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Southern Cross University

Knowledge about and Attitudes towards End of Life Care for Gay, Lesbian, Bisexual and Transgender People

Phase 2, Stage 1: State-wide Survey

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LIST OF ACRONYMS

ACON	A NSW community-based GLBT health promotion organisation (Previously the AIDS Council of NSW).
ASLaRC	Aged Services Learning and Research Centre, Southern Cross University.
GLBT	Gay, Lesbian, Bisexual and Transgender
GLBTI	Gay, Lesbian, Bisexual, Transgender and Intergender
GRAI	GLBTI Retirement Association Inc

GLOSSARY OF TERMS

Advance Care Planning: There are a number of mechanisms that people can use to plan in advance for a time of future incapacity, both in relation to their *finances* and their *medical treatment and personal care*. While terminology and regulations are different in each State/ Territory of Australia, the general principles are similar. NSW terminology is used in this report.

Enduring Power of Attorney: Allows the appointment of a person (usually a trusted relative or friend) to make decisions about financial and property matters for the person who has appointed them. The person appointed does not have authority to make medical or personal decisions for the person making the appointment. The EPA may take effect immediately or at some future specified time. “Enduring” means that it remains in effect when the person making the appointment loses capacity.

Enduring Guardian: A person may appoint a trusted relative or friend as their Enduring Guardian to make medical, dental or other health and personal care decisions for them in case the time comes when they can no longer do so for themselves. The person appointed must agree to the appointment by signing the EG form and should discuss with the person making the appointment what treatment s/he would or would not want under certain circumstances.

Person Responsible: If a person loses capacity and they have not appointed someone as their Enduring Guardian, the legislation provides that authority for making such decisions moves to the *Person Responsible*; in order of authority this is the person's spouse (if there is one); if not, a non-professional carer; if there is no carer, then the decision-making authority moves to a close relative or friend.

(Note: the legislation does not give authority to "Next-of-Kin". While in some cases the Person Responsible may be the patient's next-of-kin, their authority to make the decisions does not come from that position. For example, a close friend may have been providing care for the person, but a blood relative thinks he should have authority to make the person's health-care decisions because he is the Next-of-Kin. He does not – the close friend would be the first in the hierarchy of Person Responsible).

Advance Health Care Directive: is a written document which allows a person to make known his/her wishes for health care in case of future incompetence. It only allows actions which a person could legally consent to if they were still competent. NSW does not have specific legislation relating to AHCDs, unlike most of the other states and territories of Australia, but a case in the NSW Supreme Court in August 2009 (*Hunter New England Area Health Service vs A)* confirmed that Advance Health Care Directives are legally enforceable under the Common Law.

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EXECUTIVE SUMMARY

Introduction: Increasing evidence suggests that many gay, lesbian, bisexual and transgender (GLBT) people are being denied their legal rights in their own end-of-life care and the end-of-life care of their partners and other important people in their lives.

A study in the Northern Rivers region of NSW in 2009, which investigated end-of-life care issues for GLBT people and the use of legal mechanisms such as Advance Care Planning to support the rights of GLBT people at the end of life (Lienert T, Cartwright C, Beck K. 2010) found evidence of active discrimination and abuse of GLBT people. Building on the findings of the Phase 1 study, a second State-wide study funded by a grant from the Law and Justice Foundation of NSW was conducted in 2009-2010.

The Phase 2 study is being conducted in two stages.

- Stage 1, which is the subject of this Report, is a state-wide hard copy and on-line survey and a series of in-depth interviews.
- Stage 2 will utilise the findings from the Phase 1 study, the state-wide survey and targeted interviews to develop resources to assist GLBT people to undertake Advance Care Planning.

Methodology:

- Ethics Approval was received from Southern Cross University Human Research Ethics Committee and the ACON Ethics Committee.
- A Steering Committee was established;
- A hard-copy questionnaire was developed and modified for on-line use. The questionnaire was distributed through Newsletters, magazines and other networks of the research team and Steering Committee members.
- Four semi-structured interviews were conducted with one transmale and four transfemales.

Results:

- A total of 305 useable questionnaires was returned; as it was not possible to track actual questionnaire distribution, a response rate could not be determined.

- Respondent age range was from less than 30 to over 80, with the majority aged 40-69.
- The majority of respondents (91%) identified as Male or Female; 48% identified as Gay and 25% as Lesbian;
- The majority of respondents (75%) were open to all significant others in their lives;
- Just over half (51%) were in a relationship, with 45% being single; 77% had been in their relationship for four years or more;
- More respondents (59%) had a University or post-graduate degree than the general population and average income was above that of the general population (43% had annual income of $50,000 or more);
- Religious affiliation included 46% with no affiliation and 32% affiliated with a Christian religion;
- Only 21% rated their health as Fair or Poor, while 53% said it was Excellent or Very Good.

Knowledge of/Experience with Advance Care Planning Options was variable; respondents were most likely to have heard of, and to have had experience with Enduring Power of Attorney and least likely to have heard of or had experience with Advance Health Care Directives. However, knowledge did not translate into understanding, as the majority of respondents incorrectly identified who had legal authority for medical decision-making in a specified scenario, based on that person having the patient's Enduring Power of Attorney (which, in NSW, applies only to property and money).

Experience with Serious Illness: 25% of respondents had received care in the past 10 years because of a serious illness and 32% had provided care for someone in that situation.

Health Care Provider/End-of-Life Care Discussions: 87% of respondents had a regular GP; only 13% had discussed their preferences for end-of-life care with their health care provider, although 76% said that they would be comfortable if their health care provider raised the issue with them.

Assistance if Seriously Ill: Although the majority of respondents thought that it was very or somewhat likely that at least one person would provide them with assistance if they were seriously ill, in relation to giving advice (96%); helping with household chores (84%);

providing a place to stay for a few weeks (82%); loaning them $500 (78%); and helping with bathing or dressing (77%), from 4% to 23% (in order of tasks listed above) said that it was not very likely that they would receive such assistance.

Substitute decision-making: When asked who they would want to make medical decisions for them if they could not do so, 44% nominated their partner; 25% said a blood relative and 17% said a friend; 52% said that they had spoken to the nominated person about their wishes. Those who had not done so identified a range of reasons why not, including that the issue had not arisen (49%) or that because they were young and/or healthy they saw no need (12%); 10% regarded such as discussion as morbid and 8% could not identify a substitute decision-maker. Just over half (55%) of the respondents were confident that their wishes would be carried out if they were seriously ill and could not speak for themselves; 90% said that, if they were in the late stages of a life-threatening illness, they would want treatment that focussed on relief of symptoms, even if that shortened their life.

Preferred place to die: Respondents nominated their agreement to each of five options as preferred place to die (so responses do not add to 100%); respondents strongly agreed or agreed that they would prefer to die: at home – 79%; in a GLBT-specific care facility - 61%; in a hospice – 41%; in a hospital – 43%; and in a nursing home – 16%.

Advance Care Planning and Barriers to this: 29% of respondents had given someone Enduring Power of Attorney; 18% had appointed an Enduring Guardian but only 12% had written an Advance Health Care Directive. Barriers to undertaking Advance Care Planning included: lack of knowledge, both about the actual documents and about how to complete them, and the belief that it was “not necessary at present”, with some respondents saying that they would prefer to leave it until the situation arises.

Discussion, Conclusions and Recommendations: Although 75% percent of respondents were open about their sexuality to all significant family members, 9% were not open to any. It is possible that the sample is over-represented by those who are open about their sexuality, as they would potentially have had more opportunity than those who are not to be included in the study, given that survey distribution was undertaken by GLBT organisations, and many GLBT people who are not open about their sexuality may also not belong to such organisations. This is an important consideration as an overview of the data indicates that those who are not open about their sexuality may be at particular risk in relation to their end-of-life care. However, if this group is under-represented it would suggest that issues identified in the study may be of even more concern than the findings indicate.

In addition, people in poor health may have been under-represented in this study, with only 4% of respondents so identifying. Given the often significant negative differences in the study findings between this group and the others in relation to end-of-life care, it would be reasonable to suggest that their situation could be worse than depicted here and service providers working with GLBT people in poor health may need to be cognisant of that.

This study highlighted the urgent need for focussed education for GLBT people in NSW about legally available Advance Care Planning options and GLBT-specific Advance Care Planning resources, particularly as many GLBT people are ageing and are likely to be facing the need to make end-of-life decisions for partners and/ or friends.

We strongly recommend that GLBT organisations and NSW Health work with Divisions of General Practice to encourage GPs to become familiar with the law in NSW relating to Advance Care Planning, to discuss these issues with their GLBT patients and to assist them to appoint an Enduring Guardian and complete an Advance Health Care Directive.

Respondents identified in this study as being at particular risk in relation to receiving adequate care and treatment at the end of life included those who: were not open about their sexuality to any significant others; nominated a Gender other than Female or Male; were in a relationship other than single or partnered; were grieving the loss of a partner; had less than Year 10 education; had incomes of less than $20K per annum; or were in poor or fair health. People in such sociodemographic groups may require more support than others to talk about, and plan for, their end-of-life care.

While the majority of respondents said that they would prefer to die at home, 61% also nominated a GLBT-specific care facility as a preferred place to die. This appears to be entering the “end-of-life care for GLBT people” discussions (GRAI, 2010; Linton Estate 2009) and is an issue that may require further research to identify if the expressed need is actually for such a facility or is instead an expression of the need for a facility (or facilities) where GLBT people can feel safe to be who they are, to be treated with respect and dignity by the staff, to have the people they most care about around them and to have their wishes respected. The strong disagreement from respondents that they would prefer to die in a nursing home may also suggest that these respondents were aware of the abuse and discriminatory behaviour that has occurred is such facilities (Lienert et al, 2010).

Lack of knowledge about Advance Care Planning documents and how to complete them – which were major barriers identified by participants in relation to giving someone Enduring Power of Attorney to make financial decisions, appointing an Enduring Guardian to make health care decisions and completing an Advance Health Care Directive - underlines the need for education, and for GLBT-specific resources which can be used to address this information gap. However, the reason given for non-completion that it was "not necessary at present" indicates a misunderstanding or misinformation gap (i.e. that such documents are only completed by people who are ill) or a degree of denial that a time may come when they would need such documents.

It is therefore important that resources are developed that will address the issue of not knowing where or how to do it, especially if the organisations that provide support to GLBT people can be given access to such resources and provided with the information and education they need to ensure that their members are regularly informed about the options that are available to them – and perhaps, the consequences of what can happen if those options are not taken up.

RESOURCE DEVELOPMENT

The next stage of this study will be to use the results of this survey, plus the literature review and focus group material from the first phase of this work, to develop GLBT-specific resources to meet the needs outlined above. A limited-edition run of hard-copy resources will be produced and the resources will also be made available on relevant web-sites.

It is hoped that this research and the resulting resources will contribute to enhancing the end-of-life experiences of GLBT people and their carers/loved one/significant others in Australia.

Chapter 1 - BACKGROUND

1.1 INTRODUCTION

Increasing evidence from research, supported by anecdotal reports to relevant legal and community services, identified major issues in relation to end-of-life care for gay, lesbian, bisexual and transgender (GLBT)* people. Although all States and Territories in Australia have implemented legislation relating to end-of-life decision-making and substitute judgment it appears that many GLBT people are being denied their legal rights in their own end-of-life care and the end-of-life care of their partners and other important people in their lives.

*(Note: While this study did not specifically identify the needs of Intersex people, the issues researched/discussed are also relevant to this group).

In January 2009, the Aged Services Learning and Research Centre (ASLaRC), Southern Cross University, in conjunction with ACON (a NSW community-based GLBT health promotion organisation) conducted the first Phase of a study to examine the issue of end-of-life care for GLBT people and the use of legal mechanisms such as Advance Care Planning to support the rights of GLBT people at the end of life (Lienert T, Cartwright C, Beck K. 2010).

1.2 MAJOR FINDINGS from the phase 1 study included:

- The lack of legitimacy of same-sex relationships, sexual and gender identity accorded by family, health care professionals and society, and the subsequent failure by family and health care professionals to acknowledge the appropriate substitute decision-maker/ Person Responsible in end-of-life care for GLBT people;
- the additional grief, loss of dignity and loss of property upon the death of their partner caused by such exclusion;
- a number of service providers did not know about the rights of same-sex partners to claim status as Person Responsible (a legally-authorised decision-maker under NSW Guardianship Act 1987), and therefore to make health care decisions should their partner lack capacity;
- levels of awareness and use of the legal mechanisms that assist in Advance Care Planning varied considerably among clients of the service providers consulted. When service providers encouraged the use of legal mechanisms, awareness and use was higher;

- the importance of GLBT people communicating their end-of-life care wishes to family and health care professionals before they become incapacitated, in order to ameliorate the risk that their wishes and those of their close friends and partners would be overridden by blood relatives and health care workers;
- the important role of advocates in ensuring that the wishes of the dying person were met.

Barriers to Advance Care Planning by GLBT people identified in Phase 1 included:

- not wanting to think about the end of life;
- (for gay men only) a denial of the realities of ageing and death;
- lack of time / low priority;
- lack of knowledge;
- not knowing who to appoint to significant decision-making roles.

1.3 PHASE 2

FUNDING FOR PHASE 2

The second Phase of this research has been funded by a grant from the Law and Justice Foundation of NSW.

PHASE 2 STUDY OUTLINE

Building on findings from the Phase 1 study, Phase 2 includes a state-wide survey, some in-depth interviews and the development of GLBT-specific Advance Care Planning Resources.

Aims of the project

- To research the experiences of gay, lesbian, bisexual and transgender (GLBT) people in NSW around end-of-life care, including the level of awareness and use of legally-available mechanisms to plan for end-of-life care.
- To use the results of that research to develop printed and internet resources directed to these target groups with information about their legal rights and available legal mechanisms that can assist, and how to access them in NSW. The target group is GLBT residents in metropolitan and regional NSW, many of whom are economically and socially disadvantaged as a result of historical discrimination, social stigma and lack of

legal recognition of relationships and gender identity (*ACON Healthy GLBT Ageing Strategy, 2006-2009*). The research process itself aims to educate participants.

- The resulting resources and research report aim to inform future community legal education for the target group, as well as policy and practice developments in the area of end-of- life care more generally.

The project is consistent with the objectives of the Law and Justice Foundation of NSW in that it will conduct research into use of the justice system, and facilitate access to justice and access to information about the justice system by economically and socially disadvantaged people.

The Phase 2 study is being conducted in two stages.

- **Stage 1,** which is the subject of this Report, is a state-wide hard copy and on-line survey and a series of in-depth interviews.
- **Stage 2** will utilise the findings from the Phase 1 study, the state-wide survey and targeted interviews to develop resources to assist GLBT people to undertake Advance Care Planning.

Chapter 2 - METHODOLOGY

2.1 ETHICS APPROVAL

Given the sensitive nature of the study, a full National Ethics Application Form (NEAF) submission was made to Southern Cross University Human Research Ethics Committee, with a copy also submitted to ACON Ethics Committee. Ethics Approval was granted by both organisations.

2.2 LITERATURE REVIEW

An extensive literature review was undertaken for the Phase 1 study. Major themes in the literature included:

1. The stigma and discrimination faced by gay and lesbian people prevents end-of-life care planning for fear of being outed, leading to ‘disenfranchised grief’ and loss of entitlements for same-sex partners;
2. The legal need for GLBT people to engage with Advance Care Planning in order to protect their rights and counter discrimination;
3. The actual discrimination and violence faced by GLBT people in health care settings leads to a failure to or delays in GLBT people accessing health services, resulting in problems in end-of-life care;
4. The fear of discrimination leads to a similar failure to access services;
5. Barriers such as lack of knowledge and difficulties identifying alternative decision-makers mean there is a need for information resources;
6. Difficulties in end-of-life care mean there is a need for advocacy;
7. Advance Care Planning can work to assist GLBT people to die with dignity;
8. Future challenges, including the need for:
    - 8.1 systemic change;
    - 8.2 training of and advocacy in mainstream services;
    - 8.3 GLBT specialist and specific services; and
    - 8.4 informed GLBT people as agents of change.

2.3 ESTABLISHMENT OF STEERING COMMITTEE

As required by the Funding Agreement, a Steering Committee of relevant stakeholders was established to provide support and advice to the research team (see Acknowledgements). Given the geographic spread of Steering Committee members, meetings were conducted by teleconference.

2.4 STATE-WIDE SURVEY

2.4.1 Questionnaire Design

A questionnaire was developed for the state-wide survey, based on research previously undertaken by Professor Cartwright and modified by reference to the literature and Phase 1 findings.

Following approval of the questionnaire by the Steering Committee, it was piloted with two older gay men and minor amendments were made. Piloting confirmed that the explanation provided at the beginning of the questionnaire was valuable and immediately highlighted the importance of the issues to the participants.

A hard copy version of the questionnaire was printed (See Appendix 1) and it was also converted to Survey Monkey format for on-line distribution (a format which allows anonymous completion and submission). Reply-Paid envelopes were distributed with hard-copy questionnaires but to ensure anonymity, no identifying information was on the questionnaires or the envelopes, nor was any identifying information requested of respondents. A Promotional Flyer for the Hard Copy Survey was developed, to be placed on notice boards of supporting organisations (See Appendix 2), and an Invitation to Participate in the On-Line Survey was developed for inclusion in the relevant Newsletters (See Appendix 3).

2.4.2 Questionnaire Distribution

In order to reach as many members of the GLBT community as possible, members of the Steering Committee undertook to distribute hard copies through newsletters of their organisations and also to make them available at reception areas and drop-in centres. Mailouts included: 700 by the Gender Centre, through their Newsletter “Polare”; 500 by MAG (Mature Aged Gays – a volunteer group) through the MAGazine, and 220 by ACON to their members. Newsletter recipients were also offered the option of completing the questionnaire on-line. Anecdotal and email information indicated that some recipients photocopied the hard-copy version and sent it to friends/other people they thought may be interested while on-line completed surveys from people in other states/ territories alerted the team to the fact that the on-line link had also been widely distributed. While it was gratifying that the study was judged to be of sufficient importance that recipients took the trouble to send it on, it actually created a problem as the terminology, and the legislation which governs Advance Care Planning, is different in each state/territory; not only might this have confused interstate recipients but the resulting questionnaires had to be deleted from the study (see Chapter 3). An additional problem was that, although this methodology resulted in a wide distribution, it was not possible to track how many people actually received a questionnaire (e.g. newsletter mailing lists are often not current for everyone on the list, and there was no way of knowing how many were copied and/or linked on); therefore it was not possible to quantify the denominator for the study and to determine a response rate.

2.5 DATA ANALYSIS

As completed hard-copy questionnaires were received they were coded and entered into an Excel database, developed to accommodate both hard copy and Survey Monkey data. Following the survey closing date, all data were merged into an SPSS file for analysis. First-cut frequencies, plus chi-square analysis by demographic variables, were then undertaken. Results are reported in Chapter 3.

2.6 INTERVIEWS

Four semi-structured interviews were conducted by the lead researcher with 1 transmale and 3 transfemales; ages ranged from late 20s to mid-70s. Full transcripts of those interviews will form part of the final report of this study and only major themes are presented here. These included:

- No interviewee had experience of caring for a terminally ill person but two had spent time with someone who was dying.
- Two interviewees wanted euthanasia; one of these was prepared to commit suicide rather than go into a nursing home.
- If appointing an Enduring Guardian, 3 interviewees said that they would choose a family member and one would choose a close friend but most said that “it was not necessary yet”.

- Greatest concerns of the interviewees were: to be comfortable, to be pain free, to be in control; not wanting to be a burden on others, cause family stress;
- Two respondents thought planning ahead was a good idea.
- Barriers to end-of-life care planning identified by the interviewees included: not knowing what is available or how to do it; not needing to do it now – still healthy, “it’s a long way off”; “difficult to get information, especially if you are from the country – lack of awareness is the biggest thing”.
- Greatest barrier: other people who think they know best what is good for you – religious people.
- Three interviewees had a good GP but two still expressed lack of faith in the medical profession, especially in hospitals.
- Only one interviewee said that they would prefer a GLBTI-specific nursing home.

The results of all the research undertaken to date will be used to generate GLBT-specific Advance Care Planning resources.

Chapter 3 - RESULTS

3.1 RESPONSE

Because of the method of questionnaire distribution, as outlined in the Methodology section, it was not possible to determine a response rate. A total of 362 completed questionnaires were returned. However, examination of the post-codes reported by respondents indicated that the questionnaire had been distributed outside NSW when it was intended only for people living in NSW because of different legislation and terminology in other States and Territories. Therefore, questionnaires with non-NSW post-codes were removed from the sample, leaving a total of 305 completed questionnaires for the analysis, 202 from the hard copy distribution and 103 from the on-line Survey Monkey component.

3.2 DEMOGRAPHIC CHARACTERISTICS

Respondents were asked for demographic information to enhance understanding of variables that might affect knowledge of, and attitudes to, Advance Care Planning.

Age

Of the 292 respondents who answered this question, 26 percent were aged 50 – 59, 22 percent each were aged 40 – 49 and 60 – 69, 17 percent were under the age of 40 and 13 percent were aged over 70 (see Table 3.1).

Table 3.1: Age Group

Age group	N	%
< 30	19	6
30 – 39	32	11
40 – 49	65	22
50 – 59	74	26
60 – 69	64	22
70 – 79	33	11
80+	5	2
Total	**292**	**100**

Gender

Of the 288 respondents who answered this question, 51 percent identified as male, 40 percent as female, 4 percent as transgender, 1 percent each as transsexual and intergender and 4 percent answered 'other' (see Table 3.2).

Table 3.2: Gender

Gender	N	%
Male	148	51
Female	116	40
Transgender	10	4
Female / Male	3	1
Transsexual	3	1
Intergender	3	1
Male / Female	1	<1
Another Gender	4	2
Total	**288**	**100**

Sexual Orientation

Of the 292 respondents who answered this question, 48 percent of respondents identified as Gay, 25 percent as Lesbian, 12 percent as Bisexual, 6 percent as Heterosexual and the remaining 9 percent identified another sexual orientation (see Table 3.3).

Table 3.3: Sexual Orientation

Sexual Orientation*	N	%
Gay[1]	140	48
Lesbian[2]	74	25
Bisexual[3]	36	12
Heterosexual[4]	18	6
Queer[5]	10	4
Transvestite[6]	2	<1
Other[7]	12	4
Total	**292**	**100**

*Note: Although the majority of those who identified as Gay also identified as Male, not all did; not everyone who identified as Lesbian also identified as Female (see next page).

Sexual Orientation by participant-identified Gender

[1] Gay = 92% Male (n=136); 1% Female (n=2); 1% (n=1) each Transgender and Another Gender

[2] Lesbian = 96% Female (n=69); 1% (n=1) each Transgender, Transsexual and Intergender

[3] Bisexual = 65% Female (n=22); 21% Male (n=7); 9% Transgender (n=3); 3% (n=1) each Female/Male and Intergender

[4] Heterosexual = 56% Female (n=10); 22% Transgender (n=4); 11% (n=2) each Male and Transsexual

[5] Queer = 60% Female (n=6); 20% Another Gender (n=2); 10% (n=1) each Male and Transgender

[6] Transvestite = 50% each (n = 1) Female and Female/Male

[7] Other Orientation = 50% Female (n=6); 17% Male (n=2); 8% (n=1) each Male/Female, Female/Male, Intergender and Another Gender.

Open about Sexuality

Respondents were asked if they are open to significant family members about their sexual orientation; of the 292 respondents who answered the question, 75 percent answered 'Yes, to all', 16 percent said 'only to some' and 9 percent said 'no' (see Table 3.4).

Table 3.4: Open about Sexuality

Open about Sexuality	N	%
Yes to all	219	75
Only to some	45	16
No	27	9
Total	**292**	**100**

Relationship Status

Respondents were asked to describe their current relationship status (from a list provided, with an "other" option). Of the 288 respondents who answered this question, 45 percent were single; 34 percent are living with a partner; 17 percent have a partner but they are not living together; 3 percent are grieving the loss of a partner; and 1 percent answered "other" (see Table 3.5).

Table 3.5: Relationship Status

Relationship status	N	%
Single	131	45
Partner /Living Together	97	34
Partner /Not Living Together	48	17
Grieving Loss of Partner*	8	3
Other	4	1
Total	**288**	**100**

* Note: There is no equivalent category as widow/widower in GLBT relationships, so *Grieving Loss of Partner* has been used in this study (see also Auger, 2003).

Time in a Relationship

Of the 148 respondents who answered this question, 47 percent have been in their relationship for more than 10 years, 30 percent for 4 to 10 years and 23 percent for 4 years or less (see Table 3.6).

Table 3.6: Time in Relationship

Time in a relationship	N	%
Less than 1 month	1	<1
1 – 6 months	2	1
7 to 12 months	5	3
1 to 2 years	12	8
2 – 4 years	14	10
4 – 10 years	44	30
More than 10 years	70	47
Total	**148**	**100**

Education

Of the 291 respondents who answered this question, 26 percent have a Post-graduate degree, 33 percent have a university degree, 16 percent have a technical or trade certificate, 8 percent have completed Year 12 at high school and 17 percent have less than Year 12 level of education (see Table 3.7).

Table 3.7: Education

Education Level	N	%
Did not complete primary school	1	<1
Completed primary school	7	3
Completed year 10 at high school	41	14
Completed year 12 at high school	22	8
Technical or trade certificate	48	16
University degree	95	33
Post-graduate degree	77	26
Total	**291**	**100**

Income

Respondents were asked what their household annual income is: 287 respondents answered the question, of whom 43 percent have an income of $50,000 or more per annum; 8 percent said $40,000 - $49,000; 11 percent have $30,000 - $39,000; 13 percent said $20,000 – $29,000; and 25 percent have an annual household income of less than $20,000 (see Table 3.8).

Table 3.8: Income

Income	N	%
Less than $20,000	72	25
$20,000 to $29,000	35	12
$30,000 to $39,000	31	11
40,000 to $49,000	24	8
$50,000 or more	125	44
Total	**287**	**100**

Religion

Of the 298 respondents who answered this question, 46 percent had no religious affiliation, 13 percent were Catholic, 11 percent Anglican, 6 percent Buddhist and 24 percent nominated another religious affiliation or philosophy (see Table 3.9).

Table 3.9: Religion

Religion	N	%
No affiliation	134	46
Catholic	38	13
Anglican	31	11
Other Christian	24	8
Buddhist	19	7
Atheist	12	4
Other*	31	11
Total	**298**	**100**

*Other included Spiritual (n=8); Pagan (n=5); Agnostic (n=4); Jewish (n=3); and one respondent in each case nominated a range of other philosophies.

Religious or Philosophical Beliefs

Respondents were asked "To what extent do your religious or philosophical beliefs influence your opinions about medical decisions at the end of life?" Of the 289 respondents who answered this question, 60 percent replied that their religious or philosophical beliefs do not influence their opinions about such decisions at all; 22 percent said 'somewhat' and 18 percent said that their beliefs influenced their opinions on such matters 'a great deal' (see Table 3.10).

Table 3.10: Religious or Philosophical Beliefs

Religious or philosophical Beliefs	N	%
Not at all	173	60
Somewhat	63	22
A great deal	53	18
Total	**289**	**100**

Health Status

Respondents were asked to rate their health, on a 5-point scale from Excellent to Poor. The majority of the 291 respondents who answered the question rated their health as: Excellent (19%, n=54); Very Good (34%, n=99); or Good (26%, n=76), with 17% (n=49) saying that their health was Fair; and only 4% (n=13) rating their health as Poor (see Table 3.11).

Table 3.11: Health Status

Health Status	N	%
Excellent	54	19
Very Good	99	34
Good	76	26
Fair	49	17
Poor	13	4
Total	**291**	**100**

Private Health Insurance

Respondents were also asked if they had private health insurance; 293 respondents answered the question, of whom 47% (n=139) said that they did and 53% (n=154) said that they did not.

3.3 KNOWLEDGE OF AND EXPERIENCE WITH ADVANCE CARE PLANNING OPTIONS

Respondents were asked if, before doing the survey, they had heard of Advance Health Care Directives (AHCD), Enduring Power of Attorney (EPoA), Enduring Guardian (EG) or Person Responsible (PR) and, if they had heard of these options, if they had had any experience with them. Reporting below is from highest to lowest responses:

- 87 percent (n=239) had heard of EPoA; only 160 of these 239 respondents answered the question about whether or not they had had experience with this, with 59 percent saying that they had;
- 59 percent (n=160) had heard of EG; 57 percent of the 105 respondents who answered the question said that they had had experience with this;
- 52 percent (n=135) had heard of PR; of the 88 respondents who answered the question, 59 percent said that had had experience with this option;
- 37 percent (n=101) had heard of AHCD; 57 percent of the 56 respondents who answered the question said that they had had experience with this option (see Table 3.12)

Table 3.12: Heard of, or Had Experience With, Advance Care Planning Options

Option	**Heard Of**			**Had Experience With**		
	N	**Yes**	**No**	**N**	**Yes**	**No**
		% (n)	**% (n)**		**% (n)**	**% (n)**
Enduring Power of Attorney	276	87 (239)	13 (37)	160	59 (94)	41 (66)
Enduring Guardian	272	59 (160)	41 (112)	105	57 (59)	43 (45)
Person Responsible	262	52 (135)	48 (127)	88	59 (52)	41 (36)
Advance Health Care Directive	269	38 (101)	62 (168)	56	57 (32)	43 (24)

Chi-Square Analysis

Chi-square analysis of responses to the questions about knowledge of, and experience with, Advance Care Planning options, was undertaken by demographic characteristics of respondents.

Age

There were no significant differences by age group in relation to respondents having heard of, or having had experienced with, any of the Advance Care Planning options, although the group aged less than 30 were least likely to have heard of AHCD, EPoA or EG and those 30-39 were least likely to have heard of PR; those less than 30 were also least likely to have had experience of any of the options.

Gender

The majority of respondents (n=264) identified as Female or Male, with only 24 nominating a different gender. As numbers nominating a gender other than Female or Male were too small to allow Chi-Square Analysis by individual grouping, the gender options were collapsed for analysis into Female/Male/Another Gender.

Differences by gender in relation to respondents having heard of Advance Health Care Directives, Enduring Power of Attorney and Enduring Guardian reached significance, with Females being the most likely, and those who nominated another gender being the least likely, to have heard of these 3 options. Differences did not reach significance in relation to Person Responsible (see Table 3.13).

There were no significant differences by gender in relation to having had experience with any of the Advance Care Planning options, although Females were somewhat more likely than Males to have had experience with AHCD, EG and PR, with Males being just slightly more likely than Females and those who nominated Another Gender to have had experience with EPoA.

Table 3.13: Heard of ACP Options, by Gender

Gender Group	AHCD N= 256	EPOA N=263	EG N= 259	PR N= 250
	% (n)	% (n)	% (n)	% (n)
Female	47 (48)	92 (97)	65 (68)	54 (55)
Male	33 (44)	88 (120)	56 (76)	51 (67)
Another Gender	16 (3)	60 (12)	32 (6)	35 (6)
TOTAL	**37 (95)**	**87 (229)**	**58 (150)**	**51 (128)**
χ^2_2; **p value**	**8.726; .013**	**14.909; .001**	**7.571; .023**	**n.s**

Sexual Orientation

Categories for Chi-Square Analysis by sexual orientation were collapsed into four, i.e. Gay, Lesbian and Bisexual, as these were the largest groupings, and Other, as there were insufficient numbers in all of the other categories to allow for individual analysis. Differences by group reached statistical significance only in relation to the Advance Health Care Directive option, with respondents who identified as Lesbian (54%) being the most likely to have heard of this and those in the Other group (26%) being least likely to have done so (see Table 3.14).

More than 80% of all four groups had heard of Enduring Power of Attorney; the Lesbian group were the most likely, and the Other group were the least likely, to have heard of Enduring Guardian or Person Responsible, but differences did not reach statistical significance (see Table 3.14).

Table 3.14: Heard of ACP Options, by Sexual Orientation

Sexual Orientation	AHCD N= 259	EPoA N= 266	EG N= 262	PR N= 253
	% (n)	**% (n)**	**% (n)**	**% (n)**
Gay	32 (41)	86 (112)	57 (74)	52 (65)
Lesbian	54 (36)	94 (66)	68 (47)	57 (38)
Bisexual	35 (11)	81 (26)	61 (19)	55 (16)
Other	26 (9)	82 (28)	41 (13)	35 (11)
TOTAL	**37 (97)**	**87 (232)**	**58 (153)**	**51 (130)**
χ^2_3; p value	**10.830; .013**	**n.s.**	**n.s.**	**n.s.**

In relation to Experience with Advance Care Planning Options, differences between the groups reached statistical significance only in relation to Enduring Guardian, with the Lesbian group being almost twice as likely as the other three groups to have had experience with this option (see Table 3.15). This group was also the most likely to have had experience with the other three options but differences were not statistically significant.

Table 3.15: Experience with ACP Options, by Sexual Orientation

Sexual Orientation	AHCD N= 53	EPoA N= 158	EG N= 102	PR N= 86
	% (n)	**% (n)**	**% (n)**	**% (n)**
Gay	55 (12)	59 (49)	49 (26)	52 (23)
Lesbian	65 (11)	66 (23)	80 (20)	71 (15)
Bisexual	50 (4)	59 (10)	42 (5)	50 (5)
Other	50 (3)	43 (10)	50 (6)	64 (7)
TOTAL	**57 (30)**	**58 (92)**	**56 (57)**	**58 (50)**
χ^2_3; p value	**n.s.**	**n.s.**	**8.052; .045**	**n.s.**

Openness about Sexuality

The two groups who were Open to All, or Open to Some significant family members about their sexuality were significantly more likely to have heard of Enduring Power of Attorney and Person Responsible than the group who said No to this question. The two groups who were Open to All or Some were also more likely than the No group to have heard of Advance Health Care Directives and Enduring Guardian, but the differences did not reach statistical significance (see Table 3.16).

Table 3.16: Heard of ACP Options, by Openness about Sexuality

Openness About Sexuality	**AHCD** N= 257	**EPOA** N= 264	**EG** N= 260	**PR** N= 252
	% (n)	**% (n)**	**% (n)**	**% (n)**
Open to all	40 (77)	90 (178)	59 (117)	53 (101)
Open To Some	35 (14)	88 (36)	68 (26)	61 (22)
Not Open	21 (5)	68 (17)	37 (9)	29 (7)
TOTAL	**37 (96)**	**88 (231)**	**59 (152)**	**52 (130)**
χ^2_2; p value	**n.s.**	**9.737; .008**	**n.s.**	**6.218; .045**

There were no significant differences by Openness about Sexuality in relation to having had experience with any of the Advance Care Planning Options.

Relationship Status

There were no significant differences by Relationship Status in relation to having heard of any of the Advance Care Planning Options but differences in relation to having had experience with Enduring Guardian reached significance, with those Grieving the Loss of a Partner significantly more likely, and those who were Partnered but not Living Together being significantly less likely, to have had experience with this option (see Table 3.17). (Note: This finding must be treated with caution as the Grieving group consisted of only 2 respondents in relation to this question).

Table 3.17: Experience with ACP Options, by Relationship Status

Relationship Status	AHCD N= 53	EPOA N= 158	EG N= 101	PR N= 86
	% (n)	% (n)	% (n)	% (n)
Single	55 (11)	54 (35)	53 (21)	56 (18)
Partnered Not Living Together	44 (4)	50 (15)	35 (8)	37 (7)
Partnered, Living Together	61 (14)	66 (39)	69 (25)	70 (23)
Grieving Loss of Partner	100 (1)	75 (3)	100 (2)	100 (2)
TOTAL	**57 (30)**	**58 (92)**	**55 (56)**	**58 (50)**
χ^2_3; **p value**	**n.s.**	**n.s.**	**8.579; .035**	**n.s.**

Time in Relationship

There were no significant differences in relation to either having heard of, or having had experience with, the Advance Care Planning options by Time in Relationship.

Education Level

Differences by level of education reached significance in relation to having heard of Advance Care Planning options only for Enduring Power of Attorney, with the three groups: Postgraduate Qualifications; Completed University; and Completed Year 12 being the most likely to have heard of this option, and the Completed Year 10 group being the least likely, but the relationship was not linear, as those who had Less than Year 10 education level were more likely than the Completed Year 10 group to have heard of EPoA (see Table 3.18).

Table 3.18: Heard of ACP Options, by Level of Education

Level of Education	AHCD N= 257	EPOA N= 264	EG N= 260	PR N= 252
	% (n)	**% (n)**	**% (n)**	**% (n)**
Less Than Year 10	0 (0)	80 (4)	17 (1)	33 (2)
Completed Year 10	32 (12)	72 (28)	51 (19)	53 (19)
Completed Year 12	33 (6)	95 (18)	58 (11)	68 (13)
Have Trade Qualifications	32 (13)	82 (36)	55 (24)	51 (21)
Completed University	44 (38)	93 (81)	65 (56)	50 (43)
Postgraduate Qualifications	40 (27)	91 (64)	60 (41)	50 (32)
TOTAL	**37 (96)**	**88 (231)**	**59 (152)**	**52 (130)**
χ^2_5; p value	**n.s.**	**14.746; .012**	**n.s.**	**n.s.**

There were no significant differences by education level in relation to having had experience of Advance Care Planning options.

Income

Differences by income level reached significance in relation to having heard of Advance Care Planning options only for Enduring Power of Attorney, where those with the lowest income level were significantly less likely than the other four groups to have heard of this option. They were also somewhat less likely than the other four groups to have heard of the other three ACP options but the differences did not reach statistical significance (see Table 3.19).

Table 3.19: Heard of ACP Options, by Income

Income	**AHCD** N=253	**EPOA** N= 260	**EG** N= 256	**PR** N= 248
	% (n)	**% (n)**	**% (n)**	**% (n)**
<$20k	31 (19)	77 (47)	48 (30)	40 (24)
$20- $29k	39 (11)	89 (25)	56 (15)	63 (17)
$30- $39k	33 (10)	94 (29)	60 (18)	54 (15)
$40- $49k	45 (9)	91 (21)	57 (12)	48 (10)
$50k or >	40 (45)	92 (107)	66 (76)	56 (63)
TOTAL	**37 (94)**	**88 (229)**	**59 (151)**	**52 (129)**
χ^2_4; p value	**n.s.**	**9.485; .050**	**n.s.**	**n.s.**

Differences by income reached statistical significance in relation to having had experience with any of the Advance Care Planning options only for Advance Health Care Directives, where the group whose household income was $30,000 - $39,000 per year were significantly more likely, and those whose household income level was $20,000 - $29,000 per year were significantly less likely, than the other groups to have had experience with Advance Health Care Directives. However, this was not a linear relationship and caution must again be used in interpreting this data as the number in all but the highest group was very small (see Table 3.20).

Table 3.20: Experience with ACP Options, by Income

Income	**AHCD** N=51	**EPOA** N= 156	**EG** N= 100	**PR** N= 85
	% (n)	**% (n)**	**% (n)**	**% (n)**
<$20k	42 (5)	47 (16)	43 (9)	53 (9)
$20- $29k	17 (1)	40 (6)	37 (3)	50 (4)
$30- $39k	100 (6)	57 (13)	69 (9)	67 (8)
$40- $49k	50 (2)	58 (7)	63 (5)	57 (4)
$50k or >	65 (15)	67 (48)	58 (29)	59 (24)
TOTAL	**57 (29)**	**58 (90)**	**55 (55)**	**58 (49)**
χ^2_4; p value	**10.365; .035**	**n.s.**	**n.s.**	**n.s.**

Religion

There were no significant differences by religious beliefs in relation to having heard of Advance Care Planning options but differences reached significance in relation to having had experience with Enduring Guardian, with those who nominated an Other religion and those who had No Affiliation being significantly more likely than the other groups to have had experience with this, and those who were affiliated with the Catholic or Other Christian religions being least likely to have had such experience (see Table 3.21). (Again, caution is required in relation to this data because of the small number in most groups).

Table 3.21: Experience with ACP Options, by Religion

Religion	**AHCD** N= 53	**EPOA** N= 158	**EG** N= 101	**PR** N= 86
	% (n)	**% (n)**	**% (n)**	**% (n)**
No Affiliation	54 (15)	63 (45	69 (31)	68 (25)
Catholic	50 (2)	65 (11)	22 (2)	40 (4)
Anglican	67 (2)	53 (10)	47 (7)	75 (6)
Other Christian	100 (3)	60 (9)	30 (3)	44 (4)
Buddhist	75 (3)	40 (4)	50 (4)	40 (2)
Atheist	33 (1)	43 (3)	40 (2)	33 (2)
Other	50 (4)	56 (10)	78 (7)	64 (7)
TOTAL	**57 (30)**	**58 (92)**	**55 (56)**	**58 (50)**
χ^2_6; p value	**n.s.**	**n.s.**	**12.798; .046**	**n.s.**

Beliefs

Differences by Affect of Beliefs on opinions about medical decisions at the end of life reached significance in relation to respondents having heard of Advance Care Planning options only in relation to Enduring Guardian, with those who said that their beliefs influenced their opinions a great deal being significantly more likely to have heard of this option than those who said that their beliefs did not influence their opinions at all (see Table 3.22).

Table 3.22: Heard of ACP Options, by Beliefs

Beliefs	AHCD N= 256	EPoA N= 263	EG N= 259	PR N= 251
	% (n)	% (n)	% (n)	% (n)
A Great Deal	48 (22)	96 (47)	75 (35)	62 (29)
Somewhat	38 (22)	90 (53)	61 (35)	57 (31)
Not At All	34 (51)	84 (130)	52 (81)	46 (69)
TOTAL	**37 (95)**	**88 (230)**	**58 (151)**	**51 (129)**
χ^2_2; p value	**n.s.**	**n.s.**	**7.607; .022**	**n.s.**

There were no significant differences between the groups by Affect of Beliefs and having had experience with any of the Advance Care Planning options.

Health Status

Differences by health status in relation to having heard of Advance Care Planning options reached significance only in relation to Enduring Power of Attorney; those who rated their health status as Poor were most likely to have heard of this and those who rated their health as Fair were least likely to do so (see Table 3.23). However, the relationship is not linear; a high percentage of each group had heard of this option and those who rated their health as Very Good were almost as likely as those who rated their health as Poor to have done so.

Table 3.23: Heard of ACP Options, by Health Status

Health	AHCD N= 258	EPOA N= 265	EG N= 261	PR N= 253
	% (n)	% (n)	% (n)	% (n)
Excellent	27 (14)	87 (45)	55 (28)	38 (19)
Very Good	40 (34)	94 (83)	60 (53)	53 (45)
Good	38 (25)	82 (56)	60 (40)	62 (40)
Fair	42 (18)	78 (35)	59 (26)	49 (20)
Poor	42 (5)	100 (12)	45 (5)	50 (6)
TOTAL	**37 (96)**	**87 (231)**	**58 (152)**	**51 (130)**
χ^2_4; p value	**n.s.**	**10.765; .029**	**n.s.**	**n.s.**

There were no significant differences by health status in relation to having had experience with any of the Advance Care Planning options.

3.4 SCENARIO

In the next section of the questionnaire, respondents were given the following scenario:

> *Georgina is a 37-year-old woman who has been admitted to hospital following a serious car accident. She is on life-support and in a critical condition. Her female partner of 2 years, Rachel, is by her bedside in the Intensive Care Unit when Georgina's mother Sally arrives and demands a full report on Georgina's condition from the treating medical practitioner. He asks if Georgina had ever appointed anyone to make health care decisions for her if she lost capacity, or discussed what treatment she would/would not want if she were to become terminally ill or injured. Rachel and Sally say no but Rachel says she knows that Georgina would not want her life prolonged unless she could be returned to a good level of functioning. However, Sally insists that all possible treatment be given to Georgina and that, because she is Georgina's mother – and therefore next-of-kin - she should have the right to make decisions about what treatment Georgina does or does not receive.*
>
> *At this point Georgina's ex-husband Henry arrives; he says that when he and Georgina were married she gave him Enduring Power of Attorney which has never been revoked, so he should have the right to make the decisions.*

Respondents were then asked who they thought had the legal right to make health care decisions for Georgina. Of the 297 respondents who answered this question, 51 percent said Henry, 27 percent nominated Rachel, 15 percent said Sally and a further 7 percent nominated a range of other people (see Table 3.24).

Table 3.24: Legal Authority for Substitute Decision-Making

Who has the Legal Right?	N	%
Henry	153	51
Rachel	79	27
Sally	44	15
Other*	21	7
Total	**297**	**100**

*Other included: Unsure (n=6); Georgina (n=2) and combinations of answers.

Respondents were then asked why they thought the nominated person had the legal right. Of the 277 respondents who answered this question, 48 percent replied that having Enduring Power of Attorney gave Henry the legal right to make medical decisions, 13 percent said being a partner did and a further 13 percent said being a parent or next-of-kin gave that legal right. An additional 13 respondents gave an answer which is legally correct, such as "She has been the carer" or "She is Person Responsible" while 8 percent stated that something was "legally" correct when it was not (see Table 3.25).

Table 3.25: Reason Person has Legal Right

Reasons	**N**	**%**
Enduring Power of Attorney	133	48
Other partner-related reason[1]	38	14
Parents or Next-of-Kin	35	13
Correct legal reason[2]	36	13
Incorrect legal reason[3]	22	8
All other[4]	13	4
Total	**277**	**100**

[1] Some respondents simply said "*she is her partner*". Other reasons included:

- *Partner would know wishes; or Partner involved in daily life;*
- *Rachel is the person that Georgina would want to make her decisions*
- *The ex-husband is ex for a reason*
- *They are in a recognised long-term relationship*

[2] Correct legal reasons included:

- *She is Person Responsible (n=12)*
- *She is the most recent partner (n = 13)*
- *EPoA is for finances, not health care decisions (n= 9)*

[3] Incorrect legal reasons included:

- *By law, the husband, even though it's wrong*
- *Mother because next-of-kin (or various next-of-kin reasons)*
- *Their relationship isn't fully recognised; or This is state law, not Commonwealth*
- *If one is a beneficiary in the will*

[4] All other: Mostly confused answers demonstrating no understanding of the issues.

Chi-Square Analysis

Responses to the question of who had the legal right to make Georgina’s decisions were analysed by demographic characteristics.

Age

Differences by age group approached significance; while respondents in every age group were more likely to nominate Henry as having the legal authority for decision-making than they were to nominate anyone else, those aged 70-79 (72%) were the most likely to do so. Of respondents who nominated Rachel, those aged 40-49 and 60-69 were the most likely, and the two oldest groups were the least likely, to do so. Of those who nominated Sally, those aged <30, 30-39 and 80+ were the most likely to do so. Again the results were not linear and small numbers in some cells means that the results may not be completely reliable (see Table 3.26).

Table 3.26: Who has the Legal Right, by Age Group

Age Group	**N**	**Rachel**	**Henry**	**Sally**	**Other**
		% (n)	**% (n)**	**% (n)**	**% (n)**
<30	17	18 (3)	41 (7)	23 (4)	18 (3)
30-39	32	25 (8)	47 (15)	25 (8)	3 (1)
40-49	63	33 (21)	43 (27)	11 (7)	13 (8)
50-59	74	28 (21)	52 (38)	15 (11)	5 (4)
60-69	60	32 (19)	57 (34)	10 (6)	1 (1)
70-79	32	9 (3)	72 (23)	13 (4)	6 (2)
80+	5	0 (0)	60 (3)	40 (2)	0 (0)
TOTAL	**283**	**27 (75)**	**52 (147)**	**15 (42)**	**7 (19)**
χ^2_{18}: p value		**28.212: .059**			

Gender

There were no significant differences by gender in relation to this question.

Sexual Orientation

There were statistically significant differences by sexual orientation. While respondents in most groups were more likely to nominate Henry than they were to nominate anyone else, the Lesbian group almost equally said Rachel or Henry. Of those who nominated Henry, respondents who identified as Gay or Bisexual were significantly more likely than those who identified as Lesbian or Other to do so (see Table 3.27).

Table 3.27: Who has the Legal Right, by Sexual Orientation

Sexual Orientation	N	Rachel	Henry	Sally	Other
		% (n)	% (n)	% (n)	% (n)
Gay	137	22 (30)	58 (79)	16 (22)	4 (5)
Lesbian	73	41 (30)	42 (31)	10 (7)	7 (5)
Bisexual	36	14 (5)	55 (20)	19 (7)	11 (4)
Other	38	26 (10)	45 (17)	15 (6)	13 (5)
TOTAL	**285**	**26 (75)**	**52 (147)**	**15 (42)**	**7 (19)**
χ^2_9: **p value**		**19.078: .025**			

Open about Sexuality/Relationship Status/Time in Relationship

There were no significant differences by Open about Sexuality, Relationship Status or Time in Relationship in relation to this question.

Education/Income/Religion/Affect of Beliefs/Health Status

There were also no significant differences by Education, Income, Religion, Affect of Beliefs or Health Status in relation to this question.

Private Health Insurance

Differences did reach statistical significance by whether or not respondents had private health insurance, although this was only so for those who nominated someone Other than Rachel, Sally or Henry (2% of those with private health insurance and 11% of those without nominated someone Other: χ^2_3: 9.082; p value .028).

3.5 EXPERIENCE WITH SERIOUS ILLNESS

In the next Section of the questionnaire, respondents were asked a series of questions about their experience with serious illness – their own or that of someone else.

Care Received

Of the 298 respondents who answered the question, 25 percent said that they had received unpaid care from another person because they have had a serious illness during the past 10 years (see Table 3.28).

Care Given

Of the 300 respondents who answered the question, 32 percent said that they had provided unpaid care to another GLBT person with a serious illness in the past 10 years (see Table 3.28).

Table 3.28: Experience with Serious Illness

Care	N	Yes	No
		% (n)	% (n)
Care received	298	25 (75)	75 (223)
Care given	300	32 (95)	68 (205)

Chi-Square Analysis

For those who had received unpaid care in the past 10 years, differences between respondents reached significance only in relation to Sexual Orientation, Affect of Beliefs and Health Status, while for those who had given such care, responses reached statistical significance only in relation to Relationship Status.

Received Unpaid Care, by Sexual Orientation

Although a majority of respondents in all groups had not received unpaid care from someone in the last 10 years because of a serious illness, those who identified as Other than Gay, Lesbian or Bisexual were the most likely, and those who identified as Bisexual were the least likely, to have done so (see Table 3.29).

Table 3.29: Received Care, by Sexual Orientation

Sexual Orientation	N	Yes	No
		% (n)	% (n)
Gay	140	23 (32)	77 (108)
Lesbian	74	23 (17)	77 (57)
Bisexual	35	14 (5)	86 (30)
Other*	40	45 (18)*	55 (22)
TOTAL	**289**	**25 (72)**	**75 (217)**
χ^2_3: **p value**		**11.206; .011**	

* Responses of those who had received unpaid care and who did not identify as Gay, Lesbian or Bisexual, were as follows: Heterosexual 35% (n=6); Queer 50% (n=5) and all others 64% (n=7).

Received Care by Affect of Beliefs

There was a direct linear relationship in responses to this question by the degree to which the respondents' beliefs affected their attitudes to end-of-life issues, with those who said that their beliefs affected their decisions A Great Deal being most likely, and those who said Not At All being least likely to have received such care (see Table 3.30).

Table 3.30: Received Care, by Affect of Beliefs

Beliefs	N	YES	NO
		% (n)	% (n)
A Great Deal	53	47 (25)	53 (28)
Somewhat	62	26 (16)	74 (46)
Not At All	171	18 (31)	82 (140)
TOTAL	**286**	**25 (72)**	**75 (214)**
χ^2_2: **p value**		**18.132; <.001**	

Received Care by Health Status

Responses to this question by Health Status, while strongly statistically significant, were not quite linear; although whose health was Poor were most likely to have received such care, followed by those whose health was Fair, respondents who health was Very Good were slightly less likely than those whose health was Excellent to have received such care (see Table 3.31).

Table 3.31: Received Care, by Health Status

Health	N	YES	NO
		% (n)	% (n)
Excellent	54	19 (10)	81 (44)
Very Good	98	15 (15)	85 (83)
Good	75	29 (22)	71 (53)
Fair	48	40 (19)	60 (29)
Poor	13	54 (7)	46 (6)
TOTAL	**188**	**25 (73)**	**75 (215)**
χ^2_4; **p value**		**17.903; .001**	

Provided Care by Relationship Status

Those who were grieving the loss of a partner or in another form of relationship were the most likely to have provided care to someone with a serious illness in the past 10 years (see Table 3.32).

Table 3.32: Provided Care, by Relationship Status

Relationship Status	N	YES	NO
		% (n)	% (n)
Single	130	26 (34)	74 (96)
Partnered Not Living Together	48	23 (11)	77 (37)
Partnered, Living Together	97	37 (36)	63 (61)
Grieving Loss of Partner	8	75 (6)	25 (2)
Other	4	75 (3)	25 (1)
TOTAL	**287**	**31 (90)**	**69 (197)**
χ^2_3; **p value**		**15.335; .004**	

Issues with Service Providers or Family Members

Respondents were asked whether, in providing the care to another GLBT person, they had experienced any of the following from service providers or family members:

- lack of recognition of their relationship: 29 percent (n=28) had experienced this
- denial of involvement in care decisions: 20 percent (n=19) had
- lack of recognition of their gender: 14 percent (n=14) had
- denial of access/visiting rights in hospital or care facility: 7 percent (n=7) had

(see Table 3.33).

Table 3.33: Issues with Service Providers or Family Members

Issues	N*	Yes	No
		% (n)	% (n)
Lack of recognition of your relationship	98	29 (28)	71 (70)
Denial of involvement in care decisions	97	20 (19)	80 (78)
Lack of recognition of your gender	98	14 (14)	86 (84)
Denial of access / visiting rights in hospital or care facility	97	7 (7)	93 (90)

* Note: while only 95 people said that they had provided care, 97 & 98 answered these questions

Chi-Square Analysis

Responses were analysed by demographic characteristics but numbers in each category for all discrimination situations were too small for results to have any validity and are therefore not reported.

3.6 HEALTH CARE PROVIDER

Respondents were next asked if they had a regular GP and, if they did not, who was their main health care provider: 87 percent (n=261) of the 300 respondents who answered the question have a regular GP. Of those who do not, 35 nominated other providers, including the following: Any GP (n=18); a Naturopath (n=3) or HIV/AIDS specialist (n=4) as their main health care provider, while five said “none available”.

Chi-Square Analysis

Chi-square analysis of the question about a regular GP found statistical significance in relation to Age, Gender, Open about Sexuality, Time in Relationship and Health Status, and approached statistical significance for Religion. There were no significant differences in relation to Sexual Orientation, Relationship Status, Education, Income or Affect of Beliefs.

Age

There was a direct linear relationship in response to this question, with the youngest group being the least likely (47%) and the two oldest groups being the most likely (both 100%) to have a regular GP; the results were strongly significant because of the gap from the least likely group to the next group (see Table 3.34).

Table 3.34: Regular GP, by Age Group

Age Group	**N**	**Yes**	**No**
		% (n)	**% (n)**
<30	19	47 (9)	53 (10)
30-39	32	78 (25)	22 (7)
40-49	65	85 (55)	15 (10)
50-59	74	88 (65)	12 (9)
60-69	63	95 (60)	5 (3)
70-79	33	100 (33)	0 (0)
80+	5	100 (5)	0 (0)
TOTAL	**291**	**87 (252)**	**13 (39)**
χ^2_6: p value		**37.425; <.001**	

Gender

Although a strong majority in each group had a regular GP, respondents who identified as Male were significantly more likely to do so than those who identified as Female or Other (see Table 3.35).

Table 3.35: Regular GP, by Gender

Gender	**N**	**Yes**	**No**
		% (n)	**% (n)**
Female	115	80 (92)	20 (23)
Male	148	92 (136)	8 (12)
Another Gender	24	83 (20)	17 (4)
TOTAL	**587**	**86 (248)**	**14 (39)**
χ^2_2: p value		**8.005; .018**	

Openness about Sexuality

Those who are not yet open to any significant family members were significantly less likely than the other two groups to have a regular GP (see Table 3.36).

Table 3.36: Regular GP, by Openness about Sexuality

Degree of Openness	**N**	**Yes**	**No**
		% (n)	**% (n)**
Open to All	219	86 (189)	14 (30)
Open to Some	45	96 (43)	4 (2)
No	26	73 (19)	27 (7)
TOTAL	**290**	**87 (251)**	**13 (39)**
χ^2_2: p value		**7.202; .027**	

Time in Relationship

The two groups who have been longest in their relationships were most likely to have a regular GP, and differences reached significance, but small numbers in some cells means caution should be used in interpreting these results (see Table 3.37).

Table 3.37: Regular GP, by Time in Relationship

Time	**N**	**Yes**	**No**
		% (n)	**% (n)**
<1 Yr	8	63 (5)	37 (3)
1-2 Yrs	12	75 (9)	25 (3)
2-4 Yrs	14	71 (10)	29 (4)
4-10 Yrs	44	86 (38)	14 (6)
>10 Yrs	70	93 (65)	7 (5)
TOTAL	**148**	**86 (127)**	**14 (21)**
χ^2_4: p value		**9.966; .041**	

Health Status

While those in Poor health were the most likely, and those in Excellent or Very Good health were the least likely to have a regular GP, and the results were statistically significant, there was not a direct linear relationship, as those in Good health were slightly more likely than those in Fair health to have a regular GP (noting, however, that over 90% of both groups did so) (see Table 3.38).

Table 3.38: Regular GP, by Health Status

Health Status	N	Yes	No
		% (n)	% (n)
Excellent	54	80 (43)	20 (11)
Very Good	99	80 (79)	20 (20)
Good	76	95 (72)	5 (4)
Fair	48	92 (44)	8 (4)
Poor	13	100 (13)	0 (0)
TOTAL	**290**	**87 (251)**	**13 (39)**
χ^2_4: **p value**		**13.576; .009**	

Religion

The difference approaching statistical significance by Religious Affiliation relates to those who have No Affiliation and those who nominated a religion Other than one of the mainstream faiths being significantly less likely than those who are Anglican or belong to one of the Other Christian groups to have a regular GP. Again, small numbers in several cells suggest caution in interpretation (see Table 3.39).

Table 3.39: Regular GP, by Religion

Religion	**N**	**Yes**	**No**
		% (n)	**% (n)**
No Affiliation	134	81 (109)	19 (25)
Catholic	38	90 (34)	10 (4)
Anglican	31	100 (31)	0 (0)
Other Christian	24	96 (23)	4 (1)
Buddhist	19	90 (17)	10 (2)
Atheist	12	92 (11)	8 (1)
Other	30	80 (24)	20 (6)
TOTAL	**288**	**87 (249)**	**13 (39)**
χ^2_6: **p value**		**11.441; .076**	

Chi-Square Analysis of Responses for Main Healthcare Provider other than GP

As there were too few respondents who nominated a healthcare provider other than a GP, no chi-square analysis has been undertaken on those results.

3.7 DISCUSSION OF END-OF-LIFE CARE

Respondents were asked if they have discussed with their main health care provider their preferences for treatment in the event of a present or future terminal illness: only 13 percent (n=38) of the 300 respondents who answered this question said that they had had such a discussion and in the majority of cases (92%; n=35), the respondent themselves had raised the issue. In only 2 cases had the issue been raised by the health care provider.

Chi-Square Analysis of these results was unstable because of small numbers in each category and the results are therefore not reported.

Degree of Comfort in Discussing End-of-Life Issues: When asked how comfortable they felt in talking about death and dying with their health care provider, 73 percent of the 59 respondents who answered this question said that, in general, they felt very comfortable or comfortable in talking about the subject; 20 percent felt neither comfortable nor uncomfortable; and 7 percent felt uncomfortable or very uncomfortable (see Table 3.40).

Table 3.40: Degree of Comfort Felt When Talking about Death and Dying to Health Care Provider

Degree of Comfort Felt	N	%
Very Comfortable	32	54
Comfortable	11	19
Neither Comfortable nor Uncomfortable	12	20
Uncomfortable	3	5
Very Uncomfortable	1	2
Total	**59**	**100**

Respondents were also asked how comfortable they would feel if their health care provider raised the subject of death and dying with the: of the 298 respondents who answered this question, 76 percent would feel very comfortable or comfortable; 16 percent said that they would feel neither comfortable nor uncomfortable; and 8 percent would feel uncomfortable or very uncomfortable (see Table 3.41).

Table 3.41: Degree of Comfort if Health Care Provider Raised the Issue of Death and Dying

Degree of Comfort if Health Care Provider Raised the Issue	N	%
Very Comfortable	126	43
Comfortable	99	33
Neither Comfortable nor Uncomfortable	47	16
Uncomfortable	16	5
Very Uncomfortable	10	3
Total	**298**	**100**

Chi-Square Analysis

Responses to both questions were collapsed into Very Comfortable/Comfortable; Neither; and Uncomfortable/Very Uncomfortable and then analysed by the demographic variables. Numbers for each variable for the first question were still too small for meaningful analysis and are therefore not reported.

In relation to the degree of comfort respondents thought they would feel if their health care provider raised the issue of death and dying with them, differences reached statistical significance for Age, Gender, Openness about Sexuality, Relationship Status, Education and Income.

Degree of Comfort Would Feel if Health Care Provider Talked about Death and Dying

Age

The youngest group (<30) were significantly less likely than all of the other age groups to say that they would be Very Comfortable or Comfortable if their health care provider raised the issue of death and dying with them. However, the group aged 80+ were also less likely than those aged 30-79 to be Very Comfortable/Comfortable with this. The youngest group were the most likely to say that they would be Neither Comfortable nor Uncomfortable if their health care provider raised the issue of death and dying with them (see Table 3.42).

Table 3.42: Degree of Comfort Would Feel, by Age Group

Age Group	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
<30	19	37 (7)	47 (9)	16 (3)
30-39	31	78 (24)	19 (6)	3 (1)
40-49	64	72 (46)	19 (12)	9 (6)
50-59	74	80 (59)	12 (9)	8 (6)
60-69	63	81 (51)	9 (6)	10 (6)
70-79	33	85 (28)	9 (3)	6 (2)
80+	5	60 (3)	0 (0)	40 (2)
TOTAL	**289***	**75 (218)**	**16 (45)**	**9 (26)**
χ^2_{12}: p value		**29.469; .003**		

* Not all respondents reported their Age Group

Gender

The major difference with these responses was that those who identified as other than Female or Male were significantly less likely than the other two groups to be Very Comfortable/Comfortable and significantly more likely to say that they would be Neither Comfortable nor uncomfortable, or that they would be Uncomfortable/Very Uncomfortable (see Table 3.43).

Table 3.43: Degree of Comfort Would Feel, by Gender

Gender	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
Female	114	78 (89)	17 (19)	5 (6)
Male	148	78 (115)	13 (19)	9 (14)
Another Gender	23	52 (12)	26 (6)	22 (5)
TOTAL	**285**	**76 (216)**	**15 (44)**	**9 (25)**
χ^2_4: p value		**10.380; .034**		

Open About Sexuality

Respondents who are Open to All significant family members were significantly more likely than the other two groups to say that they would be Very Comfortable/Comfortable if their health care provider raised issues of death and dying with them (see Table 3.44).

Table 3.44: Degree of Comfort Would Feel, by Open About Sexuality

Open About Sexuality?	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
Yes to All	218	81 (176)	14 (30)	5 (12)
Yes to Some	45	58 (26)	22 (10)	20 (9)
No	25	64 (16)	16 (4)	20 (5)
TOTAL	**288**	**76 (218)**	**15 (44)**	**9 (26)**
χ^2_4: p value		**17.181; .002**		

Relationship Status

Respondents who have a current partner (living with or not) were the most likely to say that they would be Very Comfortable/Comfortable if their health care provider raised the issue of death and dying with them while those who nominated an Other form of relationship were significantly less likely to say so (see Table 3.45).

Table 3.45: Degree of Comfort Would Feel, by Relationship Status

Relationship Status	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
Single	128	70 (89)	15 (20)	15 (19)
Partner/Not Living With	48	79 (38)	15 (7)	6 (3)
Partner/Living With	97	84 (81)	13 (13)	3 (3)
Grieving Loss of Partner	8	75 (6)	12 (1)	13 (1)
Other	4	25 (1)	75 (3)	0 (0)
TOTAL	**285**	**76 (215)**	**15 (44)**	**9 (26)**
χ^2_8: p value		**21.746; .005**		

Education

Although differences between the groups reached statistical significance, by Education, with respondents having a University Degree being most likely to say that they would be Very Comfortable/Comfortable if their health care provider raised the issue of death and dying with them, the results were not linear, so Education is not predictive of Degree of Comfort in relation to such discussions (see Table 3.46).

Table 3.46: Degree of Comfort Would Feel, by Education

Education Level	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
< Year 10	8	63 (5)	0 (0)	37 (3)
Year 10	41	73 (30)	17 (7)	10 (4)
Year 12	22	64 (14)	13 (3)	23 (5)
Trade Cert.	46	72 (33)	17 (8)	11 (5)
Uni Degree	94	84 (79)	13 (12)	3 (3)
Post-Grad	77	74 (57)	18 (14)	8 (6)
TOTAL	**288**	**76 (218)**	**15 (44)**	**9 (26)**
χ^2_{10}: p value		**19.556; .034**		

Income

Again, while differences reached statistical significance, and respondents with the highest income level were most likely to say that they would be Very Comfortable/Comfortable if their health care provider raised such issue with them, the results were not linear, so Income cannot be relied on to predict Degree of Comfort in relation to such discussions (see Table 3.47).

Table 3.47: Degree of Comfort Would Feel, by Income

Income Level	N	Very Comfortable/ Comfortable	Neither	Uncomfortable/ Very Uncomfortable
		% (n)	% (n)	% (n)
< $20k	70	70 (49)	14 (10)	16 (11)
$20k - $29k	35	66 (23)	14 (5)	20 (7)
30k - $39k	30	77 (23)	17 (5)	7 (2)
$40k - $49k	24	63 (15)	29 (7)	8 (2)
$50k or more	125	85 (106)	12 (15)	3 (4)
TOTAL	**284**	**76 (216)**	**15 (42)**	**9 (26)**
χ^2_{8}: p value		**18.618; .012**		

3.8 ASSISTANCE IF SERIOUSLY ILL

The next question asked respondents, “If you became seriously ill, how likely would it be for at least one friend, relative or a partner to provide you assistance with (one of five services)?” In order of most assistance to least (see Table 3.48), responses were as follows:

- 76 percent of 294 respondents said they would be Very Likely to receive advice;
- 69 percent of 295 respondents said they would be Very Likely to receive help with household chores;
- 63 percent of 290 respondents said that it was Very Likely that they would be provided with a place to stay for a few weeks;
- 62 percent of 286 respondents felt that it was Very Likely that they would be loaned $500; and
- 58 percent of 298 respondents said that it was Very Likely that they would be provided with assistance with bathing or dressing.

Table 3.48: Likelihood of Assistance Being Provided

Option	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Giving advice	294	76 (224)	20 (57)	4 (13)
Helping with household chores	295	69 (203)	15 (45)	16 (47)
Providing a place to stay for a few weeks	290	63 (184)	19 (54)	18 (52)
Loaning you $500	286	62 (179)	16 (45)	22 (62)
Helping with bathing or dressing	295	58 (172)	19 (56)	23 (57)

Chi-Square Analysis

Responses were analysed by the demographic variables for each of the five areas of potential assistance. Differences reached statistical significance for the following, in relation to:

- **Giving Advice,** by Relationship Status; Income; and Private Health Insurance; and approached significance by Open About Sexuality;
- **Help with Chores**, by Open About Sexuality; Relationship Status; Income; Health Status; and Private Health Insurance;
- **Providing Accommodation,** by Age; Open About Sexuality; Relationship Status; Income; and Health Status.
- **Loaning $500,** by Gender; Open About Sexuality; Relationship Status; Education; Income; and Health Status; and approached significance by Religion
- **Help with Bathing or Dressing**, by Open About Sexuality; Relationship Status; Income; Religion; and Health Status;

3.8.1 GIVING ADVICE

Relationship Status

Respondents living with a partner were most likely to say that it would be Very Likely that at least one friend, relative or partner would give them advice if they were seriously ill (see Table 3.49).

Table 3.49: Giving Advice, by Relationship Status

Relationship Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Single	125	67 (83)	26 (33)	7 (9)
Partner/Not Living With	48	81 (39)	15 (7)	4 (2)
Partner/Living With	96	89 (85)	10 (10)	1 (1)
Grieving Loss of Partner	8	63 (5)	25 (2)	12 (1)
Other	4	75 (3)	25 (1)	0 (0)
TOTAL	**281**	**77 (215)**	**19 (53)**	**4 (13)**
χ^2_8: p value		**17.670; .024**		

Income

Respondents with an income of $50,000 or more per year were significantly more likely than the other four groups to say that it was Very Likely that at least one friend, relative or partner would give them advice if they were terminally ill (see Table 3.50).

Table 3.50: Giving Advice, by Income

Income Level	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
< $20k	68	65 (44)	23 (16)	12 (8)
$20k - $29k	35	68 (24)	26 (9)	6 (2)
30k - $39k	31	71 (22)	23 (7)	6 (2)
$40k - $49k	23	70 (16)	30 (7)	0 (0)
$50k or more	123	87 (107)	13 (16)	0 (0)
TOTAL	**280**	**76 (213)**	**20 (55)**	**4 (12)**
χ^2_8: p value		**24.650; .002**		

Private Health Insurance

Respondents without Private health insurance were most likely to say that it was Not Very Likely that at least one friend, relative or partner would give them advice (see Table 3.51).

Table 3.51: Giving Advice, by Private Health Insurance

Private Health Insurance	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes	137	79 (108)	20 (28)	<1 (1)
No	149	74 (110)	18 (27)	8 (12)
TOTAL	**286**	**76 (218)**	**19 (55)**	**5 (13)**
χ^2_2: p value		**8.856; .012**		

Open About Sexuality

Differences between the groups approached significance, with respondents who are Open to All significant others being most likely to say that they would receive advice from at least one friend, relative or partner if they were terminally ill (see Table 3.52).

Table 3.52: Giving Advice, by Open About Sexuality

Open About Sexuality?	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes to All	216	80 (172)	17 (37)	3 (7)
Yes to Some	43	65 (28)	28 (12)	7 (3)
No	25	64 (16)	24 (6)	12 (3)
TOTAL	**284**	**76 (216)**	**19 (55)**	**5 (13)**
χ^2_4: p value		**8.365; .079**		

3.8.2 HELPING WITH CHORES

Open About Sexuality

There was a direct linear relationship between degree of Openness about Sexuality and Likelihood of receiving Help with Chores; respondents who were Open to All were the most likely, and those who were not at all Open were significantly the least likely, to think that they would receive such help from at least one friend, relative or partner (see Table 3.53).

Table 3.53: Help with Chores, by Open About Sexuality

Open About Sexuality?	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes to All	215	72 (154)	13 (29)	15 (32)
Yes to Some	44	66 (29)	25 (11)	9 (4)
No	26	50 (13)	11 (3)	39 (10)
TOTAL	**285**	**69 (196)**	**15 (43)**	**16 (46)**
χ^2_4: p value		**14.678; .005**		

Relationship Status

Respondents with a partner (living with or not) were significantly more likely than the other three groups to say that it was Very Likely that they would receive Help with Chores from at least one friend, relative or partner if they were seriously ill, and those who were grieving the loss of a partner were the least likely to do so (see Table 3.54).

Table 3.54: Help With Chores, by Relationship Status

Relationship Status	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Single	126	51 (64)	24 (30)	25 (32)
Partner/Not Living With	48	88 (42)	6 (3)	6 (3)
Partner/Living With	96	87 (83)	6 (6)	7 (7)
Grieving Loss of Partner	8	38 (3)	50 (4)	13 (1)
Other	4	50 (2)	0 (0)	50 (2)
TOTAL	**282**	**69 (194)**	**15 (43)**	**16 (45)**
χ^2_8: p value		**52.076; <.001**		

Income

There was a direct linear relationship between income and expectation of Help with Chores from at least one friend, relative or partner, with respondents whose Income was $50,000 or more per year being significantly more likely to say that it was Very Likely that they would receive such help and those with an Income of < $20,000 being significantly less likely to do so. Likelihood of help increased with income level (see Table 3.55).

Table 3.55: Help With Chores, by Income

Income	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
< $20k	69	44 (30)	17 (12)	39 (27)
$20k - $29k	34	59 (20)	27 (9)	15 (5)
30k - $39k	30	73 (22)	13 (4)	13 (4)
$40k - $49k	24	75 (18)	17 (4)	8 (4)
$50k or more	124	84 (104)	11 (13)	6 (7)
TOTAL	**281**	**69 (194)**	**15 (42)**	**16 (45)**
χ^2_8: **p value**		**48.651; <.001**		

Health Status

While differences between the groups reached significance, and those in the best health were most likely to expect that at least one friend, relative or partner would Help with Chores if they were seriously ill, results were not completely linear, as those in Fair health were the least likely to expect such help (see Table 3.56).

Table 3.56: Help With Chores, by Health Status

Health Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Excellent	52	85 (44)	9 (5)	6 (3)
Very Good	97	72 (70)	13 (13)	15 (14)
Good	76	70 (53)	18 (14)	12 (9)
Fair	47	45 (21)	21 (10)	34 (16)
Poor	13	69 (9)	0 (0)	31 (4)
TOTAL	**285**	**69 (197)**	**15 (42)**	**16 (46)**
χ^2_8: **p value**		**26.591; .001**		

Private Health Insurance

Respondents with Private Health Insurance were significantly more likely than those without to say that it Very Likely that they would receive Help with Chores from at least one friend, relative or partner (see Table 3.57).

Table 3.57: Help with Chores, by Private Health Insurance

Private Health Insurance	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes	137	76 (104)	13 (18)	11 (15)
No	150	63 (94)	17 (25)	21 (31)
TOTAL	**287**	**69 (198)**	**15 (43)**	**16 (46)**
χ^2_2: p value		**6.635; .036**		

3.8.3 PROVIDING ACCOMMODATION

Age

The two youngest groups and the oldest group were significantly more likely than the other four groups to say that it was Very Likely that at least one friend, relative or partner would provide them with a place to stay for a few weeks (see Table 3.58).

Table 3.58: Providing Accommodation, by Age Group

Age Group	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
<30	19	79 (15)	16 (3)	5 (1)
30-39	32	91 (29)	3 (1)	6 (2)
40-49	63	58 (37)	21 (13)	21 (13)
50-59	71	62 (44)	21 (15)	17 (12)
60-69	61	54 (33)	26 (16)	20 (12)
70-79	32	50 (16)	16 (5)	34 (11)
80+	5	80 (4)	0 (0)	20 (1)
TOTAL	**283**	**63 (178)**	**19 (53)**	**18 (52)**
χ^2_{12}: p value		**23.343; .025**		

Open About Sexuality

Respondents who are not open to any significant others were significantly less likely than the other two groups to say that it was Very Likely that at least one friend, relative or partner would provide them with a place to stay for a few weeks if they were seriously ill (see Table 3.59)

Table 3.59: Providing Accommodation, by Open About Sexuality

Open About Sexuality?	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes to All	211	67 (141)	19 (40)	14 (30)
Yes to Some	44	57 (25)	23 (10)	20 (9)
No	26	39 (10)	11 (3)	50 (13)
TOTAL	**281**	**63 (176)**	**19 (53)**	**18 (52)**
χ^2_4: p value		**20.466; <.001**		

Relationship Status

Respondents with a partner (living with or not) were significantly more likely than the other three groups to say that it was Very Likely that at least one friend, relative or partner would provide them with a place to stay for a few weeks if they were seriously ill (see Table 3.60).

Table 3.60: Providing Accommodation, by Relationship Status

Relationship Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Single	126	46 (58)	29 (37)	25 (31)
Partner/Not Living With	48	77 (37)	10 (5)	13 (6)
Partner/Living With	92	78 (72)	11 (10)	11 (10)
Grieving Loss of Partner	8	63 (5)	12 (1)	25 (2)
Other	4	50 (2)	0 (0)	50 (2)
TOTAL	**278**	**63 (174)**	**19 (53)**	**18 (51)**
χ^2_8: p value		**32.685; <.001**		

Income

Although respondents with the highest income were the most likely to say that it was Very Likely that at least one friend, relative or partner would provide them with a place to stay for a few weeks if they were seriously ill, the results were not completely linear (see Table 3.61)

Table 3.61: Providing Accommodation, by Income

Income Level	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
< $20k	68	49 (33)	19 (13)	32 (22)
$20k - $29k	34	44 (15)	27 (9)	29 (10)
30k - $39k	30	66 (20)	17 (5)	17 (5)
$40k - $49k	22	54 (12)	23 (5)	23 95)
$50k or more	123	77 (94)	16 (20)	7 (9)
TOTAL	**277**	**63 (174)**	**19 (52)**	**18 (51)**
χ^2_8: p value		**27.691; .001**		

Health Status

Responses to this question by Health Status were linear, with those in Excellent health being the most likely, and those in Fair or Poor health being the least likely, to say that it was Very Likely that at least one friend, relative or partner would provide them with a place to stay for a few weeks if they were seriously ill (see Table 3.62).

Table 3.62: Providing Accommodation, by Health Status

Health Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Excellent	52	75 (39)	14 (7)	11 (6)
Very Good	95	64 (61)	20 (19)	16 (15)
Good	74	66 (49)	22 (16)	12 (9)
Fair	47	47 (22)	17 (8)	36 (17)
Poor	13	46 (6)	23 (3)	31 (4)
TOTAL	**281**	**63 (177)**	**19 (53)**	**18 (51)**
χ^2_8: p value		**17.805; .023**		

3.8.4 LOANING $500

Gender

Females were most likely, and respondents who identified as "another gender" were the least likely, to say that it was Very Likely that at least one friend, relative or partner would Loan them $500 if they became seriously ill (see Table 3.63).

Table 3.63: Loaning $500, by Gender

Gender	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Female	114	70 (80)	14 (16)	16 (18)
Male	139	60 (83)	18 (25)	22 (31)
Another Gender	21	43 (9)	14 (3)	43 (9)
TOTAL	**274**	**63 (172)**	**16 (44)**	**21 (58)**
χ^2_4: p value		**9.492; .050**		

Open About Sexuality

Respondents who were not Open to significant family members were significantly less likely than the other two groups to say either that it was Very Likely or Somewhat Likely that at least one friend, relative or partner would Loan them $500 if they were seriously ill, and much more likely to say that this was Not Very Likely (see Table 3.64).

Table 3.64: Loaning $500, by Open About Sexuality

Open About Sexuality?	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Yes to All	212	65 (138)	18 (38)	17 (36)
Yes to Some	43	65 (28)	12 (5)	23 (10)
No	21	33 (7)	0 (0)	67 (14)
TOTAL	**276**	**63 (173)**	**16 (43)**	**22 (60)**
χ^2_4: p value		**29.326; <.001**		

Relationship Status

Being partnered or in an Other relationship made it much more likely that respondents would say that at least one friend, relative or partner would Loan them $500 if they were seriously ill (see Table 3.65).

Table 3.65: Loaning $500, by Relationship Status

Relationship Status	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Single	123	50 (61)	21 (26)	29 (36)
Partner/Not Living With	46	74 (34)	11 (5)	15 (7)
Partner/Living With	92	76 (70)	12 (11)	12 (11)
Grieving Loss of Partner	8	50 (4)	0 (0)	50 (4)
Other	4	75 (3)	0 (0)	25 (1)
TOTAL	**273**	**63 (172)**	**15 (42)**	**22 (59)**
χ^2_8: p value		**24.170; .002**		

Education

Although respondents with the highest education were the most likely, and those with the lowest education were the least likely, to say that it was Very Likely that at least one friend, relative or partner would Loan them $500 if they were seriously ill, the results were not completely linear (see Table 3.66).

Table 3.66: Loaning $500, by Education

Education Level	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
< Year 10	5	20 (1)	40 (2)	40 (2)
Year 10	37	46 (17)	13 (5)	41 (15)
Year 12	21	67 (14)	5 (1)	28 (6)
Trade Cert.	44	46 (20)	27 (12)	27 (12)
Uni Degree	94	71 (67)	15 (14)	14 (13)
Post-Grad	75	72 (54)	12 (9)	16 (12)
TOTAL	**276**	**63 (173)**	**16 (43)**	**22 (60)**
χ^2_{10}: **p value**		**27.185; .002**		

Income

There was no linear relationship between income level and likelihood of someone loaning respondents $500, although those with incomes of $50,000 or more were the most likely to say that it was Very Likely that at least one friend, relative or partner would do so (see Table 3.67).

Table 3.67: Loaning $500, by Income

Income Level	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
< $20k	65	45 (29)	17 (11)	38 (25)
$20k - $29k	34	53 (18)	21 (7)	26 (9)
30k - $39k	30	67 (20)	10 (3)	23 (7)
$40k - $49k	23	52 (12)	13 (3)	35 (8)
$50k or more	120	76 (91)	16 (19)	8 (10)
TOTAL	**272**	**62 (170)**	**16 (43)**	**22 (59)**
χ^2_{8}: **p value**		**29.518; <.001**		

Health Status

There was a clear linear relationship by Health Status in response to this question, from respondents with Excellent health being the most likely, down to respondents with Poor health being the least likely, to say that at least one friend, relative or partner would Loan them $500 if they were seriously ill (see Table 3.68).

Table 3.68: Loaning $500, by Health Status

Health Status	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
Excellent	51	78 (40)	6 (3)	16 (8)
Very Good	95	67 (64)	14 (13)	19 (18)
Good	72	58 (42)	28 (20)	14 (10)
Fair	45	51 (23)	11 (5)	38 (17)
Poor	13	39 (5)	15 (2)	46 (6)
TOTAL	**276**	**63 (174)**	**16 (43)**	**21 (59)**
χ^2_8: p value		**27.783; .001**		

Religion

Differences between the groups approached significance, but again there was no clear pattern in the responses, and counts of <5 in six of the cells make the results unstable (see Table 3.69).

Table 3.69: Loaning $500, by Religion

Religion	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
No Affiliation	130	69 (90)	14 (18)	17 (22)
Catholic	35	54 (19)	17 (6)	29 (10)
Anglican	31	58 (18)	13 (4)	29 (9)
Other Christian	21	57 (12)	24 (5)	19 (4)
Buddhist	19	53 (10)	37 (7)	10 (2)
Atheist	10	90 (9)	0 (0)	10 (1)
Other	28	54 (15)	11 (3)	36 (10)
TOTAL	**274**	**63 (173)**	**16 (43)**	**21 (58)**
χ^2_6: p value		**19.485; .077**		

3.8.5 HELP WITH BATHING OR DRESSING

Open About Sexuality

Respondents who were Open About their Sexuality were most likely to say that it was Very Likely that they would receive Help with Bathing or Dressing from at least one friend, relative or partner if they were seriously ill, while those who were not open to anyone were significantly more likely to say that it was Not Very Likely that they would receive such help (see Table 3.70).

Table 3.70: Help with Bathing or Dressing, by Open About Sexuality

Open About Sexuality?	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Yes to All	215	62 (134)	20 (42)	18 (39)
Yes to Some	44	52 (23)	18 (8)	30 (13)
No	26	31 (8)	15 (4)	54 (14)
TOTAL	**285**	**58 (165)**	**19 (54)**	**23 (66)**
χ^2_4: **p value**		**18.187; .001**		

Relationship Status

Differences by respondent group were highly significant, with those who had a partner (living with or not) being much more likely than the other three groups to say that it was Very Likely that they would receive Help with Bathing or Dressing from at least one friend, relative or partner if they were seriously ill (see Table 3.71).

Table 3.71: Help with Bathing or Dressing, by Relationship Status

Relationship Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Single	127	33 (42)	26 (33)	41 (52)
Partner/Not Living With	47	83 (39)	13 (6)	4 (2)
Partner/Living With	96	85 (81)	10 (10)	5 (5)
Grieving Loss of Partner	8	12 (1)	38 (3)	50 (4)
Other	4	0 (0)	50 (2)	50 (2)
TOTAL	**282**	**58 (163)**	**19 (54)**	**23 (65**
χ^2_8: **p value**		**88.676; <.001**		

Income

There was a clear linear relationship in the responses to this question by Income; with each increase in income level, the likelihood of receiving Help with Bathing or Dressing from at least one friend, relative or partner increased. Respondents on the lowest levels of income were significantly more likely to say that it was Not Very Likely that they would receive such help (see Table 3.72).

Table 3.72: Help with Bathing or Dressing, by Income

Income Level	**N**	**Very Likely**	**Somewhat Likely**	**Not Very Likely**
		% (n)	**% (n)**	**% (n)**
< $20k	69	36 (25)	16 (11)	48 (33)
$20k - $29k	34	44 (15)	27 (9)	29 (10)
30k - $39k	30	57 (17)	23 (7)	20 (6)
$40k - $49k	24	54 (13)	33 (8)	13 (3)
$50k or more	124	75 (93)	15 (18)	10 (13)
TOTAL	**281**	**58 (163)**	**19 (53)**	**23 (65)**
χ^2_8: p value		**47.239; <.001**		

Religion

While differences between the groups reached significance there was no clear pattern of responses and several variables had small numbers, so caution is needed in interpreting results. Atheists were the most likely to say that it was Very Likely that they would receive Help with Bathing or Dressing from at least one friend, relative or partner if they were seriously ill (see Table 3.73).

Table 3.73: Help with Bathing or Dressing, by Religion

Religion	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
No Affiliation	131	66 (86)	17 (23)	17 (22)
Catholic	37	43 (16)	27 (10)	30 (11)
Anglican	31	39 (12)	32 (10)	29 (9)
Other Christian	24	50 (12)	21 (5)	29 (7)
Buddhist	19	63 (12)	5 (1)	32 (6)
Atheist	11	91 (10)	0 (0)	9 (1)
Other	30	57 (17)	13 (4)	30 (9)
TOTAL	**283**	**58 (165)**	**19 (53)**	**23 (65)**
χ^2_6: **p value**		**21.972; .038**		

Health Status

Respondents who were in Excellent health were most likely, and those in Fair health were the least likely, to say that it was Very Likely that they would receive Help with Bathing or Dressing from at least one friend, relative or partner if they were seriously ill (see Table 3.74).

Table 3.74: Help with Bathing or Dressing, by Health Status

Health Status	N	Very Likely	Somewhat Likely	Not Very Likely
		% (n)	% (n)	% (n)
Excellent	53	78 (41)	13 (7)	9 (5)
Very Good	96	59 (57)	18 (17)	23 (22)
Good	76	61 (46)	21 (16)	18 (14)
Fair	47	34 (16)	21 (10)	45 (21)
Poor	13	46 (6)	23 (3)	31 (4)
TOTAL	**285**	**58 (166)**	**19 (53)**	**23 (66)**
χ^2_8: **p value**		**24.679; .002**		

3.9 RESPONDENT ATTITUDES

3.9.1 Attitudes Towards Care

The next series of questions asked respondents how they would like to be cared for if they were seriously ill. When asked who they would like to make medical decisions for them if they were unable to do so, the majority of the 294 respondents who answered this question said that they would like their partner (44%) or a blood relative (25%) to do so; 17 percent said friend and 8 percent nominated their GP (see Table 3.75).

Table 3.75: Who Should Make Medical Decisions if you Cannot?

Person to Make Decisions	N	%
Partner	130	44
Blood Relative	72	25
Friend	51	17
GP	21	8
Partner and Relatives	3	1
Religious Advisor	2	<1
Other*	15	5
Total	**294**	**100**

*Other responses included: consensus decision; combination friend and family or GP and friend; solicitor has Enduring Power of Attorney x 2; ex-partner x 2; Advance Directive with GP; and “never religious advisor”.

Chi-Square Analysis

Because of low responses in the Partner and Relatives category and Religious Advisor category**,** the Partner and Relatives responses were collapsed into the Partner responses and the Religious Advisor responses were collapsed into Other; chi-square analysis was then undertaken. Differences reached or approached significance in relation to all variables. For some of the following Tables, while differences were very significant, many cells had small counts, so significance must be treated with caution.

Age

The youngest group was significantly more likely than any of the other groups to say that they would like a Relative to make medical decisions for them if they were unable to do so; approximately half of the four groups from 20-69 would like their Partner to make such decisions for them and all four of these groups were almost twice as likely to say Partner as to nominate any of the other options. The 70-79 year-old group were equally likely to say Friend or Relative (see Table 3.76)

Table 3.76: Would Make Medical Decisions, by Age Group

Age Group	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	19	26 (5)	16 (3)	0 (0)	53 (10)	5 (1)
30-39	32	53 (17)	16 (5)	0 (0)	28 (9)	3 (1)
40-49	65	57 (37)	20 (13)	2 (1)	15 (10)	6 (4)
50-59	72	46 (33)	18 (13)	10 (7)	25 (18)	1 (1)
60-69	62	43 (27)	10 (6)	13 (8)	24 (15)	10 (6)
70-79	32	22 (7)	28 (9)	16 (5)	28 (9)	6 (2)
80+	5	40 (2)	20 (1)	0 (0)	20 (1)	20 (1)
TOTAL	**287**	**45 (128)**	**17 (50)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_{24}: p value		**40.741; .018**				

Gender

Females and those who nominated “another gender” were most likely to say that they would like their Partner to make medical decisions for them if they were unable to do so; Males and those nominating as Another Gender were significantly more likely than Females to say that they would like their GP to make medical decisions for them if they were unable to do so; those nominating as Another Gender were significantly less likely than the other two groups to say that they would like a Relative to make medical decisions for them if they were unable to do so (see Table 3.77).

Table 3.77: Who Would Make Medical Decisions, by Gender

Gender	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
Female	115	49 (57)	16 (18)	1 (1)	27 (31)	7 (8)
Male	146	40 (59)	19 (27)	12 (17)	25 (37)	4 (6)
Another Gender	22	50 (11)	23 (5)	14 (3)	4 (1)	9 (2)
TOTAL	**283**	**45 (127)**	**18 (50)**	**7 (21)**	**24 (69)**	**6 (16)**
χ^2_8: p value		**18.625; .017**				

Sexual Orientation

Respondents who identified as Lesbian were significantly more likely than the other three groups to nominate their Partner to make medical decisions for them if they were unable to do so; respondents identifying as Gay were significantly more likely than the other three groups to nominate their GP to make medical decisions for them if they were unable to do so (although most would still prefer their partner to do so); those nominating as Bisexual were most likely to nominate a Relative; and those who identified their Sexual Orientation as Other than Gay, Lesbian or Bisexual were also significantly more likely than the other three groups to nominate a substitute decision-maker who wa snot their Partner, Friend, GP or Relative (see Table 3.78).

Table 3.78: Who Would Make Medical Decisions, by Sexual Orientation

Sexual Orientation	**N**	**Partner**	**Friend**	**GP**	**Relative**	**Other**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
Gay	**138**	41 (56)	20 (28)	11 (16)	24 (33)	4 (5)
Lesbian	**72**	58 (42)	11 (8)	1 (1)	25 (18)	4 (3)
Bisexual	**36**	36 (13)	17 (6)	6 (2)	36 (13)	5 (2)
Other	**41**	42 (17)	19 (8)	5 (2)	19 (8)	15 (6)
TOTAL	**287**	**45 (128)**	**17 (50)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_{12}: p value		**23.586; .023**				

Open About Sexuality

Respondents who were Open to All significant family members were significantly more likely than the other two groups to nominate their Partner as the person they would like to make medical decisions for them if they were unable to do so; those who were Open to Some and those who were Not Open to any were most likely to nominate a Relative to make such decisions for them. Respondents who were Open to Some were significantly more likely than the other two groups to nominate their GP to make medical decisions for them if they were unable to do so (see Table 3.79).

Table 3.79: Who Would Make Medical Decisions, by Open About Sexuality

Open About Sexuality?	**N**	**Partner**	**Friend**	**GP**	**Relative**	**Other**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
Yes to All	216	51 (109)	17 (37)	5 (11)	23 (49)	4 (10)
Yes to Some	44	25 (11)	18 (8)	21 (9)	34 (15)	2 (1)
No	25	24 (6)	20 (5)	4 (1)	32 (8)	20 (5)
TOTAL	**285**	**44 (126)**	**18 (50)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_{8}: p value		**32.978; <.001**				

Relationship Status

As would be expected, respondents who were living with a partner, followed by those who had a partner that they were not living with, were the most likely to nominate their partner as the person they would like to make their medical decisions if they could not do so. Those who were single, or grieving the loss of a partner, were most likely to nominate a relative to do so (see Table 3.80).

Table 3.80: Would Make Medical Decisions, by Relationship Status

Relationship Status	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
Single	126	9 (11)	31 (40)	11 (14)	40 (50)	9 (11)
Partner/Not Living With	48	61 (29)	8 (4)	0 (0)	27 (13)	4 (2)
Partner/Living With	97	87 (84)	2 (2)	6 (6)	3 (3)	2 (2)
Grieving Loss of Partner	8	0 (0)	13 (1)	12 (1)	75 (6)	0 (0)
Other	4	25 (1)	50 (2)	0 (0)	0 (0)	25 (1)
TOTAL	**283**	**44 (125)**	**17 (49)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_{16}: p value		**167.234; <.001**				

Time in Relationship

Responses indicate that the longer respondents have been in their relationships, the more likely they are to nominate their Partner to make their medical decisions if they could not do so (see Table 3.81).

Table 3.81: Who Would Make Medical Decisions, by Time in Relationship

Relationship Status	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
<1 Year	8	63 (5)	13 (1)	12 (1)	12 (1)	0 (0)
1-2 Years	12	58 (7)	0 (0)	0 (0)	25 (3)	17 (2)
2-4 Years	14	64 (9)	22 (3)	0 (0)	14 (2)	0 (0)
4-10 Years	44	75 (33)	5 (2)	7 (3)	11 (5)	2 (1)
>10 Years	70	86 (60)	2 (1)	4 (3)	7 (5)	1 (1)
TOTAL	**148**	**77 (114)**	**5 (7)**	**5 (7)**	**11 (16)**	**2 (4)**
χ^2_{16}: p value		**28.911; .025***				

*** Significance should be regarded with caution as 17 cells have counts <5**

Education

Differences between the groups approached significance but the relationship was not linear; those with the highest education levels were the least likely to appoint their GP to make medical decisions for them if they could not do so (see Table 3.82).

Table 3.82: Who Would Make Medical Decisions, by Education

Education Level	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	7	43 (3)	14 (1)	29 (2)	14 (1)	0 (0)
Year 10	40	38 (15)	20 (8)	12 (5)	23 (9)	7 (3)
Year 12	22	27 (6)	18 (4)	23 (5)	23 (5)	9 (2)
Trade Cert.	46	35 (16)	22 (10)	9 (4)	28 (13)	6 (3)
Uni Degree	94	49 (46)	19 (18)	5 (5)	24 (22)	3 (3)
Post-Grad	76	53 (40)	12 (9)	0 (0)	29 (22)	6 (5)
TOTAL		**44 (126)**	**18 (50)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_{20}: p value		**29.146; .085**				

By Income

Respondents with the highest income were significantly more likely than those with lower levels of income to say that they would like their Partner to make medical decisions for them if they could not do so. Respondents in the \$20k - \$29k income group were most likely to want a Relative to make such decisions (see Table 3.83)

Table 3.83: Who Would Make Medical Decisions, by Income

Income Level	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	68	23 (16)	27 (18)	16 (11)	28 (19)	6 (4)
$20k - $29k	35	20 (7)	20 (7)	6 (2)	43 (15)	11 (4)
30k - $39k	30	44 (13)	13 (4)	13 (4)	27 (8)	3 (1)
$40k - $49k	24	46 (11)	8 (2)	8 (2)	25 (6)	13 (3)
$50k or more	124	62 (77)	14 (17)	2 (2)	19 (24)	3 (4)
TOTAL	**281**	**44 (124)**	**17 (48)**	**7 (21)**	**26 (72)**	**6 (16)**
χ^2_{8}: p value		**51.934; <.001**				

Religion

There was no discernible pattern to the responses by religious affiiation, except that those who were Catholic were most likely to want a Relative to make their medical decisions if they could not do so and those who nominated an Other Christian religion were most likely to want a GP to do so (see Table 3.84).

Table 3.84: Who Would Make Medical Decisions, by Religion

Religion	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
No Affiliation	133	49 (65)	21 (28)	3 (4)	21 (28)	6 (8)
Catholic	36	28 (10)	8 (3)	11 (4)	50 (18)	3 (1)
Anglican	31	32 (10)	19 (6)	16 (5)	26 (8)	7 (2)
Other Christian	24	45 (11)	17 (4)	21 (5)	17 (4)	0 (0)
Buddhist	19	58 (11)	21 (4)	0 (0)	16 (3)	5 (1)
Atheist	11	46 (5)	27 (3)	9 (1)	18 (2)	0 (0)
Other	29	52 (15)	7 (2)	7 (2)	24 (7)	10 (3)
TOTAL	**283**	**45 (127)**	**18 (50)**	**7 (21)**	**25 (70)**	**5 (15)**
χ^2_{24}**: p value**		**40.209; .020***				

*** Significance should be regarded with caution as 19 cells have counts <5**

Health Status

Respondents who said that their health was Excellent were significantly more likely than those who said it was Fair or Poor to want their partner to make medical decisions for them if they could not do so; those in Fair or Poor health were significantly more likely than the other three groups to say that they would like their GP to do so and were also more likely to nominate someone other than a partner, Friend, GP or Relative (see Table 3.85).

Table 3.85: Who Would Make Medical Decisions, by Health Status

Health Status	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
Excellent	53	66 (35)	13 (7)	0 (0)	19 (10)	2 (1)
Very Good	98	44 (43)	19 (19)	8 (8)	26 (25)	3 (3)
Good	76	48 (36)	12 (9)	5 (4)	30 (23)	5 (4)
Fair	45	25 (11)	22 (10)	16 (7)	24 (11)	13 (6)
Poor	13	16 (2)	39 (5)	15 (2)	15 (2)	15 (2)
TOTAL	**285**	**45 (127)**	**17 (50)**	**7 (21)**	**25 (71)**	**6 (16)**
χ^2_{16}: **p value**		**39.439; .001**				

Private Health Insurance

Respondents with Private Health Insurance were significantly more likely than those without such insurance to say that they would want their Partner to make medical decisions for them if they could not do so for themselves (see Table 3.86).

Table 3.86: Would Make Medical Decisions, by Private Health Insurance

Private Health Insurance	N	Partner	Friend	GP	Relative	Other
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes	136	54 (73)	13 (17)	4 (6)	25 (34)	4 (6)
No	151	36 (54)	22 (34)	10 (15)	25 (38)	7 (10)
TOTAL	**287**	**44 (127)**	**18 (51)**	**7 (21)**	**25 (72)**	**6 (16)**
χ^2_4: **p value**		**12.840; .012**				

3.9.2 Spoken to Selected Person?

The next question asked respondents if they had spoken to the person identified in the previous question about their wishes/ideas for their medical treatment for the end stage of life. Of the 295 respondents who answered this question, 52 percent answered ‘yes’, 46 percent answered ‘no’ and 2 percent said ‘no, I don’t want to’.

Chi-Square Analysis

of these responses found that differences reached significance in relation to Open about Sexuality, Relationship Status, Time in Relationship, Income, Health Status and having Private Health Insurance.

Open About Sexuality

Respondents who are Open about their Sexuality to all significant others were significantly more likely than the other two groups to have spoken about their wishes for medical treatment, if they were seriously ill and unable to make their own decisions, to the person they would like to make such decisions (see Table 3.87).

Table 3.87: Spoken to Nominated Person about Wishes, by Open About Sexuality

Open About Sexuality?	N	Yes	No	No, I Don’t Want to
		% (n)	% (n)	% (n)
Yes to All	215	59 (126)	40 (86)	1 (3)
Yes to Some	45	31 (14)	65 (29)	4 (2)
No	26	35 (9)	61 (16)	4 (1)
TOTAL	**286**	**52 (149)**	**46 (131)**	**2 (6)**
χ^2_4: p value		**15.543; .004**		

Relationship Status

Respondents who were Living with a Partner were significantly more likely than the other four groups to have spoken about their wishes for medical treatment to the person they would like to make such decisions (see Table 3.88).

Table 3.88: Spoken to Nominated Person about Wishes, by Relationship Status

Relationship Status	N	Yes	No	No, I Don’t Want to
		% (n)	% (n)	% (n)
Single	128	39 (50)	57 (73)	4 (5)
Partner/Not Living With	48	52 (25)	46 (22)	2 (1)
Partner/Living With	96	71 (68)	29 (28)	0 (0)
Grieving Loss of Partner	8	38 (3)	63 (5)	0 (0)
Other	4	50 92)	50 (2)	0 (0)
TOTAL	**284**	**52 (148)**	**46 (130)**	**2 (6)**
χ^2_8: **p value**		**25.034; .002**		

Time in Relationship

There was a direct linear relationship between Time in Relationship and having spoken to the person the respondent would like to make their medical decisions if they could not do so; the longer the relationship, the more likely it was that they had discussed this issue. No-one who was in a relationship said that they did not want to talk to the nominated person about such decisions (see Table 3.89)

Table 3.89: Spoken to Nominated Person about Wishes, by Time in Relationship

Time	N	Yes	No	No, I Don’t Want to
		% (n)	% (n)	% (n)
<1 Yr	8	25 (2)	75 (6)	0 (0)
1-2 Yrs	12	42 (5)	58 (7)	0 (0)
2-4 Yrs	14	43 (6)	57 (8)	0 (0)
4-10 Yrs	44	68 (30)	32 (14)	0 (0)
>10 Yrs	69	74 (51)	26 (18)	0 (0)
TOTAL	**147**	**64 (94)**	**36 (53)**	**0 (0)**
χ^2_4: **p value**		**13.863; .008**		

Income

Respondents with incomes of $50k or more per year were significantly more likely than the other four groups to have spoken to nominated person about their wishes while those on the lowest incomes were the most likely to say that they had not and did not want to (see Table 3.90)

Table 3.90: Spoken to Nominated Person about Wishes, by Income

Income Level	**N**	**Yes**	**No**	**No, I Don't Want to**
		% (n)	**% (n)**	**% (n)**
< $20k	71	38 (27)	55 (39)	7 (5)
$20k - $29k	34	47 (16)	53 (18)	0 (0)
30k - $39k	30	44 (13)	53 (16)	3 (1)
$40k - $49k	23	48 (11)	52 (12)	0 (0)
$50k or more	124	65 (80)	35 (44)	0 (0)
TOTAL	**282**	**52 (147)**	**46 (129)**	**2 (6)**
χ^2_8: p value		**24.303; .002**		

Affect of Beliefs

Respondents whose beliefs do not affect their opinions about medical decisions at the end of life were less likely than the other two groups to have discussed their wishes with the person they would like to make such wishes for them (see Table 3.91).

Table 3.91: Spoken to Nominated Person about Wishes, by Affect of Beliefs

Beliefs	N	Yes	No	No, I Don't Want to
		% (n)	% (n)	% (n)
A Great Deal	52	59 (31)	35 (18)	6 (3)
Somewhat	63	60 (38)	38 (24)	2 (1)
Not At All	169	47 (79)	52 (88)	1 (2)
TOTAL	**284**	**52 (148)**	**46 (130)**	**2 (6)**
χ^2_4: p value		**10.064; .039**		

Health Status

Although there was no direct linear relationship between Health Status and having discussed their wishes with the person they would like to make them if they could not do so for themselves, respondents in the poorest health were the least likely to say that they had done so and were significantly more likely than the other four groups to say that they did not want to (see Table 3.92**).**

Table 3.92: to Nominated Person about Wishes, by Health Status

Health Status	N	Yes	No	No, I Don't Want to
		% (n)	% (n)	% (n)
Excellent	54	57 (31)	43 (23)	0 (0)
Very Good	98	49 (48)	49 (48)	2 (2)
Good	75	57 (43)	40 (30)	3 (2)
Fair	46	48 (22)	52 (24)	0 (0)
Poor	13	39 (5)	46 (6)	15 (2)
TOTAL	**286**	**52 (149)**	**46 (131)**	**2 (6)**
χ^2_8: p value		**15.946; .043**		

Private Health Insurance

Respondents with Private Health Insurance were significantly more likely than those without to have discussed their wishes with their nominated person (see Table 3.93).

Table 3.93: Spoken to Nominated Person about Wishes, by Private Health Insurance

Private Health Insurance	N	Yes	No	No, I Don't Want to
		% (n)	% (n)	% (n)
Yes	136	59 (80)	41 (56)	0 (0)
No	152	45 (69)	51 (77)	4 (6)
TOTAL	**288**	**52 (149)**	**46 (133)**	**2 (6)**
χ^2_2: **p value**		**9.268; .010**		

3.9.3 Why Not Spoken

Those who had not spoken to the nominated person were asked why they had not done so. Of the 123 respondents who answered the question, 49 percent said that the issue had not arisen, 12 percent saw no need, either because they were healthy or too young; and 10 percent answered that it was 'too hard / morbid (see Table 3.94)

Table 3.94: Why Had Not Spoken about Their Wishes to Nominated Person

Reason Not Spoken	N	%
Issue has not arisen	60	49
Don't see need/healthy/ I'm living, not dying/too young	15	12
Too hard / morbid	12	10
Intend to/haven't got around to it/ do need to	11	9
No one identified or nearby/no partner	10	8
Vaguely/unspoken agreement	9	7
Other reason*	6	5
Total	**123**	**100**

*"Other reasons" included:

- *It's a private matter/my decision/*
- *I have a plan*
- *GP would know best*
- *Have specified in Will and PoA*
- *Because we haven't*
- *I trust their decision*

Chi-Square Analysis of these results found no significant differences by any of the demographic variables.

3.9.4 Confident Wishes Will be Respected

Respondents were asked how confident they were that, if they had previously expressed their wishes but had not written them down, that their wishes would be carried out if they are not capable of making their own decision. Of the 293 respondents who answered this question, 55 percent are very confident or confident that wishes would be carried out, 31 percent were not sure and 14 percent were not very confident or not at all confident (see Table 3.95).

Table 3.95: Level of Confidence that Wishes Will be Carried Out

Confidence Level	N	%
Very Confident	61	21
Confident	99	34
Not Sure	90	31
Not Very Confident	24	8
Not at all Confident	19	6
Total	**293**	**100**

Chi-Square Analysis of these results found that differences reached or approached significance only in relation to Time in Relationship and Affect of Beliefs. As there were too many cells with very small number in relation to Time in Relationship, no Table will be presented. However, 68 percent of respondents who had been in their relationship for 10 years or more were Very Confident or Confident that their wishes would be respected, compared with only 25 percent of those who had been in their relationship for less than one year.

Affect of Beliefs

Although differences reached significance there was no discernible pattern in the responses by Affect of Beliefs (see Table 3.96).

Table 3.96: Level of Confidence that Wishes will be Respected, by Affect of Beliefs

Beliefs	**N**	**Very Confident**	**Confident**	**Not Sure**	**Not Very Confident**	**Not at All Confident**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
A Great Deal	50	8 (4)	38 (19)	36 (18)	10 (5)	8 (4)
Somewhat	63	21 (13)	40 (25)	24 (15)	14 (9)	2 (1)
Not At All	170	24 (40)	29 (50)	33 (56)	6 (10)	8 (14)
TOTAL	**283**	**20 (57)**	**33 (94)**	**31 (89)**	**9 (24)**	**7 (19)**
χ^2_8: p value		**15.301; .054**				

Approach to End-of-Life Treatment

Respondents were asked what approach they would want to take in their medical treatment if they were in the late stages of a life-threatening illness. Of the 292 respondents who answered this question, 90 percent chose an approach that focused on relieving symptoms even if it shortened their life and 10 percent would take an approach that focused on extending life even with distressing symptoms (see Table 3.97).

Table 3.97: Approach to Medical Treatment at End of Life

Focus of Approach	**N**	**%**
Focus on relieving symptoms even if it shortens life	262	90
Focus on extending life even with distressing symptoms	30	10
Total	**292**	**100**

Chi-Square Analysis of these results found that differences reached significance only in relation to Open about Sexuality and Affect of Beliefs.

Open About Sexuality

Respondents who were not Open about their sexuality to any significant family members were significantly more likely than the other two groups to take an approach to end-of-life care that focused on extending life even with distressing symptoms (see Table 3.98).

Table 3.98: Approach to End of Life, by Open About Sexuality

Open About Sexuality?	N	Extend Life	Shorten Life
		% (n)	% (n)
Yes to All	216	8 (17)	92 (199)
Yes to Some	44	11 (5)	89 (39)
No	24	29 (7)	71 (17)
TOTAL	**284**	**10 (29)**	**90 (255)**
χ^2_2: p value		**10.760; .005**	

Affect of Beliefs

Respondents whose beliefs influenced their opinions about treatment at the end of life A Great Deal were significantly more likely than the other to groups to say that they would choose an approach to end of life care that focused on extending life even with distressing symptoms (see Table 3.99)

Table 3.99: Approach to End of Life, by Affect of Beliefs

Beliefs	N	Extend Life	Shorten Life
		% (n)	% (n)
A Great Deal	51	22 (11)	78 (40)
Somewhat	63	6 (4)	94 (59)
Not At All	168	8 (14)	92 (154
TOTAL	**282**	**10 (29)**	**90 (253)**
χ^2_2: p value		**8.789; .012**	

3.10 PREFERRED PLACE TO DIE

The next question asked respondents, "If you were terminally ill, to what extent do you agree that you would prefer to die in one of the following places?" (from a list provided). Response preferences, in order by Strongly Agree/Agree were:

- of 283 respondents, 79% at home;
- of 260 respondents, 61% in a GLBT–specific care facility;
- of 265 respondents, 41% in a hospice;
- of 286 respondents, 43% in a hospital; and
- of 261 respondents, 16% in a nursing home (see Table 3.100).

Table 3.100: Preferred Place to Die

Location	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
At home	283	60 (171)	19 (53)	11 (30)	6 (18)	4 (11)
In a GLBT-specific care facility	260	26 (67)	35 (91)	23 (60)	7 (18)	9 (24)
In a hospice	265	15 (30)	26 (69)	28 (73)	16 (43)	15 (41)
In a hospital	268	14 (36)	29 (78)	25 (67)	15 (41)	17 (46)
In a nursing home	261	4 (11)	12 (32)	23 (59)	22 (58)	39 (101)
Other*	86	23(20)	12 (10)	38 (33)	2 (2)	25 (21)

SA = strongly disagree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree

*Other responses included:

- *die while travelling/final holiday/beach/stream/brothel*
- *a facility offering voluntary ending of life/euthanasia/euthanasia-friendly country*
- *anywhere else*
- *at a friend's home (many said this)/daughter's home/Mum's house, near family*
- *in the bush/forest sanctuary with my partner/outdoors/outside somewhere significant to me*
- *chance accident*
- *loving, nurturing environment*

Some people, while wanting to die at home, expressed concern about the responsibility that would leave on others to deal with “the body”.

Chi-Square Analysis

Responses were analysed by the demographic variables for each of the six areas of potential place to die. Differences reached or approached statistical significance for the following, in relation to:

- **At Home:** by Relationship Status; Religion and Health Status;
- **In a GLBT-Specific Facility;** by Relationship Status;
- **In a Hospice:** by Age; Sexual Orientation; Education; Income; Affect of Beliefs; and having Private Health Insurance;
- **In Hospital:** by Age; Gender; Sexual Orientation; Relationship Status; Education; Income; and Religion;
- **In a Nursing Home:** by Age and Religion;
- **Somewhere else:** by Sexual Orientation and Open About Sexuality.

The Key for all the following Tables are: SA = strongly disagree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree

3.10.1 AT HOME

Relationship Status

Respondents who were grieving the loss of a partner were significantly more likely than the other four groups to Strongly Agree that they would prefer to Die at Home. However, when the Strongly Agree and Agree responses were combined, all five groups scored between 73 and 86 for preference to Die at Home (see Table 3.101).

Table 3.101: Prefer to Die at Home, by Relationship Status

Relationship Status	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Single	124	53 (66)	20 (24)	17 (21)	7 (9)	3 (2)
Partner/Not Living With	45	60 (27)	24 (11)	0 (0)	5 (2)	11 (5)
Partner/Living With	94	67 (63)	17 (16)	9 (8)	5 (5)	2 (2)
Grieving Loss of Partner	7	86 (6)	0 (0)	0 (0)	14 (1)	0 (0)
Other	4	75 (3)	0 (0)	0 (0)	25 (1)	0 (0)
TOTAL	**274**	**60 (165)**	**19 (51)**	**11 (29)**	**6 (18)**	**4 (9)**
χ^2_{16}: p value		**27.137; .040***				

*** Significance should be regarded with caution as 11 cells have counts <5**

Religion

Respondents who are Anglican were much less likely than the other six groups to Strongly Agree that they would prefer to Die at Home and much more likely to disagree with that statement (see Table 3.102).

Table 3.102: Prefer to Die at Home, by Religion

Religion	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
No Affiliation	126	65 (82)	18 (22)	9 (11)	5 (7)	3 (4)
Catholic	34	59 (20)	20 (7)	12 (4)	6 (2)	3 (1)
Anglican	31	42 (13)	19 (6)	13 (4)	23 (7)	3 (1)
Other Christian	24	50 (12)	25 (6)	21 (5)	0 (0)	4 (1)
Buddhist	17	47 (8)	18 (3)	23 (4)	6 (1)	6 (1)
Atheist	12	67 (8)	17 (2)	0 (0)	0 (0)	17 (2)
Other	30	77 (23)	14 (4)	3 (1)	3 (1)	3 (1)
TOTAL	**274**	**61 (166)**	**18 (50)**	**11 (29)**	**6 (18)**	**4 (11)**
χ^2_{24}: p value		**34.666; .074***				

*** "Close to Significant" should be regarded with caution as 17 cells have counts <5**

Health Status

When the Strongly Agree/Agree responses were combined, respondents in Poor health were significantly less likely than the other four groups to Strongly Agree/ Agree that they would prefer to Die at Home (see Table 3.103).

Table 3.103: Prefer to Die at Home, by Health Status

Health Status	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
Excellent	54	52 (28)	24 (13)	15 (8)	7 (4)	2 (1)
Very Good	93	70 (65)	16 (15)	4 (4)	7 (6)	3 (3)
Good	72	54 (39)	19 (14)	17 (12)	3 (2)	7 (5)
Fair	45	65 (29)	18 (8)	2 (1)	11 (5)	4 (2)
Poor	12	50 (6)	8 (1)	34 (4)	8 (1)	0 (0)
TOTAL	**276**	**61 (167)**	**19 (51)**	**10 (29)**	**6 (18)**	**4 (11)**
χ^2_{16}: **p value**	**26.559; .047***					

*** Significance should be regarded with caution as 11 cells have counts <5**

3.10.2 IN A GLBT-SPECIFIC FACILITY

Relationship Status: Respondents with a partner (living with or not) were most likely to say that they would want to die in a GLBT-specific facility (see Table 3.104).

Table 3.104: Prefer to Die in a GLBT-Specific Facility, by Relationship Status

Relationship Status	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Single	112	27 (30)	28 (31)	29 (32)	6 (7)	10 (12)
Partner/Not Living With	45	33 (15)	38 (17)	16 (7)	4 (2)	9 (4)
Partner/Living With	90	22 (20)	43 (39)	17 (15)	10 (9)	8 (7)
Grieving Loss of Partner	5	0 (0)	0 (0)	100 (5)	0 (0)	0 (0)
Other	2	0 (0)	100 (2)	0 (0)	0 (0)	0 (0)
TOTAL	**254**	**26 (65)**	**35 (89)**	**23 (59)**	**7 (18)**	**9 (23)**
χ^2_{16}: **p value**		**31.665; .011***				

*** Significance should be regarded with caution as 11 cells have counts <5**

3.10.3 IN A HOSPICE

Age

Respondents 70-79 were the most likely to Strongly Agree that they would prefer to die in a Hospice and remained the most likely when the Strongly Agree and agree responses were combined. The two youngest groups were the most likely to Disagree with this option, especially when the Disagree and strongly Disagree responses were combined (see Table 3.105).

Table 3.105: Prefer to Die in a Hospice, by Age Group

Age Group	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	17	12 (2)	18 (3)	29 (5)	18 (3)	23 (4)
30-39	32	6 (2)	12 (4)	34 (11)	16 (5)	31 (10)
40-49	62	6 (4)	24 (15)	34 (21)	15 (9)	21 (13)
50-59	67	19 (13)	30 (20)	21 (14)	22 (15)	8 (5)
60-69	54	15 (8)	37 (20)	30 (16)	9 (5)	9 (5)
70-79	26	35 (9)	27 (7)	11 (3)	19 (5)	8 (2)
80+	4	25 (1)	0 (0)	50 (2)	25 (1)	0 (0)
TOTAL	**262**	**15 (39)**	**26 (69)**	**28 (72)**	**16 (43)**	**15 (39)**
χ^2_{24}: p value		**41.988; .013**				

*** Significance should be regarded with caution as 14 cells have counts <5**

Sexual Orientation

Respondents who identified as Gay were the most likely to Strongly Agree that they would prefer to die in a Hospice, and they remained the most likely when the Strongly Agree and Agree responses were combined. Respondents who identified as other than Gay, Lesbian or Bisexual were the most likely to Disagree with this option and became significantly most likely when the Disagree and Strongly Disagree responses were combined (see Table 3.106).

Table 3.106: Prefer to Die in a Hospice, by Sexual Orientation

Sexual Orientation	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Gay	126	19 (24)	29 (36)	30 (38)	13 (17)	9 (11)
Lesbian	68	10 (7)	25 (17)	30 (20)	13 (9)	22 (15)
Bisexual	31	16 (5)	13 (4)	32 (10)	23 (7)	16 (5)
Other	37	8 (3)	32 (12)	11 (4)	27 (10)	22 (8)
TOTAL	**262**	**15 (39)**	**26 (69)**	**28 (72)**	**16 (43)**	**15 (39)**
χ^2_{12}: **p value**		**22.004; .037**				

Education

Respondents with less than Year 10 education were significantly more likely than any of the other groups to Disagree/Strongly Disagree that they would want to die in a Hospice (see Table 3.107).

Table 3.107: Prefer to Die in a Hospice, by Education

Education Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	6	0 (0)	0 (0)	17 (1)	33 (2)	50 (3)
Year 10	33	30 (10)	16 (5)	30 (10)	12 (4)	12 (4)
Year 12	17	29 (5)	29 (5)	18 (3)	12 (2)	12 (2)
Trade Cert.	43	2 (1)	16 (7)	35 (15)	33 (14)	14 (6)
Uni Degree	87	15 (13)	28 (24)	30 (26)	11 (10)	16 (14)
Post-Grad	74	13 (10)	37 (27)	22 (16)	15 (11)	13 (10)
TOTAL	**260**	**15 (39)**	**26 (68)**	**27 (71)**	**17 (43)**	**15 (39)**
χ^2_{20}: **p value**		**39.101; .006***				

*** Significance should be regarded with caution as 10 cells have counts <5**

Income

Although differences between groups approached significance there was no linear pattern to the responses (see Table 3.108).

Table 3.108: Prefer to Die in a Hospice, by Income

Income Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	61	15 (9)	16 (10)	31 (19)	22 (13)	16 (10)
$20k - $29k	31	22 (7)	16 (5)	39 (12)	10 (3)	13 (4)
30k - $39k	29	17 (5)	21 (6)	38 (11)	10 (3)	14 (4)
$40k - $49k	20	20 (4)	10 (2)	25 (5)	20 (4)	25 (5)
$50k or more	116	11 (13)	38 (44)	21 (24)	16 (19)	14 (16)
TOTAL	**257**	**15 (38)**	**26 (67)**	**28 (71)**	**16 (42)**	**15 (39)**
χ^2_8: p value		**23.717; .096**				

Affect of Beliefs

While differences between the groups approached significance, the major difference was that those who said that their beliefs Somewhat affected their decisions about medical care were significantly less likely than the other two groups to Strongly Disagree that they would prefer to Die in a Hospice (see Table 3.109).

Table 3.109 Prefer to Die in a Hospice, by Affect of Beliefs

Beliefs	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
A Great Deal	45	13 (6)	34 (15)	22 (10)	11 (5)	20 (9)
Somewhat	58	12 (7)	38 (22)	26 (15)	19 (11)	5 (3)
Not At All	155	17 (26)	20 (31)	29 (45)	17 (27)	17 (26)
TOTAL	**258**	**15 (39)**	**26 (68)**	**27 (70)**	**17 (43)**	**15 (38)**
χ^2_8: p value		**13.484; .096**				

Private Health Insurance

Respondents who have Private Health Insurance were significantly more likely than those who do not to Agree that they would prefer to Die in a Hospice, and this result remained when the Strongly agree and agree responses were combined (see Table 3.110).

Table 3.110: Prefer to Die in a Hospice, by Private Health Insurance

Private Health Insurance	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
Yes	126	15 (19)	37 (47)	26 (33)	12 (15)	10 (12)
No	136	14 (20)	16 (22)	28 (38)	21 (28)	21 (28)
TOTAL	**262**	**14 (39)**	**26 (69)**	**27 (71)**	**16 (43)**	**15 (40)**
χ^2_4: p value		**19.413; .001**				

3.10.4 IN HOSPITAL

Age

When the Strongly Agree and Agree responses were combined, the 60-69 and 70-79 year-old age groups were the most likely to say that they would prefer to Die in Hospital (see Table 3.111).

Table 3.111: Prefer to Die in Hospital, by Age Group

Age Group	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	18	22 (4)	33 (6)	17 (3)	11 (2)	17 (3)
30-39	32	0 (0)	12 (4)	44 (14)	22 (7)	22 (7)
40-49	65	4 (3)	23 (15)	28 (18)	17 (11)	28 (18)
50-59	67	16 (11)	30 (20)	27 (18)	16 (11)	11 (7)
60-69	52	16 (8)	44 (23)	17 (9)	9 (5)	14 (7)
70-79	26	27 (7)	39 (10)	8 (2)	15 (4)	11 (3)
80+	4	50 (2)	0 (0)	50 (2)	0 (0)	0 (0)
TOTAL	**264**	**13 (35)**	**30 (78)**	**25 (66)**	**15 (40)**	**17 (45)**
χ^2_{24}: p value		**48.897; .002***				

*** Significance should be regarded with caution as 15 cells have counts <5**

Gender

When the Strongly Agree and Agree responses were combined, Males were significantly more likely than the other two groups to say that they prefer to Die in Hospital (see Table 3.112).

Table 3.112: Prefer to Die in Hospital, by Gender

Gender	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Female	108	6 (7)	24 (26)	30 (32)	19 (20)	21 (23)
Male	131	18 (24)	34 (44)	21 (28)	14 (18)	13 (17)
Anther Gender	21	19 (4)	24 (5)	24 (5)	9 (2)	24 (5)
TOTAL	**260**	**14 (35)**	**29 (75)**	**25 (65)**	**15 (40)**	**17 (45)**
χ^2_{8}: p value		**14.692; .065**				

Sexual Orientation

Respondents who identified as Gay were significantly more likely than the other three groups to Strongly Agree that they would prefer to Die in Hospital and this difference remained when the Strongly Agree and agree responses were combined (see Table 3.113).

Table 3.113: Prefer to Die in Hospital, by Sexual Orientation

Sexual Orientation	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Gay	125	19 (24)	34 (42)	21 (26)	13 (17)	13 (16)
Lesbian	67	5 (3)	28 (19)	25 (17)	21 (14)	21 (14)
Bisexual	33	9 (3)	34 (11)	24 (8)	12 (4)	21 (7)
Other	39	13 (5)	15 (6)	39 (15)	13 (5)	20 (8)
TOTAL	**264**	**13 (35)**	**30 (78)**	**25 (66)**	**15 (40)**	**17 (45)**
χ^2_{12}: p value		**19.413; .079**				

Relationship Status

By Strongly Agree/Agree, respondents grieving the loss of a partner were the most likely to say that they would prefer to Die in Hospital while those who nominated an Other relationship were the most likely to Disagree or Strongly Disagree with this option (see Table 3.114).

Table 3.114: Prefer to Die in Hospital, by Relationship Status

Relationship Status	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Single	112	16 (18)	32 (36)	24 (27)	14 (16)	14 (15)
Partner/Not Living With	46	13 (6)	33 (15)	15 (7)	11 (5)	28 (13)
Partner/Living With	92	10 (9)	24 (22)	34 (31)	19 (18)	13 (12)
Grieving Loss of Partner	6	17 (1)	50 (3)	0 (0)	0 (0)	33 (2)
Other	4	0 (0)	0 (0)	0 (0)	25 (1)	75 (3)
TOTAL	**260**	**13 (34)**	**30 (76)**	**25 (65)**	**15 (40)**	**17 (45)**
χ^2_{16}: p value		**29.278; .022**				

Education

When responses were combined, respondents who had completed year 10 and those who had completed Year 12 were the most likely to Strongly Agree/Agree that they would prefer to Die in Hospital (see Table 3.115).

Table 3.115: Prefer to Die in Hospital, by Education

Education Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	7	14 (1)	14 (1)	14 (1)	29 (2)	29 (2)
Year 10	34	35 (12)	35 (12)	18 (6)	6 (2)	6 (2)
Year 12	16	19 (3)	56 (9)	12 (2)	13 (2)	0 (0)
Trade Cert.	46	4 (2)	28 (13)	31 (14)	22 (10)	15 (7)
Uni Degree	84	10 (8)	26 (22)	25 (21)	19 (16)	20 (17)
Post-Grad	75	12 (9)	27 (20)	28 (21)	10 (8)	23 (17)
TOTAL	**262**	**13 (35)**	**30 (77)**	**25 (65)**	**15 (40)**	**17 (45)**
χ^2_{20}: p value		**38.309; .008**				

By Income

Respondents in the highest income group were significantly less likely than those in the other groups to Strongly Agree that they would prefer to Die in Hospital and this result held when the Strongly Agree and Agree responses were combined. However, they were significantly more likely to say that they Neither Agreed nor Disagreed with this option, rather than Disagreeing or Strongly Disagreeing with it (see Table 3.116).

Table 3.116: Prefer to Die in Hospital, by Income

Income Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	63	19 (12)	30 (19)	16 (10)	19 (12)	16 (10)
$20k - $29k	31	19 (6)	32 (10)	26 (8)	13 (4)	10 (3)
30k - $39k	29	14 (4)	28 (8)	20 (6)	28 (8)	10 (3)
$40k - $49k	20	20 (4)	25 (5)	15 (3)	5 (1)	35 (7)
$50k or more	116	7 (8)	30 (35)	33 (38)	12 (14)	18 (21)
TOTAL	**259**	**13 (34)**	**30 (77)**	**25 (65)**	**15 (39)**	**17 (44)**
χ^2_{16}: **p value**		**24.419; .081**				

Religion

When the Strongly Agree and agree responses were combined, Catholics, followed by Anglicans, were the most likely to say that they would prefer to Die in Hospital while those who nominated an Other affiliation were significantly more likely than the other six groups to Disagree/Strongly Disagree with this option (see Table 3.117).

Table 3.117: Prefer to Die in Hospital, by Religion

Religion	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
No Affiliation	120	9 (11)	25 (30)	31 (37)	18 (21)	17 (21)
Catholic	31	29 (9)	36 (11)	13 (4)	6 (2)	16 (5)
Anglican	29	21 (6)	38 (11)	24 (7)	10 (3)	7 (2)
Other Christian	23	9 (2)	43 (10)	26 (6)	13 (3)	9 (2)
Buddhist	18	17 (3)	17 (3)	39 (7)	22 (4)	5 (1)
Atheist	11	18 (2)	37 (4)	9 (1)	9 (1)	27 (3)
Other	28	7 (2)	21 (6)	11 (3)	21 (6)	40 (11)
TOTAL	**260**	**14 (35)**	**29 (75)**	**25 (65)**	**15 (40)**	**17 (45)**
χ^2_{24}: **p value**		**40.171; .020**				

3.10.5 IN A NURSING HOME

Age

Although differences between the groups were highly significant, there was no linear pattern to the responses (see Table 3.118)

Table 3.118: Prefer to Die in a Nursing Home, by Age Group

Age Group	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	18	6 (1)	22 (4)	17 (3)	22 (4)	33 (6)
30-39	32	0 (0)	6 (2)	28 (9)	13 (4)	53 (17)
40-49	64	0 (0)	11 (7)	25 (16)	28 (18)	36 (23)
50-59	65	6 (4)	9 (6)	20 (13)	26 (17)	39 (25)
60-69	52	2 (1)	21 (11)	16 (8)	19 (10)	42 (22)
70-79	24	17 (4)	8 (2)	33 (8)	17 (4)	25 (6)
80+	4	25 (1)	0 (0)	50 (2)	25 (1)	0 (0)
TOTAL	**259**	**4 (11)**	**12 (32)**	**23 (59)**	**23 (58)**	**38 (99)**
χ^2_{24}: p value		**38.245; .003**				

Religion

Although very few respondents of any affiliation Strongly Agreed or Agreed that they would prefer to die in a Nursing Home, Catholics were most likely to do so (see Table 3.119).

Table 3.119: Prefer to Die in a Nursing Home, by Religion

Religion	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
No Affiliation	120	4 (5)	13 (16)	23 (27)	23 (28)	37 (44)
Catholic	29	7 (2)	24 (7)	28 (8)	17 (5)	24 (7)
Anglican	28	0 (0)	18 (5)	14 (4)	36 (10)	32 (9)
Other Christian	22	9 (2)	0 (0)	27 (6)	27 (6)	37 (8)
Buddhist	18	0 (0)	0 (0)	33 (6)	22 (4)	45 (8)
Atheist	11	18 (2)	9 (1)	37 (4)	0 (0)	36 (4)
Other	28	0 (0)	11 (3)	11 (3)	14 (4)	64 (18)
TOTAL	**256**	**4 (11)**	**13 (32)**	**23 (58)**	**22 (57)**	**38 (98)**
χ^2_{24}: p value		**36.935; .044**				

*** Significance should be regarded with caution as 17 cells have counts <5**

3.10.6 SOMEWHERE ELSE (Note: for both Tables, majority of cells have counts <5)

Sexual Orientation

Of the 85 respondents who nominated somewhere other than the four listed options as preferred Place to Die, those who identified as Bisexual were significantly more likely than the other three groups to Strongly Agree that they would so prefer. However, when the Strongly Agree and Agree responses were combined, respondents who identified as Other than Gay, Lesbian or Bisexual were significantly most likely to choose another option of preferred Place to Die (see Table 3.120).

Table 3.120: Prefer to Die Somewhere Else, by Sexual Orientation

Sexual Orientation	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Gay	38	16 (6)	5 (2)	42 (16)	5 (2)	32 (12)
Lesbian	18	16 (3)	17 (3)	39 (7)	0 (0)	28 (5)
Bisexual	14	43 (6)	0 (0)	50 (7)	0 (0)	7 (1)
Other	15	33 (5)	34 (5)	20 (3)	0 (0)	13 (2)
TOTAL	**85**	**23 (20)**	**12 (10)**	**39 (33)**	**2 (2)**	**24 (20)**
χ^2_{12}: **p value**		**21.318; .046**				

Open About Sexuality

Respondents who are Not Open about their Sexuality were significantly more likely than the other two groups to Strongly Disagree that they would prefer to Die somewhere other than the four listed options (see Table 3.121).

Table 3.121: Prefer to Die Somewhere Else, by Open About Sexuality

Open About Sexuality?	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes to All	66	23 (15)	9 (6)	44 (29)	1 (1)	23 (15)
Yes to Some	10	30 (3)	20 (2)	40 (4)	10 (1)	0 (0)
No	9	22 (2)	22 (2)	0 (0)	0 (0)	56 (5)
TOTAL	**85**	**23 (20)**	**12 (10)**	**39 (33)**	**2 (2)**	**24 (20)**
χ^2_{8}: **p value**		**15.147; .056**				

3.11 ADVANCE CARE PLANNING AND BARRIERS TO THIS

Respondents were asked if they have completed Advance Care Planning documents. Of the 291 respondents who answered the question asking if they had given anyone Enduring Power of Attorney , 29 percent said Yes and of the 285 respondents who answered the question which asked if they have appointed an Enduring Guardian, 18 percent said Yes (see Table 3.122).

Table 3.122: Appointed EPA and EG

Appointed	N	YES	NO
		% (n)	% (n)
Enduring Power of Attorney	291	29 (85)	71 (206)
Enduring Guardian	285	18 (52)	82 (233)

Chi-Square Analysis

Analysis of these responses by demographic variables found that differences between respondents reached or approached significance in relation to the following:

- **Enduring Power of Attorney**: by Age; Gender; Sexual Orientation; Open About Sexuality; Relationship Status; time in Relationship; Income; and Health Insurance
- **Enduring Guardian**: by Age and Sexual Orientation.

3.11.1 ENDURING POWER OF ATTORNEY

Age

Respondents 50 and over were more likely and those 80+ significantly more likely than the three younger groups to have given someone Enduring Power of Attorney to make financial decisions for them should they lose capacity (see Table 3.123).

Table 3.123: Appointed Enduring Power of Attorney, by Age Group

Age Group	N	YES	NO
		% (n)	% (n)
<30	19	5 (1)	95 (18)
30-39	31	19 (6)	81 (25)
40-49	64	14 (9)	86 (55)
50-59	73	32 (23)	68 (50)
60-69	64	34 (22)	66 (42)
70-79	31	52 (16)	48 (15)
80+	5	80 (4)	20 (1)
TOTAL	**287**	**28 (81)**	**72 (206)**
χ^2_6: p value		**29.056; <.001**	

Gender

Males were significantly more likely than the other two groups to have given someone Enduring Power of Attorney (see Table 3.124).

Table 3.124: Appointed Enduring Power of Attorney, by Gender

Gender	N	YES	NO
		% (n)	% (n)
Female	114	21 (24)	79 (90)
Male	145	36 (52)	64 (93)
Another Gender	24	17 (4)	83 (20)
TOTAL	**283**	**28 (80)**	**72 (203)**
χ^2_2: p value		**8.644; .013**	

Sexual Orientation

Respondents identifying as Gay, followed by those identifying as Lesbian, were significantly more likely than the other two groups to have given someone Enduring Power of Attorney (see Table 3.125).

Table 3.125: Appointed Enduring Power of Attorney, by Sexual Orientation

Sexual Orientation	N	YES	NO
		% (n)	% (n)
Gay	138	36 (49)	64 (89)
Lesbian	73	27 (20)	73 (53)
Bisexual	35	14 (5)	86 (30)
Other	41	17 (7)	83 (34)
TOTAL	**287**	**28 (81)**	**72 (206)**
χ^2_3: p value		**9.511; .023**	

Open About Sexuality

Respondents who are Open to All significant people in their lives about their sexuality were much more likely than the other two groups to have given someone Enduring Power of Attorney (see Table 3.126).

Table 3.126: Appointed Enduring Power of Attorney, by Open About Sexuality

Open About Sexuality?	N	YES	NO
		% (n)	% (n)
Yes to All	214	31 (67)	69 (147)
Yes to Some	45	15 (7)	84 (38)
No	26	23 (6)	77 (20)
TOTAL	**285**	**28 (80)**	**72 (205)**
χ^2_2: p value		**4.923; .085**	

Relationship Status

Respondents living with a partner and those Grieving the loss of a partner were significantly more likely than the other three groups to have given someone Enduring Power of Attorney (see Table 3.127).

Table 3.127: Appointed Enduring Power of Attorney, by Relationship Status

Relationship Status	N	YES	NO
		% (n)	% (n)
Single	126	21 (27)	79 (99)
Partner/Not Living With	48	27 (13)	73 (35)
Partner/Living With	96	39 (37)	61 (59)
Grieving Loss of Partner	8	38 (3)	62 (5)
Other	4	0 (0)	100 (4)
TOTAL	**282**	**28 (80)**	**72 (202)**
χ^2_4: p value		**9.827; .043**	

Time in Relationship

Although the was not a direct linear relationship, respondents who had been in their relationship the longest were most likely to have given someone Enduring Power of Attorney (see Table 3.128).

Table 3.128: Appointed Enduring Power of Attorney, by Time in Relationship

Time	N	YES	NO
		% (n)	% (n)
<1 Yr	8	25 (2)	75 (6)
1-2 Yrs	12	25 (3)	75 (9)
2-4 Yrs	14	7 (1)	93 (13)
4-10 Yrs	43	33 (14)	67 (29)
>10 Yrs	70	44 (31)	56 (39)
TOTAL	**147**	**35 (51)**	**65 (96)**
χ^2_4: p value		**8.449; .076**	

Income

The relationship between income and having given someone Enduring Power of Attorney was not linear but respondents in the highest income group were significantly more likely than those in the other four groups to have done so (see Table 3.129).

Table 3.129: Appointed Enduring Power of Attorney, by Income

Income Level	N	YES	NO
		% (n)	% (n)
< $20k	70	17 (12)	83 (58)
$20k - $29k	33	30 (10)	70 (23)
30k - $39k	30	23 (7)	77 (23)
$40k - $49k	24	17 (4)	83 (20)
$50k or more	124	38 (47)	62 (77)
TOTAL	**281**	**29 (80)**	**72 (201)**
χ^2_4: p value		**11.914; .018**	

Private Health Insurance

Respondents who have private health insurance were significantly more likely than those without such insurance to have given someone Enduring Power of Attorney (see Table 3.130).

Table 3.130: Appointed Enduring Power of Attorney, by Private Health Insurance

Private Health Insurance	**N**	**YES**	**NO**
		% (n)	**% (n)**
Yes	136	38 (51)	62 (85)
No	151	21 (31)	79 (120)
TOTAL	**287**	**29 (82)**	**71 (205)**
χ^2_1: p value		**10.097; .001**	

3.11.2 ENDURING GUARDIAN

Age

Respondents 70 and above were significantly more likely than the other five groups to have appointed an Enduring Guardian to make health and personal care decisions for them if they lose the capacity to do so for themselves in the future (see Table 3.131).

Table 3.131: Appointed Enduring Guardian, by Age Group

Age Group	**N**	**YES**	**NO**
		% (n)	**% (n)**
<30	19	5 (1)	95 (18)
30-39	32	9 (3)	91 (29)
40-49	63	6 (4)	94 (59)
50-59	69	19 (13)	81 (56)
60-69	62	18 (11)	82 (51)
70-79	31	42 (13)	58 (18)
80+	4	50 (2)	50 (2)
TOTAL	**280**	**17 (47)**	**83 (233)**
χ^2_6: p value		**25.423; <.001**	

Sexual Orientation

Respondents who identified as Gay were significantly more likely than the other three groups to have appointed an Enduring Guardian (see Table 3.132).

Table 3.132: Appointed Enduring Guardian, by Sexual Orientation

Sexual Orientation	**N**	**YES**	**NO**
		% (n)	**% (n)**
Gay	136	22 (30)	78 (106)
Lesbian	72	14 (10)	86 (62)
Bisexual	33	3 (1)	97 (32)
Other	39	15 (6)	85 (33)
TOTAL	**280**	**17 (47)**	**83 (233)**
χ^2_3: p value		**7.665; .053**	

3.11.3 BARRIERS TO APPOINTING ENDURING POWER OF ATTORNEY AND ENDURING GUARDIAN

Respondents who have not given anyone Enduring Power of Attorney or appointed an Enduring Guardian were asked what is preventing them from doing so; 207 respondents gave at least one reason why they have not given anyone Enduring Power of Attorney and 224 respondents gave at least one reason why they have not appointed an Enduring Guardian (see Table 3. 133).

Table 3.133: Barriers to Advance Care Planning

BARRIERS	Barrier to EPoA N = 207	Barrier to EG N = 224
	% (n)	% (n)
Not necessary at present	35 (73)	34 (76)
Unsure who to name	27 (56)	24 (53)
I don't know about this document	24 (50)	36 (80)
Don't know where or how to do it	24 (50)	21 (47)
Haven't found the time	24 (50)	20 (45
Hard to think about	12 (24)	10 (20)

A small number of respondents in each case said: don't have anyone to appoint; intend to; not priority; too difficult or haven't thought about it.

No chi-square analysis of these responses was undertaken, as they were frequencies only.

3.12 ADVANCE HEALTH CARE DIRECTIVE

Respondents were asked if they had completed their own Advance Health Care Directive; only 12 percent had done so. Chi-square analysis of these responses found that differences only reached significance in relation to Age.

Age

Respondents aged 79 and above were very significantly more likely than the other five groups to have completed and Advance Health Care Directive (see Table 3.134).

Table 3.134: Completed Advance Directive, by Age Group

Age Group	N	YES	NO
		% (n)	% (n)
<30	19	0 (0)	100 (19)
30-39	31	3 (1)	97 (30)
40-49	62	7 (4)	93 (58)
50-59	73	11 (8)	89 (65)
60-69	62	10 (6)	90 (56)
70-79	33	42 (14)	58 (19)
80+	5	40 (2)	60 (3)
TOTAL	**285**	**12 (35)**	**88 (250)**
χ^2_6: p value		**38.884; <.001**	

Why Not? Respondents who had not completed an Advance Health Care Directive were asked what was preventing them from doing so, from a list of possible reasons, with an "other" option. Combining the Strongly Agree and Agree responses provides the following:

- 65 percent of respondents did not know where or how to do an AHCD;
- 31 percent would prefer to leave it until the situation arises;
- 29 percent said it is hard to think about end-of-life issues;
- 18 percent would prefer to leave the decision to family/friends;
- 14 percent would prefer to leave the decision to the doctor;
- 30 percent of respondents gave other reasons (see Table 3.135).

Table 3.135: Reasons for Not Completing an Advance Health Care Directive

Reason	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
I don't know where or how to do an Advance Health Care Directive	269	45 (120)	20 (53)	9 (25)	5 (13)	7 (18)
I would prefer to leave it until the situation arises	258	13 (35)	18 (46)	20 (52)	18 (46)	16 (41)
It's hard to think about end-of-life issues	252	11 (29)	18 (45)	16 (40)	17 (42)	23 (58)
I would prefer to leave the decision to family / friends	248	8 (21)	10 (25)	15 (37)	23 (56)	21 (67)
I would prefer to leave the decision to the doctor	253	7 (18)	7 (18)	15 (37)	22 (56)	34 (86)
Other*	86	20 (23)	10 (12)	33 (39)	2 (2)	21 (24)

SA = Strongly Agree; A = Agree; N = Neither agree nor disagree; D = Disagree; SD = Strongly Disagree

*Other responses included:

- *Cost of doing it/money for solicitor*
- *Haven't thought about it*
- *Procrastination/Have not felt the need/not a priority*
- *Range of partner-related statements (e.g. partner will know what to do)*
- *Next of kin understands and concurs with my wishes*
- *I had not thought it was time but I have reconsidered and will talk to my partner*
- *Degree of denial about possible loss of autonomy/haven't faced death yet*

Chi-Square Analysis of reasons for not completing an Advance Health Care Directive found that differences reached or approached significance in relation to the following:

- **Don't Know Where or How to do it:** by Private Health Insurance Only
- **Prefer to Leave it Until Situation Arises:** by Age; Education; Income; Religion and Affect of Beliefs
- **Hard to Think About End-of-Life Issues:** by Open About Sexuality; Time in Relationship; Education; Income; Affect of Beliefs; Health Status; Private Health Insurance
- **Prefer to Leave Decisions to Family/Friends:** None reached significance.
- **Prefer to Leave Decision to Doctor:** by Age; Open About Sexuality; Education; Income; and Private health Insurance.

3.12.1 DON'T KNOW WHERE OR HOW TO DO IT

Private Health Insurance

Respondents who do not have Private Health Insurance were significantly more likely than those who do to Strongly Agree that not knowing where or how to do it would be a barrier to their completing an Advance Health Care Directive. However, when the Strongly Agree and Agree responses were combined, the difference disappeared (see Table 3.136).

Table 3.136: Don't Know Where/How to do AHCD, by Private Health Insurance

Private Health Insurance	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes	104	44 (46)	32 (33)	11 (11)	5 (5)	8 (9)
No	122	60 (73)	15 (19)	11 (14)	7 (8)	7 (8)
TOTAL	**228**	**53 (119)**	**23 (52)**	**11 (25)**	**6 (13)**	**7 (17)**
χ^2_4: **p value**		**9.634; .047**				

3.12.2 PREFER TO LEAVE IT UNTIL SITUATION ARISES

Age

Respondents 70-79 were significantly more likely than the other six groups to Strongly Agree that they would prefer to leave completing an Advance Health Care Directive until the situation arises. However, when the Strongly Agree and agree responses were combined, those aged 80+ were the most likely to say this. Respondents aged 30-39 were the most likely to neither Agree nor Disagree with this option (see Table 3.137).

Table 3.137: Prefer to Leave it Until Situation Arises, by Age Group

Age Group	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	18	22 (4)	28 (5)	22 (4)	22 (4)	6 (1)
30-39	27	0 (0)	19 (5)	41 (11)	18 (5)	22 (6)
40-49	54	13 (7)	18 (10)	28 (15)	15 (8)	26 (14)
50-59	51	8 (4)	20 (10)	25 (13)	31 (16)	16 (8)
60-69	47	24 (11)	25 (12)	13 (6)	25 (12)	13 (6)
70-79	15	47 (7)	13 (2)	7 (1)	7 (1)	26 (4)
80+	3	0 (0)	67 (2)	33 (1)	0 (0)	0 (0)
TOTAL	**215**	**15 (33)**	**21 (46)**	**24 (51)**	**21 (46)**	**18 (1)**
χ^2_{24}: p value		**43.132; .010***				

*** Significance should be regarded with caution as 15 cells have counts <5**

Education

There was no linear relationship between Education level and preferring to leave it until the situation arises. Respondents with Year 10 level education were the most likely to Strongly Agree that they would prefer to do so and this result held when the strongly Agree and Agree responses were combined (see Table 3.138).

Table 3.138: Prefer to Leave it Until Situation Arises, by Education

Education Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	6	0 (0)	33 (2)	50 (3)	0 (0)	17 (1)
Year 10	24	38 (9)	12 (3)	21 (5)	0 (0)	29 (7)
Year 12	19	26 (5)	16 (3)	10 (2)	16 (3)	32 (6)
Trade Cert.	41	17 (7)	20 (8)	29 (12)	22 (9)	12 (5)
Uni Degree	64	8 (5)	20 (13)	28 (18)	30 (19)	14 (9)
Post-Grad	60	12 (7)	28 (17)	17 (10)	25 (15)	18 (11)
TOTAL	**214**	**15 (33)**	**22 (46)**	**23 (50)**	**22 (46)**	**18 (39)**
χ^2_{20}: p value		**35.567; .017***				

*** Significance should be regarded with caution as 12 cells have counts <5**

Income

Respondents with Income of $20k - $29k per year were most likely to Agree that they would prefer to leave completing an Advance Health Care Directive until the situation arises and this result held when the Strongly Agree and Agree responses were combined; those with an income of $50k or above were the least likely to Strongly Agree/ Agree and were the most likely to Disagree/Strongly Disagree with this option (see Table 3.139).

Table 3.139: Prefer to Leave it Until Situation Arises, by Income

Income Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	54	22 (12)	22 (12)	30 (16)	11 (6)	15 (8)
$20k - $29k	26	23 (6)	35 (9)	23 (6)	15 (4)	4 (1)
30k - $39k	26	23 (6)	15 (4)	24 (6)	23 (6)	15 (4)
$40k - $49k	18	22 (4)	22 (4)	17 (3)	17 (3)	22 (4)
$50k or more	88	6 (5)	19 (17)	21 (19)	31 (27)	23 (20)
TOTAL	**212**	**15 (33)**	**22 (46)**	**24 (50)**	**22 (46)**	**17 (37)**
χ^2_{16}: p value		**24.976; .070***				

*** Significance should be regarded with caution as 9 cells have counts <5**

Religion

Respondents who identified as Atheist were significantly more likely than the other six groups to Agree that they would prefer to leave it until the situation arises and this result held when the Strongly Agree and Agree responses were combined. However, as there were only six respondents in this category, the result should be treated with caution (see Table 3.140).

Table 3.140: Prefer to Leave it Until Situation Arises, by Religion

Religion	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
No Affiliation	104	14 (14)	19 (20)	25 (26)	22 (23)	20 (21)
Catholic	27	26 (7)	37 (10)	11 (3)	15 (4)	11 (3)
Anglican	25	24 (6)	8 (2)	20 (5)	20 (5)	28 (7)
Other Christian	18	11 (2)	28 (5)	17 (3)	33 (6)	11 (2)
Buddhist	13	8 (1)	15 (2)	31 (4)	23 (3)	23 (3)
Atheist	6	0 (0)	83 (5)	17 (1)	0 (0)	0 (0)
Other	20	15 (3)	10 (2)	45 (9)	20 (4)	10 (2)
TOTAL	**213**	**15 (33)**	**22 (46)**	**24 (51)**	**21 (45)**	**18 (38)**
χ^2_{24}: **p value**		**37.354; ,040***				

*** Significance should be regarded with caution as 24 cells have counts <5**

Affect of Beliefs

Respondents whose Beliefs somewhat affect their decisions about medical treatment were significantly more likely than the other two groups to Agree that they would prefer to leave completing an Advance Health Care Directive until the situation arises (see Table 3.141)

Table 3.141: Prefer to Leave it Until Situation Arises, by Affect of Beliefs

Beliefs	**N**	**SA**	**A**	**N**	**D**	**SD**
		% (n)	**% (n)**	**% (n)**	**% (n)**	**% (n)**
A Great Deal	32	16 (5)	19 (6)	25 (8)	31 (10)	9 (3)
Somewhat	47	15 (7)	36 (17)	13 (6)	25 (12)	11 (5)
Not At All	134	16 (21)	17 (23)	27 (36)	18 (24)	22 (30)
TOTAL	**213**	**15 (33)**	**22 (46)**	**23 (50)**	**22 (46)**	**18 (38)**
χ^2_{8}: **p value**		**15.726; .046**				

3.12.3 HARD TO THINK ABOUT END-OF-LIFE ISSUES

Open About Sexuality

Respondents who are Not Open to any significant others about their sexuality were significantly more likely than the other two groups to both Strongly Agree and Strongly Agree + Agree that it is hard to think about end-of-life issues (see Table 142).

Table 3.142: Hard to Think About End-of-Life Issues, by Open About Sexuality

Open About Sexuality?	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes to All	158	11 (18)	21 (33)	15 (24)	24 (38)	29 (45)
Yes to Some	35	11 (4)	26 (9)	26 (9)	11 (4)	26 (9)
No	17	35 (6)	18 (3)	29 (5)	0 (0)	18 (3)
TOTAL	**210**	**13 (28)**	**21 (45)**	**18 (38)**	**20 (42)**	**27 (57)**
χ^2_8: p value		**16.866; .032**				

Time in Relationship

While there was no linear relationship between Time in Relationship and level of agreement with this option, respondents who had been in their relationship for less than 1 year were significantly more likely to Strongly Agree that it is hard to think about end-of-life issues and this result held for the combined Strongly Agree and Agree responses (see Table 3.143).

Table 3.143: Hard to Think About End-of-Life Issues, by Time in Relationship

Relationship Status	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<1 Year	7	29 (2)	43 (3)	14 (1)	0 (0)	14 (1)
1-2 Years	11	0 (0)	27 (3)	36 (4)	9 (1)	27 (3)
2-4 Years	11	0 (0)	46 (5)	18 (2)	0 (0)	36 (4)
4-10 Years	34	6 (2)	12 (4)	12 (4)	44 (15)	26 (9)
>10 Years	44	18 (8)	16 (7)	23 (10)	20 (9)	23 (10)
TOTAL	**107**	**11 (12)**	**21 (22)**	**20 (21)**	**23 (25)**	**25 (27)**
χ^2_{16}: p value		**29.688; .020***				

*** Significance should be regarded with caution as 17 cells have counts <5**

Education

Respondents with <Year 10 level of Education were very significantly more likely than the other five groups to Strongly Agree that it is hard to think about end-of-life issues and this result held when the Strongly Agree and Agree responses were combined (see Table 3.144)

Table 3.144: Hard to Think About End-of-Life Issues, by Education

Education Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	6	67 (4)	16 (1)	0 (0)	17 (1)	0 (0)
Year 10	22	23 (5)	27 (6)	27 (6)	0 (0)	23 (5)
Year 12	19	26 (5)	16 (3)	5 (1)	5 (1)	47 (9)
Trade Cert.	41	17 (7)	15 (6)	19 (8)	27 (11)	22 (9)
Uni Degree	64	6 (4)	22 (14)	22 (14)	23 (15)	27 (17)
Post-Grad	58	5 (3)	26 (15)	16 (9)	24 (14)	29 (17)
TOTAL	**210**	**13 (28)**	**22 (45)**	**18 (38)**	**20 (42)**	**27 (57)**
χ^2_{20}: p value		**42.606; .002***				

*** Significance should be regarded with caution as 13 cells have counts <5**

Income

There was a direct linear relationship between level of Income and agreement that it is hard to think about end-of-life issues; respondents with the lowest income level were the most likely, and those with the highest income level were the least likely, to Strongly Agree that this is so and these results held when the Strongly Agree and Agree responses were combined. Those with the highest income levels were also the much more likely to Disagree/ Strongly Disagree with the option that it is hard to think about end-of-life issues (see Table 3.145).

Table 3.145: Hard to Think About End-of-Life Issues, by Income

Income Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	52	23 (12)	31 (16)	15 (8)	10 (5)	21 (11)
$20k - $29k	24	21 (5)	12 (3)	21 (5)	21 (5)	25 (6)
30k - $39k	27	15 (4)	18 (5)	19 (5)	18 (5)	30 (8)
$40k - $49k	17	12 (2)	24 (4)	23 (4)	0 (0)	41 (7)
$50k or more	88	6 (5)	19 (17)	17 (15)	30 (26)	28 (25)
TOTAL	**208**	**13 (28)**	**22 (45)**	**18 (37)**	**20 (41)**	**27 (57)**
χ^2_{16}: p value		**24.995; .071**				

Affect of Beliefs

Respondents whose beliefs affect their decision about medical treatment A Great Deal were significantly more likely than the other two groups to Strongly Agree that it is hard to think about end-of-life issues; however when the Strongly Agree and Agree responses were combined, the group who said their beliefs Somewhat affect their decisions were the most likely to agree with this option. Respondents who said that their beliefs do not affect such decisions at all were significantly more likely than the other two groups to Disagree and Strongly Disagree with this option (see Table 3.146).

Table 3.146: Hard to Think About End-of-Life Issues, by Affect of Beliefs

Beliefs	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
A Great Deal	32	22 (7)	19 (6)	28 (9)	19 (6)	12 (4)
Somewhat	45	9 (4)	38 (17)	24 (11)	9 (4)	20 (9)
Not At All	132	13 (18)	17 (22)	13 (18)	24 (31)	33 (43)
TOTAL	**209**	**14 (29)**	**21 (45)**	**18 (38)**	**19 (41)**	**27 (56)**
χ^2_8: p value		**22.102; .005**				

Health Status

Although respondents in Poor health were the most likely to Strongly Agree that it is hard to think about end-of-life issues, when the Strongly Agree and Agree responses were combined it was those in Good health who were most likely to say this. Respondents in Excellent health were significantly more likely than the other four groups to Disagree/Strongly Disagree with this option (see Table 3.147).

Table 3.147: Hard to Think About End-of-Life Issues, by Health Status

Health Status	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Excellent	41	9 (4)	5 (2)	12 (5)	32 (13)	42 (17)
Very Good	65	14 (9)	14 (9)	18 (12)	26 (17)	28 (18)
Good	58	15 (9)	38 (22)	17 (10)	16 (9)	14 (8)
Fair	36	14 (5)	25 (9)	28 (10)	8 (3)	25 (9)
Poor	10	20 (2)	30 (3)	10 (1)	0 (0)	40 (4)
TOTAL	**210**	**14 (29)**	**21 (45)**	**18 (38)**	**20 (42)**	**27 (56)**
χ^2_{16}: p value		**35.619; .003**				

Private Health Insurance

Respondents who do not have private health insurance were significantly more likely than those who do to Strongly Agree that it is hard to think about end-of-life decisions (see Table 3.148).

Table 3.148: Hard to Think About End-of-Life Issues, by Private Health Insurance

Private Health Insurance	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes	98	5 (5)	25 (24)	18 (18)	25 (24)	27 (27)
No	113	21 (24)	18 (21)	18 (20)	16 (18)	27 (30)
TOTAL	**211**	**14 (29)**	**21 (45)**	**18 (38)**	**20 (42)**	**27 (57)**
χ^2_4: p value		**12.767; .012**				

3.12.4 PREFER TO LEAVE DECISION TO DOCTOR

Age

Respondents 70-79 were significantly more likely than the other six groups to Strongly Agree that they would prefer to leave decisions about their medical treatment to the doctor if they were unable to speak for themselves and this result held when the Strongly Agree and Agree responses were combined. The 30-39 year-old group were significantly more likely than the other six groups to Disagree/Strongly Disagree that they would prefer to leave the decision to the doctor (see Table 3.149).

Table 3.149: Prefer to Leave Decisions to Doctor, by Age Group

Age Group	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
<30	18	6 (1)	11 (2)	28 (5)	22 (4)	33 (6)
30-39	27	0 (0)	0 (0)	15 (4)	41 (11)	44 (12)
40-49	52	6 (3)	0 (0)	19 (10)	23 (12)	52 (27)
50-59	53	15 (8)	10 (5)	11 (6)	28 (15)	36 (19)
60-69	44	4 (2)	23 (10)	14 (6)	23 (10)	36 (16)
70-79	15	27 (4)	6 (1)	20 (3)	20 (3)	27 (4)
80+	3	0 (0)	0 (0)	67 (2)	0 (0)	33 (1)
TOTAL	**212**	**8 (18)**	**9 (18)**	**17 (36)**	**26 (55)**	**40 (85)**
χ^2_{24}: p value		**44.529; .007***				

*** Significance should be regarded with caution as 22 cells have counts <5**

Open About Sexuality

Respondents who are Open to all significant others about their sexuality were significantly less likely to Strongly Agree/Agree that they would prefer to leave their medical treatment decisions to the doctor if they were unable to speak for themselves and significantly more likely to Disagree/Strongly Disagree with this option (see Table 3.150).

Table 3.150: Prefer to Leave Decisions to Doctor, by Open About Sexuality

Open About Sexuality?	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes to All	156	7 (11)	5 (7)	16 (25)	30 (47)	42 (66)
Yes to Some	36	11 (4)	19 (7)	19 (7)	17 (6)	34 (12)
No	18	11 (2)	22 (4)	22 (4)	6 (1)	39 (7)
TOTAL	**210**	**8 (17)**	**8 (18)**	**17 (36)**	**25 (54)**	**40 (85)**
χ^2_{8}: p value		**18.994; .015**				

Education

When the Strongly Agree and Agree responses were combined, respondents with < year 10 Education level were the most likely to agree that they would prefer to leave medical treatment decisions to the doctor if they could not make their own decisions. The group with the highest level of education was most likely to Disagree/ Strongly Disagree with this option (see Table 3.151).

Table 3.151: Prefer to Leave Decisions to Doctor, by Education

Education Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< Year 10	6	17 (1)	33 (2)	0 (0)	17 (1)	33 (2)
Year 10	22	32 (7)	9 (2)	13 (3)	13 (3)	32 (7)
Year 12	19	26 (5)	16 (3)	6 (1)	26 (5)	26 (5)
Trade Cert.	42	0 (0)	17 (7)	26 (11)	21 (9)	36 (15)
Uni Degree	62	1 (1)	1 (1)	23 (14)	29 (18)	45 (28)
Post-Grad	59	5 (3)	5 (3)	12 (7)	30 (18)	48 (28)
TOTAL	**210**	**8 (17)**	**9 (18)**	**17 (36)**	**26 (54)**	**40 (85)**
χ^2_{20}: p value		**55.939; <.001***				

*** Significance should be regarded with caution as 15 cells have counts <5**

Income

Respondents with the highest income level were significantly less likely than the other four groups to Strongly Agree that they would prefer to leave their medical treatment decisions to the doctor if they could not make their own decisions and this result was even stronger when the Strongly Agree and Agree responses were combined. That group was also significantly more likely than the other four groups to Disagree/Strongly Disagree with this option (see Table 3.152).

Table 3.152: Prefer to Leave Decisions to Doctor, by Income

Income Level	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
< $20k	53	15 (8)	13 (7)	25 (13)	17 (9)	30 (16)
$20k - $29k	24	8 (2)	17 (4)	13 (3)	29 (7)	33 (8)
30k - $39k	26	12 (3)	12 (3)	23 (6)	7 (2)	46 (12)
$40k - $49k	17	6 (1)	12 (2)	18 (3)	23 (4)	41 (7)
$50k or more	88	3 (3)	2 (2)	13 (11)	36 (32)	46 (40)
TOTAL	**208**	**8 (17)**	**9 (18)**	**17 (36)**	**26 (54)**	**40 (83)**
χ^2_{16}: **p value**		**28.490; .028***				

*** Significance should be regarded with caution as 12 cells have counts <5**

Private Health Insurance

When the response options were combined, respondents who have private health insurance were significantly less likely than those without such insurance to Strongly Agree/Agree, and significantly more likely to Disagree/Strongly Disagree, that they would prefer to leave decisions to the doctor (see Table 3.153).

Table 3.153: Prefer to Leave Decisions to Doctor, by Private Health Insurance

Private Health Insurance	N	SA	A	N	D	SD
		% (n)	% (n)	% (n)	% (n)	% (n)
Yes	98	9 (9)	4 (4)	13 (13)	37 (36)	37 (36)
No	114	8 (9)	12 (14)	19 (22)	18 (20)	43 (49)
TOTAL	**212**	**8 (18)**	**8 (18)**	**17 (35)**	**27 (56)**	**40 (85)**
χ^2_{4}: **p value**		**13.298; .010**				

3.13 ADDITIONAL ANALYSES

A number of the results above suggested that respondents who were Not Open to significant others about their sexuality may have more difficulty with organising care and ensuring that their end-of-life wishes are known and respected than those who are Open to All significant others. This has also been identified as a risk in the relevant literature and policy documents (*ACON Healthy GLBT Ageing Strategy, 2006-2009*). Therefore, to understand if the respondents in this study who were Not Open to significant others differed in any way from those who were Open to All or Some significant others, chi-square analysis was undertaken to analysis the Open About Sexuality variable by all of the other demographic variables.

Differences by Age Group reached significance and differences by Gender approached significance but there were no significant differences by any of the other demographic variables. Differences by Age and Gender are presented in Tables 3.154 and 3.155.

Age Group

Respondents <30 and those 80+ were the least likely to be Open about their sexuality to all significant others and most likely Not to be Open to any significant others. Respondents 30-49 were most likely to be Open to All (see Table 3.154).

Table 3.154: Open About Sexuality, by Age Group

Age Group	N	Yes to All	Only to Some	No
		% (n)	% (n)	% (n)
<30	19	53 (10)	26 (5)	21 (4}
30-39	31	87 (27)	7 (2)	7 (2}
40-49	65	88 (57)	11 (7)	1 (1}
50-59	74	74 (55)	22 (16)	4 (3)
60-69	63	73 (46)	11 (7)	16 (10)
70-79	33	67 (22)	18 (6)	15 (5)
80+	5	20 (1)	40 (2)	40 (2)
TOTAL	**290**	**75 (218)**	**15 (45)**	**9 (27)**
χ^2_{12}: p value		**32.957; .001**		

Gender

Respondents who identified as Another Gender were less likely than those identifying as Female or Male to be open to significant others about their sexuality (see Table 155).

Table 3.155: Open About Sexuality, by Gender

Gender	N	Yes to All	Only to Some	No
		% (n)	% (n)	% (n)
Female	115	82 (94)	12 (14)	6 (7)
Male	147	74 (108)	17 (25)	9 (14)
Another Gender	24	58 (14)	21 (5)	21 (5)
TOTAL	**286**	**75 (216)**	**15 (44)**	**9 (26)**
χ^2_4: p value		**7.907; .095**		

Chapter 4 - DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

4.1 SAMPLE SUMMARY

This study involved 305 participants who identified with the Gay, Lesbian, Bisexual and Transgender (GLBT) community in New South Wales. It is not possible to know how representative the sample is of the wider GLBT community in NSW, given that there is incomplete data available about that community. Respondents represented a range of demographic characteristics but are over-represented in relation to some, at least compared to the broader community of NSW.

Ages of participants ranged from less than 30 to over 80, distributed in a very balanced bell curve, with the majority (70%) aged between 40 and 69. The majority of respondents (91%) identified as Female or Male and the same percentage nominated their sexual orientation as Gay, Lesbian or Bisexual (but these did not exactly equate – see p11); the remaining 9 percent nominated other sexual orientations. Seventy-five percent of respondents were open about their sexuality to all significant family members (however "family" is defined) with 9 percent saying that they were not open to any; it is possible that the sample is over-represented by those who are open about their sexuality, as they would potentially have had more opportunity than those who are not to be included in the study, given that survey distribution was undertaken by GLBT organisations, and many GLBT people who are not open about their sexuality may also not belong to such organisations. This is an important consideration as an overview of the data results in Chapter 3 indicates that those who are not open about their sexuality may be at particular risk in relation to their end-of-life care. However, if this group is under-represented it would suggest that issues identified in the study may be of even more concern than the findings indicate. This issue will be discussed further below.

Relationship status of respondents was fairly evenly divided between those who are single and those who have a partner (living with or not), with 77 percent of the latter group having been in their relationship for at least four years (47% for more than 10 years).

The majority of respondents in this study were better educated and had higher incomes than the NSW average; 59 percent of the study sample had a University Bachelors or Post-Graduate degree compared with 31 percent for NSW (ABS, 2006 Census); 44 percent had incomes of $50k or more compared with 22 percent for NSW overall (ABS, 2006 Census).

A much higher percentage of the study sample (46%) said that they had no affiliation with a religious group compared to 16% of the NSW population overall; and 32 percent of the study sample nominated a Christian religion compared to 66 percent for NSW overall (ABS, 2006 Census).

In the study sample, 60 percent of respondents said that their religious or philosophical beliefs did not influence their attitudes towards medical decisions at the end of life. While not directly comparable, given the study population, this is considerably higher than a study undertaken with Australian medical practitioners (Cartwright et al, 2006) in which 22 percent of respondents said that their beliefs did not affect their attitudes at all.

Participants in this study were comparable to the NSW average in relation to those who said their health was excellent or very good (53% in this study: 56% for NSW overall) but a higher percentage of respondents in this study said that their health was fair or poor compared to NSW overall (21% in this study: 15% for NSW overall) (ABS, 2006 Census). However, only 4 percent of the sample nominated as having poor health and, as the study results demonstrate, there were often significant negative differences between this group and the others in relation to end-of-life care (see below). If GLBT people who were in poor health were less likely than those in excellent or good health to respond to this study (for which there could be many reasons, e.g. not wanting to think about end-of-life or finding completion of the survey too tiring) it may mean that GLBT people in poor health were under-represented in the study and if this is so the results may under-represent the situation for many other GLBT people. Although it is not possible to determine the reality of this, it would be reasonable to suggest that service providers working with GLBT people in poor health consider the results in this study for that group.

Advance Care Planning

One of the objectives of this study was to identify the level of awareness and use by GLBT people of the legally-available mechanisms to plan for end-of-life care. A large majority of participants (87%) said that they had heard of Enduring Power of Attorney (which allows the appointed person to make decisions about financial and property matters for the person making the appointment) and 59 percent of those who had heard of this option said that they had had experience with it. In addition, some respondents (in particular Lesbians and those living with a partner*) had higher self-reported knowledge and experience than the other respondents of

the Enduring Guardian option (which allows the appointed person to make decisions about personal and health care matters for the person making the appointment) (68% of Lesbians said that they had heard of Enduring Guardian and, of these, 80% said that they had had experience with this option; 65% of respondents who were living with a partner said that they had heard of Enduring Guardian and, of these 69% said that they had had experience with this option).
* Note: It is possible that many of these may be the same person as additional analysis of the data found that 53% of respondents who identified as Lesbian were living with a partner compared with 35% of Heterosexual respondents, 29% of those identifying as Gay, and 20% of those who identified as Bisexual).

However, this claimed knowledge and experience did not translate into a real understanding of the current legal rights of GLBT people; only 27% of the sample correctly identified who had the legal authority to make health care decisions for the person identified in the Scenario presented to them in the questionnaire, and there was no significant difference in the responses of participants by Gender or Relationship Status.

This highlights the urgent need for focussed education about legally available Advance Care Planning options for GLBT people in NSW (a need that has also been identified for the broader community), particularly as, along with the broader community, many GLBT people are ageing and are likely to be facing the need to make end-of-life decisions for partners and/ or friends. We would argue that the urgency is greater for the GLBT community because there is general acceptance among health professionals that a person's opposite-sex partner has the legal authority to make such decisions but many health professionals are ignorant of the fact that same-sex partners also have that legal right (Lienert et al, 2010). This can, and does, lead to distress and exacerbated grief, both for the patient and for their partner/close friends when their rights in relation to end-of-life care are not respected. While this study found that the majority of respondents who had provided care to another GLBT person had not experienced problems from service providers or family members of the person for whom they were caring, from 7% - 29% had had such problems, in particular lack of recognition of their relationship (29%) and being denied involvement in care decisions for that person (20%). For GLBT people, exercising their legally-available option of appointing the person of their choice as their Enduring Guardian would at least put beyond doubt their right to make that person's decisions and having a properly witnessed Appointment of Enduring Guardian Form would provide evidence of the infringement of that right should they need to take legal action to enforce it.

We would also strongly urge that education about Advance Care Planning options for GLBT people include encouragement to complete Advance Health Care Directives, in addition to appointing an Enduring Guardian. This would provide the appointed person with additional evidence of the wishes of the person for who they need to make substitute decisions and should assist them to carry out that person's wishes even if blood relatives or others do not agree with those decisions. An Advance Health Care Directive can also provide some reassurance for those GLBT people who do not have a partner or anyone to whom they are close enough to appoint as their Enduring Guardian.

GPs and Discussion of End-of-Life Care

Assisting their patients (GLBT or not) to appoint an Enduring Guardian and complete an Advance Health Care Directive is an extremely important role that GPs should be encouraged to take up. Almost all of the respondents in this study (and 100 percent of those in poor health) had a regular GP as their main health care provider (except for those aged <30). While some GPs do encourage their patients to do this, many people find that their GP is either misinformed about the law in NSW (and elsewhere) or will not take the time to assist with completion of the documents.

While 73 percent of respondents expressed a high degree of comfort in relation to talking about death and dying with their GP, whether they raised the issue or their GP did so, only 13 percent had actually had such a discussion and in most cases they had raised the issue themselves.

We would therefore strongly recommend that GLBT organisations and NSW Health work with Division of General Practice to encourage GPs to become familiar with the law in NSW relating to Advance Care Planning and to discuss these issues with their GLBT patients (as well as with patients generally).

Assistance if Terminally Ill

While approximately 60-70 percent of respondents were confident that at least one friend, relative or partner would provide assistance to them for a range of care needs if they were seriously ill there were some exceptions to this, as follows:

- Respondents who were not Open about their sexuality were significantly less likely than those who were Open to all or somewhat Open to believe that they would:

  - receive advice;
  - receive help with chores;
  - have someone provide them with a place to stay for a few weeks;
  - have someone who would loan them $500; or
  - have someone who would assist with bathing/ dressing.

- Respondents who nominated a Gender other than Female or Male were significantly less likely than the other two groups to believe that they would have someone who would loan them $500.

- Respondents who were in a relationship other than single, partnered (living with or not) or grieving the loss of a partner (e.g. possibly a casual or polyamourous relationship – note Weeks et al 2001 "families of choice") were significantly less likely than the other groups to believe that they would:
  - have someone provide them with a place to stay for a few weeks;
  - have someone who would assist with bathing/ dressing.

- Respondents who were grieving the loss of a partner were significantly less likely than those who were single or partnered to believe that they would:
  - have someone who would loan them $500;
  - have someone who would assist with bathing/ dressing.

- Respondents with less than Year 10 Education level were significantly less likely than the other groups to believe that they would have someone who would loan them $500.

- Respondents with Income of less than $20k per year were significantly less likely than the other groups to believe that they would:
  - receive help with chores;
  - have someone who would loan them $500;
  - have someone who would assist with bathing/ dressing.

- Respondents in Fair Health were significantly less likely than the other groups to believe that they would:
  - receive help with chores;

  - be provided with accommodation for a few weeks;
  - have someone who would loan them $500;
  - have someone who would assist with bathing/ dressing.

- Respondents in Poor Health were significantly less likely than the other groups to believe that they would:
  - be provided with accommodation for a few weeks;
  - have someone who would loan them $500;
  - have someone who would assist with bathing/ dressing.

Substitute Decision-Maker

Respondents nominated a range of people that they would want to make decisions for them if they could not do so for themselves at some time in the future; approximately half had and half had not spoken to the person that they nominated to make such decisions. There was very little difference between respondents in terms of characteristics which might indicate who had and who had not discussed their wishes except that those with less than Year 10 education, those with less than $20k per year income and those in poor health were significantly less likely than other respondents to have spoken about their end-of-life care wishes to the person that they wanted to make their decisions at such a time. As these characteristics could be seen to relate to more vulnerable members of the GLBT community it may be that people who are in such sociodemographic groups may require more support than others to talk about, and plan for, their end-of-life care.

Although just over half of the respondents were very confident or confident that their wishes would be carried out, the remaining respondents were not sure, not very confident or not at all confident that they would be. We suggest that this indicates a need for more education and resources to help ensure that GLBT people are empowered to record their wishes and to appoint someone to advocate for their wishes to be carried out. This, in turn, should increase confidence in relation to end-of-life care.

Approach to Medical Treatment at the End of Life

Confidence that wishes will be carried out also needs to extend to such things as ensuring that symptoms are relieved, even if so doing shortens life. This is not euthanasia – which is “the deliberate ending of a person's life at his or her request, using drugs to accelerate death" (WHO, 1986). Ninety percent of respondents said that this was the approach to medical treatment at the end of life that they wanted (rather than a focus on extending life even with distressing symptoms). However, of the 10 percent who wanted their life extended, even with distressing symptoms, respondents who are not open about their sexuality were significantly more likely than the other two groups to want this option. This again raises the possible need for education, resources and support for this group, in case this choice is related to a fear that they will not receive proper care. However, we do not have the evidence that this is the case and once again, the challenge would be to identify and access GLBT people in this category.

Preferred Place to Die

While the majority of respondents strongly agreed or agreed that they would prefer to die at home (which is also the choice of most people in the broader community), 61 percent also strongly agreed or agreed that they would prefer to die in a GLBT-specific care facility. This appears option to be entering the "end-of-life care for GLBT people" discussions (GRAI, 2010; Linton Estate 2009) and is an issue that may require further research to identify if the expressed need is actually for such a facility or is instead an expression of the need for a facility (or facilities) where GLBT people can feel safe to be who they are, to be treated with respect and dignity by the staff, to have the people they most care about around them and to have their wishes respected. The fact that 51 percent of respondents disagreed or strongly disagreed that they would prefer to die in a nursing home (now called residential aged care facilities), and very few strongly agreed or agreed that they would want to do so, may also be a reflection of the fact that these respondents were aware of the documented evidence of abuse and discriminatory behaviour that has occurred is such facilities (Lienert et al, 2010). In addition, until recently many such facilities either have not had staff training programs which could assist staff to understand the needs of GLBT people and treat them accordingly or, if they do, the training has not been translating into practice (Lienert et al, 2010).

It is of note that respondents in poor health were the least likely to strongly agree or agree that they would want to die at home; however, even in this group 58 percent said that they would prefer to do so. No-one who was grieving the loss of a partner wanted to die in a GLBT-specific facility but the study did not have the capacity to explore reasons for choices respondents made about preferred place to die.

Respondents who identified as Gay, those aged 70-79 and those who have private health insurance were the most likely to strongly agree or agree that they would prefer to die in a hospice while respondents aged <30 to 39 and those with less than year 10 education were the most likely to disagree or strongly disagree that they would choose this option. For respondents who did see hospice as a preferred place to die, it is interesting to speculate if – given their age range - these are people who supported partners and friends who died during the height of the HIV/AIDS epidemic, when gay men, in particular, were often provided with care and compassion in some of the major hospices (see interview data in Lienert et al, 2010).

Respondents aged 60-69 and 70-79, males and those who identified as Gay were also more likely than the other groups to choose hospital as a preferred place to die. Respondents with the highest level of income were the most likely to disagree or strongly disagree with this option.

Advance Care and Financial Planning

Many factors were related to the likelihood that respondents had given someone Enduring Power of Attorney to make financial and property decisions for them if they cannot do so; these included being 50 years of age or more, being male, being Gay, living with a partner, having been in a relationship for more than 10 years and having private health insurance. In relation to the likelihood that respondents had appointed an Enduring Guardian to make personal and health care decisions for them if they cannot do so, factors included being 70 years of age or more and being Gay.

Lack of knowledge, both about the actual documents and about how to complete them, were major barriers identified by participants in relation to giving someone Enduring Power of Attorney to make financial decisions, or appointing an Enduring Guardian to make health care decisions, in case of future incapacity. This underlines the need for education, and for GLBT-specific resources which can be used to address this information gap. However, for both planning options the major reason given for non-completion was that it was "not necessary at present". This indicates a misunderstanding or misinformation gap (i.e. that such documents are only completed by people who are ill) or a degree of denial that a time may come when they would need such documents. Not knowing who to name suggests an additional area for education. However, respondents did not agree that the issue was hard to think about.

Only 12 percent of respondents had completed an Advance Health Care Directive but this ranged from 0 percent for respondents aged less than 30 to 42 percent for those aged 70-79 and 40 percent for those aged 80 and above. Compared to the general community these latter percentages are very high and would potentially indicate that GLBT who are ageing may be open to discussions about planning for end-of-life care. As with previous research in the general community in Queensland (Steinberg et al 1996), the Northern Territory (Cartwright et al 1998) and New South Wales (Cartwright et al 2006b), the most common reason given for not having completed an Advance Health Care Directive was not knowing where or how to do it. Contrary to the belief of some medical practitioners, the majority of respondents disagreed or strongly disagreed that they would prefer to leave the decisions to the doctor and most also did not want to leave the decisions to family or friends.

While some respondents said that they would prefer to leave it until the situation arises (31%) or that it is hard to think about end-of-life issues (29%) more respondents disagreed than agreed with these statements.

It is therefore important that resources are developed that will address the issue of not knowing where or how to do it, especially if the organisations that provide support to GLBT people can be given access to such resources and provided with the information and education they need to ensure that their members are regularly informed about the options that are available to them – and perhaps, the consequences of what can happen if those options are not taken up.

4.2 RESOURCE DEVELOPMENT

The next stage of this study will be to use the results of this survey, plus the literature review and focus group material from the first phase of this work, to develop GLBT-specific resources to meet the needs outlined above. A limited-edition run of hard-copy resources will be produced and the resources will also be made available on relevant web-sites.

It is hoped that this research and the resulting resources will contribute to enhancing the end-of-life experiences of GLBT people and their carers/loved one/significant others in Australia.

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Appendix 1 - Questionnaire

Knowledge about and Attitudes towards End of Life Care for Gay, Lesbian, Bisexual, and Transgender People

Information Sheet: Questionnaire

***This Information Sheet is yours to keep – please detach from survey**

Hi. My name is Tania Lienert and I am conducting research with the Aged Services Learning and Research Centre, Southern Cross University. I would like to invite you to participate in a study investigating end-of-life care planning for gay, lesbian, bisexual, and transgender (GLBT) people. The aim of the research is to investigate the level of knowledge about, attitudes towards and barriers to end of life care planning for GLBT people. I am inviting all GLBT people aged over 18 to participate in this study. Participants have been recruited from across NSW, through a range of agencies that provide services GLBT people. The results will be used to produce an information booklet about this topic for GLBT people, and we hope our report will inform others and lead to better end-of-life care for GLBT people.

What does this research involve?

Participation in this research will involve completing a questionnaire. The questionnaire will take approximately 15 minutes to complete, and will involve a series of questions relating to your experiences of, attitudes towards and knowledge of end of life care planning. After filling out the form yourself, you will be asked to place the completed questionnaire into a sealed envelope so as to ensure complete confidentiality, and either hand it back to the agency that distributed the questionnaire, or return it in the stamped, self-addressed envelope provided. Please do not write your name anywhere on the survey as this is a completely anonymous study.

Possible discomforts or risks:

The questions in the survey relate directly to end of life care issues, and although much care has been taken to ensure that the questions asked involve minimal risk to participants, you may find that your participation in this research raises some unexpected emotions. Should your participation bring up any issues that you might need to discuss further, a list of available counselling services will be provided at the end of the questionnaire.

Responsibilities of the researcher:

No information given in the questionnaires will be made public in any form that could identify you. The findings from this research will be used to develop educational resources for GLBT on end-of-life care planning mechanisms, and it is hoped that this information will improve the delivery of end-of-life care for GLBT people.

Responsibilities of the participant:

Your participation in the study is strictly voluntary and your confidentiality is assured.

You may also elect not to answer any questions asked. Participation in this study will involve completing a questionnaire with a number of questions relating to your experiences with, attitudes towards and knowledge of end of life care issues. It is expected that the questionnaire will take approximately 15 minutes to complete.

Freedom to consent:

You do not have to participate in the study. Participation in this research is entirely voluntary. If you return the completed questionnaire to us, this will demonstrate that you have consented to participating in the research. However, if you change your mind about being in the study after you have returned your questionnaire, it will not be possible for your information to be withdrawn, as all questionnaires are anonymous and we could not identify which one is yours.

Use of Research Findings:

The results of this study will be published in a report and possibly in a peer-reviewed journal and presented at conferences, but only group data will be reported - no identifiable information will be presented. If you wish to receive results of this research, you may contact the Principal Researcher, and a summary will be posted or emailed to you. Alternatively a report will be published on the ASLaRC website in 2010 at http://aslarc.scu.edu.au/downloads. All data collected and analysed from this research will be stored in a secure location at Southern Cross University for 7 years, and then destroyed.

Further inquiries:

For further inquiries about any aspect of this research, you may contact:

Supervisor:	**Principal Researcher:**
Professor Colleen Cartwright ASLaRC Southern Cross University Hogbin Drive Coffs Harbour NSW 2450 Telephone: 02 6659 3197 Email: aslarc@scu.edu.au	Dr Tania Lienert ASLaRC Southern Cross University Box 157 Lismore NSW 2480 Telephone: 02 6620 3450 Email: tania.lienert@scu.edu.au

The ethical aspects of this study have been approved by the ACON Research Ethics Review Committee and the Southern Cross University Human Research Ethics Committee (HREC). The Approval Number for the Southern Cross University HREC is ECN-09-129.

If you have concerns about the ethical conduct of this research write to the following:

The Ethics Complaints Officer
Southern Cross University
PO Box 157
Lismore NSW 2480
sue.kelly@scu.edu.au

All information is confidential and will be handled as soon as possible.

Thank you for your participation!

Knowledge about and Attitudes towards End of Life Care for Gay, Lesbian, Bisexual, and Transgender People

ASLaRC
Aged Services Learning and Research Centre

Section 1: Your Knowledge

These questions ask about your knowledge of end-of-life health care and advance care planning documents, to help us assess the level of awareness among GLBT people of these matters.

1. Have you heard of, or had any experience with, any of the following? *(Please circle one number for each option for Heard Of and for any that you have heard of, please circle one number for Had Experience With)*

Option	**Heard Of**		**Had Experience With**	
	Yes	No	Yes	No
Advance Health Care Directive	1	2	1	2
Enduring Power of attorney	1	2	1	2
Enduring Guardian	1	2	1	2
Person Responsible	1	2	1	2

2. Please consider the following scenario:

Georgina is a 37-year-old woman who has been admitted to hospital following a serious car accident. She is on life-support and in a critical condition. Her female partner of 2 years, Rachel, is by her bedside in the Intensive Care Unit when Georgina's mother Sally arrives and demands a full report on Georgina's condition from the treating medical practitioner. He asks if Georgina had ever appointed anyone to make health care decisions for her if she lost capacity, or discussed what treatment she would/would not want if she were to become terminally ill or injured. Rachel and Sally say no but Rachel says she knows that Georgina would not want her life prolonged unless she could be returned to a good level of functioning. However, Sally insists that all possible treatment be given to Georgina and that, because she is Georgina's mother – and therefore next-of-kin, she should have the right to make decisions about what treatment Georgina does or does not receive. At this point Georgina's ex-husband Henry arrives; he says that when he and Georgina were married she gave him Enduring Power of Attorney which has never been revoked, so he should have the right to make the decisions.

(a) Who do you think has the legal right to make health care decisions for Georgina?

✍ ____

(b) Why?

✍ ____

3. If you wanted to appoint an Enduring Guardian or Enduring Power of Attorney for yourself, how would you go about it?

✍ ____

____

4. If you wanted to make an Advance Health Care Directive for yourself, how would you go about it?

✎ ____

____

Section 2: Your Experience

The following questions ask about your experience with serious illness in others and your own experience of advance care planning.

5. Have you provided unpaid care to someone with a serious illness in the past 10 years? *(Please circle)*

   a) Yes
   b) No

6. Do you have a regular GP? *(Please circle)*

   a) Yes (go to Question 8)
   b) No (go to Question 7)

7. If not, who is your main health care provider? *(Please circle)*

   a) Naturopath
   b) HIV/AIDS specialist
   c) Other (please specify) ______________________________

8. Have you discussed with your main health care provider your preferences for your treatment in the event of a present or future terminal illness? *(Please circle)*

   a) Yes (please go to question 9)
   b) No (please go to question 15)

9. Who raised the issue? *(Please circle)*

   a) my doctor
   b) myself
   c) other (please specify) ____________________

10. In general, how comfortable **did you** feel talking about the subject of death and dying with your doctor? *(Please circle one response only)*

    a) Very comfortable
    b) Comfortable
    c) Neither comfortable or uncomfortable
    d) Uncomfortable
    e) Very uncomfortable

    If you did feel uncomfortable, why was that the case?

    ✍ ____

    ____

11. In general, how comfortable would you feel if your doctor raised the subject of death and dying with you? *(Please circle one response only)*

    a) Very comfortable
    b) Comfortable
    c) Neither comfortable or uncomfortable
    d) Uncomfortable
    e) Very uncomfortable

    If you would feel uncomfortable, Why?

    ✍ ____

    ____

12. If you became seriously ill, how likely would it be for at least one friend, relative or a partner to provide assistance with:

	Very likely	**Somewhat likely**	**Not very likely**
Help with household chores			
Help with bathing or dressing			
Loaning $500			
Giving advice			
Providing a place to stay for a few weeks			

Section 3: Your Attitudes

The following questions ask about how you would like to be cared for if you were seriously ill.

13. If you were unable to make medical decisions for yourself, who would you like to do so? *(Please circle)*
    a) Partner
    b) Friend
    c) GP
    d) Religious advisor
    e) Blood relative (please specify) ____________________
    f) Other (please specify)___________________________

14. Have you spoken to the person identified in Question 13 about your ideas/wishes about your medical treatment for the end stage of your life? *(Please circle)*

    a) Yes
    b) No
    c) No, I don't want to

    If you answered `No' or `No, I don't want to' to Question 14, why not?

    ✍ ____

    ____

15. How confident are you that if you have previously expressed your wishes regarding your health care but have not written them down, your wishes will be carried out in the event you are not capable of making your own decision *(Please circle one response only)*

    a) very confident
    b) confident
    c) not sure
    d) not very confident
    e) not at all confident

16. If you were in the late stages of a life-threatening illness, which one of these approaches would you want to take in your medical treatment? *(Please circle one option)*

    a) An approach that focuses on extending life even with distressing symptoms;

    OR

    b) An approach that focuses on relieving symptoms even if it shortens your life.

17. If you were terminally ill, to what extent do you agree that you would prefer to die in one of the following places: (*Please circle one number for each statement: SA = strongly agree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree)*

	Location	***SA***	***A***	***N***	***D***	***SD***
a)	At home	1	2	3	4	5
b)	In a hospital	1	2	3	4	5
c)	In a hospice	1	2	3	4	5
d)	In a nursing home	1	2	3	4	5
e)	Other (please specify ____________	1	2	3	4	5

Section 4: Barriers to Advance Care Planning

The following questions ask if you have completed advance care planning documents, and if not, why not.

18. (a) Have you appointed anyone to fulfill either of the following roles? *(Please circle one number for each option)*

Role	**Appointed**	
	Yes	**No**
Enduring Power of Attorney	1	2
Enduring Guardian	1	2

(b) If you answered 'No' to either option, what is preventing you from making an appointment? *(Please circle all that apply)*

Enduring Power of Attorney	**Enduring Guardian**
I don't know about this document	I don't know about this document
Not necessary now	Not necessary now
Hard to think about	Hard to think about
Unsure who to name	Unsure who to name
Don't know where or how to do it	Don't know where or how to do it
Haven't found the time	Haven't found the time
Other (please specify) ___________________	Other (please specify) ___________________

19. Have you completed your own Advance Health Care Directive?

a) Yes (Please go to Section 5)

b) No (Please go to question 20)

20. If you answered ‘No’, what is preventing you from completing an Advance Health Care Directive? *Please circle one number for each statement: SA = strongly agree; A = agree; N = neither agree nor disagree; D = disagree; SD = strongly disagree*

		SA	***A***	***N***	***D***	***SD***
a)	I don’t know where or how to do an Advance Health Care Directive	1	2	3	4	5
b)	It’s hard to think about end-of-life issues	1	2	3	4	5
c)	I would prefer to leave it until the situation arises	1	2	3	4	5
d)	I would prefer to leave the decision to the doctor	1	2	3	4	5
e)	I would prefer to leave the decision to the family/friends	1	2	3	4	5
f)	Other (please specify)	1	2	3	4	5

Section 5: About You

To assist us to understand what gay, lesbian, bisexual and transgender people think, and what they might want in relation to their treatment, we would be grateful if you would give us just a few details about yourself. For all of the questions in this section, please circle one number only or write your answer on the line provided.

21. How old are you? (In years)____________

22. What is your postcode? ____________

23. What is your gender identification? ____________

24. How would you describe your sexual orientation?

a) Gay
b) Lesbian
c) Bisexual
d) Heterosexual
e) Other (Please specify) ____________

25. Please describe your current relationship status? (*Please circle one)*

a) Single
b) Partner/not living together
c) Partner/living together
d) Grieving loss of partner
e) Other (please describe) ____________

26. If you are currently partnered, how long have you been together? ____________

27. What is the highest level of school education you achieved?

a) Never went to school
b) Did not complete primary school
c) Completed primary school
d) Completed Year 10 at high school
e) Completed Year 12 at high school
f) Technical or trade certificate
g) University degree
h) Post-graduate degree

28. What is your current household income range per year?

a) Less than $20,000
b) $20,000 to $29,000
c) $30,000 to $39,000
d) $40,000 to $49,000
e) $50,000 or more

29. What religious or spiritual affiliation do you have, if any?

a) Anglican
b) Buddhist
c) Catholic
d) Jewish
e) Lutheran
f) Muslim
g) Uniting Church
h) No affiliation
i) Other (please specify) ____________

30. To what extent do your religious or philosophical beliefs influence your opinions with respect to issues such as medical decisions at the end of life?

   a) A great deal
   b) Somewhat
   c) Not at all

31. In general, would you say your health is:

   a) Excellent
   b) Very Good
   c) Good
   d) Fair
   e) Poor

32. Have you ever been diagnosed with:

   a) HIV/AIDS
   b) Breast cancer
   c) Ovarian cancer
   d) Other serious illness (please specify) ____________

33. Do you have private health insurance?

   a) Yes
   b) No

34. Survey Evaluation: How useful was participating in the research was in raising your awareness of end-of-life care planning and your confidence to do it?(*To help answer this question, please see the information sheet provided overleaf which is yours to keep. Please circle one answer only).*

   a) Very helpful
   b) Helpful
   c) Not helpful
   d) Not applicable - I already know all this information

THANK YOU for giving us your valuable time to assist with study. The final page of the survey document, *End-of-life care for GLBT People – What's it all about*, including *Resources for Support* – is yours to keep. **Please detach them from the survey.**

To ensure total confidentiality of your responses, please put the completed questionnaire into the large

ASLaRC
Aged Services Learning and Research Centre

End-of-life care planning for GLBT people – what's it all about?

*This information sheet is yours to keep

The care that we receive at the end of our lives – whether we have a short-term or long-term serious illness or an accident - can be planned by taking time to think about it beforehand. As GLBT people, the more planning we do, and the more we talk to our partners, friends and family about the kind of care we want, the more likely we are to receive it. If we do not plan for end-of-life care, medical practitioners and other health care professionals may provide care we would not want. It may be possible for others to make decisions not in line with ours, and people who should have a say may miss out. There are a number of ways you can plan for your end-of-life care.

Enduring Power of Attorney

An Enduring Power of Attorney is a substitute decision-maker of your choice who you can appoint to manage your financial and property affairs should you lose the capacity to make your own decisions at some time in the future. You can consult your local community legal centre to find out whether they can assist you with this appointment.

Health Care Planning - Advance Health Care Directives, Enduring Guardianship and Person Responsible

Because of accident or illness a patient may not be able to tell the doctor what life-sustaining treatments he or she wants or does not want. Some people choose to write down these preferences beforehand. This written document is an Advance Health Care Directive. Your GP can assist you in completing this document.

An Enduring Guardian is a substitute decision-maker of your choice who you can appoint to make lifestyle and health care decisions should you lose the capacity to make your own decisions at some time in the future. You can consult your local community legal centre to find out whether they can assist you with this appointment.

Medical and dental practitioners have a legal and professional responsibility to get consent for treatments before treating a patient. If the patient is unable to consent, the practitioner should seek consent from the patient's Person Responsible. The Person Responsible is not necessarily the patient's next of kin, but is, in this order, either a guardian, including an Enduring Guardian; the most recent partner, including same-sex partner, with whom the patient has a close continuing relationship; an unpaid carer (who can be on a carer payment); or a relative or friend who has a close personal relationship with the patient.

For more information on Enduring Power of Attorney, Enduring Guardianship, and Advance Health Care Directives and forms to download, visit the ASLaRC website http://aslarc.scu.edu.au. For more information on Person Responsible, visit the Office of the Public Guardian website http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/pages/OPG_glbt

Wills

The easiest way to ensure your property is distributed according to your wishes is to make a will. In your will you must appoint an Executor, preferably someone you trust, to carry out your wishes. If you don't know who to appoint, the Public Trustee will act as Executor for a fee. You can also direct how you would like to be buried or cremated and what sort of funeral service you would like, although these directions are not binding. You can complete a will by getting a free will form or purchasing a will kit from your local newsagent, or see a lawyer. For more information on Wills, visit the Lawlink website:
http://www.lawlink.nsw.gov.au/lawlink/cpd/ll_samesex.nsf/pages/samesex_equal

Resources for Support

The following support services are available should you wish to discuss any issues further:

ACON Counselling Service: 1800 063 060 (free call for initial intake)

Gender Centre Counselling Service 02 9569 2366 (reverse charges if outside metro area)

Lifeline: 13 11 14 (24 hours in all areas)

A GP can refer you to a local counsellor and help with Advance Health Care Directives

Community Legal Centres NSW at www.nswclc.org.au can help you to find your nearest Community Legal Centre, or ask at your local Legal Aid service, to see what help they can provide you with in preparing an Enduring Guardian and an Enduring Power of Attorney

APPENDIX 2: Promotional Flyer

HELP US TO HELP YOU

Invitation to Participate in Important Research!!

You are invited to participate in a landmark study on end-of-life care for gay, lesbian, bisexual, and transgender people

What? A survey exploring gay, lesbian, bisexual, and transgender people's attitudes towards and knowledge of end-of-life care planning, including decisions around medical care for life-limiting illness or an unexpected accident, and questions relating to who will make decisions on your behalf should you lose the ability to do this for yourself.

Who? This research is being conducted by the Aged Services Learning and Research Centre (ASLaRC) at Southern Cross University, funded by the Law and Justice Foundation of NSW, and is also generously supported by ACON, the Gender Centre, the Inner City Legal Centre and the Northern Rivers Community Legal Centre.

Why? The information provided from this survey will help us to identify levels of knowledge and attitudes towards end-of-life care planning, and to develop educational resources to increase awareness. We also hope the findings will help improve end-of-life care.

How? If you wish to participate, you can request a survey from the front desk of the service in which this flyer is displayed. Alternatively, you can complete the survey online by using the links displayed on the ACON website www.acon.org.au and on the Gender Centre website, www.gendercentre.org.au. For more information on this research, please contact Dr Tania Lienert by email: tania.lienert@scu.edu.au **Please note that the closing date for submitting your survey is November 20th 2009.**

APPENDIX 3: ON-LINE SURVEY INVITATION

Please distribute to your networks, with our thanks!

Invitation to Participate in Online Survey

My name is Tania Lienert, and I am conducting research into gay, lesbian, bisexual, and transgender people's knowledge of and attitudes towards end-of-life care to help inform improved care. I am writing to invite you to participate in this project. If you could spare 15 minutes, I would really appreciate it if you would complete an online questionnaire. It is quick and easy. Just log onto Survey Monkey using the link below, and follow the instructions.
http://www.surveymonkey.com/s.aspx?sm=Skt6IMclHYSzQRx4RFV19w_3d_3d
The research, which is being conducted by the Aged Services Learning and Research Centre, Southern Cross University, is funded by the Law and Justice Foundation of NSW, and is supported by the Gender Centre, ACON, the Inner City Legal Centre and the Northern Rivers Community Legal Centre. The online survey has been approved by the Southern Cross University Human Research Ethics Committee and the ACON Research Ethics Review Committee, and is completely anonymous and confidential. You will find more information on Survey Monkey about the project and how to find out about its results when it is finished.
Please note that the closing date for submitting your survey is November 20th 2009.

Thank you very much for your time, your participation is greatly appreciated!

Dr Tania Lienert

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