insisted this behaviour change. If I am no longer able to give directions which they will back up I must allocate legal responsibility for this so I am respected and my wishes taken into consideration. Thank you."

Theme: Healthcare system

The healthcare system was also a concern for one participant who was unsure if her ADs would be respected: "I am now aware of a much greater range of documents but I worry that busy medicos won't be any better at implementing these express wishes." (UID No. 374072013)

Theme: The forms themselves

Many participants expressed concerns about the number of different forms and the

differences between states. UID No. 533102013's comments were typical of those of others on the same subject: *"there were so many more than I realized and I had no idea what most of them covered or if they would be necessary in my situation. I need so much more info now before going to a lawyer so that I am prepared with my questions."* UID No. 488082013 wrote *"I had no idea there were so many different types. I only knew about a 'will after you die' and a 'power of attorney'"*, and UID No. 342072013 wrote *"An increasing number of possible ADs lead to more lack of clarity, and less action by me. Is there a simple site among the thousands that come up that handles the SA situation?"*

Although participants understood that ADs could be an important part of future care planning, it did not mean that completion was an anticipated outcome. UID No. 348072013 noted *"Just reading of the options of Advance Directives heightened my awareness. Previous [sic] I had only considered my will to be enough planning. Although my wife and I do discuss things, we each understand the others wants and needs"*; while UID No. 55102013 wrote, *"Not everyone wants to talk about this topic and it challenges one's mortality. For some people they felt leave it to the goddess, what happens, happens. What if medical science finds a cure?"*

Discussion

The purpose of conducting this randomised controlled trial was to meet the Objectives established in this chapter. The primary objectives were to evaluate the effectiveness of two different computer-based, interactive, online interventions to facilitate individuals to complete any of 4 legal ADs in South Australia as well as assess which of the two interventions were most effective in doing so. In the first instance, Question 2 (completion of advance directive documents) addressed the stated Objectives 1 to 4, providing evidence of the primary outcome of the effectiveness of either a purposively designed computer-based, interactive online AD educational model and/or email prompting to increase the number of individuals who completed any one of the four legal AD documents. Questions 4 through 7 (Q4 - who did you receive assistance from; Q5 – who did you discuss ADs with?; Q6 – did you help anyone with an AD; Q7 – did you act as a substitute decision-maker) addressed Objective 5, being to provide evidence of the effectiveness of either or both of the interventions to effect assistance from others, discussion with others, helping others to complete ADs or acting as a SDM for others. Objective 6 was met through analysing prevalence of additional questions asked through the surveys which were designed to elicit contextual preferences and information about barriers

and facilitators to computer-based, interactive online formats for AD completions, while Objective 7 was met by analysing Question 3 (why did you not complete an AD?) results and open commentary to establish elements of knowledge translation, such as participation in the study, which may enhance contemplation of ADs without facilitating completion of them.

Strengths and limitations of this study

This study relied on a sufficient number of participants completing both the Pre- and Post-surveys to see a clinical effect size of 10% difference from a baseline of 0 between intervention and non-intervention groups. To meet this goal, advertising to recruit participants for this study used every media format currently available other than television. This included both online and offline mechanisms such as social online networks, professional online networks, hard copy fliers, newspaper, magazine and radio advertisements, word-of-mouth, workshops and professional conferences, as well as interested parties from previous health surveys conducted in this state. As a general population study, not many other means within the financial constraints of this thesis were available to canvas more widely.

Using the online environment for recruitment may be easier with regard to time, logistics and human resources but it does not entail a straightforward methodological research approach. The use of online recruitment involves consideration of means of communication, learning styles, access issues, iterative development of online solutions to online problems as the study progresses, and constant communication with online participants to manage their engagement with the study (Gill et al. 2012). An example of such considerations for this study was the effort to keep within the requirements of ethical research conduct for a randomised controlled trial such that the researcher is not biasing either the participants or themselves in relation to answers to survey or data analysis as occurred with participants who asked whether they were able to complete documents after they had consented but before the Pre-survey had been distributed. Ethical considerations prevented answering in the negative and thus the trial ended up with a number of participants whose data was excluded which could have impacted on final analysis of the effectiveness of the interventions.

One of the main strengths of this study was in the use of a 2 x 2 factorial design randomised controlled trial to test two different computer-based, interactive online methods to facilitate individuals to complete ADs in this population group. Using a 2 x 2 factorial design enabled recruitment of a sufficient number of participants to test

for a clinical effect of either or both interventions. A limitation of the use of a 2 x 2 factorial design is that it is not designed to test for interaction effects of multiple factors and groups. This may have impeded generation of statistically significant associations between one intervention or the other for the primary outcome. This consideration was acknowledged by assuming that there would be no interaction effects between the two interventions and that the additive effects of the interventions would be sufficient to show effect. As randomised controlled trials measuring interventions together are minimal, which was demonstrated in the systematic review in Chapter 2, this study provides evidence of the potential for either or both of these interventions to facilitate individuals to complete ADs. With a study which looked for a lower clinical effect and/or interaction effects, it may be possible to better determine which of the two interventions is more effective, especially as there seemed to be a trend towards those in the AD education module group completing more documents.

This study had a dropout rate within the range calculated (282 started Pre-survey, 218 completed Post-survey, drop-out rate of 23%). Twenty-nine of the participants completed the Post-survey but when their pre-survey results were analysed, it was found that they had already completed one of the 4 legal ADs so their results were eliminated from the study. This left 189 participants completing both Pre- and Post-surveys **and** not having completed any of the 4 legal ADs for a 33% drop-out rate overall. The responses from these 189 participants formed the basis of the analysis and a limitation of this study is not conducting Pre-survey analysis of data prior to distribution of the interventions to ensure as large a sample as possible was available for the main study.

It may be that simply participating in the study itself was an incentive to complete documents previously uncompleted or to reconsider completion of the documents once more information was provided. In contrast, being prompted multiple times to complete documents may have created a disincentive for those who were interested in completing but were annoyed at the repeated requests to do so. Those who did not receive any intervention but needed information to complete ADs and waited for that information to be provided before completing documents may have affected completion results for the non-intervention groups. Any or all of these factors may have impacted on individuals completing documents and a more targeted, detailed and larger study may be able to unpack which of these elements is most influential in completion rates.

Results from Question 2 regarding individuals completing documents showed a similar outcome to Dexter et al. (1998) where rates of single interventions did not yield completions of ADs above the non-intervention group. The design of the research in my study was done in such a way that statistical analysis could be conducted within the time and logistic constraints of the thesis; however, if a similar study could be conducted which included those who had already completed primarily an EPA but also had completed other documents, then perhaps an argument could be made about testing for the influence of prior knowledge of these other documents facilitating completion of additional ADs not yet completed.

In my study, it appeared that there were other factors required to engage individuals to complete documents. It was interesting to note the high rates of Will completion in this cohort (>70%) and that it was similar to the similarly aged cohort in the HOS study (Project 2, Chapter 3). This verifies that the age group which incorporates the Baby Boomer generation does engage in future planning but as indicated by the secondary questions, there is ambivalence about what the right age for AD creation might be in this cohort.

Participants in this study were also likely to sign up as organ donors although the rate at which they completed Organ Donation Cards (>50%) was below the Australian average of 76% (Australian Government Organ and Tissue Authority (AGOTA) 2014). O'Carroll et al.'s study (2011) hints at other motivators for completion of these after-death documents with their findings suggesting those who were subject to anticipated regret scenarios were more motivated to complete after-death documents such as Organ Donation Cards. O'Carroll et al.'s (2011) study may provide a possible explanation regarding behaviour for the observation in my trial of higher rates of Organ Donation Card completions (<50% of participants) and Wills (>70%) rather than ADs. It may be that people are more comfortable completing instruments that will help someone else after they have died rather than completing instruments to assist their own health and lifestyle choices whilst still alive and a limitation of this study is not asking this question directly of participants.

As the study was conducted in the online environment and conditions of the study required sufficient computer and Internet capability, the use of the computer and online environment was not an impediment to completion of documents. However, lack of access to online forms could be argued as an impediment as a hidden assumption by participants was that participation in the study would provide an easier and more accessible mechanism for them to complete ADs (as evidenced in

open commentary). Not being able to provide an online form for participants was a limitation of this study.

The design of the surveys in the online environment also came under criticism as questions were deliberately constructed to have at least one answer ticked in order to proceed to the next question to reduce the number of missing answers and enable more robust statistical results. This format and the lack of an option to say “unsure” may have frustrated participants and caused some to cease completing surveys so must be regarded as a limitation to the study.

As nearly all of the survey questions allowed for more than one choice to be made, it should be noted that the frequency analysis is not indicative of only one answer per individual. Nevertheless, by constructing the questions in this way, it provided participants with the ability to nominate multiple entities and give a clearer indication of which entities had a higher rate of use. This might not have been possible if participants were given only one choice as evidence in open commentary that if the choices were not deemed relevant, then the options of not sure or prefer not to answer were substituted instead.

Non-completion of the Post-survey may have been the result of other particulars of the research methodology, such as the length of time required to participate in the study, and this may have been a limitation in seeing evidence of completion of ADs. Comments made by participants indicated that some participants did not remember having access to or seeing the AD education module while other participants complained that they did not receive surveys, information or access to either (Control and Prompt groups mainly). Greater emphasis and explanation about the conditions of participation in the study may have assisted participants to recognise to what extent they would receive information and when.

The participants in this study who did complete documents received assistance (Q4) largely from a lawyer (which could also mean solicitor/barrister) followed by family members. This mirrors the results of Brown and Jarrad (2005) and findings by the AHMAC (2011) which also showed that many people seek the services of a lawyer when considering advance planning documents such as Wills and Enduring Powers of Attorney. Lawyers can play a critical role in promoting the completion of healthcare directives at the same time that clients ask for assistance with Wills and Enduring Powers of Attorney in this population group. This study showed however that although people may use lawyers to assist with document completion, they

don't choose to discuss these documents with them. A limitation of this study was not being able to identify why this was so.

Another limitation of this study was not following up on reasons for dropping out of the study by those who did drop out before the Post-survey. Knowing the reasons may have provided the ability to adjust information in such a way as to make it more relevant or to chase up those who may not have received email prompts due to website servers moving such items to junk mail, which was the case for one participant who enquired of the researcher when the study was to begin. This notification led to the creation of specific subject headings to avoid emails going into junk mail.

There was no indication that either the AD Module or Prompt was effective in increasing participant assistance to others (Q6) with ADs or acting as a SDM (Q7). The results of these two questions were confounded by higher rates of assistance and agency in the Pre-survey with much lower rates of assistance and agency declared in the Post-survey. This may have been due to survey question design such that participants interpreted the question to mean that they had assisted or acted during the study rather than at any time before or after. To ascertain this effect, future research question design will need to make these questions more explicit.

Family members or others who provide assistance for completion of ADs experience the conduct required around these documents, including the conversations required, negotiation with others and where to source information needed. Open commentary in this domain showed that when assisting others with these documents, the complexity and number of forms can be daunting which may explain why so many people choose to seek the services of a lawyer when contemplating or completing these documents. A strength of this study was that participants were able to voice this and provide evidence that even for this knowledgeable cohort, terminology can still be a barrier for AD completion and recognition.

Another limitation to this study is that of self-reporting without verification of actual document completion. However, the intent of this study was to determine the effectiveness of online interventions to facilitate individuals to complete documents. If there was to be any negative effect of self-reporting, it was hypothesised that we would see a greater than 10% clinical effect from a group of people who were prepared to participate in this study with conditions which required a long period of

time between surveys. The fact that only 13 individuals overall reported completing any documents suggests that self-reporting may not have been an issue, especially as those who reported completing ADs in the Pre-survey did not know they would be eliminated from analysis.

An additional limitation to the study is that the results only reflect one point in time and particularly before the implementation of the new South Australian ACD form. Open commentary suggested that many people had heard information about ADs in association with the new form. This knowledge may have influenced them to wait to complete the new form rather than complete the older documents. Therefore, the motivation to complete documents during this study may have been positively affected (those wanting a prompt to do so used the study as a prompt to initiate action) or negatively affected (those who heard about a new form coming out may have decided to wait for the new ACD form and so did not complete documents they had been intending to complete) by participation in this study.

Generalisability

Due to the focus on a particular cohort (Baby Boomers), this study does not claim to be generalisable across the whole of the South Australian population as it is targeted towards a particular age group known as the Baby Boomers. It is recognised and accepted that the “Baby Boomers” are not homogenous (Taverner 2010) in character so the study does not claim to be generalisable for all those who may be in this generational grouping.

The study is also not generalisable for forms other than the 4 legal AD documents focused upon in this study. Excluding those who had already completed one of the documents but not the others has meant that the results in this study are only comparable to other studies where no one had previously completed any AD documents. However, the fact that rates of completion of Wills and Organ Donation Cards were similar in the same age group between the HOS study and this RCT suggests that future research might find generalisability in relation to the use of these particular AD documents in this generational age group at a particular time point.

It was encouraging to see that over 50% of participants found the AD module language easy to understand but a significant minority of 25% did not. Unfortunately, sociodemographic information on education levels was not available to identify whether lower levels of education were the cause affecting e-Health literacy,

especially on issues to do with end-of-life care (Capuro et al. 2014). This was a limitation to the study. Another limitation to the study was not assessing for levels of health literacy. For example, some health literacy deficits were identified through open comments made about the complexity of the documents, the lack of recognition that they were legal documents, and requests for further assistance. Advance directives are complicated documents and if a person is unwell or unable to understand the information being provided, then the likelihood of completion will likely remain low regardless of whether they are made available in an online format for ease of accessibility.

Additional limitations to this study included the timing of promotion of the new SA Advance Care Directive Act, form and guidelines which may have led to reticence to complete older forms that were used in the study, as well as no direct online link to the trial forms for ease of completion. Having immediate access to the forms at time of heightened contemplation may have resulted in more people completing at least one of the documents during the time of the study.

What this means: Utility of the online environment for AD completions

In relation to Objectives 4 and 5, this study was able to show that the application of one or both of two computer-based, interactive online interventions did not act as barriers to AD document completions. Demographic information on computer and Internet comfort and use demonstrated very high rates of comfort and use such that this participant group were experienced users of the online environment. Comments about the AD module were largely positive with few complaints about use or access to the online surveys, readability or other issues associated with the online mechanism of engagement. Where there were complaints, these were largely due to elements of research design rather than online activities.

Open commentary suggested that other factors in the online environment may play a more critical role for AD completions, especially when prompting people through email to complete these documents. Points of comparison with the literature indicate that although Murphy et al. (1997) and Dexter et al. (1998) showed that e-medical record prompting could facilitate hospital physicians to increase discussion and completion of ADs, prompting of the general population through the email environment (as done within this study) did not achieve a similar effect. It was not through lack of interest or intention that participants in this study did not complete ADs; however, unlike the medical population in Murphy et al.'s (1997) and Dexter et al.'s (1998) studies where prompting necessitated an action be entered into as part

of hospital protocol, it may be that a lack of systematic or structural requirement for completion (e.g. similar to driver's licence renewals) for the general population is hindering the impetus for completing ADs. This was demonstrated by the response to Question 3 which indicated that most participants did not complete documents because they were either too busy or felt it was not the right time to do so. Open commentary from those in the Prompt groups suggested they needed repeated reminders continually and over a long period of time to keep the topic uppermost in their mind; otherwise, other life events took precedence.

Research studies in the literature which used educational information via websites to provoke AD completions were not able to show clear representation of Pre- and Post- completion rates of ADs based on the website effect, as demonstrated by the systematic review in Chapter 2 (Project 1). In contrast, my randomised controlled trial showed that a group of participants exposed to an educational website on ADs without personal or administrative assistance could gain enough information about ADs to make a decision as to whether or not to complete the forms. The fact that very few chose to complete forms was complicated not only by external personal factors, such as difficulty in having discussions, but also by the fact that online AD forms were not made directly available to them. Open commentary suggested that if in this experiment online AD forms had been made available then completion rates may have been higher. Nevertheless, for those intent on completing forms, participation in the study provided the catalyst to seek documents required through online or other means as demonstrated by Post-survey results of increased rates of Will and Enduring Power of Attorney completions as well as the high rate of likelihood that documents would be completed within three months of the trial as indicated in Question 32 (see Figure 4.16).

Identifying sociodemographic characteristics of those most likely to complete ADs using the online environment

Within Australia, the empirical evidence of the number of ADs completed and by whom has been lacking but is now known through the work of White et al. (2014). My study offers a more comprehensive understanding of completion of particular state ADs and the barriers and facilitators for completing any of the four legal South Australian ADs in recognition of Objective 6 of this study.

Bravo, Dubois and Wageneur (2008), Ramsaroop, Reid & Adelman (2007) and Tamayo-Velasquez et al. (2010) have demonstrated that sociodemographic factors such as age, education, occupation and income can differentiate those who

complete ADs from those who don't. These factors can also prevent or lead to underutilisation of ADs by non-users of mediums contained within the online environment used to disseminate healthcare information.

Butler et al. (2014) declared that:

Well-designed, validated tools that are easily accessible, readable, understandable, and appropriate to patients across various settings working with various facilitators ... remains to be done. A broad array of tools may be needed to meet the needs of the broad array of professionals, in different settings, and at various stages. (p. 32)

This study has shown in several ways that the same sentiments apply to non-patient populations as well. This was demonstrated with participants in this study indicating that although the majority had a laptop or desktop computer (Q12A, Figure 4.20), a significant minority did not have an iPad or Kindle (30% or less) with only half owning a smartphone or mobile phone. These latter devices are being targeted for mobile AD information but will miss their mark if not targeted in a way that matches generational use of the technology.

It is not only hardware that needs to be considered. Although many Baby Boomers in this study used software programs such as Word and Excel, half or more also used social engagement platforms such as email or Facebook. Over 70% of participants chose email as their main platform for reminders rather than YouTube or Twitter (Q13, Figure 4.33). If YouTube or Twitter is not preferred by this generation as a resource for healthcare educational information or updates, then visual demonstration of AD use or updates or news on the latest workshop or educational sessions on ADs may miss their mark.

It was encouraging to see that reminders helped those in the Prompt groups to think about or complete ADs (Qs 14,15 & 27, Figure 4.32) with many (85%) finding the online surveys easy to use. Perhaps annual participation in email surveys on AD use can serve to keep this healthcare initiative in the subliminal consciousness of healthcare considerations such that when the time is right, the email provides the means and motivation for completing the document.

More than just about the medium

Interestingly, if people in the population believe a cause is worthy and they have been provided with education and promotion of an issue over a period of years, as has been the case with organ donation (AGOTA 2014), sociodemographic

differences may be less relevant. Bradley (2012) showed that for Baby Boomers in SA, experience and knowledge were essential to contemplation of AD creation yet 75% of participants in this study had no experience as a SDM (Q7, Table 4.13) even though 50% or more participants (Q8, Figure 4.15) said they would be happy to be one. Tilse et al. (2014) found that many who do become substitute decision-makers do not understand the accountability and responsibility that the role entails. This could be mitigated through practical experience and application of ADs. Carr (2012a, 2012b) and Moorman and Boerner (2013) found that when families have high quality relationships, the odds that a particular person will be chosen as SDM with the right kind of qualifications and perspectives are high while poor family relationships lead to decreased odds of advance care planning, ADs or SDMs. Open commentary provided by participants in this study indicated several times that participants had experienced abuse of power with family members using ADs – these types of experiences if not exposed and controlled may find people not completing ADs to prevent such adverse experiences.

Similar motivations may have influenced the number of people who declared that they did not have an interest in completing ADs or were unlikely to complete ADs in the next three months (approximately 19%, Q32, Figure 4.15). Considering that these participants were self-selected for the study indicating a high rate of interest in this area, these numbers plus those from Q3, Figure 4.13 indicating that now was not the right time to complete ADs (20%) showed that for a number of the participants in this study, further contemplation and consideration of external factors pertinent to ADs may be influencing their decision-making.

The fact that 30% of the participants in this study had not helped anyone with any of these documents and 75% had not acted as an SDM may have meant that the experience of making challenging and highly emotional medical treatment decisions at a time of crisis had other factors influencing these choices that were not addressed by this study, such as family conflict or psychological/emotional distress in the role. Wendler & Rid (2011) found that substitute decision-making is a stressful role and can place the decision-maker under psychological and emotional distress that may not have been foreseen. Pope (2013) found that when there is no one authorised to make decisions, then clinicians have to make them. This can be risky because there is no oversight to the actions undertaken.

It is important to understand who people are not willing to discuss ADs with as much as it is to know who they are having conversations with, as this may show a change

in relationships with professionals from one generation to the next. Several studies (Brown 2002; Coleman 2012) have shown that people do not discuss ADs with healthcare professionals but would like to, yet participants in this study did not discuss ADs with doctors or allied health professionals as indicated in Questions 4 and 5 (Tables 4.8 and 4.10). If this does not occur, then a gap remains in the awareness and translation of AD intention into knowledge for those expected to carry out healthcare for an individual. Neither the medium (online environment) nor the human information resource (family, friends, lawyers) may be sufficiently, practically or confidently able to assist HCPs with the decisions to be made at a time of crisis decision-making even if discussions with individuals under their care may have previously been done. This may explain the hesitancy of HCPs to act upon ADs if these documents are thrust upon them without previous context in a highly emotional and charged emergency care situation.

Utilising the medium to improve AD completions

Hammes, Rooney & Gundrum (2010) found that intensity of intervention was most likely to increase AD completion rates including oral information over multiple sessions to produce the greatest likelihood of AD completion. This level of engagement may be more practicable when the need to complete ADs arises. A number of participants in this study in open commentary suggested this was likely to be the case for them as they often recorded the fact that they needed reminders, were waiting for additional information, and would have liked conversations with others directly with regard to their own individual circumstances, possibly as a result of acting as a SDM for others.

In relation to Objective 7, participants in this study provided evidence of the way in which elements of knowledge translation facilitated their contemplation of ADs. They did this through open commentary with some participants acknowledging that a health or illness state for themselves or loved ones was the driver for their participation in the study. Volandes et al. (2009, 2012a and 2012b) showed that providing video representations of real life illness and wellness states of individuals with different diseases assists people to make informed and autonomous decisions about future healthcare while also assisting those who have been asked to act as SDM. However, as described previously, just making such visual representations available on publicly accessible websites such as YouTube may not hit the mark. Nevertheless, when participants in this study were asked on how the AD module could be improved, 12% requested examples of completed ADs (Question 24,

Figure 4.28), something to consider with regard to future Volandes-like productions.

The majority of the participants said that learning about ADs through the Internet was the most preferred option (80%, Q14A, Figure 4.21) with consistently high rates of preference for other online assistance, such as forms, training or online register. Interestingly, preferences for telephone or face-to-face consultation and provision of information on ADs were low, perhaps indicating the private nature of these documents and hesitancy to share such information or family attitudes with strangers.

Projects such as *The Conversation Project* (2014) provide guidelines on how to have conversations with family members on advance care planning. Participants in my trial showed some inclination to use websites and social media sites to further their understanding but the majority of websites that participants accessed during the course of the trial were more directly affiliated with government and legal entities. This reinforces the observation that wealth AD creation may be easier to understand and make decisions about than future healthcare ADs, even with a highly educated and digitally literate group such as the Baby Boomers.

Although participants in this study were digitally proficient, comments and answers to questions regarding the usefulness of the AD module in this study hinted at deficits in both health and digital literacy (Q21, Figure 4.27). For example, in open commentary a digital deficit emerged for some participants when they indicated they had not seen the AD module although the link was provided at the conclusion of the Post-survey. For those in the AD Groups the link was provided at the beginning of the survey and able to be accessed throughout the life of the study.

Nevertheless, over 60% of those who had accessed the AD Module said they would recommend it to family and/or friends suggesting that it provided sufficient information that was readily understood. Perhaps in future, asking about participant recommendations to others of useful websites for this topic would provide a measurement of transferability in relation to knowledge translation.

Knowledge Translation and stages of behaviour change in this study

In the National Framework for Advance Care Directives (AHMAC 2011) it was acknowledged that there was very little evidence on how many ADs are actually used for decision-making and what influences their use. Bowen, Martens and The Need to Know Team (2005) used community members to explore how knowledge

was translated into action in their Canadian Need to Know project. They learned that seeing the development of knowledge translate into action requires evaluation over a period of years and that academia may hinder researchers from conducting and seeing such evaluation through inexperience in networking, group building and facilitation of the use of the community to assist in such research projects.

Researchers may act as a conduit for community members to explore issues that government and other agencies are promoting (Bowen, Martens & The Need to Know Team 2005). The research conducted in this study and its results indicate that this is how the participants in this study viewed their participation and it was made easier through engagement using computer-based, interactive online methods leading to direct information sources at the time of need. Figure 4.30 (Q29) provides the best evidence yet to indicate how the Baby Boomer community in South Australia wants information on ADs. They prefer it through the Internet and overwhelmingly want direct access to online forms. Fortunately, the new SA ACD form and guidelines have been designed to meet this need.

Summary and implications

This randomised controlled trial has demonstrated that creating documents as complicated as ADs requires time, resources and an event that makes initiating document completion seen as beneficial rather than risky. It confirms that even with provision of information in an environment familiar to participants and that is regularly and easily accessible, completion of ADs remains subject to external factors that e-Health formats may not be able to compensate for. The fact that only 13 people out of 189 Baby Boomer participants completed any document over a period of approximately six months confirms that completing AD documents requires more than just ease and accessibility in this age group.

Nevertheless, as participants in this study have indicated, education provides a means for further exploration, discussion and decision-making on this subject. The fact that many participants in the study found information provided was useful hints that other factors may be more responsible for pushing contemplation into preparation and action.

What this study has added to the research in AD use is that Baby Boomers are comfortable seeking information and assistance through the online environment for AD information. It has also demonstrated that timely prompts and online educational

modules may assist those who already have an interest in completing an AD. Nevertheless, lack of time and other more personal factors may still undermine completion of these documents in a timely fashion in this age group. Continued online engagement over a number of years or at particular times in a person's life may afford better opportunities to complete ADs, including the provision of online forms.

There is an acceleration of effort in trying to use every mode of the online environment to assist AD information dissemination and completion as evidenced by a large number of websites dedicated to this idea (Butler et al. 2014). Although the online environment may be the key to enabling the consideration of timeliness in AD completion through mechanisms which allow the individual to access, store, change and share AD information, nevertheless this study has shown that online accessibility is not sufficient to change the stage of preparation for completion of ADs into a stage of action such that ADs are actually completed.

To eliminate the factor of age from AD completions and computer or Internet use, this study targeted a generation which has quickly become comfortable with and uses the online environment to access information on topics of interest to them. This study therefore provides useful and original information of this generation's health and digital literacy for health promotion messages in the e-Health environment.

By evaluating the effectiveness of both online interventions individually and combined through surveys and commentary in an RCT, this has not only shed light on the barriers and facilitators to AD completion but also the likelihood of the online environment to facilitate completion.

Results of this study suggest that to initiate preparation and action stages for AD completion online and offline for this generation, engagement will be required over a long period of time. This will require more careful consideration of what kind of online entities will be useful, the best social media mechanism to use for engagement, as well as resources for prompting and upgrading information appropriate to the individual at the time of need. Discussion of the evidence provided in this thesis for the effectiveness of the e-Health environment to assist AD completions in South Australia is provided in the chapter that follows.

CHAPTER 5 – DISCUSSION, IMPLICATIONS AND CONCLUSIONS

The objectives of this thesis were to demonstrate the current level of engagement by South Australians with ADs and the effectiveness of the online environment to assist this process. These objectives were met in three ways: firstly, a systematic review of the literature determined the effectiveness of previous computer-based, interactive online formats to enhance AD completion rates; secondly, a population-based survey determined the current levels of South Australian AD use, including a sub-analysis of one particular generation's (Baby Boomers) use of these documents; and, finally, a randomised controlled trial was developed and executed to test whether the two most effective means of computer-based, interactive online formats, as evidenced from the systematic review, could increase AD completion rates by SA Baby Boomers to the levels seen in the population-based survey or above.

What this thesis has provided is original and significant evidence of South Australians' intentions with regard to completion of ADs as well as demonstrating that there may be potential for a computer-based, interactive online educational AD module to assist or facilitate AD completion by Baby Boomers. In addition, email prompting, although not effective at enhancing completion rates, may provide a mechanism to keep the topic front of mind for the time when it is required to be acted upon.

These findings add to a very limited empirical evidence base of AD use across the general population and are the first to identify in the state of South Australia not only the use of individual documents but also factors influencing their use, such as online capability, age and preferred mechanism for access to knowledge about these documents. Theoretical positioning on any of these elements may be engaged in more depth in future research on these subjects.

Summary of key findings

The three studies identified that the South Australian population at large is more amenable to completing documents regarding future wealth distribution (e.g. Wills and Enduring Powers of Attorney) rather than future healthcare decision-making. However, this activity changes to include healthcare and lifestyle decision-making documents as people get older, with those over the age of 65 most likely to complete these documents on a population level. Yet, there is also now evidence

that those under the age of 65 in what is known as the Baby Boomer generation are becoming more engaged with these documents by seeking information or knowledge based on their experience with others as attested to by rates of assistance and discussions with others evidenced in Project 3 (RCT, Chapter 4). What is clear from the findings of Projects 2 (HOS, Chapter 3) and 3 (RCT, Chapter 4) is that those under the age of 45 are unlikely to complete any ADs.

Results from the studies in this thesis show that that the Pre-contemplation stage of ADs may begin at an earlier time point in the ageing trajectory than for previous generations as a result of experience with older or terminally ill loved ones. What is not yet clear based on the results of the studies in this thesis is whether this means that Baby Boomers will enter the contemplation, preparation and action stages to complete healthcare and lifestyle documents earlier than 65. Moving from the contemplation to action stage may be stalled by other factors such as time and work or other activities. These factors are outside the control of any process model that will dictate when these documents should be completed. In essence, the medium of AD information and creation is just the medium and acts as a facilitator not a mediator of AD completion.

Factors identified by participants in the randomised controlled trial which may facilitate more completions of ADs are messages in the social media, such as television advertisements, and messages linked to organ donation or estate planning. In both Projects 2 (HOS, Chapter 3) and 3 (RCT, Chapter 4), it was highly evident that people are more comfortable preparing financial documents such as Wills and after-death body disposal instruments such as Organ Donation Cards than any documents that have to do with the here and now. The predilection for completing Wills and Organ Donation Cards may be an opportunity to facilitate completion of documents that provide instructions for pre-death acute medical care. But how to take this contemplation stage into the action stage for people who are healthy and feel it is “not the right time” to complete ADs? In Project 3 (RCT, Chapter 4), the strongest indicators of what might assist this indicated that the medium, i.e. the e-Health environment, does have a role to play. Examples of who to choose as substitute decision-maker, how to complete documents, when to complete them and guidance on the role of the SDM were all nominated as preferences for more information. The fact that so many of the participants were comfortable and often use the online environment suggests that for knowledge translation through e-Health initiatives to be successful, it is important for people to

be able to access information that has a practical application and be able to see or read about the applicability to their own unique circumstances and choices.

All three projects in this thesis provided insight into barriers and facilitators for the use of computer-based, interactive online formats in a way that may be more suitable for those who are computer proficient. The most important lesson learned was that contemplation of these documents occurs earlier than anticipated but completion is contemplated over a long period of time until the time is right for the individual. E-Health can play a leading role in making sure the information on ADs is easily accessible during the contemplation stage, that the documents are available online at the preparation stage and that other factors critical to completion, such as choice of SDM, have online illustrations meaningful to a range of contexts which incorporate all levels of socioeconomic status. Table 5.1 illustrates these conclusions through the findings from all three projects.

Table 5.1: Key findings from each of the three Projects in this thesis

Chapter Number	Chapter Title	Key Findings	Description
Chapter 2	Systematic Literature Review on the effectiveness of computer-based, interactive online AD information to increase AD completion rates	Difficulty identifying online mechanisms	The studies investigated all used different types of online mechanisms.
		Online completion as process	Often the completion rates of ADs were measured as part of the process, not as part of the intervention.
		E-medical records	One of 2 most utilised means for measuring effectiveness of AD interventions but also as a means for prompting physicians to engage in discussions or complete ADs with patients.
		Computer-based interactive online websites	A number of different formats most of which also included additional information formats which obfuscated the link of completion rates to the online website.
		RCTs	Only one RCT which measured effectiveness of online intervention to induce higher rates of AD completions (Dexter 1998) showing that prompting through e-medical records to physicians could increase AD completion rates.
		Different populations, different mechanisms	E-medical record prompting may be better suited for in-hospital or other healthcare sites for prompting of healthcare professionals to complete ADs with patients while computer-based, interactive online websites may be better for general populations, although measurement of effectiveness of such sites is limited by poor research design.
		Evaluating effectiveness	For true assessment of the effectiveness of either e-medical records or computer-based, interactive online websites to facilitate AD completions, more rigorous and robust pre- and post- AD completion rates should be measured as directly linked to the electronic resource without additional materials to inform participants about ADs.
Chapter 3	Prevalence and preferred mechanisms of engagement with ADs and the online environment in South Australia	Overall and Baby Boomer use of ADs	Few differences except that Baby Boomers had higher rates of completion and assistance over younger aged groups across all documents and were nearly equal to those 65+ for completion and assistance. Financial instruments more often completed than healthcare documents.
		Older age predictive factor for completing ADs	Range of older age begins younger than 65 – more like 47+.

Chapter Number	Chapter Title	Key Findings	Description
		Sociodemographic influences – ADs	<p>Rarely difference between genders with completion use or interest in learning about ADs although females assist others more often than males.</p> <p>Metropolitan/Rural and Regional divide – more rural completed financial documents, more metro assisted others to complete documents.</p> <p>Those born in Australia/New Zealand much more likely to complete, assist and act for others with ADs over those born elsewhere.</p> <p>Marital status, education, occupation and income indicators for completion with those unmarried less likely to complete (except for widows in Overall population); those with less education less likely to complete; blue collar or those not working less likely to complete; lower income led to less completion of ADs.</p> <p>Positive sociodemographic characteristics associated with completion include: older age; being in a relationship; having education above Year 12; being in a white-collar profession; and having incomes above \$40,000 per year.</p>
		Sociodemographic influences – online	<p>Females prefer offline means for learning about ADs rather than online.</p> <p>Accessing Internet dependent upon higher levels of education, occupation, income and location. Those with less income, blue collar or unemployed, lower education levels were less likely to use online environment for completing.</p>
		Non-completion	<p>Large proportion of those over 67 still not completing documents. Those under 45 not completing documents.</p>
Chapter 4	Prompting Baby Boomers to complete ADs: Randomised controlled trial of electronic prompting or online information to actuate completion	Recruitment	<p>Relatively easy using online environment but complicated by research design factors including lay knowledge of ADs and lay expertise with computers.</p> <p>Expensive to recruit for general population and success minimal with regard to generalisation across Baby Boomer cohort.</p> <p>High interest in study but exclusion criteria eliminated a number of people who already had completed EPA.</p>
		Sociodemographic	<p>Largely mirrored Baby Boomer group in Project 2 with very few in both studies (6).</p>

Chapter Number	Chapter Title	Key Findings	Description
		Under-powered	Statistically significant effects could not be seen between the two interventions and Control with Post-survey results as the study was underpowered to see interaction effects. The study was underpowered due to time and logistical considerations which saw some people disqualified from analysis due to completing ADs after Consent but prior to receiving the Pre-survey – this was not predicted to happen. The power of the study was also affected by the length of time with many in the study suggested they needed more time to contemplate the ADs after receiving or not receiving information, therefore these factors should be considered when adopting any similarly-designed trials in future to ensure an adequate number of receipts of completed ADs such that robust statistical analysis can occur.
		Trends	Based on frequency analysis, trends seen indicated that those who received the AD education module were possibly more likely over Control or Prompt groups to complete some of the AD documents. Greater numbers of completions of Pre- and Post-surveys may have provided more generalisable results for the population that was studied. The study seemed to be a trigger for those in the process of preparation for acting on ADs to complete them. For others, however, curiosity about the documents or those who may have had experiences which necessitated consideration of them, the study was another prompt for consideration without necessitating taking action – this led to less completions in the Post-survey than predicted.
		Effectiveness of online interventions	Could not be conclusively assessed.
		Online barriers or facilitators	Those in Prompt group less likely to complete ADs and all 3 surveys. May be irritation of repeat surveys asking same questions – research design flaw. Those with AD module appeared to appreciate information provided but this did not necessarily lead to completion of documents.
		Other barriers and facilitators	From answers to questions assessing reasons for non-completion, factors external to the online environment held sway such as age, time, need and requirement for additional information.

Contribution of the studies to the literature on the effectiveness of the online environment to enhance completion rates of ADs

The studies showed that the use of the online environment for facilitating completion of ADs is reasonable for those generations who have more familiarity with computer and Internet use although it may have no more success in actuating completion than offline strategies. Online email prompting to a general population did not show the same levels of effectiveness as Dexter et al.'s (1998) study using e-medical records to prompt hospital-based physicians in discussing or completing ADs. This may be because population groups such as healthcare professionals working in a healthcare environment are required to comply with electronic prompts in this environment as part of professional and institutional regulations whereas the general population has no such obligation. Nevertheless, email prompting was a means for keeping the topic of AD completion at front of mind for participants in Project 3 and was a successful mechanism of use in other studies investigating online applications.

Provision of online information about ADs has expanded rapidly in a short time (Butler et al. 2014) and more recent studies on the effectiveness of this format to enhance advance care planning and AD creation suggest there is a basis for support in their use to disseminate knowledge on ADs. Although South Australian Baby Boomers indicated they were comfortable with computers and using the Internet for receiving information about ADs, this comfort in and of itself did not yield completion. Rather, the online environment enabled those who were ready to complete ADs access to the information and forms that enabled their completion.

This thesis confirmed that which previous studies in the United States and elsewhere have concluded: AD completion is complicated by factors external to the environment in which knowledge about them are conducted (Wilkinson et al. 2007). These factors influence the stage of behaviour change alluded to in the Transtheoretical Model – that is, time is required to contemplate the need for ADs with information-seeking occurring as part of the preparation to action stages leading to completion.

Contribution of population survey for determining the rates of AD completions, computer and Internet use in South Australia

Understanding South Australians' current level of comfort with use of computer-based, interactive online formats provides a platform for research and policy development promoting or exploring the effectiveness of this medium for

disseminating knowledge about or promotion of ADs. Projects 2 (HOS, Chapter 3) and 3 (RCT, Chapter 4) in this thesis confirmed that comfort and use of the online environment differed for different age groups. Those over the age of 65 were less comfortable with and used the computer and Internet less often while those under the age of 40 used these on a daily or weekly basis. The Baby Boomer generational group had high levels of comfort and use with both computers and the Internet but didn't use the variety of social networks commonly linked to dissemination of quick facts and updates, such as Twitter and YouTube. Understanding which format is most often used by different generational groups will assist in targeting information about ADs appropriately and successfully.

Contribution of studies to the measurement of effectiveness of computer-based, interactive online mediums to actuate AD completions

The combination of the first two studies informed the third study such that a more targeted population sample could be investigated with regard to use of computer-based, interactive online mechanisms to facilitate AD completions by South Australian Baby Boomers. Participants in the randomised controlled trial had similar characteristics of computer and Internet engagement to those in the HOS which allowed for a closer examination of the effect that the online environment could play in facilitating AD completion.

Results of the randomised controlled trial were not conclusive in determining the effectiveness of either or both computer-based, online interventions to facilitate ADs. Nevertheless, a number of factors about the effectiveness and use of the online environment by South Australian Baby Boomers were uncovered, such as rates of computer and Internet use, types of computer devices used, software used, and which particular online facilities would be most useful for gaining knowledge about ADs. Of particular interest was that 40% of participants indicated that having online forms to complete would be most useful for AD completions. Unfortunately, online forms were not an option for Project 3 (RCT, Chapter 4) due to the introduction of a new ACD form in South Australia at the time of the trial, this was a limitation of the trial. Including old forms online would not have been possible due to copyright and the new South Australian ACD form was not available in time. Possibly because of this, a very low rate of completion (<10%) was seen.

Influence of sociodemographic characteristics on AD completions and computer-based, interactive online use

Identified barriers to completion of ADs using computer-based, interactive online formats included sociodemographic characteristics such as age, location, education, occupation and income. These characteristics have been recorded before in the literature as being critical factors in the completion of ADs regardless of the medium used (Carr, Moreman and Boerner 2013; Carr 2012a, 2012b; Hammes et al. 2010). Those younger than 45, living in rural or regional areas, who are unmarried, with less education, working in blue collar occupations or not working at all, and with low incomes, are less likely to complete these documents, and this was confirmed by the general population in South Australia. As these characteristics include a substantial proportion of South Australians, it is highly likely that the percentage of people who complete ADs will remain low and comprise the married, more highly educated and wealthier people of this state.

Application of studies to theory generation on willingness of Baby Boomers to be autonomous decision-makers

Grounded theory requires an understanding of basic issues underlying a phenomenon and then testing the themes generated to gain a better understanding of how the phenomenon relates to practice (Glaser & Strauss 2008 (1967)). The theory underpinning this thesis is that Baby Boomers have more social contextual experience relevant to ADs than other generational groups; therefore they should be willing to complete these instruments more than any other generational group to preserve the personal autonomy that is a hallmark of this generation.

To test this theory, grounded theory requires using as many relevant groups as possible in the testing so that groups can be eliminated or disqualified based on the fact that they “don’t compare” whilst allowing for themes to emerge that may be transposable from one similar group to another (Glaser & Strauss 2008 (1967)). Controlling types of groups yields the generality of scope of population and conceptual level of theory (Glaser & Strauss 2008 (1967) pp. 51–52). Analysing the results from the Baby Boomer generation and those comprising the age group of 47–66 years in Project 2 (HOS, Chapter 3) provided the opportunity to study this age group’s similarities and differences from within two separate Baby Boomer cohorts.

When differences eventually minimise between comparative groups this yields a category which is verified (Glaser & Strauss 2008 (1967) pp 55–57). In the case of

the participants in these studies, the category of contemplation dominates for AD completion. The studies in this thesis have confirmed international, national and state research which has shown that AD completion rates remain low even amongst those who are inclined to think they are important, such as the Baby Boomers. The reason for this is not due to the medium of information exchange but rather to a stage of behaviour which for many is pre-contemplative in nature and may incorporate a range of beliefs, norms or attitudes that are contrary to AD completion.

The results in Project 3 indicated that Baby Boomers were prepared to shift into the action stage when reminded or had knowledge about ADs, though this action was demonstrated as a infrequent occurrence in Project 3 (RCT, Chapter 4). Participants in the randomised controlled trial indicated their intentions to complete by commenting that they had been thinking about ADs, needed more information, and were having discussions with family and friends about it with the intention to complete. Their intention to act may have occurred within a relatively short period of time after receipt of such information but as this was did not happen for the majority of participants, future research would benefit from a longitudinal study that more fully explores intent and completion.

What became most evident from Projects 2 (HOS, Chapter 3) and 3 (RCT, Chapter 4) was that people are more willing to complete Wills, Enduring Powers of Attorney and Organ Donation Cards but far fewer are willing to complete documents involved in future healthcare and lifestyle decision-making. This suggests that for the South Australian population some issues, such as wealth dissemination, may be more important to consider than others.

Yet, evidence from the projects in this thesis indicates that contemplation of ADs at a younger age may be due to other factors aside from financial or estate planning. Based on evidence provided in Project 3 (RCT, Chapter 4) regarding discussions about ADs and experiences with them, this research shows for the first time that assisting others to complete these documents may be a factor in shifting the emphasis from advance wealth decisions to advance health decisions. The effect of this thesis then is to have provided information about Baby Boomers who may have now reached a stage of accumulated experience, knowledge and ability for understanding the importance of ADs and how this knowledge and experience impacts on their willingness to complete them.

Implications

Implications for health consumers such as the Baby Boomers

Research in this thesis has focused on a discrete population, namely the Baby Boomer generation of South Australia, to ascertain their willingness towards and use of the online environment for actuating completion of ADs. The results provide preliminary evidence of Baby Boomer preferences for use of the online environment, preferred mechanism of online knowledge dissemination regarding AD completion, and stage of behaviour influencing their engagement with these documents.

Many of the barriers previously identified in the literature (Fagerlin and Schneider 2004) in relation to completion of ADs may not be specific to the Baby Boomers. This thesis does provide, however, for the first time in Australia empirical evidence of this generation's engagement with ADs, intentions, barriers and limitations in relation to their use of these documents. It also provides evidence of the type of computer-based, interactive online formats preferred by this generation such that information and reminders to complete ADs can be targeted to health consumers using specific resources and specific times; for example, birthday reminders through email. This research shows that this generation's familiarity with the online environment supports use of this medium for AD knowledge when needed and subsequent translation of this knowledge into action at the appropriate time.

The point in targeting research in this thesis on the Baby Boomer generation is due to anecdotal and empirical evidence (ABS 2012a) that this generation was due to them possibly experiencing the necessity of providing increasing levels of care to family members. Increased exposure to caring for others may enable this generational cohort to act as both SDMs and the disseminators of AD information to others (through both online and offline means). For themselves, acting as caregivers and SDMs may enable greater comfort and familiarity with these documents. With such experience, the Baby Boomers may be able to facilitate normalising the experience of AD use for multiple and future generations such that they become a regular part of future care planning. This could occur at a familiar time of need, such as at retirement or when they may be asked to become the SDM for others.

Substitute decision-makers may be poorly informed about the range of accountability and responsibility they have under different documents if they have not assisted in completing the ADs or experienced substitute decision-making before (Tilse, et al. 2014). Accessing timely information using the immediacy of the

online environment may assist at these times and Baby Boomers within this study indicated that the online environment may be able to assist them for this purpose.

If future research on use of these documents by this generation does not see an increase in use or acceptance, then it should be accepted that the majority of the population does not feel the need or the worth of these documents for future healthcare decision-making. And, if that is the case, then the ethical basis of personal autonomy for advance healthcare decision-making may need to be explored to determine if it is the primary basis upon which South Australians expect the provision of their present and future healthcare.

Implications for healthcare professionals

As with healthcare consumers, healthcare professionals will vary in their understanding of the type, need and time for AD completions. Results from Project 3 (RCT, Chapter 4) in this thesis provide evidence that the Baby Boomer population may not choose to discuss these documents with healthcare or allied health professionals, preferring instead to discuss them with family, friends or lawyers. This means that the provision of health information which may assist in informing AD directions may largely come from non-healthcare professionals. The influence of these other professionals and non-professionals in facilitating completion rates of ADs has not yet been measured in South Australia.

In addition, the actual presentation of ADs to HCPs may remain low such that many HCPs will rarely see the documents or have adequate practice in how to mediate, negotiate and inform healthcare consumers about the particulars of their use. Healthcare professionals may also experience the benefits and risks to use and implementation of these documents such that it affects their own consideration of these documents for themselves. Exploring how HCPs engage with those 65 years and older on AD completion and use may offer evidence for better opportunities and mechanisms to translate knowledge of these documents to the patients under their care such that individuals learn how the documents might apply to them and their unique situation. This would necessitate GPs being willing to engage with their older patients in the role of knowledge translation of ADs. Evidence from the literature (Ahluwalia et al. 2012; Coleman 2012) however suggests we still have a long way to go in this particular aspect. Nevertheless, in South Australia, there is considerable effort being undertaken in assisting GPs to better understand these documents and their potential application to their older clients (K. Williams, SA Health, personal communication, 29 July 2013).

For those healthcare professionals who engage with the public on ADs, technical skills and use of computer-based, interactive online systems may need to be enhanced to meet the expectations of more digital-literate people who seek online information or forms. With a large proportion of healthcare professionals aged over 50 in South Australia (ABS 2013), technical skills and use of computer-based, interactive online systems may also need to be enhanced. More digitally literate people may request that information be downloaded to their own devices, ask to view onscreen information with the healthcare professional at the same time, or be sent online forms to complete or store in safe and secure environments accessible to the healthcare professional and other interested parties. With the proliferation of websites providing a varied and diverse range of online information about ADs, the challenge will be for HCPs to recognise old and new ADs in South Australia as well as the documents that are legal in South Australia and other states and territories in Australia (AHMAC 2011; White et al. 2014) whilst operating in a dynamic technological environment (Butler, et al. 2014). These same HCPs will also need to improve their legal understanding of ADs to provide accurate information to those acting as SDMs for others at a time of crisis care.

Implications for services and organisations

For groups commissioning or creating websites or web pages on ADs, it is necessary to understand the health and digital literacy of the audience targeted. Unfortunately, this study was not able to assess the health literacy of the people in either the HOS (Project 2, Chapter 3) or RCT (Project 3, Chapter 4) due to time and cost constraints.

Nevertheless, this study found that completion of ADs was dependent on factors such as age, time of need and other external considerations such as location and marital status that may have impacted on health and digital literacy.

People may visit a particular website or webpage once for information but require its services again years later when a similar time of need arises. Maintaining such services so they become a familiar and regularly accessed and sustainable resource will assist people who may need a long time to contemplate completion of ADs until such time as they are ready to complete them. Lack of funding for maintenance of computer-based, interactive online mechanisms for dissemination of AD knowledge has seen a number of AD websites disappear prematurely (Klugman & Usatine 2012). This may engender distrust in the online environment for accessing knowledge or even storing completed ADs - an offering provided by newer websites

such as *MyDirectives*, (ADVault Inc. 2015). Unfortunately, these newer websites can be fee-based which will inhibit those from lower socioeconomic circumstances from participating with these websites.

Results from the projects in this thesis have also identified that it will be important for services and organisations seeking to promote or assist with AD information to understand their audience such that they provide appropriate levels of information for different audiences at different times. With age being a dominant factor in time of completing ADs, it is important to critically assess which age groups should be targeted, when, how and over what period of time. For example, it may be reasonable to suggest to young men and women playing competitive sport that they may wish to nominate a SDM in case of injury which leads to incapacitation for decision-making but, at the present, it is unlikely that such young people may formalise this decision with a completed AD.

Marital status has often been linked to completion of ADs, so marriage celebrants may wish to provide counselling in this area at the same time that marriage celebrations are being discussed. Organ donation may need to be more fully discussed with community groups after provision of online resources describing the parameters of organ donation. Financial and estate planning at the time of marriage or retirement may be an opportune time to discuss ADs, with a clear explanation that Wills are not ADs. What is clear from the studies in this thesis and the literature on this subject is that the creation of ADs requires complicated considerations of the availability of a SDM, time for discussions, and considerations of circumstances that can accurately be envisaged and discussed before ADs will be completed. For many, this involves private contemplation which the online environment may be able to assist with.

Implications for disciplines and professional bodies

The literature has shown that healthcare consumers may wait for their HCP to provide an opportunity to discuss ADs (Aitken 1999; Brown 2002; Booj et al. 2013; Ahluwalia et al. 2012). Healthcare professionals, mostly physicians, have argued that they do not have the time to engage in such lengthy and considered discussions (Coleman et al. 2012). One way to break this impasse is for HCPs to use the online environment to provide preliminary information on ADs such that repeat visits can answer any questions that may ensue.

Baby Boomers however seem not to be inclined to seek advice or assistance on

ADs from HCPs. Nevertheless, if healthcare professionals use Baby Boomer visits as opportunities to engage in AD discussions through online mechanisms with which they are familiar, this may provide the opportunity for the development of a trusting and sustained relationship which accepts and respects person-centred care needs.

It is interesting that so many people associate ADs with financial documents (Brown & Jarrad 2005; White et al. 2014). This means that law and finance disciplines may need to incorporate in-depth education on the requirements for AD completions of both healthcare and lifestyle documents. This may provide an opportunity for professional bodies encompassing law and healthcare to work together to provide requisite education and assistance both online and offline. The Legal Services Commission website in South Australia is an example of this combination. It hosts information on the new South Australian ACD form and will be monitoring access and use of the documents over time.

Implications for developers of online resources

Although there is a growing list of guides for online resource development (Tieman 2011), the evidence of effectiveness of the use of such material to develop online resources to assist in AD completion is minimal. Tieman and Bradley (2013) found that this may be a result of the type of method and evaluation undertaken when measuring the effectiveness of an online resource or as Klugman and Usatine (2012) found, it may be due to a lack of ongoing funding for evaluation at a suitable time. If resources are underfunded for evaluation over time (more than three years) then it is unlikely that measurement of effectiveness of online resources will produce more than preliminary or pilot study results.

It may be that only bodies which incorporate financial revenues of independent standing will be able to provide and sustain online resources on ADs for greater periods of time. There are several ways in which this can occur. Government bodies which create review periods with protected funding, such as has occurred with the SA Health new ACD process, provide the capacity for longitudinal assessment of the effectiveness of the website to enhance completions of ADs and at the same time measure the use of documents such as ADs. Within the commercial sector, monitoring of AD use may be effected through data collection systems within commercial websites which have a dedicated AD program. Both systems offer a means for more accurate measurement over time of how consumers may approach the use of ADs.

If entities engaged in the online provision of ADs do not continue the funding of websites or online resources, this could lead consumers to use cost-free resources for storage of completed ADs, such as free “cloud” services like Dropbox®. However, consumers who do so run the risk of losing documents if the service provider folds. Access to documents by others may also be restricted through password protection measures. Being able to evaluate the effectiveness of ADs will also be compromised by the use of such systems.

Confidentiality may also become an issue and the influence of this factor may have been hinted at in Project 2 (HOS, Chapter 3) when the rate of those comfortable with using the online environment for accessing information on ADs did not necessarily match the rate for the use of online mechanisms for engagement with ADs. Instead, participants in the HOS showed an equal preference for other means such as hard copy, face-to-face discussion or other forms of knowledge translation such that, it is presumed, contemplation about the use of these documents for the individual could be considered in private after engagement. This may mean that the online environment is useful for providing information or documents but not necessarily for lodgement. The issue of what happens with the form itself after completion highlights the most vexing issue with regard to AD use: a lack of direct access to completed ADs online by people who need to access them at the appropriate time, mostly SDMs and HCPs. This gap between online completion and storage/access may undermine confidence in the implementation and accessibility of these documents at a time of need.

Implications for health systems

Nationally, the Personally Controlled Electronic Health Record (PCEHR, Australian Government Health Direct 2015) provides the opportunity to engage in AD decision-making through naming a SDM but not the ability to upload a completed AD. In addition, the P-CEHR is not connected to individual state or territory e-medical record systems. This means any AD lodged therefore will not be accessible at the locality of choice at the time of need. In South Australia, health systems, such as SA Health, are increasingly incorporating web-based and online resources to assist with promotion and provision of healthcare messages. This is evidenced by the SA Health Advance Care Directive website (SAGDOH, 2015b) which has partnered with the Legal Services Commission of SA (2015) to provide web-site based information on the new SA ACD form.

The South Australian state-based e-medical record system called E-Pas (Enterprise

Patient Administration System) (SAGDOH 2015c) is in its infancy however and there is no direct lodgement facility from the completion of the online form within the advance care directives websites to E-Pas. This may mean that as Tieman (2013) found, “given the diversity in users of health information, simple solutions are unlikely to lead to universal access”.

The plethora of hardware and online platforms as evidenced by the many social media platforms (Anderson 2012) may seem like a paradise of choice for dissemination of healthcare information; however, Baby Boomers in this study preferred to use older platforms like email for communication on ADs. Results of Project 3 (RCT, Chapter 4) indicated that the AD module designed for the study met the needs of participants interested in learning more about ADs but fell short by not providing a form that could be completed.

Consideration of which platforms are better for provision of complicated information such as ADs led SA Health to create a video representation to assist those with lower health literacy in understanding the essence of these documents. At the time of completion of this thesis, this video had been removed. Whether these simpler formats are preferred or accessed by those with lower or higher education levels has not been assessed but will be important to know for future evaluation and upgrades of information.

Implications for CareSearch

As CareSearch is a nationally funded palliative care knowledge network conducted in the online environment, the results from this thesis provide a deeper understanding of the intention of HCPs, consumers and researchers interested in ADs to use the online environment to meet their information needs. CareSearch is in a unique situation to be able to use this information to improve not only dissemination about ADs but also to assess the best technological formats for proffering such information using empirically-based evidence. Evidence of this nature has been demonstrated in this project through the use of the expertise of CareSearch personnel and its Research Data Management System to not only house the AD Module involved in this study but also to manage the data from Project 3 (RCT, Chapter 4) in a rigorous and methodical fashion. This enabled monitoring and evaluation of information asked for by participants in this project through a nationally subsidised resource.

The provision of the CareSearch scholarship for this PhD enabled the delivery of an

iterative process for both me and CareSearch to answer questions associated with how best to use the online environment for dissemination of palliative care information, such as ADs. The PhD scholarship also enabled thorough and timely research to build the knowledge base on use and engagement with ADs for the Australian consumer.

As Baby Boomer participants in Project 3 (RCT, Chapter 4) indicated, often they are considering ADs in relation to someone else, i.e. the need for an elderly relative or friend to complete the document for residential aged care placement or hospital admission. The person they are assisting may not yet be receiving palliative care. Yet Baby Boomers in Project 3 (RCT, Chapter 4) still found the CareSearch website helpful when exploring online for more information on ADs while engaged in the study. Therefore, extending the remit and reach of CareSearch to those beyond palliative care could facilitate wider dissemination of AD information and reduce the current confusion associated with multiple documents across the country.

Implications for researchers

There are many opportunities and issues associated with research using the online environment for such a complicated topic such as ADs; recruitment, ethics, access, provision of testable materials, assessment of the effectiveness of advance care planning, ADs and online platforms for different generational groups. Early research in the field of AD use found that videos of particular elements of healthcare decision-making (now called decision aids) could assist with imparting a practical reality to the instructions suitable for an AD (Vollandes et al. 2007–2012a and 2012b). Additional research showed that the use of the electronic medical record to prompt AD completion could assist HCPs in having conversations with their patients on this topic (Murphy et al. 1997, Dexter et al. 1998).

However, there were few studies that investigated the behaviour of different generational groups in relation to the utility of ADs and the use of the online environment to assist with this topic. Generational context may be important for a number of reasons. The first is that different generational perspectives on death or dying are occurring as longevity distorts the norms from previous generations and times. In addition, perceptions of death may be distorted by the limited contact we now have with death, where death occurs and the way that people die in a medically advanced society.

In tandem with these generational changes are technological changes that are

creating ethical and existential considerations (Pope 2013; Stewart 2005) .

Therefore, continuing research on the impact of forward planning decision-making about healthcare and lifestyle in a non-conflict country will enhance investigation of the prime motivators for discussion of and completion of ADs and how much these documents will actually be used either by healthcare consumers, HCPs or both. What these motivators could be might include some of the issues pertinent to sociodemographic factors as evidenced in Projects 2 (HOS, Chapter 3) and 3 (RCT, Chapter 4) such as marital status, income, occupation or other factors not yet experienced, e.g. changes in government or healthcare policy. Without such research, health policy in this area continues to be practised in a vacuum regarding known outcomes or goals.

To date there have been few randomised controlled trials of interventions on general populations to increase the use of ADs in Australia, yet RCTs remain the highest level of evidence on which to determine the effectiveness of different types of interventions (National Health and Medical Research Council, 2005). Creating more and better opportunities to trial different online formats to different generational groups for AD dissemination and completion will require strategic planning, funding and cooperation over a long period of time as healthcare consumers absorb the AD message and prepare for any actions they wish to take in this area. Randomised controlled trials also need homogenous and rigorous methodological approaches for statistically significant results such that empirical evidence is clear and consistent. Such results may encourage the development of more facile and accessible online modes of AD information at a time and place of a person's choosing, as participants in Project 3 (RCT, Chapter 4) requested.

Based on what has been found in this set of studies, further research in the area of computer-based, interactive online dissemination and use of ADs, particularly for the Baby Boomer generation, relating to the following areas could assist our understanding of the relevancy of these documents over time for this and other generational groups.

1. Research on the usage patterns of various online websites incorporating not only page views and utilisation metrics but also the availability to provide open commentary feedback on the usefulness of the information being proffered, gaps in information being proffered and other indicators of need. It is not enough to provide static information for particular groups of people with particular illness states if the emphasis is to have the general population complete ADs for any

time of incapacitation event. The emphasis placed in the past on ADs being applicable at end of life has meant that the wider application of these instruments to times of incapacity during medical crises at any age has been lost.

2. Research into the motivation for seeking information on ADs could help determine what information should be provided when for different categories of assistance as also suggested by Butler et al. (2014). For example, Baby Boomers currently engaged with care provision for older relatives may focus on the use of these documents for their relatives without associating the documents for use by themselves as well. Only after the experience with the relative has created new knowledge for the Baby Boomer may the Baby Boomer consider creating ADs for themselves. Assisting Baby Boomers to recognise the applicability of these documents to themselves while still healthy and well could alleviate the distress caused by substitute decision-making for their children or other nominated substitute decision-makers, with discussions beginning early and often.

Conversely, if the experience with ADs is negative because HCPs do not abide by the documents or there is conflict, then people may not perceive the value in these documents for future healthcare decision-making (Wendler and Rid, 2011; Khodyakov and Carr 2009). It will be important for policy makers to understand the motivations occurring over time to ascertain the negative and positive external factors influencing decision-making and the likelihood of this impacting on AD creation. Future research should explore whether those who have chosen to complete ADs have done so as a result of witnessing poor outcomes of those with and without ADs at the time of need.

3. Research is needed into how to better provide information on ADs for those in socioeconomic groups which are disadvantaged by marital status, education level, occupation, location or income. Many people may be without access to computers or the online environment and miss out on important information about ADs if the information is only made available through online means. In addition, many people may not have anyone to appoint as SDM due to fragmented family dynamics or sufficient opportunity to discuss with friends, family, healthcare professionals or others their perceived future needs. Without potential surrogates and opportunities to discuss healthcare needs in advance, ADs may continue to suffer from poor uptake and may be seen as irrelevant regardless of the means for accessing them.

For example, Fagerlin, et.al, (2004) and Lynn, et.al, (1993) argued that instructional ADs, such as those in the US, failed to promote personal autonomy for a number of reasons including; cultural inhibitions, hesitation to face one's own mortality, and not understanding enough about disease or illness to nominate preferred medical treatments. Therefore, they argued, persistence in advocating the use of ADs should cease (Fagerlin, et.al, 2004; Lynn, et.al, 1993). Nevertheless, there has continued to be widespread support politically and philosophically for people to be able to appoint and instruct SDMs through the use of ADs to preserve at least some element of self-determination in healthcare and welfare management (Detering, et.al, 2010; Clements, 2009).

To assist those at the end of life, new forms of ADs such as the POLST (Physician Orders for Life-Sustaining Treatment) and MOLST (Medical Orders for Life-Sustaining Treatment) in the US have sought to provide clarification for HCPs as to the clinical care to be provided when people choose Life-sustaining or Life-limiting treatments although these forms are not a replacement for an AD (Miljkovic, Jones & Miller 2013). Rather, these forms act as a corollary to provide clinical care consistent with the aims of the AD and it is felt that by doing so, more consistent action in the hospital or residential aged care environment reflecting the contents of an AD can occur. The success of these other forms is not yet substantially clear although their uptake is increasing in the US in institutions and hospitals where many end their lives. Recent research by Zive et al. (2015) and Tuck et al. (2015) indicate that POLST forms may improve EOL care especially closer to the terminal event. However, these forms are not widely used in Australia which has sought more to keep the decision-making at the level of the individual rather than the clinical treating team. Should the evidence for POLST and MOLST indicate that these forms enable better commitment and care relevant to the AD itself perhaps then these documents will find a place within the legalistic hierarchy of ADs in Australia but until then efforts in Australia emphasise discussion and conversations between relevant individuals with what will be expected for end of life care.

For example, in Australia the increase in use of ADs has largely been through the efforts of programs like Respecting Patient Choices® (RPC) (Austin Health, 2006). These programs encourage HCPs to assist those with terminal illness or entering residential aged care facilities to complete ADs and ACP (RPC, 2008; Altmore, et.al, 2007; Austin Health, 2006) with an emphasis on family and significant others' discussions with advance care planning. This program incorporates clinical care plans consistent with the treatment decision-making of the patient and family.

4. The Baby Boomer generation is likely to suffer with chronic illness for a much longer period of time than the healthcare community is used to (Hugo 2013b), necessitating repeat instances of AD use for temporary periods of incapacity. There is no research on the effectiveness of ADs from the AD-maker's perspective as to whether these documents perform in the manner intended. Such research is required to provide evidence of the effectiveness of these documents to assist those with chronic illness as well as terminal illness.
5. Inadequate access to information or forms through offline means will disadvantage a large number of people in the population who are increasingly ageing and may require AD information. The fact that SA Health has recognised this early in the creation of the new ACD form by enabling minimal cost purchase of hard copy ACDs means that future research can assess whether and for how long offline means of engagement with ACDs is required.
6. More targeted research on how HCPs seek information on ADs via the online environment would assist in generating more direct links to information relevant for them. CareSearch has begun this process with its My Information Kit series designed to allow healthcare professionals to download fact sheets which meet particular client needs. Baby Boomers in the studies in this thesis commented that information on ADs was complicated and would be easier to understand if broken down further. Researching whether client-directed information provides better comprehension of information will enable better resource and more cost-effective resource management.
7. More detailed understanding of the impact of changing social values and roles would assist in understanding whether the application of ADs in an Australian context fits the standards of community values in Australia. The need for ADs first arose in the United States (Kutner 1967 cited in Hong and Lee 1996) which has different ideological standards than those of Australians and also operates healthcare systems under different models. Research that can determine whether the Australian healthcare model precludes the need for ADs or other forms such as POLST and MOLST would assist in understanding whether ADs are practicable for the Australian population.
8. More detailed assessment of the preferred mode of online advertisement about ADs, including the use of television, for creating awareness and timeliness of ADs would provide information about the way people engage with the advertisement process. Information from Project 3 in this thesis suggests that traditional methods of advertisement such as newspapers, magazines and television still have a large effect in disseminating healthcare information for

particular sociodemographic groups, such as those without access to computers or Internet, those who are older, and those who prefer offline means of obtaining news.

The use of mobile phones and tablets in Australia and the pushing for use of these devices for information retrieval and dissemination of healthcare information through the use of “apps” is gaining momentum as Butler et al. (2014) demonstrated in their review. Evidence of the effectiveness of these newer hardware and software methodologies is minimal. Newer technological advances such as Google Glasses and Google or Apple watches may also impact on the delivery of information both in form and function.

9. Further research into the function and applicability of family and friends for discussions on ADs would be helpful. In particular, continued research should be conducted on the barriers and facilitators for these discussions and whether online platforms can assist through the provision of immediate access to information for discussion should be done.

In the commentary provided in the randomised controlled trial in this thesis, reasons given by participants for seeking information on ADs included illness or family dysfunction. Family dysfunction may indicate incidences of elder abuse such that ADs take on a different role than just self-determined future healthcare and lifestyle decision-making. The use of ADs may act as a deterrent to family members seeking to abuse elderly friends or relatives. More research of this link could uncover ways in which ADs may be used which have not previously been anticipated.

10. Research is also required into the suitability and utility of new e-medical record systems both in South Australia and nationally for linking completed ADs to healthcare professional use at the appropriate time and need. Without such research, evaluation of AD use will continue to be subjected to obfuscations of AD use based on technological considerations rather than intention to implement from the healthcare professional point of view. If consumers do not believe their ADs will be accessible in the online environment at the time of need, they may rightly ask what the point is in completing them. Discussions with family members or others may suffice for the individual but not for the healthcare team at the time of crisis implementation.
11. Longitudinal research is needed to understand when behaviour changes from contemplation of ADs to preparation and action. This requires long-term research funding such that more regular survey events can occur. Creating studies which involve consumers over a long period of time such as the

Australian Longitudinal Study on Women (Lee et al. 2005) not only allows consumers to participate in the research that most directly affects them, it also provides them with an opportunity to gain greater insight into societal activities that may be influencing their decision-making. Baby Boomers may be especially willing to engage in such research as participants in Project 3 (RCT, Chapter 4) mentioned that just participating in the study and waiting to see the results influenced their ideas on ADs. Similar studies could, at the same time, monitor the influence of technology in this area.

12. Finally, grounded theory is a process which involves multiple cycles of testing before middle-range social theory explaining a phenomenon can be developed. The studies in this thesis have reinforced the hypothesis that without experience, knowledge, SDMs, and timeliness, ADs are likely to go uncompleted. To better understand the biopsychosocial forces most responsible for non-completion, the next stage of testing the applicability of ADs to Baby Boomers using the online environment should focus on experience and knowledge, attitudes, beliefs, and social norms. Using the Theory of Planned Behaviour to assist in this type of research design and analysis could uncover the motivating factors for Baby Boomer use or non-use of ADs in the online environment and the circumstances dictating this action. Participants in the RCT (Project 3, Chapter 4) used this study and multiple online and offline resources to improve their knowledge of ADs but this did not increase completion rates to a rate of clinical effect. With the majority of participants in the HOS (Project 2, Chapter 3) and RCT (Project 3, Chapter 4) having never experienced substitute decision-making, it may be important to understand whether experience and assistance with others plays a more important role in consideration of these documents than any external mechanism of information provision or knowledge. When this is known then knowledge translation can be improved in this area such that knowledge of ADs can be more practicably targeted to individuals at the right time and in the right manner.

Such a research agenda would require sustained funding, careful ethical considerations, technically diverse and multidisciplinary project teams and the collaboration of researchers and policy makers with consumer healthcare groups.

Conclusions

This research has investigated the use of computer-based, interactive online environments to facilitate AD completions through the use of three theoretical perspectives; grounded theory, stages of behaviour change (TTM) and knowledge translation. It has also investigated a segment of the population, the Baby Boomers, with regard to interest in and use of ADs. By conducting the research projects in this thesis in the manner in which they were conducted, this research has been able to show some of the barriers and facilitators to AD completion in South Australia across different age groups. It has also been able to show the effectiveness of using the online environment to facilitate AD completions in these groups.

Moreover, the studies showed that regardless of the computer-based, interactive online mechanisms used to facilitate AD completion, factors external to the online environment carry far more weight for consideration of ADs than the online environment itself, such as age, time of need, knowledge, experience, comfort, and access to the online environment.

Continuous cycles of investigation over a long period of time can help build a better picture of the stages of behaviour change for a given population and create middle-range sociological theory to explain phenomena. Focusing on a particular generation such as the Baby Boomers, who have quickly developed digital proficiency even as they age, may provide a better understanding of not only the utility of ADs but also preferences for dissemination of AD instructions, such as discussions, online forms and lodgement with online facilities. Given the complexity of AD decision-making and a rapidly changing technological environment, a more targeted approach to exploring one segment of the population's use of these documents may provide better understanding of the likelihood for these documents finding a place in the psyche of Australians.

Finally, as a dual citizen of the United States and Australia, I wanted to know if the fiercely held views of personal autonomy, which exist in the United States and were responsible for the creation of ADs, were mirrored in the Australian attitude towards these documents. The results of my research have shown that although Australians are interested in ADs, this interest does not necessarily extend to engaging in autonomy in future healthcare decision-making through the creation of legal documents. The reasons for this hesitancy remain unclear especially considering that the conditions under which these documents might be considered, e.g.

providing aged care for elderly relatives and friends is accelerating. A corollary and next phase of research would explore whether the difference in the healthcare systems themselves between the United States and Australia influence AD decision-making and, if so, how and to what extent.

Death is inevitable but how we age and the choices we make in healthcare and lifestyle decision-making are less predictable and more complicated. Baby Boomers have been responsible for breaking the mould of so many social values – it remains to be seen whether they will break the mould when it comes to planning their future healthcare needs and end of life care. Will it be done their way, as instructed through an AD? Or will they bow and succumb to healthcare and familial pressures to conform to the preferences of others? What this thesis has proven is that the Australian public is not yet ready to declare their certainty about the not so simple act of the need for individual preferences for end of life care to be encapsulated in a legal document.

APPENDICES

Appendix 2.1: Search strategies for all databases searched

Medline (OvidSP) search strategy (1946 to February Week 2 2014)

1	Exp Advance Care Planning/OR Advance Directive Adherence/ OR advance* directive*.ti,ab. OR advance*care.ti,ab. OR living will*.ti,ab. OR Ulysses contract*.ti,ab. OR power of attorney.ti,ab OR health care prox*.ti,ab. OR power of guardianship.ti,ab. OR anticipatory direction.ti,ab. OR enduring guardian*.ti,ab. OR enduring power*.ti,ab.
2	Patient Education as Topic/OR exp educational technology/OR Intervention Studies/ OR Telemedicine/ OR exp Internet/ OR Remote Consultation/ OR exp Video Recording/ OR exp telecommunications/ OR exp Computer Communication NetwORks/ OR User-Computer Interface/ OR exp Computers/ OR Attitude to Computers/ OR Computer-Assisted Instruction/ OR Electronic Mail/ OR Medical Records Systems, Computerized/
3	1 AND 2
4	Limit 3 to English Language
5	Limit 4 to yr="1960 – 2013"

Note: '/'denotes a MeSH term (i.e. subject heading) search; '*' denotes truncation; the '.ti,ab.' suffix forces a search in the title and abstract fields of a citation. 'Exp' forces a search on all narrower subject headings below a heading in the MeSH hierarchy (e.g. social media/is a narrower heading of Internet/).

SCOPUS search strategy

1	(TITLE-ABS-KEY-AUTH("living will")) AND (electronic OR online) AND (LIMIT-TO(DOCTYPE, "ar") OR LIMIT-TO(DOCTYPE, "re")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUJAREA, "HEAL")) AND (LIMIT-TO(EXACTKEYWORD, "Living will") OR LIMIT-TO(EXACTKEYWORD, "Advance Directives"))
2	(TITLE-ABS-KEY-AUTH("living will*") OR TITLE-ABS-KEY-AUTH("advance*directive*") OR TITLE-ABS-KEY-AUTH("advance*care directive*")) AND (TITLE-ABS-KEY-AUTH("electronic")OR TITLE-ABS-KEY-

	AUTH("online") OR TITLE-ABS-KEY-AUTH("video")) AND (LIMIT-TO(DOCTYPE, "ar") OR LIMIT-TO(DOCTYPE,"re")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "SOCI") OR LIMIT-TO(SUBJAREA, "NURS") OR LIMIT-TO(SUBJAREA, "PSYC") OR LIMIT-TO(SUBJAREA, "HEAL"))
3	1 OR 2
4	Limit 3 to English Language
5	Limit 4 to 1987–2013

PsycINFO (OvidSP) search strategy (1806 to February Week 3 2014)

1	(Advance Directive/ OR advance* care directive*.ti,ab. OR living will*.ti,ab. OR Ulysses contract.ti,ab.)
2	(Internet/ OR Internet.mp OR exp Electronic Communication/ OR electronic.mp OR onine.ti,ab. OR intervention.mp. OR exp Intervention/ OR telemedicine.mp. OR telehealth.mp.)
3	1 AND 2
4	Limit 3 to English Language
5	Limit 4 to yr="1960 – 2013"

Note: '/' denotes a Thesaurus subject term search; '*' denotes truncation; the '.ti,ab.' suffix forces a search in the title and abstract fields of a citation. The '.mp.' suffix forces a search in the title, abstract, heading word, table of contents, key concepts, original title, tests & measures fields of a citation. 'Exp' forces a search on all narrower subject headings below a heading in the Thesaurus hierarchy (e.g. Computer Mediated Communication/ is a narrower term of Electronic Communication/)

JBI search strategy (1998 to 19 February 2013)

1	("advance care" or "advanced care" or "advance directive*" or "advanced directive*" or "living will*" OR prox*).mp.
2	(electronic or web or Internet or online or "on line" or ehealth or "e health" or telehealth or telemedicine or video*).mp.
3	1 AND 2
4	Limit 3 to yr "1998–2013"

Note: '*' denotes truncation; the '.mp' suffix usually includes Title, Original Title, Abstract, and Subject Heading

Cochrane search strategy (to 12 January 2014)

1	"advance directive" or "advance care" or "living will" or "advance directives" or "living wills"
2	electronic or telehealth or online or "on line" or web or Internet or intervention or telemedicine
3	1 AND 2

PubMed search strategy (1946–2014)

The following PubMed search strategy is a sensitive strategy using both MeSH headings ([mh]) and natural language terms, or textwords ([tw]). It is designed to search across both the indexed part of PubMed and the non-indexed subset that includes very recently published studies not yet available in Medline, as well as citations from journals not included in Medline. The * symbol denotes truncation in PubMed.

```
(advanced directive*[tw] OR advance directive* [tw] OR advanced care directive*
[tw] OR advance care directive*[tw] OR living will* [tw] OR Ulysses contract* [tw] OR
"power of attorney" [tw] OR health care prox* [tw] OR "power of guardianship" [tw]
OR "anticipatory direction" [tw] OR Advance directives [mh] OR resuscitation orders
[mh] OR choice behaviour [mh])

AND

(patient education as topic [mh] OR intervention[tw] OR Electronic[tw] OR digital[tw]
OR digitised[tw] OR "on line"[tw] OR Internet[tw] OR web*[tw] OR computer*[tw] OR
video[tw] OR videotape*[tw] OR Telemedicine[mh] OR Internet[mh] OR remote
consultation[mh] OR videoconferencing[mh] OR computers, handheld[mh] OR
cellular phone[mh] OR telecommunications[mh] OR user-computer interface[mh] OR
Computer Communication Networks[mh] OR videotape recording[mh] OR computer
assisted instruction[mh] OR electronic mail[mh] OR webcasts as topic[mh] OR video
recording[mh] OR television[mh] OR Medical Records Systems, Computerized[mh])

AND

(clinical trial[PT] OR randomized controlled trial[PT] OR Interviews as topic[mh] OR
prospective studies[mh] OR questionnaires[mh] OR completion[tw] OR
evaluation*[tw] OR measurement[tw] OR follow-up AND English[la])
```

Date range was limited to 1960–2013

CINAHL search strategy (1982 – February 2012)

S13	S12 limited to – English Language
S12	S4 AND S11
S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10
S10	(MH "Online Services") OR (MH "Online Systems+") OR "online"
S9	(MH "Videorecording+") OR (MH "Digital Versatile Disc") OR (MH "Audiovisuals+") OR (MH "Videoconferencing") OR "video"
S8	(MH "Website Development") OR (MH "World Wide Web+") OR (MH "Web Browsers") OR (MH "World Wide Web Applications+") OR (MH "Blogs") OR (MH "Knowbots") OR (MH "Social Media") OR "web"
S7	(MH "Internet+") OR "Internet"
S6	(MH "Telehealth+") OR "telehealth"
S5	"electronic" OR (MH "Computerized Patient Record"
S4	S1 OR S2 OR S3
S3	(MH "Durable Power of Attorney") OR (MH "Guardianship, Legal") OR "power of guardianship"
S2	(MH "Advance Directives+") OR "advance directive"
S1	(MH "Living Wills") OR "living will"

Note: MH=subject heading; *denotes truncation.

Ageline search strategy (1978 to 2013)

S6	S4 and S5
S5	S1 OR S2 OR S3
S4	electronic OR web* OR Internet OR video*
S3	proxy or proxies

S2	advance directive*
S1	living will*

Informit search strategy (in Health and Law, to 2013)

("advance directive") OR ("living will") OR ("advance care") OR ("advanced directive") OR ("advanced care")

Appendix 2.2: Data extraction form for SR*

*modified from Tieman and Bradley, 2013 "Systematic review of the types of methods and approaches used to assess the effectiveness of healthcare information websites." Australian Journal of Primary Health 19: 319–324.

Record No:	
Authors:	
Citation details:	
Abstract :	
Name of online resource reviewed:	
Website address of online resource reviewed:	
Websites and search engines used for study:	
Healthcare Content Area of Website:	
Intended audience:	
Year study conducted:	
Description of Evaluation (what did they do?):	
Evaluation Type (see Appendix 1 guidelines):	
Focus of Website Measurement:	
Data Collection Method:	
Effectiveness /Outcome Measures :	
Statistical Analysis:	
Stage of Development (see Note 1 guidelines):	
Category of evaluation (see Note 2 guidelines):	
Completion Rates of ADs pre vs post intervention	
Comments:	
Evaluation type	Description
Website group (Single topic)	Groups of websites identified by a stated process where the characteristics of the websites are compared and contrasted

	Websites share a content area (e.g. asthma, cancer)
Website Groups (Comparative between groups)	Groups of websites identified by a stated process where the characteristics of the website groups are compared and contrasted to another group (e.g. comparing the characteristics of cancer websites to those of asthma websites)
Website groups (Comparative over time)	Groups of websites identified by a stated process where the characteristics of the website groups are compared and contrasted over two or more time points (e.g. how cancer websites changed between 1990 and 2000)
Program evaluation	Assessment by funders, policy makers of the value of online websites
Economic assessment	Cost benefit analysis, economic analysis, cost pricing e.tc at the group level
Individual website	
Feasibility assessment	Formative evaluation identifying need, consideration of audience, items for inclusion etc.
Heuristic evaluation	Systematic inspection of a user interface design for usability by an expert
User testing	Feedback of the prototype website by intended users
Text content assessment	Includes readability assessment, literacy testing, text analysis
Content quality	Studies of the accuracy, currency and quality of the website content. Can include automated assessment
Visual/graphic quality	Studies looking at presentation of the website (e.g. inclusion of high quality pictures)
Metric analysis	Retrieval and analysis of site metrics such as visitor numbers, referrals
Search engine optimisation	Studies that assess the effectiveness of page tagging, search term analysis etc. that lead a user to the website
Visitor satisfaction surveys	Online/offline surveys of satisfaction with the resource
Knowledge transfer	Studies that assess that whether access and engagement with the website has led to an increase in knowledge or understanding by the web visitor

Behaviour change	Studies that assess whether visitor's health behaviours have changed due to engagement with a website (e.g. stopped smoking, anxiety reduced etc.)
Project evaluation	Assessment by funders, policy makers of the value of their website project
Economic assessment	Cost benefit analysis, economic analysis, cost pricing of an individual website

Note 1: At what stage of web/resource development does this evaluation look?

Pre-release of website

1. Concept analysis, needs assessment
2. Development phase
3. Release/Launch

Post-release of website

4. Post release effectiveness
5. Iterative enhancement
6. Redesign
7. Other, explain

Note 2 What does the study hope to assess?

1. Access, quality, accuracy and availability of resource – development to enable user friendliness, accessibility, etc. This work maximises the possible utility.
2. Use – markers of use, indicators of uptake, e.g. webmetrics
3. Usefulness – investigations into the consequences/impact of the resource on activity or individual (e.g. behaviour change, knowledge gain), e.g. pre- and post-testing for smoking cessation.

Appendix 2.3: Excluded articles and reasons: N=55

Key

E1 = not a research study (RCT, controlled trial, evaluation or meta-analysis)

E2 = not computer-based, interactive, online (excludes videos, CDs, DVDs if no interactive capacity)

E3 = does not deal with advance directives (any document referred to as an AD, e.g. Living Will)

E4 = does not mention completion rates

E5 = article unavailable or outside date parameters of systematic review

Author, Article Information	Reason (see Inclusion and Exclusion Criteria Key)
Barnato AE, Arnold RM. The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment decisions: A randomized simulation experiment. <i>Crit Care Med</i> 2013; 41 (7):1686–1691	E4
Barry MJ. Health Decision Aids to Facilitate Shared Decision Making in Office Practice. <i>Ann Intern Med</i> 2002; 136: 127–135.	E1
Beck A, Brown J, Boles M et al. Completion of advance directives by older health maintenance organization members: the role of attitudes and beliefs regarding life-sustaining treatment. <i>J Am Geriatr Soc</i> 2002; 50: 300–306.	E2
Betz Brown JB, Beck A, Boles M et al. Practical methods to increase use of advance medical directives. <i>J Gen Intern Med</i> 1999; 14(1): 21–26.	E2
Bose-Brill S, Pressler TR. (2012). "Commentary Opportunities for Innovation and Improvement in Advance Care Planning Using a Tethered Patient Portal in the Electronic Health Record." <i>J Prim Care Community Health</i> 2012; 3(4): 285–288.	E1
Bricker LJ, Lambing A, Markey C. Enhancing communication for end-of-life care: an electronic advance directive process. <i>J Palliat Med</i> 2003; 6(3): 511–519.	Inc/Discuss/Exclude – unclear how many new ADs were lodged based on process as people could lodge AD notes, scanned ADs or other documentation referring to ADs. AD completions were part of process not intervention. The article doesn't mention how many direct AD completions occurred as a result of using the AD Wizard (enables completion of AD document).

Author, Article Information	Reason (see Inclusion and Exclusion Criteria Key)
Caligtan C, Dykes P. Electronic health records and personal health records. <i>Semin Oncol Nurs</i> 2011; 27(3): 218–228.	E1
Clark D. (2002). Older adults living through and with their computers. <i>Comput Inform Nurs</i> 2002; 20(3): 117–124.	E3
Cohen-Mansfield J, Libin A, Lipson S. Differences in presenting advance directives in the chart, in the minimum data set, and through the staff's perceptions. <i>Gerontologist</i> 2003; 43(3): 302–308	E2
Cugliari AM, Sobal J, Miller T. Use of a videotape for educating patients about advance directives. <i>Am J Health Behav</i> 1999; 23: 105–114.	E2
Deep KS, Hunter A, Murphy K, et al. "It helps me see with my heart": How video informs patients' rationale for decisions about future care in advanced dementia. <i>Patient Educ Couns</i> 2010; 81: 229–234.	E4
Ditto PH, Hawkins NA. Advance directives and cancer decision making near the end of life. <i>Health Psychol</i> 2005; 24(4 (Supp)): S63–S70.	E2
Durbin CR. Healthcare decision-making in community-dwelling adults, PhD. Saint Louis, MO: University of Missouri-Saint Louis, 2007.	E2
Epstein AS, Volandes AE, Chen LY, et al. A Randomized Controlled Trial of a Cardiopulmonary Resuscitation Video in Advance Care Planning for Progressive Pancreas and Hepatobiliary Cancer Patients. <i>J Palliat Med</i> 2013; 16(6): 623–631.	E2
Fagerlin A, Ditto PH, Hawkins NA, et al. The use of advance directives in end-of-life decision making: Problems and possibilities. <i>Am Behav Sci</i> 2002; 46: 268–283.	E2
Finucane TE, Shumway JM, Powers RL, et al. Planning with elderly outpatients for contingencies of severe illness. <i>J Gen Intern Med</i> 1988; 3 (July/August): 322–325.	E2
Frosch DL, Kaplan RM, Felitti VJ, et al. A randomized controlled trial comparing Internet and video to facilitate patient education for men considering the Prostate Specific Antigen Test. <i>J Gen Intern Med</i> 2003; 18(October): 781–787.	E3
Green MJ, Levi BH. Development of an interactive computer program for advance care planning. <i>Health Expect</i> 2009; 12 (1): 60–69.	E4
Heffner JE, Barbieri C, Fracica P, et al. Communicating do-not-resuscitate orders with a computer-based system. <i>Arch Intern Med</i> 1998; 158(10): 1090–1095.	E2
Hickman RL, Lipson AR, Pinto MD, et al. Multimedia decision support intervention: A promising approach to enhance the intention to complete an advance directive among hospitalized adults. <i>J Am Assoc Nurse Pract</i> 2014; 26: 187–193.	Exclude – published outside of search criteria dates.

Author, Article Information	Reason (see Inclusion and Exclusion Criteria Key)
Ho VW, Thiel EC, Rubin HR, et al. The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS. <i>AIDS Care</i> 2000; 12(1): 97–108.	E2 – patients screened, completed self-administered Patient Satisfaction Questionnaire, viewed 17-minute educational video about ADs, THEN randomised to receive 2 different LW forms to review and complete in draft form at home. This was excluded as there was no direct computer-based, interactive online mechanism involved that was directly linked to the online mechanism as the intervention.
Jain N, Kahn MG. Using knowledge maintenance for preference assessment. <i>AMIA Annu Symp Proc</i> 1995; 263–269.	E3
Johnson-Greene D, Anderson CM, Adams KM, et al. The psychologist's role in assessing and facilitating patients' knowledge of advance directives in medical settings: A preliminary investigation. <i>J Clin Psychol Med Settings</i> 1996; 3: 103–113.	E4
Kohut A, Keeter S, Doherty C, et al. <i>More Americans Discussing and Planning End of Life Treatment</i> . Washington, DC: Pew Research Centre, 2006.	E2
Lam M. (2012). <i>Vital choices: Making advance care directives</i> . <i>Law Soc J</i> 2012; 50(5): 16–19.	E1
Levi BH, Green MJ. Too soon to give up: re-examining the value of advance directives. <i>Am J Bioeth</i> 2010; 10(4): 3–22.	E1
Levi BH, Heverley SR, Green MJ. Accuracy of a decision aid for advance care planning: simulated end-of-life decision making. <i>J Clin Ethics</i> 2011; 22(3): 223–238.	E4
Levi BH, Wilkes M, Der-Martirosian C, et al. An interactive exercise in advance care planning for medical students. <i>J Pall Med</i> 2013; 16(12): 1523–1527.	E4
Mamlin B, Gramelspacher G, Tierney WM. Do computer-stored advance directives affect inpatient resus orders? <i>J Gen Intern Med</i> 1996; 11(Supp 1): 135.	E4
McBride D. Patients are more likely to choose comfort care after watching video on end-of-life options. <i>ONS connect</i> 2010; 25(5): 15.	E1
McCann R, Chodosh J, Frankel R, et al. Advance care directives and end of life decisions: an educational module. <i>Gerontol Geriatr Educ</i> 1998; 18(3): 3–19.	E1
McConatha D, McConatha JT, Dermigny R, et al. The use of interactive computer services to enhance the quality of life for long-term care residents. <i>Gerontologist</i> 1994; 34(4): 553–556.	E3

Author, Article Information	Reason (see Inclusion and Exclusion Criteria Key)
Mercer ZB, Chiriboga D, Sweeney MA. Using computer technology with older adults: a pilot study on advanced directives. <i>Gerontol Geriatr Educ</i> 1997; 18(1): 61–76.	E2
Morgan MW, Deber RB, Llewellyn-Thomas HA, et al. (2000). Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease. <i>J Gen Intern Med</i> 2000; 15(October): 685–693.	E3
Murphy CP, Sweeney MA, Chiriboga D. An educational intervention for advance directives. <i>J Prof Nurs</i> 2000; 16(1): 21–30.	E4
Olszewski EA, Newgard CD, Zive D, et al. Validation of physician orders for life-sustaining treatment: electronic registry to guide emergency care. <i>J Am Geriatr Soc</i> 2012; 60(7): 1384–1386.	E4
Peto T, Srebnik D, Zick E, et al. Support Needed to Create Psychiatric Advance Directives. <i>Adm Policy Ment Health</i> 2004; 31(5): 409–419.	Exclude – AD completions had to be completed as part of the study and were inherent part of the process of the study, not of an online intervention.
Reinke LF, Griffith RG, Wolpin S, et al. Feasibility of a webinar for coaching patients with chronic obstructive pulmonary disease on end-of-life communication. <i>Am J Hosp Palliat Med</i> 2011; 28(3): 147–152.	Exclude – ADs were largely completed prior to the stud so difficult to assess impact of intervention.
Rocker G, Dodek P, Heyland DK, et al. Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: Insights from a multicentre study. <i>Can Respir J</i> 2008; 15(5): 249–254.	E2
Schubart JR, Levi BH, Camacho F, et al. Reliability of an interactive computer program for advance care planning. <i>J Palliat Med</i> 2012; 15(6): 637–642.	Exclude – ADS were largely completed prior to the study so difficult to assess impact of intervention. Largely about reliability rather than completions.
Sherman PS. Computer-assisted creation of psychiatric advance directives. <i>Community Ment Health J</i> 1998; 34(4): 351–362.	Exclude – study was about the model, not AD completion rates.
Siegert EA, Clipp EC, Mulhausen P, et al. Impact of advance directive videotape on patient comprehension and treatment preferences. <i>Arch Fam Med</i> 1996; 5(4): 207–212.	E4
Srebnik D, Appelbaum PS, Russo J. Assessing competence to complete psychiatric advance directives with the Competence Assessment Tool for Psychiatric Advance Directives. <i>Compr Psychiatry</i> 2004; 45(4): 239–245.	E4

Author, Article Information	Reason (see Inclusion and Exclusion Criteria Key)
Sulmasy DP, Marx ES A computerized system for entering orders to limit treatment: implementation and evaluation. J Clin Ethics 1997; 8(3): 258–263.	Exclude – no direct link to influence of online facility as all participants also received education over time. Online facility used for data collection more than actuating AD completions.
Terry M, Zweig S. Prevalence of advance directives and do-not-resuscitate orders in community nursing facilities. Arch Fam Med 1994; 3: 141–145.	E2
Tulsky JA, Arnold RM, Alexander SC, et al. Enhancing communication between oncologists and patients with a computer-based training program. Ann Intern Med 2011; 155: 593–601.	E3
van Uden-Kraan CF, Drossaert CHC, Taal E. Participation in online patient support groups endorses patients' empowerment. Patient Education & Counseling 2009; 74: 61–69.	E3
Volandes AE, Ariza M, Abbo ED. et al. Overcoming educational barriers for advance care planning in Latinos with video images. J Palliat Med 2008; 11(5): 700–706.	E4
Volandes AE, Barry MJ, Chang Y, et al. Improving decision making at the end of life with video images. Med Decis Making 2010; 30(1): 29–34.	E4
Volandes AE, Brandeis GH, Davis AD, et al. A Randomized Controlled Trial of a Goals-of-Care Video for Elderly Patients Admitted to Skilled Nursing Facilities. J Palliat Med 2012; 15(7): 805–811.	E4
Volandes AE, Lehmann LS, Cook F, et al. Using video images of dementia in advance care planning. Arch Intern Med 2007; 167(8): 828–833.	E4
Volandes AE, Levin TT, Slovin S, et al. Augmenting advance care planning in poor prognosis cancer with a video decision aid: a preintervention-postintervention study. Cancer 2012;118(17): 4331–4338	E4
Volandes AE, Paasche-Orlow MK, Barry MJ, et al. Video decision support tool for advance care planning in dementia: randomised controlled trial. BMJ 2009; 338: b2159.	E4
Wilson CJ, Newman J, Tapper S, et al. Multiple Locations of Advance Care Planning Documentation in an Electronic Health Record: Are They Easy to Find? J Palliat Med 2013; 16(9): 1089–1094.	E4
Yamada R, Galecki AT, Goold SD, et al. A multimedia intervention on cardiopulmonary resuscitation and advance directives. J Gen Intern Med 1999; 14(9): 559–563.	E4

Appendix 4.1: Recruitment flier

(see next page)

Would you be interested...

in participating in an online study about
Advance Directives?

An Advance Directive is:

- Enduring Power of Attorney (*for finances*)
- Enduring Power of Guardianship
(*for health and lifestyle issues*)
- Medical Power of Attorney (*for medical treatment*)
- Anticipatory Directive
(*for when you are at the end of your life*)
- Or anything like the above called by other names, like a “living will”

If you are interested, you will need to complete 4 online questionnaires over the course of 12 months. There is no travel or face-to-face meeting involved.

Questionnaires should take less than 30 minutes to complete and involve questions about knowledge and use of advance directives

Eligibility Criteria:

- You must be born between the years 1946-1965
- You must be able to comprehend written English well enough to answer the questionnaires
- You must not have already completed any of the above documents
- You must have access to a computer and the Internet and have a current email address
- You must be willing to participate and be contactable on that or another email address over the next 12 months
- You must be a South Australian resident as these documents apply in South Australia only

If you would like more information on the project or would like to volunteer to participate, please contact:

Sandra L Bradley
Palliative and Supportive Services, School of Medicine
Flinders University
Email: Sandra.bradley@flinders.edu.au

**This study has been approved by the Flinders University Social & Behavioural Research Ethics Committee 2013
Project No 6069**

Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au	Sandra.bradley@flinders.edu.au
--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Appendix 4.2: Website and email version of recruitment

I am undertaking research leading to the production of a thesis or other publications on the subject: **Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates.**

This project will investigate whether electronic formats of information dissemination encourage completion of advance directives by people in South Australia born 1946–1965 (known as the Baby Boomer generation). An advance directive is a legal document that expresses a person's healthcare or welfare wishes in advance in the event that mental capacity is lost sometime in the future. You might know these documents by other names such as Power of Attorney, Power of Guardianship, Medical Power of Attorney or something called a Living Will; Statement of Choices or Good Palliative Care Plan.

I am seeking volunteers to participate in this project who meet the following criteria:

- Born in any year between 1946–1965
- Understand written English
- Have a computer
- Have an email address
- Are willing to be available to answer three (3) online questionnaires over a period of 12 months
- Have not completed any of the following forms:
 - Power of Attorney
 - Power of Guardianship
 - Medical Power of Attorney
 - Anticipatory Direction/ Living Will/ Statement of Choices or other such document

It is anticipated that no more than 30 minutes on any one occasion would be required to complete the questionnaires. There will be no face-to-face meetings or need to travel.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

If you are interested in participating in this project, please contact the researcher, Sandra Bradley via email at this address: sandra.bradley@flinders.edu.au.

For email version, an additional line: "Please find attached an Information Sheet and Consent Form. Please return the Consent Form by printing, signing, scanning and uploading electronically back to my email address. If you have difficulties signing the Consent Form, please contact me".

Appendix 4.3: Information Sheet for Project 3

INFORMATION SHEET

Title: Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates

Investigator:

Ms Sandra L Bradley, Palliative and Supportive Services, School of Medicine

Flinders University, South Australia,

Ph: 08 7221 8224

Description of the study:

This project is part of a PhD thesis entitled: *Advance Directive use by South Australian Baby Boomers in the Online Environment*. The project described in this information sheet investigates ways in which the online environment may assist members of the Baby Boomer group in South Australia to engage with advance directives. This project is supported by Care Search in the Flinders University Palliative and Supportive Services department.

Purpose of the study:

This project aims to find out if advance directive use in the online environment:

- Assists Baby Boomers in gaining knowledge about advance directives
- Provides the means to help Baby Boomers to complete advance directives

What will I be asked to do?

You will be invited to complete up to four (4) questionnaires over a period of 12 months. These questionnaires will ask for your personal details such as age and gender; whether you have completed advance directive forms; and your computer use and familiarity with the online environment. These questionnaires will take approximately 30 minutes or less to complete. This information will be gathered through online questionnaires and resources. Answers to the questionnaires will be collected through a secure computer database with the information provided de-identified (this means none of your answers will be directly linked to you). The information will be stored as a computer file and then destroyed once the results have been finalised. Your participation in this research is strictly voluntary.

What benefit will I gain from being involved in this study?

The sharing of your choices and knowledge will improve the planning and delivery of future advance directive programs. We are very keen to deliver online advance directive services that are engaging, informative and suitable to the Baby Boomer demographic group.

Will I be identifiable by being involved in this study?

Your participation will only be identified through a unique identification number given to you. This number ensures that none of your personal details are linked to information you provide in the course of the study. Participants are assured that any information provided under this unique identification number will be treated in the strictest confidence; will not be linked to your name in any form accessible to anyone else and that no participant will be individually identifiable in the resulting thesis, report or other publications. The information provided in the conduct of this study will be stored on a password protected computer that only the Investigator (Ms Sandra Bradley) has access to.

Are there any risks or discomforts if I am involved?

The investigator anticipates few risks from your involvement in this study. However, should you have any concerns or questions,

you can contact free support services such as those listed below:

Office of the Public Advocate, South Australia

ABC Building, Level 7, 85 North East Road, Collinswood, SA 5081

New local numbers for our office are: Phone 8342 8200 Fax 8342 8250

Toll Free number for country callers: 1800 066 969

Web address: <http://www.opa.sa.gov.au/cgi-bin/wf.pl>

Legal Services Commission, South Australia

Adelaide Office

82-98 Wakefield Street, Adelaide, SA 5000

Postal Address:

GPO Box 1718, Adelaide SA 5001 DX 104

Telephone (08) 8463 3555, Fax (08) 8463 3599

LEGAL HELP LINE 1300 366 424

Telephone Advice Monday to Friday 9am-4.30pm

TTY Phone (08) 8463 3691

Web address: http://www.lsc.sa.gov.au/cb_pages/contact.php

How do I agree to participate?

Participation is voluntary. You can answer 'no comment' or refuse to answer any questions and you are free to withdraw from participation in completion of questionnaires at any time without effect or consequences. A Consent Form accompanies this information sheet. If you agree to participate please read and sign the form (download form, sign, scan after signing and then upload as Word or pdf document) and return via email to: sandra.bradley@flinders.edu.au.

How will I receive feedback?

Outcomes from the project will be published in peer-reviewed journals, at conferences and in a PhD thesis accessible online and in hard copy at Flinders University where you are welcome to access it at any time. You will also have the opportunity to request a summary of the results of the research. No individual data will be available for review or release from this study.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6069). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 4.4 Consent form for participation in Project 3



CONSENT FORM FOR PARTICIPATION IN RESEARCH

By Online Questionnaire

Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates
--

I

being over the age of 18 years hereby consent to participate as requested in the Information Sheet for the research project on *Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates*.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
4. I understand that:
 - I may not directly benefit from taking part in this research.
 - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
 - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature.....**Date**.....

I certify that the volunteer has been provided with an Information Sheet about the study and upon return of this consent form consider that she/he understands what is involved and freely consents to participation.

Researcher's name: Sandra L Bradley

Researcher's signature.....**Date**.....

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

Appendix 4.5: Permission to advertise for recruitment to Project 3

Australian Nursing and Midwifery Federation

PO Box 861

Regent Park, BC SA 5942

ATTN: Ms Elizabeth DaBars

School of Medicine

GPO Box 2100

Adelaide SA 5001

01 March 2013

Dear Ms Dabars

As per the Flinders University Social and Behavioural Sciences Ethic Committee application guidelines, I hereby request permission to use the ANMF website and In Touch magazine to recruit participants for the following research project as part of my PhD candidature:

Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates

I (Sandra L Bradley) am the primary investigator and will be supported by my three (3) supervisors: Professor Paddy Phillips, Associate Professor Jennifer Tieman and Associate Professor Richard Woodman. An Information Sheet and website request format are provided with this letter. Ethics approval to conduct the research is currently being sought within which this permission request is required.

If you consent to my use of the ANMF website and In Touch magazine as described in the attached, please sign and date this letter as indicated below:

Title and Name

Date

Thank you for your time and assistance with this request. When completed, please scan and email to sandra.bradley@flinders.edu.au. Should you have any concerns or queries, please don't hesitate to contact me on 08 7221 8224.

INFORMATION SHEET FOR PERMISSION REQUESTS

Title: Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates

Description of the study:

This study is part of a PhD project and is entitled: *Prompting South Australian Baby Boomers to Complete Advance Directives: Randomised Controlled Trial of Electronic Interventions to Increase Completion Rates.*

This project is supported by CareSearch palliative care knowledge network located in the Palliative and Supportive Services Division of the School of Medicine, Flinders University.

This project will investigate whether electronic formats of information dissemination encourage completion of advance directives by people in South Australia born 1946–1965 (known as the Baby Boomer generation). An advance directive is a legal document that expresses a person's healthcare or welfare wishes in advance in the event that mental capacity is lost sometime in the future. You might know these documents by other names such as Power of Attorney, Power of Guardianship, Medical Power of Attorney or something called a Living Will; Statement of Choices or Good Palliative Care Plan.

Purpose of the study:

This project aims to find out if:

- Electronic information on advance directives assists Baby Boomers to complete them
- What are the things that help/don't help Baby Boomers to complete advance directives in the online environment

What will participants be asked to do?

Participants will be invited to complete up to three (3) questionnaires over a period of 12 months. These questionnaires will ask about personal details such as age and gender and whether they have completed any of the advance directive forms.

Are there any risks or discomforts for participants?

There are no risks or discomforts involved in participating in this study.

Investigator:

Ms Sandra L Bradley, Caresearch palliative care knowledge network

Palliative and Supportive Services, School of Medicine, Flinders University, 08 7221 8224

Appendix 4.6: Advertisement in newspapers for recruitment for Project 3

Are you a Baby Boomer (b. 1946–1965)?

Haven't completed your advance directives yet?

Research Study – Volunteers needed

Study investigates usefulness for Baby Boomers of online information on advance directives.

An advance directive is a legal document that expresses a person's healthcare, financial or lifestyle wishes in advance in the event that mental capacity is lost sometime in the future.

Volunteers will be asked to complete up to 4 online surveys over 12 months.

No travel or face-to-face interviews.

Are you:

- a resident of South Australia
- born between 1946–1965
- contactable by email for the next 12 months
- and have not yet completed the following documents for yourself:

Enduring Power of Attorney

Enduring Power of Guardianship

Medical Power of Attorney

Anticipatory Direction

If you are, then this study is for you!

To register your name and contact details

email sandra.bradley@flinders.edu.au.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. CRICOS No. 00114A (Project no. 6069).

Mini – advert

Are you a Baby Boomer (b. 1946–1965)?

Haven't completed your advance directives yet?

Research Study – Volunteers needed – 4 online surveys over 12 months.

To register your name and contact details email sandra.bradley@flinders.edu.au.

Appendix 4.7: Pre-survey

ADVANCE DIRECTIVES
<p>Welcome to the Baby Boomer/Advance Directive Project</p> <p>In this survey you will be asked a series of questions which explore your current use of advance directives. An advance directive is a legally binding document that expresses a person's instructions for future finances, healthcare and lifestyle in the event that mental capacity is lost. There are currently 4 different advance directive documents in South Australia. You will be asked questions about your knowledge and use of these documents. This survey will also ask questions about some of your personal details to establish baseline characteristics of participants involved in this study. Thank you once again for your participation in this study and please don't hesitate to contact me on sandra.bradley@flinders.edu.au if you have any questions or concerns. Kind regards, Sandra Bradley</p>
<p>Participant UID</p>
<p>D1 Have you completed any of the following documents for yourself? <i>Please tick all answers that apply</i></p> <ol style="list-style-type: none">1 Enduring Power of Attorney (for finances)2 Power of Attorney (for finances)3 Enduring Power of Guardianship (for healthcare and lifestyle)4 Will (for after your death)5 Medical Power of Attorney (for medical treatment only)6 Anticipatory Direction7 Living Will8 Advance Care Plan9 Statement of Choices10 Life Values Statement11 Organ Donation Card12 Ulysses Agreement or Psychiatric Advance Directive13 Have not completed any of these types of instruments14 None of the above15 Prefer not to answer

16 Other – please describe

D2 If you have completed any of the documents listed in Question 2, did you seek assistance from any of the following to complete the document *Please tick all answers that apply*

- 1 Family member
- 2 Friend
- 3 Lawyer or Solicitor
- 4 Financial Planner
- 5 Justice of the Peace
- 6 Doctor or other Medical Specialist
- 7 Nurse
- 8 Allied Health Worker (such as physiotherapist, occupational therapist, podiatrist, speech pathologist or other)
- 9 Pharmacist
- 10 Personal Care Worker (or Assistant in Nursing)
- 11 Social Worker or Counsellor
- 12 Chaplain or Spiritual Guide
- 13 Complementary Therapist
- 14 Work Colleague
- 15 Website
- 16 Facebook or Social Network Friends
- 17 Did not seek assistance from anyone
- 18 None of the above
- 19 Prefer not to answer
- 20 Other – Please describe

D3 When you heard about this project, did you discuss your thoughts on advance directives with any of the following? *Please tick all answers that apply*

- 1 Family member
- 2 Friend
- 3 Lawyer or Solicitor
- 4 Financial Planner
- 5 Justice of the Peace
- 6 Doctor or other Medical Specialist
- 7 Nurse
- 8 Allied Health Worker (such as physiotherapist, occupational therapist, podiatrist, speech pathologist or other)
- 9 Pharmacist
- 10 Personal Care Worker (or Assistant in Nursing)
- 11 Social Worker or Counsellor
- 12 Chaplain or Spiritual Guide
- 13 Complementary Therapist
- 14 Work Colleague
- 15 Website
- 16 Facebook or Social Network Friends
- 17 Did not seek assistance from anyone
- 18 None of the above
- 19 Prefer not to answer
- 20 Other – Please describe

D4 Thinking about your family and friends, have you helped anyone complete any of the following documents? *Please tick all answers that apply*

- 1 Enduring Power of Attorney (for finances)
- 2 Power of Attorney (for finances)

- 3 Enduring Power of Guardianship (for healthcare and lifestyle)
- 4 Will (for after your death)
- 5 Medical Power of Attorney (for medical treatment only)
- 6 Anticipatory Direction
- 7 Living Will
- 8 Advance Care Plan
- 9 Statement of Choices
- 10 Life Values Statement
- 11 Organ Donation Card
- 12 Ulysses Agreement or Psychiatric Advance Directive
- 13 Have not helped anyone
- 14 None of the above
- 15 Prefer not to answer
- 16 Other – please

D5 Have you ever acted as the Substitute Decision-Maker (SDM) for someone using any of the following documents?

- 1 Yes – Enduring Power of Attorney
- 2 Yes – Power of Attorney
- 3 Yes – Enduring Power of Guardianship
- 4 Yes – Power of Attorney and Enduring Power of Guardianship
- 5 Yes – Enduring Power of Attorney and Enduring Power of Guardianship
- 6 Yes – Medical Power of Attorney
- 7 Yes – Enduring Power of Attorney and Medical Power of Attorney
- 8 Yes – Power of Attorney and Medical Power of Attorney
- 9 Yes – Enduring Power of Guardianship and Medical Power of Attorney
- 10 Yes – Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney
- 11 Yes – Enduring Power of Attorney, Medical Power of Attorney and Enduring Power of

Guardianship

- 12 Guardianship Order
- 13 Yes – Ulysses Agreement or Psychiatric Advance Directive
- 14 Not sure
- 15 No
- 16 Prefer not to answer
- 17 Other – Please describe

COMPUTER USE

This next section asks questions about your comfort with computers and use of the Internet.

D6 On a scale from 0% to 100%, how comfortable are you using a computer? *Please tick the one box that best describes your comfort level with using a computer*

0 10 20 30 40 50 60 70 80 90 100

D7 On a weekly basis, how often do you use your computer? *Please tick the one box that best describes your current weekly use of the computer at work, home or both*

Once a week or less Two to three times a week More than three times a week

D8 On a scale from 0% to 100%, how comfortable are you using the Internet? *Please tick the one box that best describes your comfort level with using the Internet*

0 10 20 30 40 50 60 70 80 90 100

D9 On a weekly basis, how often do you use the Internet for things like email, banking, online shopping, googling for information or any other activities? *Please tick the one box that best describes your current weekly use of the Internet either at work, home or both*

Once a week or less Two to three times a week More than three times a week

D10 Do you currently use any of the following social networks? *Please tick all answers that apply*

- 1 Facebook (or similar)
- 2 Twitter (or similar)
- 3 YouTube
- 4 Chat Rooms
- 5 Blogs
- 6 I use Email for social networking
- 7 I don't use online social networks
- 8 None of the above
- 9 Prefer not to answer
- 10 Other – Please describe

D11 Which of the following devices do you use on a daily or weekly basis? *Please tick all answers that apply*

- 1 Desktop Computer (PC or MAC)
- 2 Smartphone (iPhone or other)
- 3 Laptop or Notebook Computer
- 4 Tablet Device (iPad or other)
- 5 Kindle or other e-reader
- 6 Mobile Phone that is not a smartphone
- 7 None of the above
- 8 Prefer not to answer
- 9 Other – Please describe

D12 Which of the following software applications would you use on a regular basis for home use? *Please tick all answers that apply*

- 1 Word or similar word processing software
- 2 Excel or similar basic mathematical software
- 3 Publisher or other media software
- 4 Apps such as those found on iPhones, iPads, Android, etc.
- 5 Genealogy or Family History software
- 6 Online register for keeping documents
- 7 Education software for teaching or learning
- 8 Software for Professional Development
- 9 Skype
- 10 None of the above
- 11 Prefer not to answer
- 12 Other – Please describe

D13 Which of the following would you find helpful if you wanted to learn more about advance directives? *Please tick all answers that apply*

- 1 Information on the Internet
- 2 Online Advance directive forms
- 3 Online training on how to complete ADs
- 4 Online training on how and when to use an AD
- 5 Online register to put my ADs
- 6 Healthcare professionals online to answer questions about ADs
- 7 Telephone consultation
- 8 Prefer other ways to learn about ADs such as face-to-face
- 9 I am not interested in learning about ADs
- 10 None of the above
- 11 Prefer not to answer

12 Other – Please describe

DEMOGRAPHIC INFORMATION

This next section requires personal detail information. This information is required for assessing your answers against those made by others who may share similar characteristics. Please answer as many as you can but if you prefer not to answer please click the “Prefer not to answer” box.

D14 Gender Please tick only one box

- 1 Male
- 2 Female
- 3 Prefer not to answer

D15 Year you were born Please tick only one box

- 1 1946
- 2 1947
- 3 1948
- 4 1949
- 5 1950
- 6 1951
- 7 1952
- 8 1953
- 9 1954
- 10 1955
- 11 1956
- 12 1957
- 13 1958
- 14 1959
- 15 1960
- 16 1961

17 1962

18 1963

19 1964

20 1965

21 None of the above

22 Don't know

D16 Do you identify as an Aboriginal or Torres Strait Islander? Please tick only one box

1 Yes

2 No

3 Prefer not to answer

D17 What region of the world were you born in? Please tick only one box

1 Australia and New Zealand

2 UK and Ireland

3 Europe

4 Asia

5 Africa

6 North America

7 South America

8 Oceania (for example Vanuatu, Fiji, Philippines or other)

9 Prefer not to answer

10 Other – Please describe

D18 What is your marital status? Please tick only one box

1 Married

2 De Facto

3 Separated

4 Divorced

- 5 Widowed
- 6 Single
- 7 Prefer not to answer

D19 What is your current yearly household income *Please tick only one box*

- 1 \$180,001 or more
- 2 \$160,001 – \$180,000
- 3 \$140,001 – \$160,000
- 4 \$120,001 – \$140,000
- 5 \$100,001 – \$120,000
- 6 \$80,001 – \$100,000
- 7 \$60,001 – \$80,000
- 8 \$40,001 – \$60,000
- 9 \$20,001 – \$40,000
- 10 Under \$20,000
- 11 Prefer not to answer

D20 Which group best describes your current employment *Please tick only one box*

- 1 Farming or Other Agricultural Employment
- 2 Art or Media
- 3 Business, Human Resource or Marketing
- 4 Design, Engineering, Science or Transport
- 5 Teacher (primary or secondary)
- 6 Health Professional (all types)
- 7 Information Technologist (ICT, Software or Hardware, or Analysis)
- 8 Legal, Social or Welfare
- 9 Technician (any kind)
- 10 Trades (any kind)

- 11 Apprentice (any kind)
- 12 Community and Personal Service
- 13 Clerical and Administrative
- 14 Sales (any kind)
- 15 Machine Operator or Driver (any kind)
- 16 Labourer (any kind)
- 17 Academic
- 18 Sportsperson
- 19 Student (no employment)
- 20 Housewife
- 21 Carer (Paid or Unpaid)
- 22 Retired
- 23 Currently not employed
- 24 None of the above
- 25 Prefer not to answer
- 26 Other – Please describe

D21 In which part of South Australia do you currently live? *Please tick only one box*

- 1 Metropolitan Adelaide (Adelaide and surrounding suburbs)
- 2 Rural or Regional (Adelaide Hills, Barossa, Eyre Peninsula and Western South Australia, Far North, Fleurieu Peninsula and Kangaroo Island, Limestone Coast, Murray Mallee, Yorke Peninsula and Mid North)
- 3 Prefer not to answer
- 4 Other – Please describe

D22 Finally – can you please tell me how you learned about this study? *Please tick all answers that apply*

- 1 Flier posted on a noticeboard
- 2 Electronic newsletter
- 3 Email
- 4 Paper newsletter
- 5 Word of mouth
- 6 Friend
- 7 Family member
- 8 Work or School Colleague
- 9 Health Omnibus Survey
- 10 Newspaper
- 11 None of the above
- 12 Prefer not to answer
- 13 Other – Please describe

Appendix 4.8: Surveys sent as email prompts for completing ADs (same survey sent for each prompt occasion)

ADVANCE DIRECTIVES	
<p>This section will ask you for responses to questions about advance directives. An advance directive is a legally binding document that expresses a person's wishes or directions in advance in the event that mental capacity is lost in the future. There are currently different documents in South Australia to cover specific areas of decision making (Office of the Public Advocate of South Australia, 2011)</p>	
D1	<p>Have you completed any of the following forms for yourself since beginning this study? <i>Circle all of the ones you have done</i></p> <p>1 Power of Attorney (for finances)</p> <p>2 Power of Guardianship (for healthcare and welfare)</p> <p>3 Will (for after you have died)</p> <p>4 Medical Power of Attorney (for healthcare)</p> <p>5 "Living Will"</p> <ul style="list-style-type: none">a. Advance Care Planb. Statement of Choicesc. Good Palliative Care Pland. Life Values Statemente. Organ donation cardf. Other – please describe <p>6 None of the above</p> <p>7 Prefer not to answer</p>

D2 If you have completed any of the documents listed in Item 1, did you seek assistance from any of the following (circle all of the ones that assisted you):

- 1 Family member
- 2 Friend
- 3 Lawyer or Solicitor
- 4 Financial Planner
- 5 Doctor or any other Healthcare Professional (nurse, social worker, physiotherapist, occupational therapist)
- 6 Website with information on advance directives
- 7 Other (please specify: _____)
- 8 None of the above
- 9 Prefer not to answer

D3 Since participating in this study, have you discussed advance directives or the need to do them with (please circle all that apply)

- 1 Family member
- 2 Friend
- 3 GP or other medical practitioner
- 4 Nurse or other healthcare professional
- 5 Work colleague
- 6 Facebook or other Social Media Friends
- 7 Spiritual Counsellor (for example, Minister, Chaplain, Elder)
- 8 Social Worker
- 9 Prefer not to answer

D4 Thinking about your family and friends, have you helped someone learn about or complete any of the following forms since the commencement of this study? Circle all of the ones you have helped someone else with

- 1 Power of Attorney (for finances)
- 2 Power of Guardianship (for healthcare and welfare)
- 3 Will (for after you have died)
- 4 Medical Power of Attorney (for healthcare)
- 8 "Living Will"
 - a. Advance Care Plan
 - b. Statement of Choices
 - c. Good Palliative Care Plan
 - d. Life Values Statement
 - e. Organ donation card
 - f. Other – please describe
- 5 None of the above
- 6 Prefer not to answer

D5 Since the commencement of this study, have you acted as the power of attorney or guardianship for someone else?

- 1 Yes
- 2 No
- 3 Prefer not to answer

Thank you for providing your time to answer the questions in this survey. All of the information that you provide is important to the study and we hope you will continue with your participation until the end of the study. Should you have any queries or concerns with information requested, please do not hesitate to contact the researcher: Sandra Bradley by email at sandra.bradley@flinders.edu.au. A reply will be sent within two standard business days.

Should you require further information about advance directives, please access the Legal Services Commission and Office of the Public Advocate in South Australia either in person or via their websites at:

<http://www.lsc.sa.gov.au/> – Legal Services Commission

<http://www.opa.sa.gov.au/cgi-bin/wf.pl> – Office of the Public Advocate

Appendix 4.9: Post-survey Group A

ADVANCE DIRECTIVES	
Welcome to the Final Survey in the Baby Boomer/Advance Directive Project	
So we can identify any differences that occurred from the beginning of the study to its conclusion, in this final survey you will be asked a series of questions which again explore your use of advance directives. You will also be asked questions about your use of the online environment in assisting you with gaining more information about these documents and/or completing them.	
Participant UID	
D1	Have you completed any of the following documents for yourself? Please tick all answers that apply
	1 Enduring Power of Attorney (for finances)
	2 Power of Attorney (for finances)
	3 Enduring Power of Guardianship (for healthcare and lifestyle)
	4 Will (for after your death)
	5 Medical Power of Attorney (for medical treatment only)
	6 Anticipatory Direction
	7 Living Will
	8 Advance Care Plan
	9 Statement of Choices
	10 Life Values Statement
	11 Organ Donation Card
	12 Ulysses Agreement or Psychiatric Advance Directive
	13 Have not completed any of these types of instruments
	14 None of the above
	15 Prefer not to answer
	16 Other – please describe
D2	If you have not completed any of the documents described in Question 1 (researcher note: should have been Question 2), could you please explain why?

The choices below are examples of what previous respondents have identified – if none of these apply to you, please choose “Other-please describe” and explain what stopped you from completing them. Please tick all answers that apply.

- 1 Too Busy
- 2 Not the right time
- 3 Couldn't get the documents
- 4 Couldn't choose a substitute decision-maker
- 5 Didn't have anyone to discuss with
- 6 Couldn't find a witness
- 7 Couldn't understand the forms
- 8 Needed more information
- 9 Don't feel the need to complete them
- 10 Prefer the doctor to make decisions
- 11 Prefer the family to make decisions
- 12 Against my religious beliefs
- 13 Against my cultural beliefs
- 14 Prefer not to answer
- 15 Other – Please describe

D3 If you have completed any of the documents listed in Question 2, did you seek assistance from any of the following to complete the document *Please tick all answers that apply*

- 1 Family member
- 2 Friend
- 3 Lawyer or Solicitor
- 4 Financial Planner
- 5 Justice of the Peace
- 6 Doctor or other Medical Specialist
- 7 Nurse
- 8 Allied Health Worker (such as physiotherapist, occupational therapist, podiatrist, speech pathologist or other)
- 9 Pharmacist
- 10 Personal Care Worker (or Assistant in Nursing)
- 11 Social Worker or Counsellor
- 12 Chaplain or Spiritual Guide
- 13 Complementary Therapist
- 14 Work Colleague
- 15 Website
- 16 Facebook or Social Network Friends
- 17 Did not seek assistance from anyone
- 18 None of the above
- 19 Prefer not to answer
- 20 Other – Please describe

D4 Since participating in this project, have you discussed your thoughts on advance directives with any of the following? Please tick all answers that apply

- 1 Family member
- 2 Friend
- 3 Lawyer or Solicitor
- 4 Financial Planner
- 5 Justice of the Peace
- 6 Doctor or other Medical Specialist
- 7 Nurse
- 8 Allied Health Worker (such as physiotherapist, occupational therapist, podiatrist, speech pathologist or other)
- 9 Pharmacist
- 10 Personal Care Worker (or Assistant in Nursing)
- 11 Social Worker or Counsellor
- 12 Chaplain or Spiritual Guide
- 13 Complementary Therapist
- 14 Work Colleague
- 15 Facebook or Social Network Friends
- 16 Did not discuss with anyone
- 17 None of the above
- 18 Prefer not to answer
- 19 Other – Please describe

D5 Thinking about your family and friends, have you helped anyone to complete any of the following documents since your participation in this study? Please tick all answers that apply

- 1 Enduring Power of Attorney (for finances)
- 2 Power of Attorney (for finances)
- 3 Enduring Power of Guardianship (for healthcare and lifestyle)
- 4 Will (for after your death)
- 5 Medical Power of Attorney (for medical treatment only)
- 6 Anticipatory Direction
- 7 Living Will
- 8 Advance Care Plan
- 9 Statement of Choices
- 10 Life Values Statement
- 11 Organ Donation Card
- 12 Ulysses Agreement or Psychiatric Advance Directive
- 13 Have not helped anyone
- 14 None of the above
- 15 Prefer not to answer
- 16 Other – please

D6 Have you ever acted as the Substitute Decision-Maker (SDM) for someone using any of the following documents? Please tick all answers that apply

- 1 Yes – Enduring Power of Attorney
- 2 Yes – Power of Attorney
- 3 Yes – Enduring Power of Guardianship
- 4 Yes – Power of Attorney and Enduring Power of Guardianship

- 5 Yes – Enduring Power of Attorney and Enduring Power of Guardianship
- 6 Yes – Medical Power of Attorney
- 7 Yes – Enduring Power of Attorney and Medical Power of Attorney
- 8 Yes – Power of Attorney and Medical Power of Attorney
- 9 Yes – Enduring Power of Guardianship and Medical Power of Attorney
- 10 Yes – Power of Attorney, Enduring Power of Guardianship, Medical Power of Attorney
- 11 Yes – Enduring Power of Attorney, Medical Power of Attorney and Enduring Power of Guardianship
- 12 Guardianship Order
- 13 Yes – Ulysses Agreement or Psychiatric Advance Directive
- 14 Not sure
- 15 No
- 16 Prefer not to answer
- 17 Other – Please describe

D7 Would you act as a substitute decision-maker if someone asked you to?

- 1 Yes
- 2 No
- 3 Maybe
- 4 Depends on who asked
- 5 Prefer not to answer

D8 Since participating in this research study, which of the following did you find particularly helpful when you wanted to learn more about advance directives?

- 1 Information on the Internet
- 2 Online advance directive forms
- 3 Online training on how to complete ADs
- 4 Online training on how and when to use an AD
- 5 Online register to put my ADs
- 6 Apps
- 7 Healthcare professionals online to answer questions about ADs
- 8 Telephone consultation with knowledgeable professional
- 9 URL links to information from websites
- 10 Videos about ADs, e.g. YouTube
- 11 The surveys in this research study
- 12 Emails sent during the study prompted me to learn more about completing ADs
- 13 Prefer other ways to learn about ADs such as face-to-face
- 14 Discussions with family or friends
- 15 I am not interested in learning about ADs
- 16 None of the above
- 17 Prefer not to answer
- 18 Other – Please describe

D9 Since participating in this research study, which of the following did you find particularly helpful when you wanted to complete advance directives?

- 1 Information on the Internet
- 2 Online advance directive forms
- 3 Online training on how to complete ADs

- 4 Online training on how and when to use an AD
- 5 Online register to put my ADs
- 6 Healthcare professionals online to answer questions about ADs
- 7 Face-to-face discussion with knowledgeable professionals
- 8 Discussions with family or friends
- 9 Telephone consultation with knowledgeable professional
- 10 URL links to information from websites
- 11 Videos about ADs, e.g. YouTube
- 12 Emails sent during the study prompted me to learn more about completing ADs
- 13 I do not intend to complete any ADs
- 14 None of the above
- 15 Prefer not to answer
- 16 Other – Please describe

D10 Have any of the following devices assisted you to learn more about advance directives or to complete the documents? *Please tick all answers that apply*

- 1 Desktop Computer (PC or MAC)
- 2 Smartphone (iPhone or other)
- 3 Laptop or Notebook Computer
- 4 Tablet Device (iPad or other)
- 5 Kindle or other e-reader
- 6 Mobile Phone that is not a smartphone
- 7 Television
- 8 None of the above
- 9 Prefer not to answer
- 10 Other – Please describe

D11 Have any of the following software applications helped you to learn about advance directives? Please tick all answers that apply

- 1 Word or similar word processing software
- 2 Excel or similar basic mathematical software
- 3 Publisher or other media software
- 4 Apps such as those found on iPhones, iPads, Android, etc.
- 5 Genealogy or Family History software
- 6 Online register for keeping documents
- 7 Education software for teaching or learning
- 8 Software for Professional Development
- 9 Skype
- 10 CareSearch Website
- 11 Other Website
- 12 None of the above
- 13 Prefer not to answer
- 14 Other – Please describe

D12 If you currently use social networks and could get reminders to complete advance directives, which of the following networks would you prefer reminders be sent to?

- 1 Facebook (or similar)
- 2 Twitter (or similar)
- 3 SMS or text messaging
- 4 Email
- 5 Television Advertisement
- 6 Advertisement in cinema

- 7 Advertisement on websites
- 8 Don't want to be reminded
- 9 None of the above
- 10 Prefer not to answer
- 11 Other – Please describe

D13 If you wanted to be reminded to complete advance directives, when would it be the best time for a reminder to be sent to you? Please tick only one box

- 1 Your birthday
- 2 When your car registration is due
- 3 During a visit to your GP or local clinic
- 4 During a visit to the hospital
- 5 When getting or renewing a passport
- 6 When travelling overseas
- 7 When completing a Will
- 8 When visiting a financial planner or lawyer/solicitor
- 9 When completing an organ donation card
- 10 When completing an advance directive for someone else
- 11 On your 40th birthday
- 12 On your 50th birthday
- 13 On your 60th birthday
- 14 On your 70th birthday or older
- 15 Don't want reminders
- 16 Prefer not to answer
- 17 Other – Please describe

Ok – Final Section – general questions about the survey structure and design

D14 Did you find the online surveys (like the Pre-survey and this survey) easy to use? *Please tick only one box*

- 1 Yes
- 2 No
- 3 Sometimes
- 4 Not sure
- 5 Prefer not to answer

D15 If you did NOT find the online surveys (like the Pre-survey and this survey) easy to use, could you please describe in detail the difficulties you had with using these online surveys. The more detail you provide, the better future surveys can be made to meet the needs of other consumers such as yourself. *Please describe as clearly and in as much detail as possible*

D16 How do you think online information about advance directives could be improved? *Please tick all answers that apply*

- 1 Make terms clearer
- 2 Use language I understand
- 3 Give more examples
- 4 Provide better reasons for completing them
- 5 Have direct access to the forms
- 6 Provide information on how to have a conversation about advance directives
- 7 Provide guidelines for choosing a substitute decision-maker
- 8 Tell me who to go to when I can't find a substitute decision-maker
- 9 Tell me more specifically when I should do advance directives
- 10 More graphs, figures or illustrations to describe information
- 11 Show successful use of advance directives in different situations
- 12 Testimonials from healthcare professionals, families, carers and people who have created or used advance directives

13 Show famous people describing their experience with advance directives

14 Prefer not to answer

15 Other – Please describe

D17 Was there anything that you experienced during the course of this study that heightened your awareness of advance directives? If so, please explain what this was. Please also include the names of any websites you visited to learn more about advance directives.

D18 Would you agree that you now know more about advance directives? Please tick only one box

1 Yes

2 No

3 Maybe

4 Not sure

5 Don't Know

6 Prefer not to answer

D19 How likely are you to complete any advance directive document in the next three (3) months? Please tick only one box

Unlikely Maybe Very likely Am in the process of completing Have already completed documents

Am not interested in completing advance directives

D20 Are there any other comments you would like to make about this study, the surveys or advance directives in general? Please describe as clearly and in as much detail as possible

You have now concluded the study. Your time and participation in this research study has been greatly appreciated. You will be given the opportunity of viewing the results from this research when the PhD has been completed (this takes 6–9 months). If you would like a report of the results, please let me know by email at sandra.bradley@flinders.edu.au

I am also hoping to conduct future research in this area. If you would be prepared to be followed up in future years on your use of advance directives, please indicate by email that you would be happy to do this. I will add your name to the list of people who can be contacted. This list is kept by myself and no one

else will have knowledge or access to this list to assure your anonymity and confidentiality in relation to this study.

The links below go to an education module on advance directives in South Australia that was created for the study. Some participants have already received this information while others have not. This is your opportunity to access this module so that all participants have access to all information used in the study.

To access the education module click on one of the two links below.

Please use the Next buttons throughout to progress to each page. To conclude the module, please use the small "x" button in the lower right hand corner of the module.

For PC or laptop, please note that you may need to first download FlashPlayer of Adobe Acrobat to view the education module.

- If you are using an iPad, please click on this link
- If you are using a PC or laptop, please click on this link

If you have any difficulties viewing or understanding how to view the education module, please contact me at sandra.bradley@flinders.edu.au

Your access to the module will conclude when the study has been finalised (approximately September 2014) but until then you are able to access the module as often as you like provided you keep this email.

Thank you once more for your participation in this study.

Appendix 4.10 Example of Coding and Categories from Open Commentary Provided to Other Outcomes Questions (3-32)

Open Coding	Category	Themes
Want to, just haven't	Barriers to Completion	Need to get my act together
Can't walk		Having the Discussion
Forgot about it		
Cost, commitment		
Waiting for new form		
Complexity		
Gathering information		
Not aware of documents existence		
Trouble deciding on substitute decision-maker		

REFERENCES

- Abadir, P, Finucane, T & McNabney, M 2011, 'When doctors and daughters disagree: twenty-two days and two blinks of an eye', *Journal of the American Geriatrics Society*, vol. 59, no. 12, pp. 2337-40.
- ADVault Incorporated 2015, *MyDirectives*, viewed 30 April 2015, <https://mydirectives.com/>
- Adams, R, Appleton, S, Hill, C, Dodd, M, Findlay, C, & Wilson, D 2009, 'Risks associated with low functional health literacy in an Australian population', *Medical Journal of Australia*, vol. 191, no. 10, pp. 530-534.
- Advance Care Planning Australia 2015, *Advance Care Planning*, Advance Care Planning Australia, Victoria, viewed 19 October 2015, <http://advancecareplanning.org.au/>
- Ahluwalia, S, Levin, J, Lorenz, K, & Gordon, H 2012, 'Missed opportunities for advance care planning communication during outpatient clinic visits', *Journal of General Internal Medicine*, vol. 27, no. 4, pp. 445-51.
- Aitken, P 1999, 'Incorporating advance care planning into family practice', *American Family Physician*, vol. 59, no. 3, pp. 605-14.
- Allen, R, Allen, J, Hilgeman, M, & DeCoster, J 2008, 'End-of-life decision-making, decisional conflict, and enhanced information: race effects', *Journal of the American Geriatrics Society*, vol. 56, no. 10, pp. 1904-09.
- Alter, D, Ko, D, Tu, J, Stukel, T, Lee, D, Laupacis, A, Chong, A, & Austin, P 2012, 'The Average Lifespan of Patients Discharged from Hospital with Heart Failure', *Journal of General Internal Medicine*, vol. 27, no. 9, pp. 1171-79.
- Altmore C, Naksook C 2007, 'Respecting patient choices - Literature review', Austin Health & Health Issues Centre, Victoria.
- Alzheimer's Australia National Quality Dementia Care Initiative 2015, *Start2Talk*, Canberra, viewed 30 April 2015, <http://www.start2talk.org.au/>
- American Association of Retired Persons 2009, *Boomer Women's Long-term Care Planning: Barriers and levers: Executive Summary*, AARP, Washington, DC.
- Anderson, K 2012, 'Social media: A new way to care and communicate', *Australian Nursing Journal*, vol. 20, no. 3, pp. 22-5.
- Anderson, M, & Whitcomb, P 2014, *Two level factorial design*, 2nd edn, DOE (Design of Experiments) Simplified: Practical Tools for Effective Experimentation, Stat-ease, Incorporated, Minneapolis, USA, viewed 5 November, 2014, <http://www.statease.com/pubs/doesimp2excerpt--chap3.pdf>
- Aronsky, D, Kasworm, E, Jacobson, J, Haug, P, & Dean, N 2004, 'Electronic

screening of dictated reports to identify patients with do-not-resuscitate status', *Journal of the American Medical Informatics Association*, vol. 11, no. 5, pp. 403-09.

- Ashby, M, & Thornton, R 2011, 'Who makes use of the Enduring Guardianship Provisions in Tasmania and what do they write on the forms?', *British Medical Journal Supportive & Palliative Care*, vol. 1, p. 67 viewed 19 April 2015 <http://spcare.bmj.com/content/1/1/67.2.abstract>
- Austin Health 2006, *Report on the evaluation of the national implementation of the Respecting Patient Choices Program*, Austin Health, Adelaide.
- Australian Bureau of Statistics 2001, *Australian Schools: Participation and Funding 1901 to 2000*, cat. no. 1301.0, ABS, Canberra.
- Australian Bureau of Statistics 2003, *South Australia's Baby Boomers: A profile*, cat. no. 4149.4, ABS, Canberra.
- Australian Bureau of Statistics 2006, *Adult literacy and life skills survey: Summary results, Australia 2006*, cat. no. 4233.0, ABS, Canberra.
- Australian Bureau of Statistics 2011a, *Reflecting a nation: Stories from the 2011 Census, 2012-2013*, cat. no. 2071.0, ABS, Canberra
- Australian Bureau of Statistics 2011b, *Household use of Information Technology, Australia, 2010-2011*, cat. no. 8146.0, ABS, Canberra.
- Australian Bureau of Statistics 2011c, *Population by Age and Sex, Australia, 2011*, cat. no. 3235.0, ABS, Canberra.
- Australian Bureau of Statistics 2012a, *Caring in the Community, Australia, 2012*, cat. no. 4436.0, ABS, Canberra.
- Australian Bureau of Statistics 2012b, *Mortality, life expectancy and causes of death*, cat. no. 1301.0, ABS, .Canberra.
- Australian Bureau of Statistics 2013, *Australian Social Trends*, cat. no. 4102.0, ABS, Canberra.
- Australian Communications and Media Authority 2009, *Communications Report 2008-2009*, ACMA, Melbourne.
- Australasian Epidemiology Association 2015, *What is epidemiology?* AEA, Australia, viewed 19 April, 2015, <http://www.aea.asn.au/>
- Australian Government Health Direct 2015, *Personally controlled electronic health record*, Health Direct, Canberra, viewed 01 May, 2015, from http://www.healthdirect.gov.au/#!/ehealth?qclid=CJb1_PnXn8UCFYiUvQod0ZQAzw
- Australian Government Organ and Tissue Authority 2014, *DonateLife*, AGOTA, Canberra, viewed 16 November, 2014,

<http://www.donatelife.gov.au/discover/facts-and-statistics>

Australian Government Seniors Information Services 2015, *Advance Care Directive and Enduring Power of Attorney*, HACC Program, Canberra, viewed 01 May, 2015, from

http://www.seniors.asn.au/centric/legal_consumer/advance_care_directive_and_enduring_power_of_attorney.jsp

Australian Health Ministers' Advisory Council 2011, *A National Framework for Advance Care Directives*, The Clinical Technical and Ethical Principal Committee, AHMAC, Adelaide.

Australian Institute of Health and Welfare 2015, *Deaths in Australia 2013*, cat. no. HWI 120, AIHW, Canberra, AIHW, Canberra, viewed 21 October 2015, from <http://www.aihw.gov.au/deaths/>

Australian Institute of Health and Welfare 2014, *Palliative Care Services in Australia, 2014*, cat. no. HWI 120, AIHW, Canberra.

Aziz, N, Miller, J, & Curtis, J 2012, 'Palliative and end-of-life care research: Embracing new opportunities', *Nursing Outlook*, vol. 60, no. 6, pp. 384-90.

Barnato, A, & Arnold, R 2013, 'The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment decisions: A randomized simulation experiment', *Critical Care Medicine*, vol. 41, no. 7, pp. 1686-91

Barnes, K, Jones, L, Tookman, A, & King, M 2007, 'Acceptability of an advance care planning interview schedule: A focus group study', *Palliative Medicine*, vol. 21, pp. 23-8.

Barnett, K 2013, 'Ageing and Aged Care', in J. Spoehr (ed.), *State of South Australia: Turbulent Times*, Wakefield Press, Kent Town.

Barry, M 2002, 'Health Decision Aids to Facilitate Shared Decision Making in Office Practice', *Annals of Internal Medicine*, vol. 136, no. 2, pp. 127-35.

Bayer, W, Mallinger, J, Krishnan, A, & Shields, C 2006, 'Attitudes toward life-sustaining interventions among ambulatory black and white patients', *Ethnicity and Disease*, vol. 16, no. 4, pp. 914-19.

Beck, A, Brown, J, Boles, M, & Barrett, P 2002, 'Completion of advance directives by older health maintenance organization members: the role of attitudes and beliefs regarding life-sustaining treatment', *Journal of the American Geriatrics Society*, vol. 50, no. 2, pp. 300-06.

Berg, J 2012, 'Surrogate decision making in the Internet age', *The American Journal of Bioethics*, vol.12, no.10, pp. 28-33.

Besirevic, V 2010, 'End-of-life care in the 21st century: Advance directives in Universal Rights discourse', *Bioethics*, vol. 24, no. 3, pp. 105-12.

- Bessell, T, Silagy, C, Anderson, J, Hiller, J, & Sansom, L 2002, 'Prevalence of South Australia's online health seekers', *Australia and New Zealand Journal of Public Health*, vol. 26, pp. 170-73.
- Betz Brown, J., Beck, A, Boles, M, & Barrett, P 1999, 'Practical methods to increase use of advance medical directives', *Journal of General Internal Medicine*, vol. 14, no. 1, pp. 21-6.
- Booij, S, Engberts, D, Rodig, V, Tibben, A, & Roios, R 2013, 'A plea for end-of-life discussions with patients suffering from Huntington's disease: The role of the physician', *Journal of Medical Ethics*, vol. 39, pp. 621-24.
- Bose-Brill, S, & Pressler, T 2012, 'Commentary Opportunities for Innovation and Improvement in Advance Care Planning Using a Tethered Patient Portal in the Electronic Health Record', *Journal of Primary Care & Community Health*, vol. 3, no. 4, pp. 285-88.
- Bowen, S, Martens, P, & The Need to Know Team 2005, 'Demystifying knowledge translation: learning from the community', *Journal of Health Services Research and Policy*, vol. 10, no. 4, pp. 203-11.
- Boyd, N 2014, *Main effects in factorial design*, Study.com, Mountain view, California, viewed 19 April, 2015, <http://study.com/academy/lesson/main-effects-in-factorial-design.html#lesson>
- Bradley, S 2012, 'I know I should but I haven't: South Australian Baby Boomers forever contemplating advance care directives', Master of Science Research Thesis, Flinders University, Adelaide.
- Bradley, S, Woodman, R, Tieman, J, & Phillips, P 2014, 'Use of advance directives by South Australians: Results from the Health Omnibus Survey Spring 2012', *Medical Journal of Australia*, vol. 201, no. 8, pp. 467-69.
- Braun, K, Onaka, A, & Horiuchi, B 2001, 'Advance directive completion rates and end-of-life preferences in Hawaii', *Journal of American Geriatric Society*, vol. 49, no. 12, pp.1708-13.
- Bravo, G, Dubois, M, & Wagneur, B 2008, 'Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis', *Social Science and Medicine*, vol. 67, pp. 1122-32.
- Bricker, L, Lambing, A, & Markey, C 2003, 'Enhancing communication for end-of-life care: an electronic advance directive process', *Journal of Palliative Medicine* vol. 6, no. 3, pp. 511-19.
- Brown, M, Wakefield, M, Beilby, J, & Gargett, E 1997, *Advance directive (Schedule 2) community study*, South Australian Health Commission, SAHC, Adelaide.

- Brown, M 2002, 'Participating in end-of-life discussion: The role of general practitioners', *Australian Family Physician*, vol. 31, no. 1, pp. 60-2.
- Brown, M, Fisher, J, Brumley, D, Ashby, M, & Milliken, J 2005, 'Advance directives in action in a regional palliative care service: "Road Testing" the provisions of the Medical Treatment Act 1988 (VIC)', *Journal of Legal Medicine*, vol. 13, pp. 186-90.
- Brown, M, & Jarrad, S 2005, 'Putting 'the powers' in place: Planning for the future', Alzheimer's Australia (SA) Incorporated, Adelaide.
- Buchtel, H, Anderson, C, Adams, K, & Johnson-Greene, D 1996, 'Advance directives: making them more available to hospitals patients', *Hospital topics* vol. 74, no. 3, pp. 11-14.
- Butler, M, Ratner, E, McCreedy, E, Shippee, N, & Kane, R 2014, *Decision Aids for Advance Care Planning*, cat. no. 14-EHC039-EF, Agency for Health Research and Quality (AHRQ) Publications, Minnesota Evidence-based Practice Center, Rockville, Maryland.
- Caligtan, C, & Dykes, P 2011, 'Electronic health records and personal health records', *Seminars in Oncology Nursing*, vol. 27, no. 3, pp. 218-28.
- Campbell, M, Edwards, M, Ward, K, & Weatherby, N 2007, 'Developing a parsimonious model for predicting completion of advance directives', *Journal of Nursing Scholarship*, vol. 39, no. 2, pp.165-171.
- Capuro, D, Ganzinger, M, Perez-Lu, J, & Knaup, P 2014, 'Effectiveness of eHealth Interventions and information needs in Palliative Care: A Systematic Literature Review', *Journal of Medical Internet Research*, vol. 16, no. 3, p.72.
- CareSearch 2015, *CareSearch, palliative care knowledge network*, CareSearch, Adelaide, viewed 19 April 2015, <http://www.caresearch.com.au/Caresearch/Default.aspx>
- Carr, D 2012a, 'Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles', *Journal of Aging and Health*, vol. 24, no. 6, pp. 923-947.
- Carr, D 2012b, 'The social stratification of older adults' preparations of end-of-life health care', *Journal of Health and Social Behavior*, vol.53, no. 3, pp. 297-312.
- Carr, D, Moorman, S, & Boerner, K 2013, 'End-of-life planning in a family context: Does relationship quality affect whether (and with whom) older adults plan?', *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, vol. 68, no. 4, pp. 586-92.
- Carrese, J, Mullaney, J, Faden, R, & Finucane, T 2002, 'Planning for death but not

- serious future illness: qualitative study of housebound elderly patients', *British Medical Journal*, vol. 325, pp.127-131.
- Cartwright, C 2011, *Planning for the End of Life for People with Dementia: Vols. 1 and 2*, reported prepared for Alzheimer's Australia, Canberra.
- Center for Aging Research and Educational Services 1997, *Baby Boomers at Mid-Life: The future of aging in North Carolina*, CARES, School of Social Work, University of North Carolina, Chapel Hill.
- Christian, M 2004, 'The sandwich generation', *Exceptional Parent*, vol. 34, no. 4, pp. 41-3.
- Cintron, A, Phillips, R, & Hamel, M 2006, 'The effect of a Web-based, patient-directed intervention on knowledge, discussion, and completion of a health care proxy', *Journal of Palliative Medicine*, vol. 9, no. 6, pp. 1320-28.
- Clark, D 2002, 'Older adults living through and with their computers', *CIN: Computers, Informatics, Nursing*, vol. 20, no. 3, pp. 117-124.
- Clements, J 2009, 'Patient Perceptions on the Use of Advance Directives and Life Prolonging Technology', *American Journal of Hospice & Palliative Medicine*, vol. 26, no. 4, pp. 270-76.
- Cohen-Mansfield, J, Libin, A, & Lipson, S 2003, 'Differences in presenting advance directives in the chart, in the minimum data set, and through the staff's perceptions', *Gerontologist*, vol. 43, no. 3, pp. 302-08.
- Coleman, A 2012, 'Physician attitudes toward advanced directives: A literature review of variables impacting on physicians attitude toward advance directives', *American Journal of Hospice and Palliative Medicine*, online version, viewed 2 November 2012, <http://ajh.sagepub.com/content/early/2012/11/01/1049909112464544>
- Critical Appraisal Skills Programme 2010a, *Critical Appraisal Checklist for an article on treatment or prevention*, in Public Health Resource Unit (ed.), CASP, Institute of Health Science, Oxford University, London.
- Critical Appraisal Skills Programme 2010b, *Critical appraisal skills programme: 12 questions to help you make sense of cohort study*, in Public Health Resource Unit (ed.), CASP, Institute of Health Science, Oxford University, London.
- Cugliari, A, Sobal, J, & Miller, T 1999, 'Use of a videotape for educating patients about advance directives', *American Journal of Health Behavior*, vol. 23, no. 2, pp. 105-14.
- Deep, K, Hunter, A, Murphy, K, & Volandes, A 2010, "'It helps me see with my heart": How video informs patients' rationale for decisions about future care in advanced dementia', *Patient Education and Counselling*, vol. 81, no. 2, pp.

229-34.

- Department of Health 2015, *eHealth*, DOH, Canberra, viewed 19 April, 2015, <http://www.ehealth.gov.au/Internet/ehealth/publishing.nsf/content/home>
- Detering, K, Hancock, A, Reade, M, & Silvester, W 2010, 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *British Medical Journal*, vol. 340, pp.e1345.
- Dexter, P, Wolinsky, F, Gramelspacher, G, Zhou, X, Eckert, G, Waisburd, M, & Tierney, W 1998, 'Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms', *Annals of Internal Medicine*, vol.128, pp. 102-10.
- Dharmarajan, T, Yunus, A, Patel, K, Hossain, M, Alam, S, Gunturu, S, Relekar, K, Goel, G, Hasan, A, Rodriguez, R, Margallo, R, & Norkus, E 2010, 'Implementation of advance directives in adults in ambulatory and hospital settings: Perception of health matters!', *Paper abstract (A51)*, American Geriatrics Society Annual Meeting Annual Meeting, Florida, pp. S35.
- Ditto, P, & Hawkins, N 2005, 'Advance directives and cancer decision making near the end of life', *Health Psychology*, vol. 24, no. 4 (Supp), pp. S63-70.
- Drinka, P, Spears, R, & Voeks, S 1993, 'Obtaining a durable power of attorney for health care from nursing home residents', *Journal of Family Practice*, vol. 36, no. 4, pp. 409-12.
- Dupont, W, & Plummer, W 1990, 'Power and Sample Size Calculations: A Review and Computer Program', *Controlled Clinical Trials*, vol. 11, pp.116-28.
- Dupont, W, & Plummer, W 1998, 'Power and Sample Size Calculations for Studies Involving Linear Regression', *Controlled Clinical Trials*, vol. 19, pp. 589-601.
- Durbin, C 2007, 'Healthcare decision-making in community-dwelling adults' PhD thesis, University of Missouri - Saint Louis
- Durbin, C, Fish, A, Bachman, J & Smith, K 2010, 'Systematic review of educational interventions for improving advance directive completion', *Journal of Nursing Scholarship*, vol. 42, no. 3, pp. 234-41.
- Emanuel, L 1995, 'Appropriate and inappropriate use of advance directives', *The Journal of Clinical Ethics*, vol. 5, no. 4, pp. 357-59.
- Epstein, A, Volandes, A, Chen, L, Gary, K, Li, Y, Agre, P, Levin, T, Reidy, D, Meng, R, Segal, N, Yu, K, Abou-Alfa, G, Janjigian, Y, Kelsen, D, & O'Reilly, E 2013, 'A randomized controlled trial of a cardiopulmonary resuscitation video in advance care planning for progressive pancreas and hepatobiliary cancer patients', *Journal of Palliative Medicine*, vol. 16, no. 6, pp. 623-31.
- Fagerlin, A, Ditto, P, Hawkins, N, Schneider, C, & Smucker, W 2002, 'The use of

- advance directives in end-of-life decision making: Problems and possibilities', *American Behavioral Scientist*, vol. 46, no.2, pp. 268-83.
- Fagerlin, A & Schneider, C 2004, 'The failure of the living will', *The Hastings Centre Report*, vol. 34, no.2, p. 42.
- Field, A 2011, *Discovering Statistics Using SPSS*, SAGE Publications Ltd, London.
- Fingerman, K, Pillemer, K, Silverstein, M, & Sutor, J 2012, 'The Baby Boomers' Intergenerational Relationships', *The Gerontologist*, vol. 52, no. 2, pp. 199-209.
- Finucane, T, Shumway, J, Powers, R, & D'Alessandri, R 1988, 'Planning with elderly outpatients for contingencies of severe illness', *Journal of General Internal Medicine*, vol. 3, no. (July/August), pp. 322-325.
- Foreman, L, Hunt, R, Luke, C, & Roder, D 2006, 'Factors predictive of preferred place of death in the general population of South Australia', *Palliative Medicine*, vol. 20, pp. 447-53.
- Frosch, D, Kaplan, R, & Felitti, V 2003, 'A randomized controlled trial comparing Internet and video to facilitate patient education for men considering the Prostate Specific Antigen Test', *Journal of General Internal Medicine*, vol. 18, no. (October), pp. 781-87.
- Gill, P, Gill, T, Kamath, A, & Whisnant, B 2012, 'Readability assessment of concussion and traumatic brain injury publications by Centers for Disease Control and Prevention', *International Journal of General Medicine*, vol. 5, pp. 923-33.
- Gillick, M 2006, *The Denial of Aging*, Harvard University Press, Cambridge.
- Glaser, B 1978, *Theoretical sensitivity*, Sociology Press, California.
- Glaser, B & Strauss, A 2008 (1967), *Discovery of Grounded Theory: Strategies for qualitative research*. Aldine-Atherton, New Brunswick.
- Google Scholar 2015, *advance directives*, Australia, viewed 18 April 2015, http://scholar.google.com.au/scholar?hl=en&q=advance+directive&btnG=&as_sdt=1%2C5&as_sdtp=
- Green, M & Levi B 2009, 'Development of an interactive computer program for advance care planning', *Health Expectations*, vol. 12, no. 1, pp. 60-9.
- Grol, R, Bosch, M, Hulscher, M, Eccles, M & Wensing, M 2007, 'Planning and Studying Improvement in Patient Care: The Use of Theoretical Perspectives', *The Milbank Quarterly*, vol. 85, no. 1, pp. 93-138.
- Guberman, N, Lavoie, J, Blein, L, & Olazabal, I 2012, 'Baby Boom Caregivers: Care in the Age of Individualization', *The Gerontologist*, vol. 52, no. 2, pp. 210-18.
- Hammes, B, Rooney, B, & Gundrum, J 2010, 'A comparative, retrospective,

- observational study of the prevalence, availability and specificity of advance care plans in a county that implemented and advance care planning microsystem', *Journal of the American Geriatrics Society*, vol. 58, no. 7, pp. 1249-55.
- Hanks, P (ed.) 1996a, 'Computer', *The Oxford English Reference Dictionary*, Oxford University Press, Oxford, p. 298.
- Hanks, P (ed.) 1996b, 'Interactive', *The Oxford English Reference Dictionary*, Oxford University Press, Oxford, p.732.
- Harrison Health Research (2012), *Findings from Spring 2012 Health Omnibus Survey*, Harrison Health Research, Adelaide.
- Heffner, J, Barbieri, C, Fracica, P, & Brown, L 1998, 'Communicating do-not-resuscitate orders with a computer-based system', *Archives of Internal Medicine*, vol. 158, no. 10, pp. 1090-95.
- Hickman, R, Lipson, A, Pinto, M, & Pignatiello, G 2014, 'Multimedia decision support intervention: A promising approach to enhance the intention to complete an advance directive among hospitalized adults', *Journal of the American Association of Nurse Practitioners*, vol. 26, pp. 187-193.
- Higgins, J & Green, S (eds.) 2011, *Cochrane Handbook for Systematic Reviews of Interventions*, Version 5.1.0, The Cochrane Collaboration, viewed 19 April 2015, www.cochrane-handbook.org
- High, D 1993, 'Advance directives and the elderly: A study of intervention strategies to increase use', *The Gerontologist*, vol. 33, no. 3, pp. 342-49.
- Hill, J 2009, *Palliative Care Services Plan 2009-2016*, South Australia Department of Health (SAGDOH), Adelaide.
- Ho, V, Thiel, E, Rubin, H, & Singer, P 2000, 'The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS', *AIDS Care*, vol.12, no. 1, pp. 97-108.
- Hong, C, & Lee, H 1996, 'The advance directive - a review', *Singapore Medical Journal*, vol. 37, no. 4, pp. 411-18.
- Hossler, C, Levi, B, Simmons, Z, & Green, M 2011, 'Advance care planning for patients with ALS: Feasibility of an interactive computer program', *Amyotrophic Lateral Sclerosis*, vol. 12, no. 3, pp. 172-77.
- Hsieh, J 2011, 'A Multilevel Growth Assessment of the Diffusion of Management Innovation Nested in State Levels: The Case of US Local Economic Development Programs', *Innovation: Management Policy and Practice*, vol. 13, no. 1, pp. 2-19.
- Hugo, G 2013a 'Population Growth', in J. Spoehr (ed.), *State of South Australia:*

- Turbulent Times*, Wakefield Press, Kent Town.
- Hugo G 2013b, 'The changing demographics of Australia over the last 30 years', *Australasian Journal on Ageing*, vol. 32 (Supplement 2), pp.18-27.
- Humpel, N, O'Loughlin, K, Wells, Y, & Kendig, H 2009, 'Ageing Baby boomers in Australia: Evidence informing actions for better retirement' *Australian Journal of Social Issues*, vol. 44, no. 4, pp. 399-415.
- Humpel, N & O'Loughlin, K 2010, 'The health of Australian Baby Boomers', *Australasian Journal on Ageing*, vol. 29, no. 1, pp. 8-13.
- Jackson, J, Derderian, L, White, P, Ayotte, J, Fiorini, J, Hall, R, & Shay, J 2012, 'Family Perspectives on End-of-Life Care: A Metasynthesis', *Journal of Hospice & Palliative Nursing*, vol. 14, no. 4, pp. 303-11.
- Jain, N & Kahn, M 1995, 'Using knowledge maintenance for preference assessment', *AMIA Annual Symposia Proceedings*, pp. 263-69.
- Jezewski, M, Meeker, M, Sessanna, L, & Finnell, D 2007, 'The Effectiveness of Interventions to Increase Advance Directive Completion Rates', *Journal of Aging and Health*, vol.19, no. 3, pp. 519-36.
- Johnson-Greene, D, Anderson, C, Adams, K, & Buchtel, H 1996, 'The psychologist's role in assessing and facilitating patients' knowledge of advance directives in medical settings: A preliminary investigation', *Journal of Clinical Psychology in Medical Settings*, vol. 3, no. 2, pp. 103-13.
- Kaplan, F 2009, *1959: The Year That Changed Everything*, John Wiley & Sons, Incorporated, New Jersey.
- Kerridge, I, Lowe, M, & Stewart, C 2009, 'Introduction to Principle-based Ethics', in I Kerridge, M Lowe, C Stewart (eds.) *Ethics and Law for the Health Professions*, The Federation Press, Annandale, NSW.
- Khodyakov D, Carr D 2009, 'The impact of late-life parental death on adult sibling relationships: Do parents' advance directives help or hurt?', *Research on Aging*, vol. 31, no. 5, pp.495-519.
- Klugman, C, & Usatine, R 2012, 'An Evaluation of 2 Online Advance Directive Programs', *American Journal of Hospice & Palliative Care*, vol. 30, no. 7, pp. 657-63.
- Ko, E & Lee, J 2013, 'Completion of advance directives among low-income older adults: Does race/ethnicity matter?' *American Journal of Hospice and Palliative Medicine*, vol. 31, no. 3, pp. 247-253.
- Kohut, A, Keeter, S, & Doherty, C 2006, *More Americans Discussing and Planning End of Life Treatment* prepared by the Pew Research Centre, Washington,

DC.

- Lam, M 2012, 'Vital choices: making advance care directives', *Law Society Journal*, vol. 50, no. 5, pp. 16-9.
- Lee, S, Gorawara-Bhat, R, Chin, M, & Scott, D 2005, 'Promote health for seniors: Older adults perceptions of a computer based health survey', *Journal of the American Geriatrics Society*, vol. 53, no. 4, p. S103.
- Legal Services Commission of South Australia 2015, *advance care directive*, LSCSA, Adelaide, viewed 30 April 2015, <http://www.lsc.sa.gov.au/>
- Levi, B, Dellasega, C, Whitehead, M, & Green, M 2010, 'What influences individuals to engage in advance care planning?', *American Journal of Hospice & Palliative Care*, vol. 27, no. 5, pp. 306-12.
- Levi, B, Heverley, S, & Green, M 2011, 'Accuracy of a decision aid for advance care planning: simulated end-of-life decision making', *The Journal of Clinical Ethics*, vol. 22, no. 3, pp. 223-38.
- Levi, B, Wilkes, M, Der-Martirosian, C, Latow, P, Robinson, M, & Green, M 2013, 'An interactive exercise in advance care planning for medical students', *Journal of Palliative Medicine*, vol.16, no.12, pp. 1523-27.
- Lin I-F, Brown S 2012. 'Unmarried Boomers Confront Old Age: A National Portrait'. *The Gerontologist*, vol. 52, no. 2, pp.153-65.
- Lynn, J, & Teno, J 1993, 'After the Patient Self-Determination Act: the need for empirical research on formal advance directives' *The Hastings Centre Report*, vol. 23, no. 1, pp. 20-4.
- Lynn, J, Arkes, H, Stevens, M, Cohn, F, Koenig, B, Fox, E, Dawson, N, Phillips, R, Hamel, M, & Tsevat, J 2000, 'Rethinking fundamental assumptions: SUPPORT's implications for future reform', *Journal of the American Geriatrics Society*, vol. 48, no. 5, pp. S214-21.
- Mamlin, B, Gramelspacher, G, & Tierney, W 1996, 'Do computer-stored advance directives affect inpatient resus orders?', *Journal of General Internal Medicine*, vol. 11, Supplement 1, p. 135.
- McBride, D 2010, 'Patients are more likely to choose comfort care after watching video on end-of-life options', *ONS connect*, vol. 25, no. 5, p. 15.
- McCann, R, Chodosh, J, Frankel, R, Katz, P, Naumburg, E, Tulskey, A, & Hall, W 1998, 'Advance care directives and end of life decisions: an educational module', *Gerontology and Geriatrics Education*, vol. 18, no. 3, pp. 3-19.
- McCannon, J, O'Donnell, W, Thompson, B, El-Jawahri, A, Chang, Y, Ananian, L, Bajwa E, Currier, P, Parikh, M, Temel, J, Cooper, Z, Wiewer, R & Volandes, A 2012, 'Augmenting communication and decisionmaking in the Intensive

- Care Unit with a cardiopulmonary resuscitation video decision support tool: A temporal intervention study', *Journal of Palliative Medicine*, vol. 15, no. 12, pp. 1382-86.
- McConatha, D, McConatha, J, & Dermigny, R 1994, 'The use of interactive computer services to enhance the quality of life for long-term care residents', *The Gerontologist*, vol. 34, no. 4, pp. 553-56.
- McCrindle Research ND, *Seriously Cool: Marketing, communicating and engaging with the diverse generations*, prepared by McCrindle Research, New South Wales.
- McLaren, C 2009, 'Alberta creates electronic registry for personal directives' *Canadian Medical Association Journal*, vol.180, no. 7, p. 708
- Mercer, Z, Chiriboga, D, & Sweeney, M 1997, 'Using computer technology with older adults: a pilot study on advanced directives', *Gerontology & Geriatrics Education*, vol. 18, no. 1, pp. 61-76.
- Miljkovic, M, Jones, B, & Miller, K 2013, 'From the Euthanasia Society to Physician Orders for Life-Sustaining Treatment: End-of-life care in the United States', *The Cancer Journal*, vol. 19, pp. 438-443.
- Moher D, Schulz K, Altman D 2001, 'The CONSORT statement: revised recommendations for improving the quality of reports of parallel-group randomized trials', *Journal of the American Medical Association*, vol. 285, pp. 1987-91.
- Moher, D, Liberati, A, Tetzlaff, J, Altman, D, & The PRISMA Group 2009, 'Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement', *PLoS Medicine*, vol. 6, no. 7, e1000097.
- Morgan, M, Deber, R, Llewellyn-Thomas, H, Gladstone, P, Cusimano, R, O'Rourke, K., Tomlinson, G, & Detsky, A 2000, 'Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease', *Journal of General Internal Medicine*, vol. 15, (October), pp. 685-93.
- Morhaim, D, & Pollack, K 2013, 'A personal, economic, public policy and public health crisis', *American Journal of Public Health*, vol. 103, no. 6, e8-e10.
- Moorman, S, & Inoue, M 2013, 'Persistent problems in end-of-life planning among young-and middle-aged American couples', *Journals of Gerotology Series B: Psychological Sciences and Social Sciences*, vol. 68, no. 1, pp. 97-106.
- Morrow, D, Clark, D, Tu, W, Wu, J, Weiner, M, Steinley, D, & Murray, M 2006, 'Correlates of health literacy in patients with chronic heart failure', *The Gerontologist*, vol. 46, no. 5, pp. 669-76.

- Mueller, L, Reid, K, & Mueller, P 2010, 'Readability of state-sponsored advance directive forms in the United States: a cross sectional study', *BMC Medical Ethics*, vol. 11, p. 6.
- Murphy, C, Sweeney, M, & Chiriboga, D 2000, 'An educational intervention for advance directives', *Journal of Professional Nursing*, vol.16, no. 1, pp. 21-30.
- Murphy, G, Schenkenberg, T, Hunter, J, & Battin, M 1997, 'Advance directives: a computer assisted approach to assuring patients' rights and compliance with PSDA (Patient Self-Determination Act) and JCAHO standards', *HEC forum: an interdisciplinary journal on hospitals' ethical and legal issues*, vol. 9, no. 3, pp. 247-55.
- National Health and Medical Research Council 2005, *NHMRC additional levels of evidence and grades for recommendations for developers of guidelines: Pilot program 2005-2007*, NHMRC, Canberra.
- National Seniors Australia Productive Ageing Centre 2012, *Ageing Baby Boomers in Australia: Informing actions for better retirement*, NSPAC, Canberra.
- New South Wales Government 2004, *Using Advance Care Directives: New South Wales*, NSWGDH, Sydney, viewed 30 April 2015, <http://www.health.nsw.gov.au/patients/acp/Pages/default.aspx>
- O'Carroll, R, Dryden, J, Hamilton-Barclay, T, & Ferguson, E 2011, 'Anticipated regret and organ donor registration--a pilot study', *Health Psychology*, vol. 30, no. 5, pp. 661-64.
- O'Loughlin, K, Humpel, N, & Kendig, H 2010, 'Impact of the global financial crisis on employed Australian Baby Boomers: A national survey', *Australasian Journal on Ageing*, vol. 29, no. 2, pp. 88-91.
- Office of the Public Advocate, South Australia 2015, *Advance directives in South Australia Pamphlet 8*, OPA, Adelaide.
- Olszewski, E, Newgard, C, Zive, D, Schmidt, T, & McConnell, K 2012, 'Validation of physician orders for life-sustaining treatment: electronic registry to guide emergency care' *Journal of the American Geriatrics Society*, vol. 60, no. 7, pp. 1384-86.
- Oxford Dictionaries 2015, 'Online', Oxford University Press, viewed 19 April 2015 <http://www.oxforddictionaries.com/definition/english/online>
- Palliative Care Australia 2015, *Good Palliative Care Plan*, PCA, Canberra, viewed 26 April 2009, <http://www.pallcare.asn.au/info-resources/resources-for-sale/palliative-care-plans>
- Patel, R, Sinuff, T, & Cook, D 2004, 'Influencing Advance Directive Completion

- Rates in Non-terminally Ill Patients: A systematic review', *Journal of Critical Care*, vol. 19, no. 1, pp. 1-9.
- Peto, T, Srebnik, D, Zick, E, & Russo, J 2004, 'Support needed to create psychiatric advance directives', *Administration and Policy in Mental Health*, vol. 31, no. 5, pp. 409-19.
- Pope, T 2013, 'Making medical decisions for patients without surrogates', *New England Journal of Medicine*, vol. 369, no. 21, pp.1976-78.
- Prochaska, J, DiClemente, C, & Norcross, J 1992, 'In search of how people change: Applications to addictive behaviours', *American Psychologist*, vol. 47, no. 9, pp. 1102-14.
- Prochaska, J& Velicer, W 1997, 'The Transtheoretical Model of Health Behavior Change', *American Journal of Health Promotion*, vol.12, pp. 38-48.
- Productivity Commission 2011, 'Caring for Older Australians: Productivity Commission Inquiry Report Overview (Volumes 1 and 2)', PC, Australian Government, Canberra.
- Pruchno, R 2012, 'Not Your Mother's Old Age: Baby Boomers at Age 65', *The Gerontologist*, vol. 52, no. 2, pp. 149-152.
- Queen Elizabeth Hospital 2004, *Findings from the Autumn 2004 Health Omnibus Survey*, Harrison Health Research, Adelaide.
- Ramsaroop, S, Reid, M, & Adelman, R 2007, 'Completing an advance directive in the primary care setting: What do we need for success?', *Journal of the American Geriatrics Society*, vol. 55, no. 2, pp. 277-83.
- Reinke, L, Griffith, R, Wolpin, S, Donesky-Cuenco, D, Carrieri-Kohlman, V, & Nguyen, H 2011, 'Feasibility of a Webinar for Coaching Patients With Chronic Obstructive Pulmonary Disease on End-of-Life Communication', *American Journal of Hospice & Palliative Medicine*, vol. 28, no. 3, pp. 147-52.
- Respecting Patient Choices Program 2008, 'Respecting Patient Choices News', In: Services DoH, editor. Melbourne: Victorian Government Department of Human Services.
- Respecting Patient Choices Program, Advance Care Planning Organisation 2015, *Statement of Choices*, Melbourne, viewed 19 April 2015
http://advancecareplanning.org.au/library/uploads/documents/sa/5.SA_SOC_Aged_Care_20112505.pdf
- Reuben, D 2009, 'Medical Care for the Final Years of Life: "When you're 83, it's not going to be 20 years"', *Journal of the American Medical Association*, vol. 302, no. 24, pp. 2687-94.

- Rocker, G, Dodek, P, Heyland, D, & Canadian Researchers at the End of Life Network 2008, 'Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: Insights from a multicentre study', *Canadian Respiratory Journal*, vol. 15, no. 5, pp. 249-54.
- Rosnick, C, & Reynolds, S 2003, 'Thinking ahead: Factors associated with executing advance directives', *Journal of Aging and Health*, vol. 15, no. 2, pp. 409-29.
- Rubin, L 2007, *60 on Up: The truth about aging in America*, Beacon Press, Boston.
- Schubart, J, Levi, B, Camacho, F, Whitehead, M, Farace, E, & Green, M 2012, 'Reliability of an Interactive Computer Program for Advance Care Planning', *Journal of Palliative Medicine*, vol. 15, no. 6, pp. 637-42.
- Sherman, P 1998, 'Computer-assisted creation of psychiatric advance directives', *Community Mental Health Journal*, vol. 34, no. 4, pp. 351-62.
- Siebert, E, Clipp, E, Mulhausen, P, & Kochersberger, G 1996, 'Impact of advance directive videotape on patient comprehension and treatment preferences', *Archives of Family Medicine*, vol. 5, no. 4, pp. 207-12.
- Silverman, H, Tuma, P, Schaeffer, M, & Singh, B 1995, 'Implementation of the Patient Self-Determination Act in a hospital setting: An initial evaluation', *Archives of Internal Medicine*, vol.155, no. 5, pp. 502-10.
- South Australian Department of Health 2009, *Health Service Framework for Older People 2009-2016*, SAGDOH, Adelaide.
- South Australian Department of Health 2009, *Palliative Care Services Plan 2009-2016*, SAGDOH, Adelaide.
- South Australian Department of Health 2011, *The South Australian approach to Health in All Policies: background and practical guide*, SAGDOH, Adelaide.
- South Australian Government 1983, *Natural Death Act 1983 (ceased)*, Adelaide, viewed 19 April 2015
<http://www.legislation.sa.gov.au/LZ/C/A/NATURAL%20DEATH%20ACT%201983.aspx>
- South Australian Government 1984, *Powers of Attorney and Agency Act 1984*, SAG, Adelaide, viewed 19 April 2015
<http://www.legislation.sa.gov.au/LZ/C/A/POWERS%20OF%20ATTORNEY%20AND%20AGENCY%20ACT%201984/CURRENT/1984.25.UN.PDF>
- South Australian Government 1993, *Guardianship and Administration Act 1993*, SAG, viewed 19 April 2015
<http://www.legislation.sa.gov.au/LZ/C/A/GUARDIANSHIP%20AND%20ADMINISTRATION%20ACT%201993.aspx>
- South Australian Government 1995, *Consent to Medical Treatment and Palliative*

- Care Act 1995, SAG, Adelaide, viewed 19 April 2015
<http://www.legislation.sa.gov.au/LZ/C/A/CONSENT%20TO%20MEDICAL%20TREATMENT%20AND%20PALLIATIVE%20CARE%20ACT%201995.aspx>
- South Australian Government 2007, *South Australian Advance Directives Review: Background Paper*, SAGDOH, Adelaide.
- South Australian Government Department of Health 2008, *Advance Directives Review: Planning ahead - your health, your money, your life - First Report of the Review of South Australia's Advance Directives, Proposed Changes to Law and Policy*, SAGDOH, Adelaide.
- South Australian Government 2013, *Advance Care Directives Act 2013*, SAG, viewed 19 April 2015
<http://www.legislation.sa.gov.au/LZ/C/A/ADVANCE%20CARE%20DIRECTIVES%20ACT%202013.aspx>
- South Australian Government 2015a, *Services SA 2015 (now sa.gov.au)*, SAG, Adelaide, viewed 30 April 2015, <http://www.sa.gov.au/topics/citizens-and-your-rights/planning-ahead/making-health-wishes-known>
- South Australian Government Department of Health 2015b, *Advance Care Directives*, SAGDOH, viewed 22 October 2015
<http://www.advancecaredirectives.sa.gov.au/>
- South Australian Government Department of Health 2015c, *Enterprise Patient Administration System*, SAGDOH, viewed 22 October 2015
<http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+reform/ehealth/enterprise+patient+administration+system+epas/enterprise+patient+administration+system+epas>
- South Australian Voluntary Euthanaisa Society 2010, *Life Values Statement*, SAVES, Kent Town, viewed 19 April 2015
<http://www.saves.asn.au/advance/lvs.pdf>
- SPSS Incorporated 2010, *IBM SPSS Statistics (Version 19.0.01)*, IBM Corporation, Somers, NY.
- Srebnik, D, Appelbaum, P, & Russo, J 2004, 'Assessing competence to complete psychiatric advance directives with the Competence Assessment Tool for Psychiatric Advance Directives', *Comprehensive Psychiatry*, vol. 45, no. 4, pp. 239-45.
- Stampfer, M, Buring, J, Willett, W, Rosner, B, Eberlein, K, & Hennekens, C 1985, 'The 2 x 2 factorial design: its application to a randomized trial of aspirin and carotene in U.S. physicians', *Statistics in Medicine*, vol. 4, no. 2, pp.111-16.
- Stewart, C 2005, 'The Australian experience of advance directives and possible

- future directions', *Australasian Journal on Ageing*, vol. 24, pp. S25-S29.
- Straus, S, Tetroe, J, & Graham, I 2011, 'Knowledge translation is the use of knowledge in health care decision making', *Journal of Clinical Epidemiology*, vol. 64, no. 1, pp. 6-10.
- Street, A, & Ottmann, G 2006, *State of the Science Review of Advance Care Planning Models*, Respecting Patient Choices Program & Department of Health and Ageing, Bundoora.
- Sudore, R, Knight, S, McMahan, R, Feuz, M, Farrell, D, Miao, Y, & Barnes, D 2014, 'A novel website to prepare diverse older adults for decision making and advance care planning: A pilot study', *Journal of Pain and Symptom Management*, vol. 47, no. 4, pp. 674-86.
- Sulmasy, D, Song, K, Marx, E, & Mitchell, J 1996, 'Strategies to promote the use of advance directives in a residency outpatient practice', *Journal of General Internal Medicine*, vol. 11, pp. 657-63.
- Sulmasy, D, & Marx, E 1997, 'A computerized system for entering orders to limit treatment: Implementation and evaluation', *The Journal of Clinical Ethics*, vol. 8, no. 3, pp. 258-63.
- Tamayo-Velazquez, M, Simon-Lorda, P, Villegas-Portero, R, Higuera-Callejon, C, Garcia-Gutierrez, J, Martinez-Pecino, F, & Barrio-Cantalejo, I 2010, 'Interventions to promote the use of advance directives: an overview of systematic reviews', *Patient Education and Counseling*, vol. 80, pp.10-20.
- Taverner, M 2010, 'Your Bloomin' Lot: An empirical study of the popular Baby Boomer stereotype', PhD thesis, University of Newcastle, Newcastle.
- Teno, J, Hill, T, & O'Connor, M 1994, 'Advance care planning: Priorities for ethical and empirical research' *Hastings Center Report*, vol. (November-December), pp. S1-36.
- Teno, J, Stevens, M, Spornak, S, & Lynn, J 1998, 'Role of written advance directives in decision making: Insights from qualitative and quantitative data', *Journal of General Internal Medicine*, vol. 13, pp. 439-46.
- Terry, M, & Zweig, S 1994, 'Prevalence of advance directives and do-not-resuscitate orders in community nursing facilities', *Archives of Family Medicine*, vol. 3, pp. 141-45.
- The Conversation Project 2014, *The Conversation Project*, The Conversation Project, Cambridge, MA, viewed 16 November, 2014, from <http://theconversationproject.org/>
- The SUPPORT Investigators 1994, 'Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients?',

The Journal of Clinical Ethics, vol. 5, no.1, pp. 23-9.

- The SUPPORT Investigators 1995, 'A controlled trial to improve decision-making for seriously ill hospitalized patients: the struggle to understand prognoses and preferences for outcomes and risks of treatments', *Journal of the American Medical Association*, vo. 274, no.20, pp.1591-98.
- Tieman, J 2011, 'Investigating barriers to accessing online palliative care information', PhD Thesis, Flinders University, Adelaide.
- Tieman, J, & Bradley, S 2013, 'Systematic review of the types of methods and approaches used to assess the effectiveness of healthcare information websites', *Australian Journal of Primary Health*, vol. 19, pp. 319-24.
- Tilse, C, Wilson, J, White, B, Willmott, L, & McCawley, A 2014, 'Enduring Powers of Attorney: Promoting attorneys' accountability as substitute decision makers', *Australasian Journal on Ageing*, vol. 33, no. 3, pp. 193-97.
- Tobler, D, Greutmann, M, Colman, J, Greutmann-Yantiri, M, Librach, S, & Kovacs, A 2012, 'Knowledge of and Preference for Advance Care Planning by Adults With Congenital Heart Disease', *American Journal of Cardiology*, vol. 109, no. 12, pp. 1797-1800.
- Tulsky, J, Arnold, R, Alexander, S, Olsen, M, Jeffreys, A, Rodriguez, K, Skinner, C, Farrell, D, Abernethy, A, & Pollack, K 2011, 'Enhancing communication between oncologists and patients with a computer-based training program', *Annals of Internal Medicine*, vol. 155, pp. 593-601.
- Tuck, K, Zive, D, Schmidt, T, Carter, J, Nutt, J, & Fromme, E 2015, 'Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's disease', *Parkinsonism and Related Disorders*, <http://dx.doi.org/10.1016/j.parkreldis.2015.08.021>.
- Tung, E, Vickers, K, Lackore, K, Cabanela, R, Hathaway, J, & Chaudhry, R 2011, 'Clinical Decision Support Technology to Increase Advance Care Planning in the Primary Care Setting', *American Journal of Hospice & Palliative Medicine*, vol. 28, no. 4, pp. 230-35.
- van Uden-Kraan, C, Drossaert, C, Taal, E, Seydel, E, & van de Laar, M 2009, 'Participation in online patient support groups endorses patients' empowerment', *Patient Education & Counseling*, vol. 74, pp. 61-9.
- Volandes, A, Lehmann, L, Cook, E, Shaykevich, S, Abbo, E, & Gillick, M 2007, 'Using video images of dementia in advance care planning', *Archives of Internal Medicine*, vol. 167, no. 8, pp. 828-33.
- Volandes, A, Ariza, M, Abbo, E, & Paasche-Orlow, M 2008, 'Overcoming educational barriers for advance care planning in Latinos with video images',

Journal of Palliative Medicine, vol. 11, no. 5, pp. 700-06.

- Volandes, A, Paasche-Orlow, M, Barry, M, Gillick, M, Minaker, K, Chang, Y, Cook, E, Abbo, E, El-Jawahri, A, & Mitchell, S 2009, 'Video decision support tool for advance care planning in dementia: randomised controlled trial', *British Medical Journal*, vol. 338, pp. 2159 - 64.
- Volandes, A, Barry, M, Chang, Y, & Paasche-Orlow, M 2010, 'Improving decision making at the end of life with video images', *Medical Decision Making*, vol. 30, no. 1, pp. 29-34.
- Volandes, A, Brandeis, G, Davis, A, Paasche-Orlow, M, Gillick, M, Chang, Y, Walker-Corkery, E, Mann, E, & Mitchell, S 2012a, 'A Randomized Controlled Trial of a Goals-of-Care Video for Elderly Patients Admitted to Skilled Nursing Facilities', *Journal of Palliative Medicine*, vol. 15, no. 7, pp. 805-11.
- Volandes, A, Levin, T, Slovin, S, Carvajal, R, O'Reilly, E, Keohan, M, Theodolou, M, Dickler, M, Gerecitano, J, Morris, M, Epstein, A, Naka-Blackstone, A, Walker-Corkery, E, Chang, Y, & Noy, A 2012b, 'Augmenting advance care planning in poor prognosis cancer with a video decision aid: a preintervention-postintervention study', *Cancer*, vol. 118, no. 17, pp. 4331-38.
- Wendler, D, & Rid, A 2011, 'Systematic Review: The effect on surrogates of making treatment decisions for others', *Annals of Internal Medicine*, vol. 154, no. 5, pp. 336-46.
- Wetle, T 1994, 'Individual preferences and advance directives', *The Hastings Centre Report*, vol 24, no. 6, p. S5.
- White, B, Tilse, C, Wilson, J, Rosenman, L, Strub, T, Feeney, R, & Silvester, W 2014, 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, vol. 44, no. 10, pp. 975-80.
- Wilkinson, A, Wenger, N, Shugarman, L, & Rand, C 2007, 'Literature Review on Advance Directives', United States Department of Health and Human Services, Washington DC.
- Wilson, C, Newman, J, Tapper, S, Lai, S, Cheng, P, Wu, F, & Tai-Seale, M 2013, 'Multiple Locations of Advance Care Planning Documentation in an Electronic Health Record: Are They Easy to Find?', *Journal of Palliative Medicine*, vol. 16, no. 9, pp. 1089-94.
- World Health Organisation 2014, *eHealth*, WHO, viewed 19 April 2015, <http://www.who.int/trade/glossary/story021/en/>
- Yamada, R, Galecki, A, Goold, S, & Hogikyan, R 1999, 'A multimedia intervention on cardiopulmonary resuscitation and advance directives', *Journal of*

General Internal Medicine, vol. 14, no. 9, pp. 559-63.

Zive, D, Fromme, E, Schmidt, T, Cook, J & Tolle, S 2015, 'Timing of POLST form completion by cause of death', *Journal of Pain and Symptom Management*, post-author corrections.