Prevalence of advance care planning documents in the community
Overview

- 2 ARC-funded research projects
  - Families and Generational Asset Transfers: Making and Challenging Wills in Contemporary Australia
  - Enhancing Community Knowledge and Engagement with Law at the End of Life
- Wider focus but opportunity to include prevalence of advance care planning documents in community
- Disclaimer: only early results in second study so provisional and not finalised (and so not public)
- Limited discussion of method
Study 1 – Families and Generational Asset Transfers: Making and Challenging Wills in Contemporary Australia
Research team

• Chief Investigators:
  – A/Prof Cheryl Tilse
  – Prof Jill Wilson
  – Prof Ben White
  – Prof Linda Rosenman
  – With Dr Tanya Strub and Dr Rachel Feeney

• Research partners
  – Seven public trustee organisations across Australia
Project overview

• Objectives: who does and does not make a will and why, and how do people distribute their assets, as well as the nature of will contests in Australia and factors associated with their occurrence and resolution

• Multi-method research included a national prevalence study of will-making which included questions about financial enduring powers of attorney and advance directives
Method

• Survey via computer assisted telephone interview
  – National sample over 18, representative of age and state (oversampling in small jurisdictions)
• Whether had ‘a document where you make decisions about what sort of medical treatment you want or don’t want. In [State], this would be called [name of main advance directive, e.g. refusal of treatment certificate]’
Key results

- n=2405 (response rate 33%)
- 14% nationally had advance directive (cf 30% financial EPA; 59% will)
  - SA and Queensland more likely; WA less likely
- Preparation of other documents predict advance directive
- Only demographic associated with advance directive was relationship status
  - Single or not in legally recognised relationship (1.7 more likely than if married)
Key implications

• Lower rate of advance directives than other documents
• ‘Planners’ are more likely to complete an advance directives
• Those outside relationship may be inclined to have advance directive without spouse as substitute decision-maker
Conclusions and residual questions

• More research needed generally
• Limited utility of demographic predictors – experiences more important? Some research but more needed about their role
• Single question, limitation of respondents’ knowledge and recollection of their advance care planning
  – More research needed

https://eprints.qut.edu.au/75940/
Study 2 – Enhancing Community Knowledge and Engagement with Law at the End of Life
Research team

- Prof Ben White, Australian Centre for Health Law Research, QUT
- Prof Lindy Willmott, Australian Centre for Health Law Research, QUT
- A/Prof Cheryl Tilse, School of Nursing, Midwifery and Social Work, UQ
- Prof Jill Wilson, School of Nursing, Midwifery and Social Work, UQ
- Dr Deborah Lawson, Cancer Council Victoria
- Prof Jeff Dunn, CEO, Cancer Council Queensland
- Ms Angela Pearce, Cancer Council New South Wales
- Prof Joanne Aitken, Cancer Council Queensland
- With Dr Rachel Feeney and Michele Ferguson
- Research partners: Cancer Councils Victoria, NSW and Queensland
Project overview

- **Objectives:** determine level of community knowledge of relevant law, sources of knowledge, and community, patient and family engagement with the law in end of life decision-making
  - Victoria, New South Wales, Queensland

- **Multi-method research** included a community survey of knowledge of end of life law as well as experiences in decision-making
Method

• Survey via computer assisted telephone interview
• Dual-frame sample (aged over 18) using random digit dialling within Victoria, New South Wales and Queensland
  – 40% landline calls, 60% mobile calls
• Quota sampling based on population size by location, gender and age, with oversampling in smaller jurisdictions (Victoria and Queensland)
Method

• For advance care planning
  – First explained two different types of documents
  – One question about first document – making your own decisions about medical treatment
    • If queried: ‘In [State], this is usually called [document]’
  – Likewise for separate question about second document – appointing another to make health decisions
Early results: prevalence

• Discussion of early results; not yet publicly available
End of Life Law in Australia provides accurate, practical and relevant information to assist you in navigating the challenging legal issues that can arise with end of life decision-making.

This website is an initiative of the Australian Centre for Health Law Research. It is designed to be used by patients, families, health and legal practitioners, the media, policymakers and the broader community to access information about Australian laws relating to death, dying and decision-making at the end of life. These laws are very complex, particularly in Australia where the law differs between States and Territories, and where areas of uncertainty about the law exist. This website provides you with a broad introduction to these laws. It can also help you stay up to date with Recent Developments in the end of life area.

How to use this website
You can select a topic to explore a legal issue, and where the law differs between States and Territories, you can select the webpage which explains the law in a particular jurisdiction. On this website there is also:

- A Legal Overview which outlines fundamental concepts relating to the law at end of life in Australia.
- A Glossary of health law terms used throughout this website.
- Links to external resources you may find useful.

We hope End of Life Law in Australia will provide you with valuable information which enhances both your understanding of the law at end of life, and your knowledge about your legal rights and responsibilities.

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End of Life Law in Australia website
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