




**An analysis of the specific directions regarding  
medical care and lifestyle decisions within completed  
Enduring Guardianship forms (Tasmania)**

Prepared for

**Office of the Public Guardian  
Tasmania**

**by**

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# Executive Summary

## Background

The Office of the Public Guardian was established by the *Guardianship and Administration Act 1995* in order to promote, speak for, and protect the rights and interests of people with disabilities in Tasmania. Under the provisions of this Act a person can appoint a substitute decision-maker known as an Enduring Guardian (and an alternate Enduring Guardian), and the document of appointment is registrable with the Guardianship and Administration Board. This registration requirement is the only one of its sort in Australia, and one of the few in the world. This therefore provides a unique opportunity to study what people write in their Enduring Guardianship (EG) forms, who they appoint as enduring guardians, and also gives other valuable demographic information about the appointment of substitute decision-makers, the making of advance care directives, and the wider advance care planning process in Tasmania. It also gives a rare opportunity to obtain ‘denominator’ data about the uptake of these provisions in a defined population.

In 2006-7, the Royal Hobart Hospital was a site for a pilot project of the nationally funded Respecting Patients Choices program. This stimulated considerable local interest in advance care planning. The pilot project used an adaptation of the existing EG form. Advance care planning is clearly a topic of widespread current local, national and international interest. In order to ascertain present uptake and use of the Tasmanian legislative provisions, and to gain information to inform future developments in advance care planning in Tasmania, the Office commissioned and funded a research project led by Professor Michael Ashby at the Menzies Research Institute, and Dr Robert Thornton. This study examined a sample of Tasmanian EG forms to address three research questions:

- What specific directions are documented by persons completing an enduring guardianship form in Tasmania?
- What are the demographic characteristics of the populations who appoint guardians under the legislation (age, place of residence, occupation), and the persons they appoint?
- Are there any differences between the Respecting Patient Choices and non-Respecting Patient Choices populations?

## Methods

One in twenty EG forms lodged with the GAB were sampled, 502 forms in total. Mixed qualitative and quantitative methods were employed. The initial categorisation of the directions within the EG forms was undertaken by a process of content analysis – systematic analysis of the content. Content analysis is a research tool that focuses on the actual content and its internal features – in this case the written enduring guardianship directions. It is used to determine the presence of certain words, concepts, themes, phrases, characters, or sentences within texts or sets of texts and to quantify this presence in an objective manner.

The collection and analysis of this semi-structured information was initially undertaken manually with a systematic compressing of many words of text into fewer content categories. However due to the unexpectedly large volume of written text encountered in the forms the manual method of coding was abandoned, and the qualitative research software NVivo™ was used to manage, shape and make sense of this unstructured information.

## **Results**

A total of 502 Enduring Guardianship forms were analysed. In total there were 298 females and 176 males, with 28 forms where gender was not recorded.

The majority of the sample consisted of forms completed by retired persons aged over 60. Despite the fact that legal assistance is not necessary to complete an EG form, 197/502 (39%) showed evidence of some qualified legal input. The age group most commonly using legal assistance were those aged 60–69 and were more likely to be female.

Of the 486 responses regarding choice of enduring guardian most individuals (95%) indicated a friend/relative as their choice of enduring guardian.

238/502 (47%) of the forms contained some kind of statement about care at the end of life, and indicated a preference for the deployment of timely and appropriate palliative care. These directions were usually made in general terms, often in a prescribed format with wording taken from the advice pamphlet.

As expected, there was no evidence of a consistent ACP or ACD approach. No Respecting Patient Choices Statements of Wishes were identified in this sample due to small numbers.

A wide range of personal care, values and beliefs were documented.

Few individuals indicated their religion (16.8%) but those who did were mostly Jehovah's Witnesses (n = 76)

Wishes for events after death, such as distribution of belongings, funerals and organ donation were frequently made, although the power of EG lapses at the moment of death.

## **Conclusions and recommendations**

- The fact that 2% of the Tasmanian population has availed itself of the provisions of the Act in its 15 years of operation sets a benchmark of whole of community uptake for substitute decision-making instruments in Australia, and possibly internationally as well.
- Persons who appoint enduring guardians in Tasmania are predominantly older retired citizens whose single major identified concern is palliative care at the end of life.
- Persons completing EG forms should therefore be encouraged to write an advance care directive (ACD) and attach it to their form.
- This ACD format should be in the prototype format developed by the Palliative Care Clinical Network Working Party and the Clinical Ethics Committee of the Royal Hobart Hospital (attached) . This focuses on the end of life, but can contain anything

the person wishes to specify for their care when they lack capacity. It emphasises personal beliefs and values, and unacceptable outcome states that the person wishes to avoid. This is in line with draft guidelines under development for AHMAC (Ashby personal communication).

- Younger persons should be encouraged to appoint EGs and complete ACDs.
- EG form directions, including those that specify aspects of personal care, should be actively sought and incorporated into a care plan if the person is admitted into hospital or aged care facility.
- Clarification needs to be sought regarding the appropriateness of incorporating directions for after death. Undoubtedly, there is community interest in doing this in the EG form, even though guardianship lapses at the moment of death. This particularly affects the inclusion of requests about organ donation in EG directions, especially in situations where the appointed guardian is not the senior 'next of kin'.
- EG is a legal appointment and hence professional legal assistance is commonly sought to complete the form, and lawyers may have a significant role in initiating EG appointment. Legal wording is often copied out verbatim into the form.
- Lawyers therefore might benefit from more information about the process of advance care planning, and be important initiators and conduits back to the person's health care professionals for assistance in these matters.
- Future promotional approaches need to project a less legalistic emphasis, and locate EG appointment in a process of advance care planning.

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## Introduction

The Office of the Public Guardian was established by the *Guardianship and Administration Act 1995* in order to promote, speak for, and protect the rights and interests of people with disabilities in Tasmania. Under the provisions of this Act a person can appoint a substitute decision-maker known as an Enduring Guardian (and an alternate Enduring Guardian), and the document of appointment is registrable with the Guardianship and Administration Board. This registration requirement is the only one of its sort in Australia, and one of the few in the world.

Tasmania is the only Australian jurisdiction to require completed advance directives to be registered with EPGs must be registered with the Guardianship Board in order to be considered valid. In its 2009 review the Advance Directives Review reported it had:

*considered schemes such as the Tasmanian register and examined the benefits of registering an AD at 'activation'. However, for most people 'activation' is not an event, it is a process that happens over time. The person sets the trigger for its use, and may or may not set conditions on the agent. Decision-making ability is usually lost by degrees, and the agent takes on progressively more decisions over time. Fluctuating capacity can mean that the agent makes some decisions for a period of time, but when the person recovers decision-making reverts to the person. Consultations indicate public support for advance directives to be used during episodic mental illness to respect the person's autonomy."*

*The Review Committee investigated the Tasmanian register and found that the Tasmanian EPG register was similarly unsuccessful in the beginning, with only 200 EPGs registered in the first six years. More recently an active publicity and education campaign by the Tasmanian Guardianship Board and Public Advocate increased awareness of ADs and there are now approximately 8,000 registered documents. About 2,500 of these have been completed by Jehovah's Witnesses, who have adapted the statutory form for the specific purpose of refusing blood transfusions.*

*Overseas registers in Scandinavia, Canada and the USA were examined, but many of these are privately run, voluntary and expensive for registrants. No international model covers both financial and personal ADs. Clearly the usefulness of a register relies not on the person registering their AD, but on the professional who is required to abide by it seeking to affirm its existence. Establishing a register without mandating it be accessed would inappropriately raise registrants' expectations that their wishes will be known and acted upon in the future should they lose the ability to make their own decisions.*

*However, international evidence suggests that medical practitioners are prepared to consult agents who identify themselves as such and relatives, but are reluctant to access registers of patients' preferences. It is therefore more important that relatives are made aware of the existence and contents of an AD. This is also borne out by the Australian experience with the national register OF organ donation intentions. Medical practitioners are expected to check the Australian Organ Donor Register routinely when a person is diagnosed as brain dead to determine if they recorded their wishes about donation, however a high proportion of intensivists surveyed stated they did not (and in many cases would*



*not) check the register, despite the high registration rate of potential organ donors.* (Advance Directives Review (2009, pp. 38–39)

Tasmania therefore provides a unique opportunity to study what people write in their Enduring Guardianship forms, who they appoint as enduring guardians, and also gives other valuable demographic information about the appointment of substitute decision-makers, the making of advance care directives, and the wider advance care planning process in Tasmania. It also gives a rare opportunity to obtain ‘denominator’ data about the uptake of these provisions in a defined population.

As part of its mandate, the Office of the Public Guardian funded this research project entitled “An analysis of the specific directions regarding medical care and life style decisions within completed Enduring Guardianship forms (Tasmania)”, which was carried out by the Menzies Research Centre.

Two versions of the Enduring Guardianship (EG) form exist. The first, and most widely used, is the version originally developed by the Guardian and Administration Board (GAB), and comprises the EG appointment tool, together with a section for people to write any specific directions for the guardian in free text. The second form (approximately 200 completed) was developed for the Respecting Patient Choices (RPC) program at the Royal Hobart Hospital in consultation with the Public Guardian and GAB. The RPC version contains the generic EG form, and in addition there is a ‘Statement of Wishes’ advance directive section with specified options to choose from.

This study examined a sample of these forms to address three research questions:

- What specific directions are documented by persons completing an enduring guardianship form in Tasmania?
- What are the demographic characteristics of the populations who appoint guardians under the legislation (age, place of residence, occupation), and the persons they appoint?
- Are there any differences between the Respecting Patient Choices and non-Respecting Patient Choices populations?

## **Brief Outline of the Original Study Proposal**

### **Aims:**

To determine the demographic characteristics of the populations who appoint guardians under the Tasmanian legislation (age, occupation), the persons they appoint and the specific directions regarding medical care lifestyle decisions by persons completing an enduring guardianship form in Tasmania.

### **Justification:**

End-of-life decision making in Tasmania is assisted by government department of Health and Human Services (DHHS) guidelines promulgated in 1998, and guardianship legislation passed in 1995. These guidelines include a section on Advance Care Directives(ACDs) (section (e) page 4) but Common Law and professional ethics codes also apply.

The Guardianship and Administration Act 1995 makes provision for competent adult persons residing in Tasmania to appoint an agent (guardian) to act for them when they lack capacity to do so for themselves due to illness or injury. Such a duly appointed guardian (or guardians, as you can name two) are empowered by law to make medical and general life decisions on a person's behalf – but only when they lose capacity to decide for themselves, either temporarily or permanently.

Guardians are appointed by completion of an enduring guardianship (EG) form accordance with the provisions of the Act.

The Respecting Patient Choices Program is a national demonstration project showing how advance care planning can improve the end-of-life journey. It helps people avoid unnecessary and distressing hospital admissions at the end of life, by respecting their wishes and allowing them to die in their place of residence. (A randomised controlled trial has since been completed at Austin Health that confirms the very promising original US data, and Australian pilot study (see Detering et al., 2010). The key events and findings at the Royal Hobart Hospital site were:

- From April 2006–February 2007, RPC was implemented on for acute “pilot” wards.
- 217 patients were approached, and 297 discussions were held. This resulted in the registration of 28 Enduring Guardianship forms with the Office of the Public Guardian, and placed in the patient's medical records. In addition, 7 patients completed a Statement of Wishes form but chose not to appoint a guardian. These results compared favourably with other RPC sites.
- Five RPC Consultant training courses were held, 150 staff being trained as consultants -19 medical, 77 nurses, 21 social workers and 99 other disciplines, and/or external to the hospital.
- Patients and families were found to be receptive to discussion of end-of-life issues and, in the majority of cases, elected for palliative care, with an emphasis on dignity.
- Avid interest was encountered in nursing home sector.
- Since the completion of the pilot the RPC program has continued with a focus on aged care in the south –TCU, Gem and Karingal. A reference group continued to meet with Professor Michael Ashby nominated as Clinical Leader and chair of this group (this has now been superseded by a Goals of Care Project at RHH/STAHS, and a statewide “Healthy Dying” project concept).

This group made a number of observations and recommendations:

- RPC has been hospital- and specifically RHH-based. This limits the exercise, and ACDs now need to be seen as transcending the hospital – community divide, and geography.
- Roll-out into the community will require a broad-based and appropriately resourced public health promotion exercise that addresses ACDs in the broad context of death and dying, loss and grief.

- Sustainability can only be ensured if long-term funding and resources are available in each health region to drive the process and maintain education.
- Joint DHHS and Office of Public Guardian End-of Life Care and Decision-making Reference and Steering Groups need to be established.
- A state-wide “roll-out” of an RPC-inspired ACD program is required.
- There needs to be a community capacity-building health-promotion program of dissemination education and information.
- Education concerning ACDs needs to be implemented at undergraduate level and linkages need to be established among main hospitals (public and private), residential care facilities, general practice, and Tasmanian Ambulance Service.
- Teams should be based at the three major acute hospitals, comprising funded dedicated time to undertake ACD work in Aged Care and Palliative Care consultative services, and in social work.
- Formulations of consistent Institutional End-of-Life policies across the state is needed.
- Research and evaluation to be fostered by linking the program to the Menzies Research Institute.
- The state should support the national initiative to formulate guidelines for ACDs. This, however, is no substitute for local, jurisdiction-specific work to ensure that ACDs become widespread, useful and effective.
- Reciprocal recognition of ACDs in all jurisdictions is an important goal. This would seem to be an ethical imperative that the health professions should support now, even if legal standardisation is a more challenging longer-term goal.
- Advance directives have been embraced by general practice and information is available on the Tasmanian Divisions website via GP South. A legal avenue for ACDs therefore exists, and is in use within the context of the RPC project and beyond. However, unlike the Guardian, who has statutory legal force, an ACD, in the absence of an appointed guardian, has common law and ethical status as evidence of the patient’s wishes, but is not provided for in statute. While it would seem that law and professional ethics require such directions to be followed, this absence of statutory force may lessen the professional requirement to abide by them in some eyes (Cartwright, 2007).
- Uptake of ACDs has been low in most jurisdictions, and Singer and colleagues have suggested that this is because they do not meet the needs of patients, who are looking at preparation for death and their family and social relationships rather than medical precision (Singer et al., 1999). By contrast, doctors have historically been more focused on making the right medical decision at the time, and err on the side of the potential to prolong life (Cartwright, 2007). What people specify in their directives is therefore important, yet there is little known about this area.
- There is no “ideal” ACD form or format, and ultimately one needs to be agreed to and road-tested. In Tasmania a workable format is available and is being adopted by

individuals in the community when they are aware of it. The current Tasmania forms will benefit from further research and community consultation, and consequent refinement – this is the purpose of this proposed study.

Tasmania is one of the few jurisdictions that hold a register of its guardianship forms, and these contain an advance direction section. In the generic form, there is a blank “free text” section for people to state their wishes, and an optional information sheet to assist them in the form’s completion. For the RPC project there is an amended official guardianship form that includes the RPC “Statement of Wishes”. This is a structured three-choices form that allows a person to choose to (a) have all life- saving treatment, (b) elect to have palliative care only if they are dying and (c) a default choice for a “best interest” decision by their medical attendants and person responsible if they choose neither of the first two.

Thus two types of forms exist. The first, and most widely used with approximately 4800 completed was originally developed by the Guardian and Administration Board (GAB); it comprises the EG appointment tool and a section for people to write any specific directions for the guardian in free text.

The second form (approximately 200 completed) was developed for the Respecting Patients Choices (RPC) program at The Royal Hobart Hospital in consultation with Public Guardian and GAB. The RPC version contains the generic EG form, and in addition there is a “statement of wishes” advance directive section with specified options to choose from.

Persons completing either form are provided with information about what decisions an enduring guardian may make on their behalf when and if they lack future capacity.

Little is currently known about what people elect to add to the GAB forms, or which choices they make on the RPC form. This information will be important for any future research-based development of advance care directives in Tasmania, and to streamline the forms.

Therefore, it is proposed that a retrospective study be undertaken of the completed Tasmania EG documents registered with the GAB to collect demographic data and to analyse the written requests using a content analysis methodology.

## **Ethics Approval**

A submission was made to the Tasmanian Social Science Human Research Ethics Committee using a minimal risk application form. Ethics reference no: H10377

## Methods

The research questions posed in this study required the researchers to examine both the qualitative and quantitative aspects of the data so therefore the methodology approach can be seen as mixed method. Mixed method research, the combined use of qualitative and quantitative methods, is increasingly popular in health services research, especially as a way to examine 'complex interventions'. A basic description of a mixed methodology is simply that it is a methodology with methods that have comparisons between quantitative and qualitative data. Quantitative data is data in numerical form, often derived from questionnaires or structured interviews. Qualitative data relates to descriptive data such as that from observation or unstructured interviews. The separation of methodologies into quantitative and qualitative is a common distinction; the tendency has been to link quantitative methods with a natural science (positivist) and qualitative methods with a social science (interpretivist).

Mixed methods was utilised to illuminate different aspects of an enduring guardianship directions and to provide greater insight into particular issues. The researchers are aware that the qualitative and quantitative results may be discrepant, and methods need to be developed to deal with such discrepancies. However, exploring seemingly discrepant results can often lead to greater insight.

Given the data to be used in this research comprised individuals' written directions, the qualitative research component of this study enabled some insight into people's attitudes, behaviours, value systems, concerns, motivations, aspirations, culture or lifestyles.

The initial categorisation of the directions within the EG forms was undertaken by a process of content analysis – systematic analysis of the content. Content analysis is a research tool that focuses on the actual content and its internal features – in this case the written enduring guardianship directions. It is used to determine the presence of certain words, concepts, themes, phrases, characters, or sentences within texts or sets of texts and to quantify this presence in an objective manner. It was considered that content analysis would offer several advantages to researchers with regards to this research. In particular, content analysis:

- looks directly at communication via texts or transcripts, and hence gets at the central aspect of social interaction, and can allow for both quantitative and qualitative operations,
- allows a closeness to text which can alternate between specific categories and relationships and also statistically analyses the coded form of the text. (Busch et al., 2005)

## *Sample Size*

The minimum information needed to calculate sample size for a randomised controlled trial in which a specific event is being counted includes the power, the level of significance, the underlying event rate in the population under investigation and the size of the treatment effect sought. The calculated sample size should then be adjusted for other factors, including expected compliance rates and, less commonly, an unequal allocation ratio.

Sampling for qualitative analysis is not required to meet the statistically valid formulae of quantitative analysis. Nevertheless, sampling for in-depth qualitative study should not be simply drawn at the researcher's whim, and even random methods may not yield useful data as the purpose of qualitative research is to investigate certain issues or themes in detail.

Random or even representative methods of sampling may not capture the issues or themes that are the subject of qualitative analysis. Miles and Huberman (1994) argue that sampling strategies for qualitative research should be driven by a conceptual question, not by concern for "representativeness".

While recognising the above, estimating the sample size was important to this research as the intention was to provide both qualitative and quantitative information regarding the directions embedded in the enduring guardianship forms. Following advice from the Menzies Centre it was determined that a 1 in 20 sample size would reflect, as closely as possible, the characteristics of the whole dataset.

### ***Sampling Method***

Approval was provided by from the Guardianship Board for a research assistant to attend and extract the information from individual files without recording identifying details such as names and addresses so that confidentiality was maintained. Every 20<sup>th</sup> file was extracted and the advanced care plan information of each file was recorded on a dictaphone. This information was then transcribed to a hard copy and subsequently entered into a data analysis program (NVivo 8™).

Information recorded included gender, occupation, year of birth, postcode/suburb, whether legal assistance was required when completing details, the enduring guardian nominated and the decisions a person wished to make in advance.

### **Data Collection and Analysis**

The collection and analysis of this semi-structured information was initially undertaken manually with a systematic compressing of many words of text into fewer content categories. However, due to the unexpectedly large volume of written text encountered in the forms the manual method of coding was abandoned, and the qualitative research software NVivo™ was used to manage, shape and make sense of this unstructured information.

NVivo 8™ software was used because of its capacity to handle rich information, where in-depth analysis on both small and large volumes of data is required. It assists data analysis by removing many of the associated such as classifying, sorting and arranging information, so that the focus can be on exploring trends, testing theories and dealing with questions.

Using NVivo™ the data can be interrogated and can therefore improve the rigour of the analysis process by validating (or not) some of the researcher's own impressions of the data. Issues of validity and reliability in the themes that emerge during data analysis are less strongly a feature of the software and due to the way that themes emerge. Both manual and electronic tools in qualitative data analysis and management need to be used rather than relying heavily on one format alone (Jones, 2007). Many of the more repetitive and mechanical aspects of qualitative research can be improved by using qualitative data analysis software.

*Qualitative data analysis uses a process of reduction to manage and classify data. In this process, units of text are first de-contextualised by removing them from their source –*

*with their meaning intact – and then re-contextualised by drawing from them a more robust, context independent, meaning based on an accumulation of evidence. (Jones, 2007, p. 2)*

Data is coded as it occurs in the original documents once these are loaded into the program, becoming a textual segment defined by Tesch as “a segment of text that is comprehensible by itself and contains one idea, episode, or piece of information” (1990, p.116). These segments retain their full meaning but are tagged with descriptors and coded and grouped in categories for later analysis. It is important that this process of coding extracts segments of data that are logical and valuable to the research and that labels or categories are sufficiently descriptive yet abstract enough to allow for further data addition.

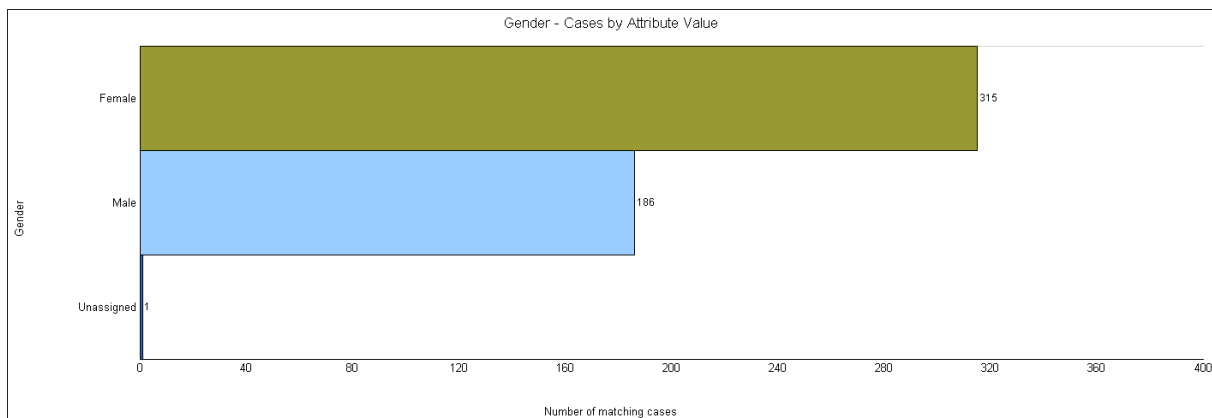
The researcher must still collect the data, decide what to code and how to name the categories but the software simplifies the repetitive and mechanical tasks of data analysis. Another great feature of the software approach is that categories and nodes can be changed or moved around as required. The coding remains an intellectual exercise as the researcher must still think and deliberate, generate codes, and reject and replace them with others that seem more illuminating and explain each phenomenon better.

## Results

### *Demographic Data*

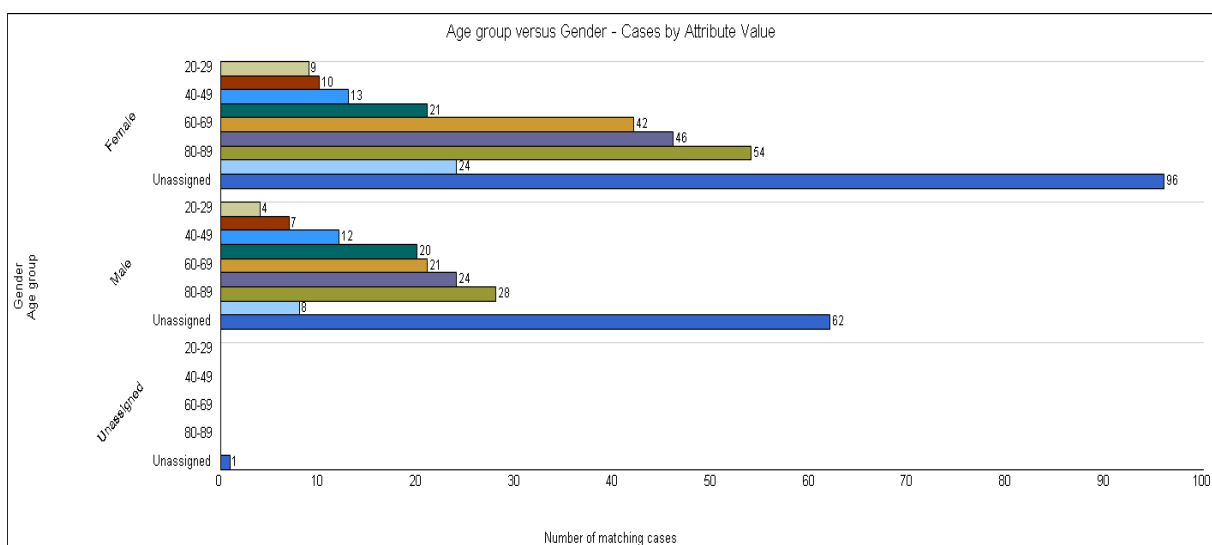
A total of 502 Enduring Guardianship forms were analysed (one in twenty sequential sampling of the 10040 forms lodged at the time. In total there were 315 females and 186 males in the sample, with 1 form where gender was not recorded.

**Figure 1: Gender distribution**



The age of individuals was calculated using their documented year of birth on the form and determining an equivalent age at the time of data analysis. While this is obviously an imprecise approach and does not adequately reflect age at time of form completion it does allow some portrayal of the distribution across age groups (date of form completion was not recorded during initial data collection). The earliest year of birth was 1908 and the youngest individual was born in 1988. Simple allocation within a 10-year range was used and results are shown in Figure 2 below.

**Figure 2: Age group and gender in 10-year increments**

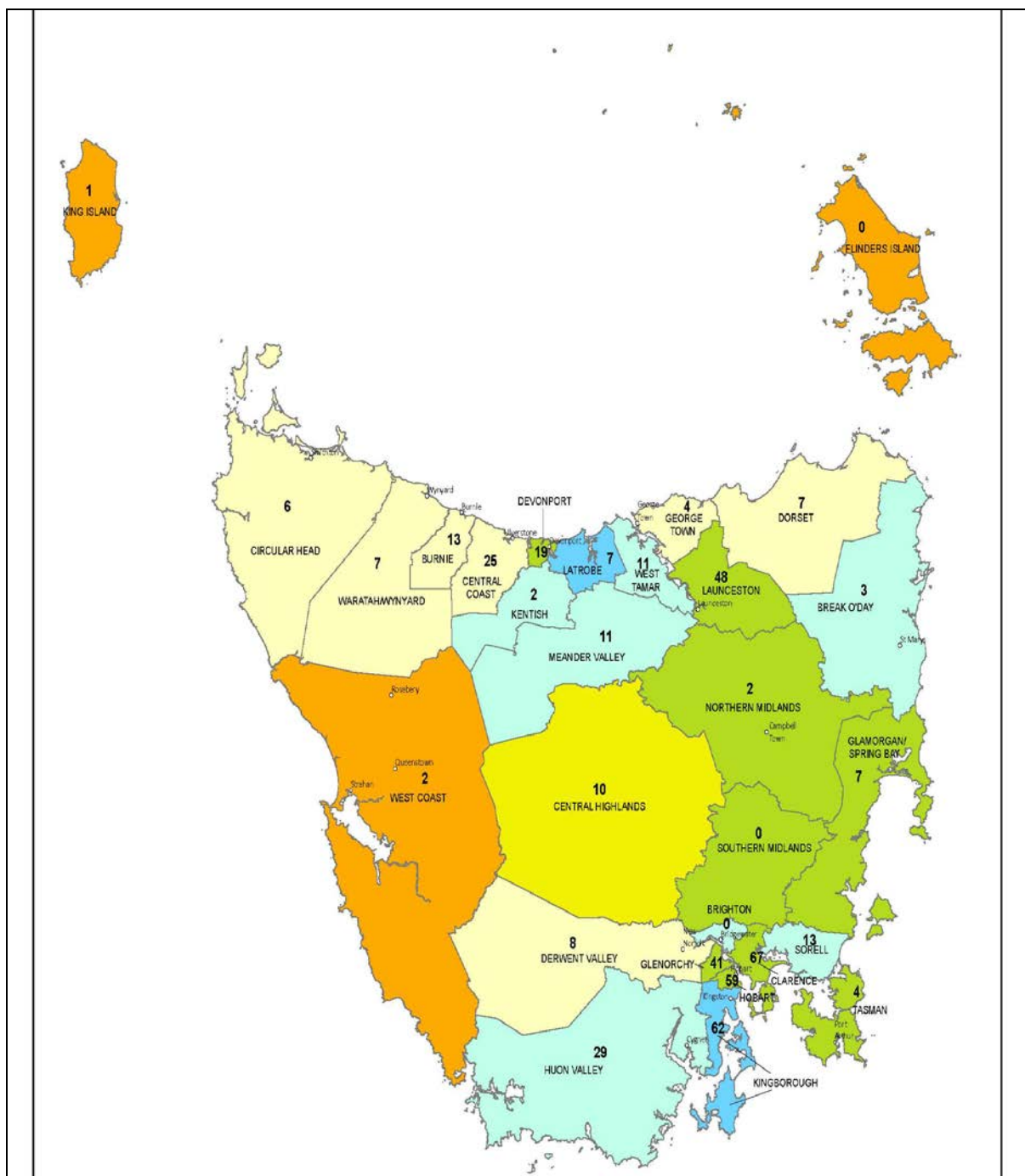




## Council Area Where Individuals Lived

Individual's postcodes recorded on the forms were allocated into local government areas and recorded on a map to show distribution within Tasmanian council areas. The highest number were from Clarence (n = 67) followed by Kingborough (n = 62), Hobart (n = 59), Launceston (n = 48).

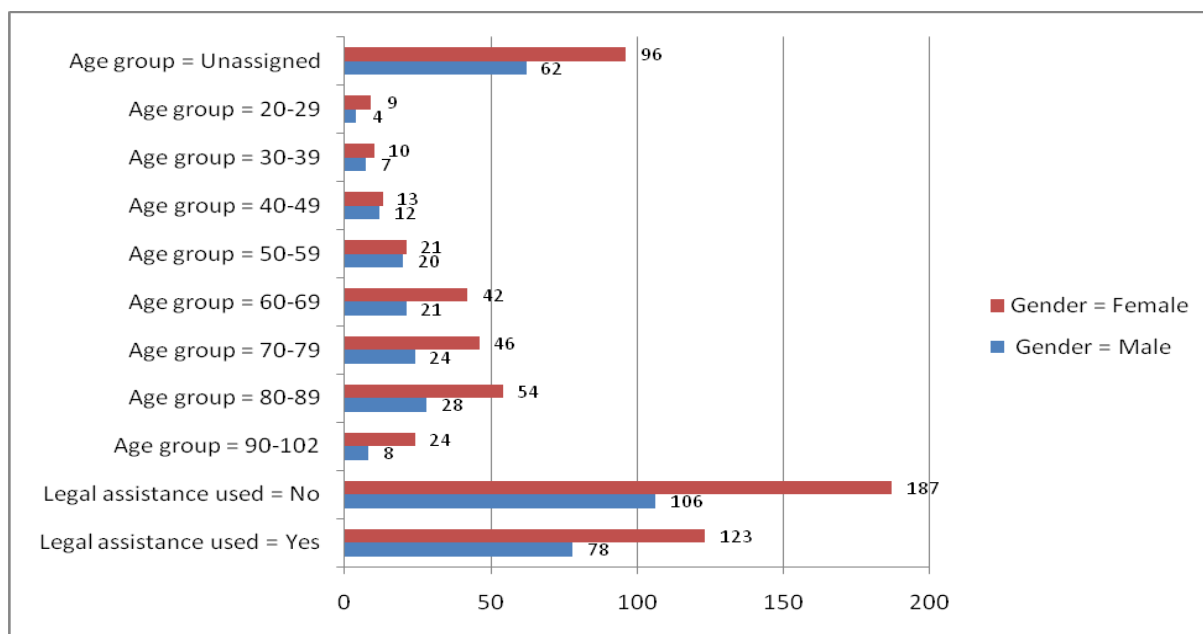
Figure 3: Local government area where respondents lived



## Use of Legal Assistance

Only 201 used some legal input into the preparation of their enduring guardianship form while the majority did not (293) and only 8 had no response in this section. Data were coded as having used legal assistance where the individuals' forms had a legal practitioner's signature as witness. The age group most commonly using legal assistance were those aged 60–69 and were more likely to be female.

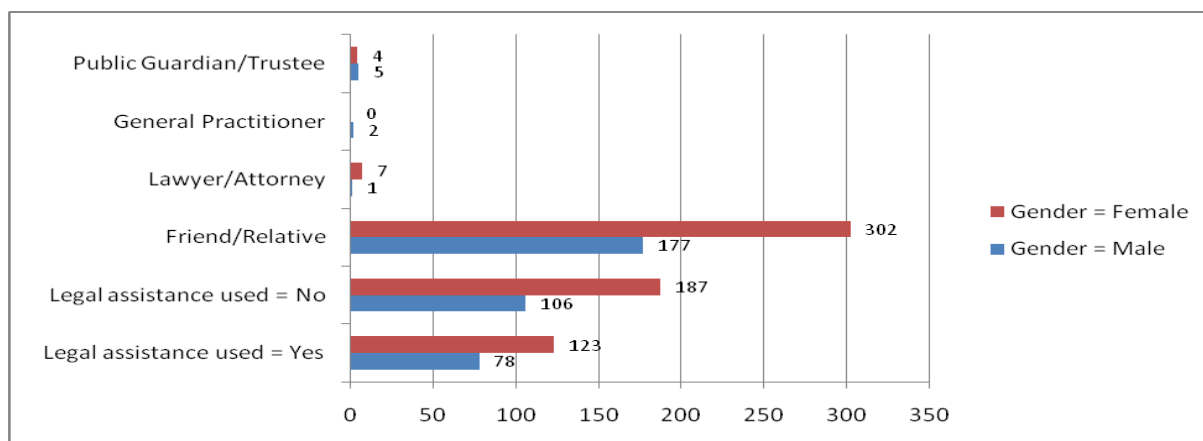
**Figure 4: Legal assistance used by gender and age group**



## Choice of Enduring Guardian

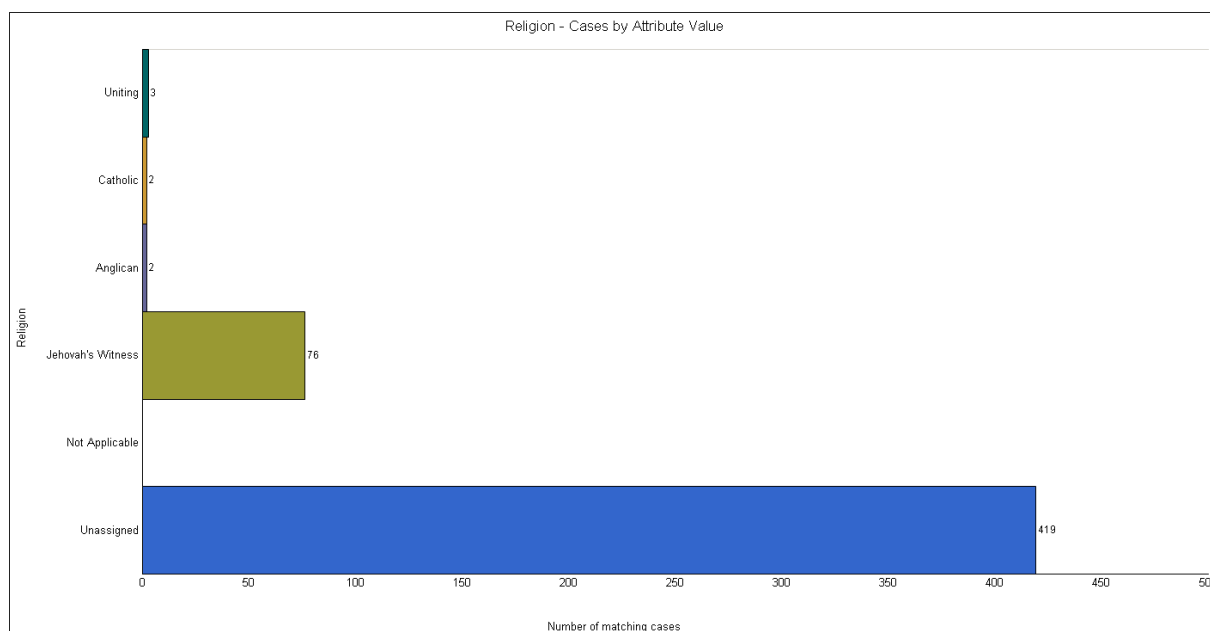
Of the 502 responses regarding choice of enduring guardian most individuals (95%) indicated a friend/relative as their choice of enduring guardian. This categorisation was made based on the annotations on the EG form, often indicating type of relationship/connection to the individual. Some individuals had specified their GP/legal practitioner's name.

**Figure 5: Choice of enduring guardian by gender**



Few individuals indicated their religion (16.8%) but those who did were mostly Jehovah's Witnesses (n = 76)

**Figure 6: Religion as indicated on EG forms**



## Occupation

Each form had the option for individuals to indicate their occupation and this was completed whether people were currently active in the workforce or retired. Many elderly/retired people also reported their occupation in the form of as 'retired manager' and so forth.

The occupations of all those who indicated same on the EG form were primarily simply 'retired' although some also specified their previous, for example 'retired nurse' retired farmer'. Table 1 presents those respondents who reported their occupation and where there was more than one response in the same group. There were 110 who recorded no occupation and the remaining forms each contained a single response to an occupation description varying from retired biochemist to retired fisherman and all types in between.

**Table 1: Occupation of respondents**

<b>Occupation</b>	<b>Number</b>
Retired	159
Home duties	61
Pensioner (includes all types)	31
Retiree	26
Farmer	6
Carer	4
Company Director	4
Widow	4
Accountant	3
Engineer	3
Public Servant	3
Religious Sister	3
Sales Assistant	3
Secretary	3
Artist	2
Bricklayer	2
Business Proprietor	2
Customer Services Officer	2
Draftsman	2
Linesman	2
Nurse	2
Office Manager	2
Registered Nurse	2
Retail Assistant	2
Sales manager	2

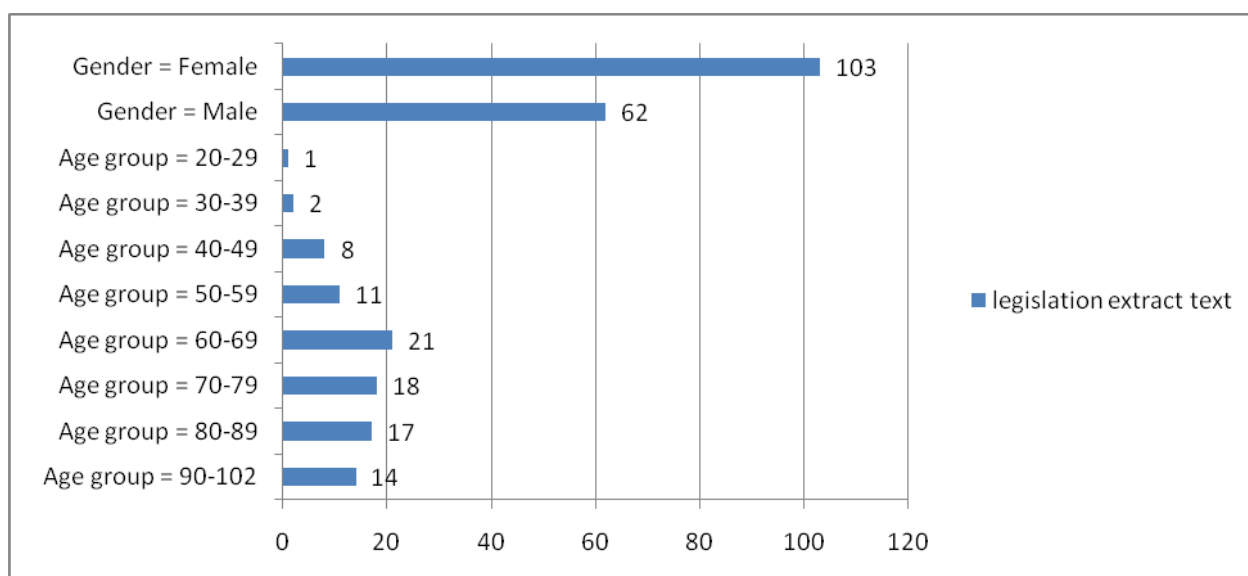
## Qualitative data

The guidelines for completion of the EG form provide examples of conditions – ‘particular decisions about your medical care or lifestyle’ that individuals could include and that indicated ‘what you would desire if you were unable to decide for yourself because of accident or illness’. Many individuals used these examples of specific conditions verbatim in their forms but there were also many who chose to personalise their requests as outlined later in this section.

There were some 165 forms (32.8%) that contained **only** the extract contained in the *Guardianship and Administration Act 1995* Form 1(Section 32(2) (a) and (b) on the Instrument Appointing Enduring Guardian(s) for Tasmania to guide their specific requests regarding enduring guardianship

*I authorise my guardian in the event that I become unable by reason of a disability to make reasonable judgements in respect of matters relating to my personal circumstances, to exercise the powers of a guardian under Section 25 of the Guardianship and Administration Act 1995.*

Figure 7: Specific extract from legislation only by age and gender



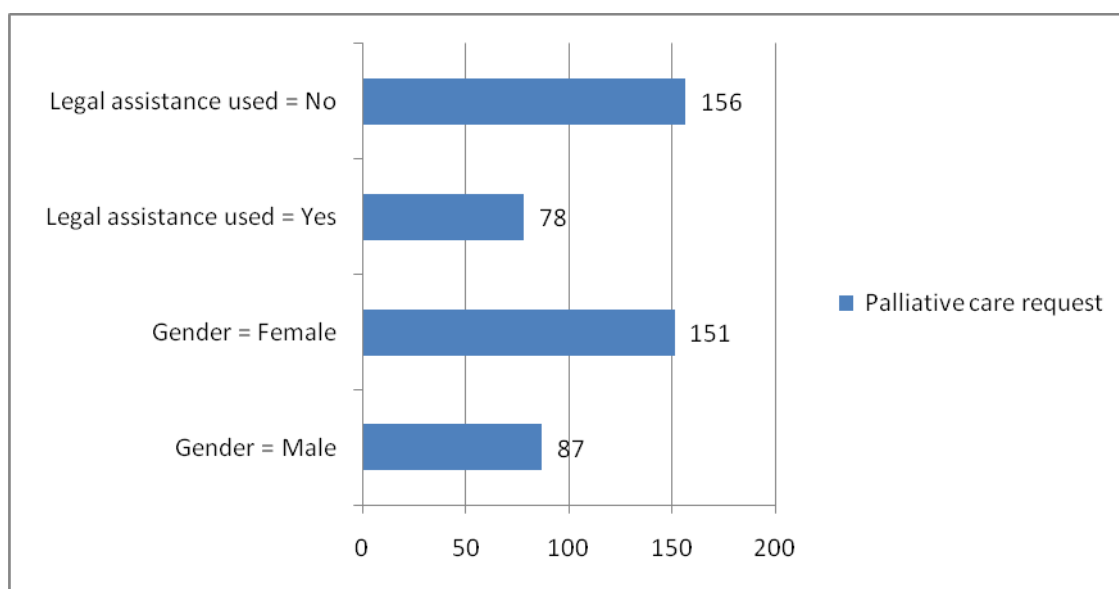
Of those who used this extract 111 indicated they had accessed legal assistance in completion of their EG form while 51 included it without recourse to legal advice (3 incomplete forms).

### Palliative care request

The area of great interest for the researchers was that of request made for palliative care. There were 238 cases where a description was given of the preferred level of intervention/care requested by those who completed the EG form. This was by far the most widespread request on the forms. There were 76 cases (female =53, males = 23) who included the following specific statement that is currently given as an example on the EG form:

*If I am acutely ill and unable to communicate responsively with my family and friends and it is reasonably certain that I will not recover, I want to be allowed to die naturally and to be cared for with respect for my dignity. I do not want to be kept alive by extraordinary or overly burdensome treatments that might be used to prolong my life. If any of these treatments have been started, I request that they be discontinued. However, I do want palliative care that includes medications, and other treatments to alleviate suffering and keep me comfortable, and to be offered something to eat or drink.*

**Figure 8: Request for palliative care by gender with legal assistance used**



Similarly a further 38 within this palliative care request section used the following statement/condition from the EG form:

*If two doctors conclude that I have a terminal illness or a condition that is totally incapacitating physically and mentally I direct that no life-saving or life-prolonging medical intervention be given to me. Instead I would prefer the best standards of palliative care and treatment to control distressing symptoms, even if that treatment may shorten my life.*

Individuals who used the EG form to specify their personal requests reflected many useful and interesting comments as shown in the following section and grouped under themes.

### **Specific Palliative Care Requests**

Of those individuals who used the form to specify their particular requirements at end of life there were some diverse requests but the predominant need was for comfort and relief from pain. The following indicates some of the situations whereby individuals identified a need for their guardian to act on their behalf:

Some used the specific terms within the condition on the EG form below

*If I am acutely ill and unable to communicate responsively with my family and friends and it is reasonably certain that I will not recover. I want to be allowed to die naturally and to be cared for with respect for my dignity. I do not want to be*

*kept alive by extraordinary or overly burdensome treatments that might be used to prolong my life. If any of these treatments have been started I request that they be discontinued. However I do want palliative care that includes medications and other treatments to alleviate suffering and keep me comfortable and to be offered something to eat or drink.*

Others chose to specify situations requiring particular interventions

*If I become irreversibly incontinent and/or immobile and unable to perform necessary functions of normal living*

*I lose my mental capacity*

*I become subject to constant pain and suffering*

*I do not wish to have any life-saving or life-prolonging medical intervention. I would prefer the best standards of palliative care.*

*I do not wish to be kept alive by respirator or any artificial means whatsoever in the following circumstances:*

*If I develop dementia of any form and unable to communicate sensibly as a result thereof and there is no realistic chance of recovery*

*If I am in a coma for whatever reason and there is a big chance that I will be brain damaged should I wake up*

*If I become a paraplegic and am completely dependent on others*

*Also if I have a terminal illness such as cancer, I would not want invasive or aggressive treatment unless more than one doctor agreed that there would be a good outcome.*

### **Request for Life-Prolonging Treatment**

Although only 39 individuals specified a request for life-saving/prolonging treatment and many used the conditions from the EG form:

*I would like life-prolonging treatments to be commenced and continued including CPR while they are medically appropriate and remain in my best interests.*

*When I am unable to speak for myself I would like full medical intervention for any medical problem.*

*I would like life-prolonging treatment to be commenced and continued (including CPR artificial ventilation antibiotic therapy, naso-gastric tubes, PEG feeds, renal dialysis) while they are medically appropriate (as deemed by the treating team) and remain in my best interests and for the duration of time to allow the gathering of my family to my bedside and for the duration of time for me to be in the presence of my family.*

There were a few forms where the individual had specified the level of medical intervention they were prepared to accept and many of these obviously correlated with religious beliefs (Jehovah's Witness).

*I do not wish to be put on any life support machine; in particular, I do not wish to be put on a ventilator.*

*I refuse resuscitation if I have ceased breathing from either a heart attack or stroke*

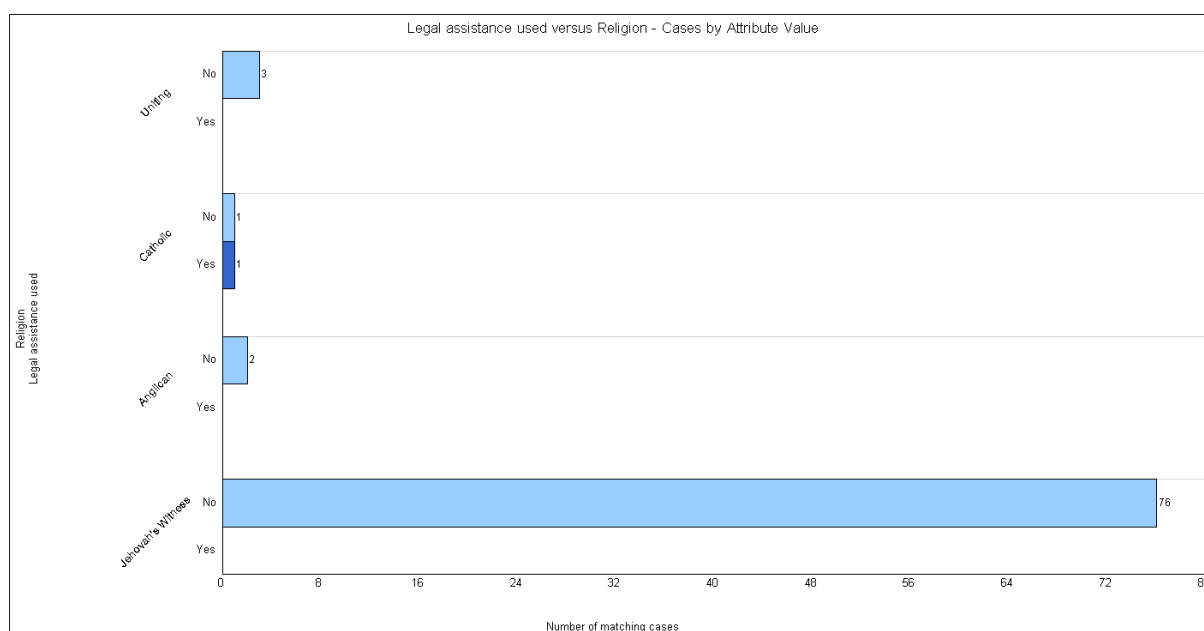
*I accept the use of cell saving use as a last resort of treatment.*

*I will not accept transplanted organs*

*I will accept the use of blood fractions.*

Given that many of the medical interventions were very specific, when the data were examined to correlate religion with the access to legal assistance to prepare the form it was not surprising to note that all who specified JW as their religion also used legal help.

**Figure 9: Legal assistance and religion**



The following examples are drawn from respondent's forms that we classified under the heading of 'Jehovah Witness Wishes':

*I will accept the following medical treatment alternatives EPO, non-blood sources of albumin, non-blood clotting factors, non-blood derived interferons, non-blood volume expanders, cauterisers during surgery. I will also accept any non-blood medications that the doctors see fit to use.*

*Concerning procedures, including the medical use of my own blood I accept a heart lung machine and dialysis provided machines are not primed with blood or blood products from a foreign source.*

*I refuse cell salvage, hemodilution, epidural blood patch, plasma phoresis labelling or tagging and platelet gel and autologous.*

*I direct my guardian to allow non-blood fractions, i.e. products that mimic the actions of real blood fractions but do not originate from any blood source.*



*I direct my guardian to allow plasmaphoresis where it is done in a continuous circuit without using any plasma from another person or animal. I will accept a plasma substitute.*

*I also direct my guardian to allow self salvage where it is done in a continuous circuit without storage. It must be in a continuous process*

## **Refusal of Blood Products**

*Because of my religious beliefs I do not wish to receive a blood transfusion, nor blood primary components of red blood cells, white blood cells, platelets and plasma under any circumstances.*

*I direct my guardian to refuse consent for a transfusion of whole blood, red cells, white cells, platelets or blood plasma to be given to me under any circumstances, even if healthcare providers believe that such are necessary to preserve my life, or any of my family, my relatives or my friends disagree with my considered and non-negotiable decision. I also direct my guardians to refuse any pre-donation and storage of my blood for later infusion under any circumstances.*

By far the most illuminating section of the forms related to individualised requests for care and these reflect the diverse nature of personal preferences.

## **Personal care**

Some made specific requests directing personal care (23), for example:

*If I become incapable of looking after myself I want arrangements made to make life easy. I do not want to disrupt the normal day to day life of my family and friends, particularly my daughter. In a nutshell no bother, no fuss.*

*When I am unable to walk outside by myself I would like to be taken out to the sun for a few hours every day whenever possible.*

*As a lover of fine music I would like to be able to listen to classical music in the evenings.*

*I wish to hear Christian music even if I seem to show no response. Care should be taken to ensure that others are not annoyed.*

*I do not want to be force fed.*

*If I am bed ridden and only able to verbally communicate by sounds, not speech, and if the sounds which I make annoy others around me I do not wish to be given medication to silence me unless the noise is extreme and all other measures have been tried.*

## **Choice of Long-Term Care**

Drawing on another of the conditions on the EG form some 56 made a direction regarding choice of long-term care, for example:

*If I require long-term care in a facility outside my home I would prefer to live close to my husband and other family members.*

*If I require long-term care in a facility outside my home I would prefer to live close to my husband or a member of my family*

*If I require long-term care in a facility outside my home I would prefer the Queen Victoria Home*

A number of individuals (n = 20) used the scope of the EG form to specify their requests regarding their funeral arrangements (n = 14) or to indicate they wanted to be cremated (n = 6).

*I direct my guardian to arrange a requiem mass for me according to the rites of the RC church*

*I would prefer my body to be cremated and my ashes scattered in an appropriate garden.*

*I wish my wedding ring to be left on my finger and not be removed after my death.*

*In the event of my death I wish to be cremated and my ashes spread on rose gardens at garden chapel, Ulverstone. Service to be held at Garden Chapel.*

*When I do pass away I would prefer a private funeral, would like only a very simple casket and for this process to be performed in a short time frame. I would like to be cremated.*

*Observe my request for a private funeral, cremation and my ashes to be combined with my husbands and scattered off Maria Island.*

Others chose to be more creative and descriptive in their wishes and to indicate their preferred funeral arrangements.

*I find it hard to make decisions. I trust my guardians, between them to help me to make the best decisions. I am happy here at the nursing home with all the people caring for me. I might like to spend some time at my home if and when I feel well enough. St Stephens is the church where all my family were christened and confirmed there. I only go to church when it is necessary for weddings and funerals and funeral arrangements will be a family decision. It is important to me that I know that the whole family have been consulted and are in agreement with the guardians taking the role of joint enduring guardians for me.*

A few respondents obviously had an aversion to formality or religion when considering their final departure and reflected this in their requests.

*Upon my death I wish that my family dispose of the body in the fastest most cost effective manner.*

*Would like a simple funeral with a religious touch either a church or a service at the funeral directors. To be cremated and ashes over mum and dad's grave at Scottsdale. A small plaque "with those I loved".*

*I detest funerals and wish to be privately cremated as inexpensively as possible. If my family wish they may hold a non-religious memorial service and play some good jazz.*

Some individuals took the opportunity to appoint an alternative guardian or to specify who should be consulted with regard to their care.

*When my guardian assumes his/her role I direct my guardian to advise my child's father of my condition so that he can assume full time care and responsibility for our son.*

*I direct my guardian to consult my daughter and my brother-in-law on any important decisions about my health and welfare.*

*I direct my guardian to consult my sister on any important decisions about my health and welfare.*

The care and environment during the last days of life received some rich comments from individuals and there were many individuals who provided described how they wanted their final days to be managed by specifying their choice of music, environment and activity. This section provides some useful information that could assist health care providers consider the individuality of terminal care and to not assume that all want the same thing.

*I have broad musical tastes, particularly classical but also jazz, swing, big band, early rock n roll, country and western, middle of the road and also forms of ethnic music. I do not enjoy heavy metal, grunge, etc.*

*I feel the cold and would like to be kept warm.*

*If I am incapacitated or unable to move I would like ABC FM music sometimes*

*Should I become unable to walk by myself I would like to be taken out into the sun whenever possible.*

*When I cannot (for any reason) go outside by myself, would really appreciate someone taking me out to get some fresh air, either in the home garden, by a beach or in the country where I can enjoy the beauty of nature (weather permitting).*

*I enjoy going on short trips visiting friends and having a meal out, picnics, etc when well enough.*

*When I am no longer able to toilet, shower or feed by myself I request palliative care only please*

*I wish to be permitted to die naturally and be care for with respect for my dignity*

*This includes mediations, etc to relieve pain and keep me comfortable.*

*Short visits (of 10–20 minutes) from friends would be welcome*

*If I am bedridden and only able to verbally communicate by sounds, not speech, and if the sounds which I make annoy others around me I do not wish to be given medication to silence me unless the noise is extreme and all other measures have been tried.*

*I have lived alone or virtually alone for much of my life and set a high value on silence. Should I need to live in a nursing home I would prefer a quiet room without continuous "entertainment" and with a garden outlook and with the opportunity to be outdoors whenever possible.*

*I prefer to be hospitalised for care when my guardian feels the time to be admitted.*

*If I require long-term care in a facility outside my home I would prefer a location where I can see trees, hills, water and clouds. I would also like to hear birds singing*

*If I require care in a facility outside my home I would prefer to live close to my sister.*

Some respondents provided guidelines for the disposal of their property within their EG forms and indicated the location of financial information.

*If I require long-term care in a nursing home, sell my house to pay for it.*

*Advise my financial planner of my condition so that he or she can make arrangements for my income protection policy to be put into effect.*

*There is money in the ANZ and maybe MyState to pay for it or else sell my block of land in Summers Bay.*

Reflecting some family conflict there were a few forms where directions were given to certain family members.

*There is a letter to be sent to my daughter if she does not return to the truth which explains why she does not inherit after my death.*

*I am the sole parent of two minor children. I would like it known that if I am unable to speak for myself that I would like my guardian to speak on my behalf as to my healthcare needs of my children.*

*Under no circumstances is my step son to have any involvement whatsoever in the management of my financial affairs.*

Others chose to specify the allocation of certain items to family members.

*My three granddaughters are to receive one each of my three rings of their choice. My necklace with green stones insert on a gold chain is to be kept as a family keepsake by my daughter. The brooches given me over time by my sister are to be returned to her*

*All my papers and will, etc are in my file case. I have no debts whatsoever. My house is willed to the WT Society.*

*I would like my guardian to have my car, or if mine is wrecked money for a new one. If home is sold, furniture to be auctioned, smaller items to be decided upon by my guardians and money to go to society.*

Care of pets received some mention in the forms with concern being shown for their ongoing care or humane treatment.

*In the event of my permanent incapacity I request that any animals in my care should receive appropriate and humane arrangements for their ongoing care or welfare, or if necessary due to their age or health that they be euthanised under veterinary supervision*

*To confer my resource library of reference books and literature to the library of the University of Tasmania and to care for the welfare of my domestic animals.*

*Any pets that I own are to stay with me as long as I am able to care for them. If I am not able to care for them, ownership is to transfer to my guardian.*

### **Donate Body to Science**

A small number of individuals specified their desire to donate their body to science

*My body has been gifted to the anatomy department of the University of Tasmania. If not accepted then my organs can be donated.*

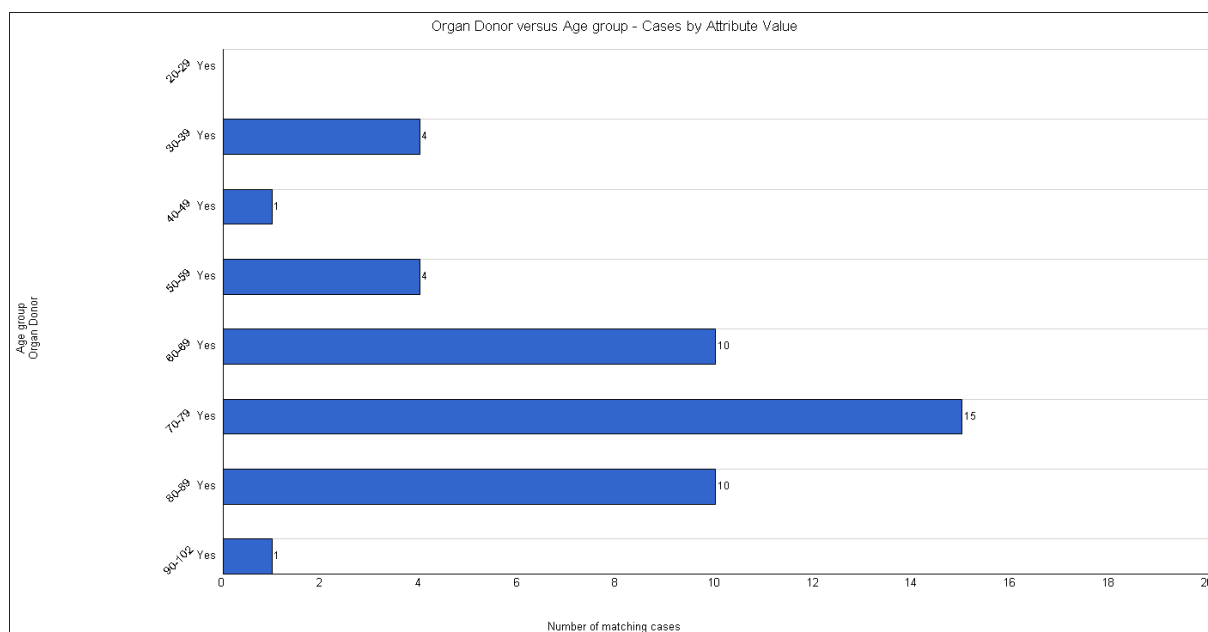
*My body is willed to the University of Tasmania, if they will accept it.*

*I have bequeathed my body to the University of Tasmania.*

### **Request to be an organ donor**

Only a few respondents used the EG form to specify their wish to be an organ donor 12.1% (n = 61) with most those aged 70–79, 29 were female and 18 were male.

**Figure 10: Request to be an organ donor by age group**



Some of the specific statements made included:

*I am a registered organ donor and would like to donate my eyes, liver and any other organs that can be used.*

*Wife is a registered organ donor and wishes to donate her organs and the point for her—does not wish the family to oppose should this time arrive.*

*Husband is not an organ donor.*

*Upon my death body parts may be used for the sole purpose of transplantation to another living person or the condition that such transplantation has a 60% or better chance of improving the quality of life of such said person.*

Only 10 respondents specifically refused organ donation (male = 3, female = 7)

*No body parts to be removed if I am acutely ill and unable to communicate.*

*I definitely do not want to be an organ donor and do not want anyone else's organs transplanted into me.*

*I do not wish any organs to be removed for organ donation, at all.*

### Concern for Guardian

Under this classification we grouped responses that reflected some concern for the guardian and personalised the requests made.

*Have complete confidence in my guardian's decision about my health and welfare and leave it to her if I am not able to, place me in care. All I ask is to be kept clean and comfortable and to be as little trouble as possible to family.*

*When I become unwell I would like my guardian to help me make decisions around health issues. I would like my guardian to manage and coordinate my health care needs at the times I am unwell making any decisions where necessary. Specifically I would like the guardian to:*

- *Determine which health care professionals I consult*
- *Consent to any medication I may need*
- *Withdraw any medication they deem not needed*
- *Help me when I refuse to eat, make decisions about me receiving nourishment and nutrition*
- *Ensure my diabetes is monitored and practices put in place to monitor diabetes*

While few indicated a religion on the EG form there were a number who specified their preferences for attention or non-interference from religious leaders.

### **No Religious Intervention**

*I do not wish any minister of religion to attend to me*

*I do not wish to be attended by a member of a religious faith at any time.*

*I also direct my guardian to ensure that under no circumstances do I want any religious official of any denomination to attend my funeral. Should a service be obligatory I wish that only my wish should she survive me, be present and no speeches or memorials held.*

*I have no religious beliefs and do not want any religious attendants*

### **Request for Religious Leader to Visit**

*I want a priest to give me the last rites*

*I direct my guardian to assume their role and arrange for an elder of Jehovah Witness to attend to me on a regular basis.*

*If there are Quakers who are willing to hold a meeting for worship in my room occasionally, whether or not I appear to be aware of them I should value that.*

### **Euthanasia**

In the EG forms only seven made a specific request regarding euthanasia:

*If in the above mentioned circumstances when euthanasia becomes law I direct that I be euthanised as soon as possible instead of above stated alternatives.*

*If as a result of an accident, mishap, illness, I become a paraplegic or similar, etc and am unable to take care of myself and if the law at that time permits euthanasia, then I direct my guardian to arrange for euthanasia, taking my organ donor status into account.*

*When my quality of life is no longer sustainable I request that I receive assisted voluntary euthanasia when it is legally permitted to do so.*



## Discussion and Conclusions

This discussion will focus on the outcomes of this study based on the three research questions underpinning this examination of enduring guardianships in Tasmania as follows:

*Research Question 1:* What specific directions are documented by persons completing an enduring guardianship form in Tasmania?

*Research Question 2:* What are the demographic characteristics of the populations who appoint guardians under the legislation (age, place of residence, occupation), and the persons they appoint?

*Research Question 3:* Are there any differences between the Respecting Patient Choices and non- Respecting Patient Choices populations?

### ***Research Question 1: What specific directions are documented by persons completing an enduring guardianship form in Tasmania?***

The intent of enduring guardianship forms is to provide directions to the appointed guardian regarding medical and lifestyle decisions. It is noted that a large number of Tasmanians sought to state either verbatim the extract as contained in the *Guardianship and Administration Act 1995* or incorporate into the form the exact wording as provided in the information sheet accompanying the formal enduring guardianship document. The implication of completion of the forms is firstly that the persons appointed as Enduring Guardians (n = 328) are fully aware of the legal intention of the Act and secondly that they implicitly know the wishes of the person that they have been appointed to act for. It is probable that (111/165)67% who only quoted the Act had completed their forms with the assistance of a legal practitioner.

From the demographic data collected [for all %s] 478/502 (95%) had indicated a friend or relative as their choice of enduring guardian and only 8 (14%) had indicated a legal practitioner to act on their behalf.

### ***Palliative Care***

In this study 238/502 (47%) of the forms contained some kind of statement about care at the end of life, and indicated a preference for the deployment of timely and appropriate palliative care. These directions were usually made in general terms, and often in a prescribed format and wording taken from the EG Infosheet pamphlet (see Figure 7, page 14). The onus is therefore on the appointed guardian while the statement is sufficient in detail to indicate that the person does not want to be 'kept alive by extraordinary or overly burdensome treatments' duly indicates palliative care in very general terms and once again leaves the detail to be negotiated between the guardian and the attending health care staff, no indication is provided regarding any other personal likes and dislikes to guide the palliative care requested. A small cohort of persons completing the EG form specified particular conditions and/or circumstances when, in their judgment, active treatment should be withdrawn they included the following:

- Irreversible incontinence
- Loss of mental capacity

- Constant pain and suffering
- Coma as a result of brain damage
- Dementia of any form
- Paraplegia
- Cancer which involves aggressive treatment.

In summary, a majority of persons completing EG forms did not want active treatment in the event of an acute illness that left them unable to communicate and from which they were unlikely to recover. Contrary to this cohort some 8% requested life-prolonging treatment—a fact that could potentially be overlooked given that the majority of persons in Tasmania indicate a wish not to have active treatment.

### ***Life-Prolonging Treatment***

Persons who indicated this direction statement in that the decision to undertake active management was only to commence when deemed medically appropriate and was in their best interest. This direction brings into play discussions and subsequent decisions requiring the appointed guardian to facilitate such a meeting and give direction following deliberation regarding the continuance of treatment or withdrawal of same.

A few individuals had specified the level of medical intervention. The main cohort indicated also Jehovah's Witness as their religion. In summary, wishes indicated the following regarding:

- Non-blood products that are acceptable
- Refusal of blood products and blood transfusion

Full details are described on page 18.

### ***Specific Care Directions***

From all the quantitative data generated from the research the most information came from a very small cohort (4.5%) regarding their personal preferences for the following:

- Personal care
- Choice of long-term care
- Funeral arrangements
- Required family/friends consultation
- Care of pets
- Donation of body to science
- Direction to guardian
- Euthanasia

- Religious intervention

Below is a summary of the above headings regarding personal care directives, the voices of the person making these directions can be found on pages 18 to 24. The clarity of the direction provided by Tasmanians to their appointed guardian/s allows both medical and lifestyle issues to be dealt with in a holistic manner, reflecting attitudes and values that may not be known to an appointed guardian when an EG form is completed without additional specific written directions.

Specific requests giving direction to personal care centred on aspects like access to sunlight, classical and Christian music, allowance to communicate by sounds, choice of long-term care, finding facility close to a spouse/family, and nomination of a specific aged care facility if placement became necessary. Funeral arrangement directions included requests for a specific religious service, a preference for cremation, location of funeral service and directive regarding scattering of ashes, cost-effective funeral arrangements and type of funeral required.

Within the directions regarding personal care, some individuals requested their guardians to consult with their family and friends before deciding the care that was given to them.

Music and other requests and thus direction to the guardian during the last days of life demonstrated a plurality of values that would be hoped could be incorporated into the person's final care. Given that the majority of persons who completed the EG forms were in the older age bracket it is not surprising that classical music rated highly along with indications about the ambient temperature that a person's enjoyed and repeated requests for access to fresh air.

The amount, duration and naming of the person the individual would like to have visit gave a strong indication that this was an important aspect of a person's wishes, especially as they reached a stage of receiving end of life care. Some Tasmanians indicated a 'more the merrier' approach to visitors, while others indicated a restricted visitor stance.

While out of the ambit of the directions that can legally be incorporated into an Enduring Guardianship form some Tasmanians took the opportunity to give directions to events that would occur following death, some of these have been already cited, such as funeral arrangements. Such directions can help to bridge the gap between death and the reading of the will. Some respondents provided guidelines for disposal of property, wishes regarding the ongoing support of children and allocation of certain items to family members, although these matters are outside the scope of ACDs as they relate to matters after death, at which point the guardian's powers lapse.

The ongoing care of animals also featured in some person's directions as they became less able to render care to their pets. Some wished their pets to be transferred to the care of their appointed guardian while others directed animals to be euthanized in certain circumstances.

The theme of euthanasia continues regarding the persons completing EG forms in Tasmania with a very small percentage (1.5%) requesting euthanasia if it became available in Tasmania. One person indicated that this would be a part of palliative care if this was legally possible.

Very specific directions to appointed guardian featured in some forms regarding aged care placement, health professionals to be consulted, medication to be used, ongoing management of diabetes and ongoing nourishment if the person refused to eat. This level of specificity could be viewed as giving clarity to end of life directions however it also places an increased

amount of responsibility on the appointed guardian to negotiate these wishes with health care professionals.

The penultimate specific direction centred around religious intervention with some persons clearly indicating at no time did they want attendance by a minister of religion, and others indicating a strong desire to have a minister visit on a regular basis.

The remaining specific directions focus on the desires to donate one's body to science or to donate organs following death. Directions regarding donation to science was straightforward and probably has been interpreted as an aide-de-memoir for the guardian and attending health care professional.

Finally regarding organ donation, persons in Tasmania directed appointed guardians either to facilitate the process if possible (12.1%) or refused organ donation (2%). As stated previously in most circumstances such direction would not be able to be enacted by the appointed guardian as the events such as organ donation would occur following death and therefore the guardian's legal responsibilities and direction would be null and void. An exception to this statement could possibly arise in the future in Tasmania considers the introduction of organ donation following cardiac death. In such circumstances it would appear that a guardian could indicate that the persons wished to be an organ donor and therefore direct in the appropriate circumstances that this type of organ donation proceed.

It is of interest to note that when this topic/situation was raised at a national jurisdictional meeting of public guardians this issue had not been considered and in light of recent NHMRC publication it is a potential area that warrants attention.

***Research Question 2: What are the demographic characteristics of the populations who appoint guardians under the legislation (age, place of residence, occupation), and the persons they appoint?***

Based on the agreed 1 in 20 sample a total of 502 Enduring Guardianship forms were analysed. These data from the analysis is presented under the following headings and reflects the research questions pertaining to the demographic data collected:

- Age
- Place of residence
- Occupation
- Persons appointed

The calculated age of persons completing the EG forms ranged from 22–92 years. The following data set consisting of the mean, median and mode has been produced as a result of this research and indicate the measures of central tendency as these three measures focus on where this data is centred or clustered.

MEAN = 64 years of age, this assists in predicting future results however does not take into consideration extreme values in the data set.

MEDIAN = 65 years of age, this indicates the middle value in this research data set and is not affected by extreme data values.

MODE = 79 years of age, this was the most common age of the persons who had completed an enduring guardianship form.

Details of the age distribution can be found in Figure 2. From the 502 persons within the sample, 298 were female, 176 males and there were 28 forms where gender was not indicated.

To assist in the identification of place of residence each individual postcode was recorded at the time of data entry and then aligned with the local Tasmanian government area. As might be expected, the greatest concentration of persons completing EG forms was centred around the major population centres of Hobart, Launceston and Burnie/Devonport.

Given the high proportion of persons completing these forms were over the age of 65 the description of 'retired'/'retiree' is predictable. It is of note that EG forms can be legally completed by any competent person over the age of 18, however the large proportion are not undertaken until individuals are retired.

The vast majority appointed a friend or relative. This would seem to be congruent as the person who is appointed guardian acts on behalf of the persons and therefore, by implication, needs to know that person's wishes and desires regarding medical and lifestyle decisions.

No significant difference was apparent between the appointment of friends and relatives as guardians when compared to the gender of persons completing EG forms and the same result was shown irrespective of whether the person completed the form with or without legal assistance.

### ***Research Question 3: Are there any differences between the Respecting Patient Choices and non- Respecting Patient Choices populations?***

Investigation of this topic was limited due to the very small number of EG forms completed as part of the project and lodged with the Guardianship Board.

Records held by Royal Hobart Hospital indicated the some 341 persons have had some initial discussion regarding the RPC version of the form. This only translated to 10 completed forms being registered with the Guardianship Board. A critical review of these forms indicated that they had been fully completed at the behest of a medical consultant wanting to put into place a mechanism that allows a patient to legally express their views that they wanted no more active treatment for a terminal illness.

The driving force in all situations that led to the completion of the RPC forms was the availability within the hospital of a RPC consultant who was prepared to follow through with the person and family wishing to completed an EG form. This process often required a number of visits to ensure completion within the hospital context and without this commitment from the RPC consultant and the desire of the patient and family to complete same the vast majority of these forms were never completed and registered with the Guardianship Board.

The above information was derived from the Social Worker and administrative staff monitoring the use of these forms using a data recording sheet within the hospital context. This RPC Consultant Activity Monitoring Sheet registers initial discussion, written material provided and if an Enduring Guardianship form was completed and forwarded to both the medical records section and the Guardianship Board. Within the context of this study only three forms were indentified in the 1 in 20 audit of the completed forms held by the

Guardianship Board. Persons completing these forms had nominated Option 2 on the RPC form, which as reported earlier is different from the standard guardianship form in that it provides persons with some options regarding their directions to appoint a guardian rather than having to complete a blank form.

*If I am acutely ill or unable to communicate responsively with my family or friends, and it is reasonably certain that I will not recover, I want to be allowed to die naturally and be cared for with respect for my dignity. I do not want to be kept alive by extraordinary or overly burdensome treatments that might be used to prolong my life. If any of these treatments have been started, I request that they be discontinued. However I do want Palliative Care that includes medications, and other treatments to alleviate suffering and keep me comfortable, and to be offered something to eat or drink.*

### **Conclusions and recommendations (to be developed in any future papers)**

- The fact that 2% of the Tasmanian population has availed itself of the provisions of the Act in its 15 years of operation sets a benchmark of whole of community uptake for substitute decision-making instruments in Australia, and possibly internationally as well.
- Persons who appoint enduring guardians in Tasmania are predominantly older retired citizens whose single major identified concern is palliative care at the end of life.
- Persons completing EG forms should therefore be encouraged to write an advance care directive (ACD) and attach it to their form.
- This ACD format should be in the prototype format developed by the Palliative Care Clinical Network Working Party and the Clinical Ethics Committee of the Royal Hobart Hospital (attached) . This focuses on the end of life, but can contain anything the person wishes to specify for their care when they lack capacity. It emphasises personal beliefs and values, and unacceptable outcome states that the person wishes to avoid. This is in line with draft guidelines under development for AHMAC (Ashby personal communication).
- Younger persons should be encouraged to appoint EGs and complete ACDs.
- EG form directions, including those that specify aspects of personal care, should be actively sought and incorporated into a care plan if the person is admitted into hospital or aged care facility.
- Clarification needs to be sought regarding the appropriateness of incorporating directions for after death. Undoubtedly, there is community interest in doing this in the EG form, even though guardianship lapses at the moment of death. This particularly affects the inclusion of requests about organ donation in EG directions, especially in situations where the appointed guardian is not the senior 'next of kin'.
- EG is a legal appointment and hence professional legal assistance is commonly sought to complete the form, and lawyers may have a significant role in initiating EG appointment. Legal wording is often copied out verbatim into the form.

- Lawyers therefore might benefit from more information about the process of advance care planning, and be important initiators and conduits back to the person's health care professionals for assistance in these matters.
- Future promotional approaches need to project a less legalistic emphasis, and locate EG appointment in a process of advance care planning.

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