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**Dementia Training for Legal Practitioners: Results from a pilot evaluation study and implications for building dementia capability in the legal profession**

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### **Abstract**

A growing number of Australians live with, or are at risk for, dementia. A diagnosis is a common prompt for people to seek legal advice to plan for their future. It is important that lawyers are equipped with up-to-date knowledge and resources to work effectively with clients in these circumstances. This article reports on a research project that involved the delivery of dementia-focused online training for lawyers and the piloting of an evaluation strategy. Legal practitioners in two Australian states were recruited for this pilot study. Wills/estates and elder law were common areas of practice. Data were collected through in-course activities (eg, polls, discussion posts) and surveys administered at course completion and at four-month follow-up. The findings were positive both in terms of the suitability of the training and the feasibility of the evaluation model. This study also contributes insights into the role of the legal profession and lawyering practices in advancing the objectives of Australia's National Dementia Action Plan.

### **Key words**

Legal profession; law; dementia; capacity; continuing professional education; online training; evaluation; workforce

## 1. Introduction

The Australian population is ageing<sup>1</sup> and more people are living longer with chronic diseases, including conditions that affect their cognitive abilities. Dementia is of particular concern as a major cause of ill health for older Australians. Over 480,000 people have a dementia diagnosis and most – around 70 percent – live at home in their communities.<sup>2</sup> Other conditions, including mild cognitive impairment, hypertension, obesity and depression are risk factors for developing dementia and many of these are of increasing prevalence.<sup>3</sup> In addition to the number of people living with a dementia diagnosis, around 1.6 million people in Australia are carers of someone with dementia.

The Australian federal, state and territorial governments are collaborating on a *National Dementia Action Plan 2023-2033*.<sup>4</sup> Objectives of the Plan include reducing stigma and discrimination surrounding dementia, improving dementia capability in workforces, and ensuring that people with dementia and their carers receive adequate post-diagnostic support. In broad terms, dementia capability refers to the knowledge, skills, attitudes and behaviours required to meet the needs of and work effectively with people living with dementia.<sup>5</sup> Dementia capability is important not only for the health and aged care sectors,<sup>6</sup> but also for the legal sector in order to build dementia-friendly communities that promote ‘dignity, empowerment, engagement, and autonomy’ for people with dementia.<sup>7</sup> A diagnosis of dementia or other progressive, life-limiting condition is a common prompt for people to seek legal advice to organise their affairs and put plans in place for future financial, health and lifestyle decisions.<sup>8</sup> Australian clinical practice guidelines for the care of people with dementia recognise the importance of legal advice following a diagnosis,

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<sup>1</sup> Australian Institute of Health and Welfare, ‘Older Australians, Demographic Profile’, *Australian Institute of Health and Welfare* (2021) <<https://www.aihw.gov.au/reports/older-people/older-australians/contents/demographic-profile>>.

<sup>2</sup> Dementia Australia, ‘Dementia Statistics - Key Facts and Statistics’ (January 2022) <<https://www.dementia.org.au/statistics>>.

<sup>3</sup> Gill Livingston et al, ‘Dementia Prevention, Intervention, and Care: 2020 Report of the Lancet Commission’ (2020) 396(10248) *Lancet* 413.

<sup>4</sup> Australian Government, Department of Health and Aged Care, *National Dementia Action Plan - Public Consultation Paper* (November 2022) 13 <<https://consultations.health.gov.au/aged-care-division/ndap-public-consultation/>>.

<sup>5</sup> Shih-Yin Lin and Frances Marcus Lewis, ‘Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future’ (2015) 55(2) *The Gerontologist* 237.

<sup>6</sup> Soo Borson and Joshua Chodosh, ‘Developing Dementia-Capable Health Care Systems: A 12-Step Program’ (2014) 30(3) *Clinics in Geriatric Medicine* 395; Soo Borson, ‘Dementia-Capable Healthcare: One Step Closer’ (2019) 67(3) *Journal of the American Geriatrics Society* 419.

<sup>7</sup> Catherine A Hebert and Kezia Scales, ‘Dementia Friendly Initiatives: A State of the Science Review’ (2019) 18(5) *Dementia* 1858.

<sup>8</sup> Jamie Bryant et al, ‘Experiences and Preferences for Advance Care Planning Following a Diagnosis of Dementia: Findings from a Cross-Sectional Survey of Carers’ (2023) 18(6) *PLoS ONE* e0286261; Nola M Ries et al, ‘How Do Lawyers Assist Their Clients With Advance Care Planning? Findings From a Cross-Sectional Survey of Lawyers in Alberta’ (2018) 55(3) *Alberta Law Review* 683; Karen A Sullivan et al, ‘Public Awareness of Legal Decision-Making Capacity and Planning Instruments in Dementia: Implications for Health Care Practitioners’ (2023) 30(4) *Psychiatry, Psychology and Law* 565.

especially for advance planning purposes.<sup>9</sup> National guidelines for Memory and Cognition Clinics recommend that clinics refer clients to a range of services with ‘dementia expertise’, including legal services.<sup>10</sup>

Yet dementia expertise within the legal profession cannot be assumed. Available literature reveals gaps in lawyers’ knowledge about dementia<sup>11</sup> and deficiencies in their practices when working with clients who experience changes in their cognitive abilities. These deficiencies include: poor processes for assessing client capacity; unfamiliarity with strategies to support decision-making; use of stigmatising language about dementia; inadequate advice about legal rights for planning ahead; preparation of advance planning documents that do not meet best practice guidance; and unwittingly facilitating the abuse of people with dementia by their legal representatives.<sup>12</sup>

Training for legal practitioners and law students has been recommended to foster dementia capability in the profession, however, there is little reported research on training initiatives, curricula and evaluation.<sup>13</sup> As a start, American elder law expert James Pietsch proposed several core competencies for lawyers who advise clients with dementia: advising on advance planning for financial and health matters; drafting legal documents to appoint substitute decision-makers; and working effectively with other professionals and carers.<sup>14</sup> This article reports on a research project that involved the delivery of dementia-focused online training for legal practitioners and the piloting of an evaluation strategy. Through these activities, the project elicited insights into practitioners’ views concerning dementia capability for the legal profession and contributes to evidence on current practices, perceived challenges and opportunities for improving legal service delivery to meet the needs of clients with or at risk for dementia.

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<sup>9</sup> Cognitive Decline Partnership Centre, *Clinical Practice Guidelines and Principles of Care for People with Dementia* (Guideline Adaptation Committee, 2016).

<sup>10</sup> Australian Dementia Network, ‘ADNeT Memory and Cognition Clinic Guidelines: National Service Guidelines for Specialised Dementia and Cognitive Decline Assessment Services in Australia’ (2021) 63, 67 <<https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/adnet-memory-and-cognition-clinic-guidelines/>>.

<sup>11</sup> Tacara Soones et al, ‘“My Older Clients Fall Through Every Crack in the System”: Geriatrics Knowledge of Legal Professionals’ (2014) 62(4) *Journal of the American Geriatrics Society* 734.

<sup>12</sup> Nola M Ries, ‘Elder Abuse and Lawyers’ Ethical Responsibilities: Incorporating Screening into Practice’ (2018) 21(1) *Legal Ethics* 23; Lise Barry, ‘“He Was Wearing Street Clothes, Not Pyjamas”: Common Mistakes in Lawyers’ Assessment of Legal Capacity for Vulnerable Older Clients’ (2018) 21(1) *Legal Ethics* 3; Craig Sinclair et al, ‘Professionals’ Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia:’ (2021) 20(1) *Dementia* 84; Perla Werner and Israel Doron, ‘Alzheimer’s Disease and the Law: Positive and Negative Consequences of Structural Stigma and Labeling in the Legal System’ (2017) 21(11) *Aging & Mental Health* 1206.

<sup>13</sup> David M Godfrey, ‘Developing Dementia-Friendly Communities and Dementia-Capable Professionals’ (2015) 36(3) *Bifocal* 5; Nola M Ries, Briony Johnston and Shaun McCarthy, ‘Legal Education and the Ageing Population: Building Student Knowledge and Skills Through Experiential Learning in Collaboration with Community Organisations’ (2016) 37(1) *Adelaide Law Review* 495; Perla Werner and Israel Doron, ‘The Legal System and Alzheimer’s Disease: Social Workers and Lawyers’ Perceptions and Experiences’ (2016) 59(6) *Journal of Gerontological Social Work* 478.

<sup>14</sup> James H Pietsch, ‘Becoming a “Dementia-Capable” Attorney - Representing Individuals with Dementia’ (2015) 19(13) *Hawaii Bar Review* 1.

## 2. Method

### 2.1. *Development of dementia-focused online training courses for lawyers*

The following summary of the training addresses the criteria in the TIDieR (Template for Intervention Description and Replication) checklist.<sup>15</sup> This reporting guideline ensures that an intervention is described in sufficient detail to allow others to understand and replicate it.

#### *Brief Name*

Three online training courses were developed for legal professionals: (1) Understanding Dementia: Facts & Foundations; (2) Planning Ahead: Focus on Advance Care Planning (ACP); and (3) Elder Abuse: Strategies for Prevention. The first two courses were included in the pilot evaluation project. The third course was excluded due to budget limitations.

#### *Rationale*

The courses were based on the concept of a 'dementia-capable' legal practitioner, which encompasses attributes in four areas: knowledge; professionalism; legal rights and risks; and capacity.<sup>16</sup> On completion of Understanding Dementia: Facts & Foundations, participants were expected to be able to: identify the attributes of dementia-capable legal practitioners; evaluate their own knowledge and skills; explain the 10 Principles of Dignity in Care<sup>17</sup> for people with dementia and their relevance to legal practice; describe common types of dementia and identify dementia risk factors; use respectful language; and recognise and support the needs of diverse populations with dementia, including people with younger onset dementia, Indigenous people and people from culturally and linguistically diverse (CALD) backgrounds. On completion of Planning Ahead: Focus on Advance Care Planning (ACP), participants were expected to be able to: explain features and benefits of planning ahead; implement strategies to increase uptake and quality of ACP among clients with dementia; explain principles of decision-making capacity; respond appropriately when client capacity is in question; and use strategies to support decision-making for clients with dementia.

The course content and intended outcomes were based on a combination of expert and evidence-based recommendations and resources. These included national practice guidelines for the care of people with dementia, a national framework for advance care planning documents, as well as practice guidelines from legal professional bodies and resources from peak bodies such as Dementia Australia and Advance Care Planning Australia.<sup>18</sup>

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<sup>15</sup> Tammy C Hoffman et al, 'Better Reporting of Interventions: Template for Intervention Description and Replication (TIDieR) Checklist and Guide' (2014) 348 *BMJ* g1687.

<sup>16</sup> Pietsch (n 14).

<sup>17</sup> Guideline Adaptation Committee (n 9).

<sup>18</sup> Ibid; Australian Government, Department of Health, *National Framework for Advance Care Planning Documents* (2021) 36 <<https://www.health.gov.au/sites/default/files/documents/2021/06/national->

### *Mode of Delivery, Materials & Procedures*

Participants individually accessed the courses on the Canvas online learning system. The courses incorporated the features of effective web-based training, including active and reflective learning strategies, peer interaction, and learning that can be implemented into practice.<sup>19</sup> Participants worked through the courses at their own pace and completed self-assessment questionnaires to reflect on their current knowledge and attitudes, answered quizzes to receive immediate feedback on their learning, and compiled their own 'Dementia-Capable Toolkit' by downloading resources as prompted throughout the courses. Interactive features summarised current research, invited participants to share experiences with peers through discussion posts, and audio and video clips provided insights from dementia advocates and medical and legal practitioners. The courses were designed to meet lawyers' continuing professional development (CPD) requirements and, at the end of each course, participants were able to request a certificate of completion.<sup>20</sup> Participants were asked to complete an end-of-course survey and were sent a follow-up survey four months after completing the courses (explained further below).

### *Provider*

The lead author, an expert in health and elder law, developed the courses with the support of a university online learning design team. All online tools for the project were tested internally for usability.

### *Location & Duration*

Participants completed the online courses remotely from the location of their choice. Each course was designed for completion in around two hours of self-directed study.

### *Tailoring & Modifications*

The intervention was not personalised, nor was it modified during the course of the study.

### *Delivered as Planned*

The intervention was delivered as planned, with participants engaging in the online courses and completing the end of course and follow-up surveys at the designated times.

## **2.2. Participants**

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framework-for-advance-care-planning-documents.pdf>; The Law Society of New South Wales, 'When a Client's Capacity is in Doubt: A Practical Guide for Solicitors' (2016).

<sup>19</sup> Anne Moehead et al, 'A Web-Based Dementia Education Program and Its Application to an Australian Web-Based Dementia Care Competency and Training Network: Integrative Systematic Review' (2020) 22(1) *Journal of Medical Internet Research* e16808. These features align with adult learning principles that are endorsed for continuing legal education: see eg, Barbara A Bichelmeyer, 'Best Practices in Adult Education and E-Learning: Leverage Points for Quality and Impact of CLE' (2006) 40(2) *Valparaiso University Law Review* 509.

<sup>20</sup> For example, in New South Wales, Rule 6.1 of the *Legal Profession Uniform Continuing Professional Development (Solicitors) Rules 2015* under the *Legal Profession Uniform Law (NSW)* requires all practitioners to complete at least 10 CPD points each year. The Rules requires a minimum of 1 CPD point in designated areas, including ethics and professional responsibility and professional skills, which are focus areas in the dementia courses.

To gain insights from practitioners with relevant experience and interests, participants were sought from three different groups: (1) lawyers involved in Law Society committees with a focus on elder law; (2) lawyers in the community legal sector, who provide low- or no-cost advice and supports for older adults; and (3) generalist practitioners in regional areas who serve older clients and who may benefit from the accessibility of online training. Up to ten practitioners in each category was anticipated to provide adequate data for pilot purposes, similar to sample sizes in other pilots of dementia education initiatives.<sup>21</sup>

### **2.3. Recruitment**

E-mail invitations were sent to identified practitioners and notices regarding the online courses were distributed to relevant organisations and through social media channels (e.g., Law Societies; seniors rights services; Legal Aid services). Interested individuals contacted a member of the study team to receive a Participant Information Sheet and Consent Form. Participants who chose to take part gave written informed consent. Eligibility was confirmed by locating the participant's publicly available online profile which indicated that they were currently in legal practice. Participants were enrolled in the courses by a staff member in the online learning team at the authors' institution. This staff member emailed log-in information to the participants so they could access the two courses. Enrolments occurred between December 2021 and March 2022.

The course fee was covered by grant funding for the pilot evaluation so participants were able to access the courses free of charge. The project was ethically approved by the University of Technology Sydney Human Research Ethics Committee. Participants gave written informed consent to participate.

### **2.4. Evaluation design**

The evaluation was structured using the four-level Kirkpatrick Framework:<sup>22</sup> Level 1) Reaction, What is participants' reaction to and satisfaction with the training?; Level 2) Learning, To what extent do participants gain desired knowledge, skills and attitudes through the training?; Level 3) Behaviour, To what extent do participants apply the training in their professional practice?; and Level 4) Results, To what extent do desired outcomes occur in relation to client care? The measures for the pilot evaluation focused on outcomes

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<sup>21</sup> See eg, Julia Lühnen, Ingrid Mühlhauser and Tanja Richter, 'Informed Decision-Making with and for People with Dementia: Developing and Pilot Testing an Education Program for Legal Representatives (PRODECIDE)' (2019) 18(6) *Dementia* 2303, which involved 12 participants who were professionals serving as legal representatives; Shelley Cobbett et al, 'On-Line Dementia Education: Cultivating Nursing Students' Comprehension, Application and Critical Thinking Skills' (2016) 39(1) *Perspectives* 7, which involved 23 nursing students in the intervention group that completed online dementia training; and Joy W Douglas, Christine Ferguson & Beth Nolan, 'The Feasibility and Acceptability of a Dementia Care Training Program for Registered Dietitian Nutritionists' (2022) *Gerontology & Geriatrics Education*, DOI: 10.1080/02701960.2022.2105841, which involved 20 dietetics professionals in a training and follow-up survey.

<sup>22</sup> 'The Kirkpatrick Model', *Kirkpatrick Partners, LLC*. <<https://www.kirkpatrickpartners.com/the-kirkpatrick-model/>>.

at Levels 1 to 3. Participants' views on measuring Level 4 results were explored to inform further research as these outcomes are often missing in evaluations of training.<sup>23</sup>

## **2.5. Data collection and analysis**

Data were collected in three stages, modelled on approaches used to evaluate online dementia training for health professionals.<sup>24</sup> Reminders were sent at all stages to encourage completion of the activities.

**Stage 1) In-course data collection:** Data were collected anonymously through questionnaires, polls and discussion posts that were part of the online learning activities. The first short course: measured baseline knowledge of dementia using questions from the Dementia Knowledge Assessment Scale (DKAS);<sup>25</sup> asked participants to identify the top three of the 10 Principles of Dignity in Care for people with dementia most relevant to legal practice and explain their choices; invited participants to share examples of language used to portray dementia within legal/justice systems and assess language against Dementia Australia guidelines; and elicited participants' views on the role of lawyers and law reform in reducing risk factors for dementia.

The second short course: elicited participants' views on the features of and barriers to effective advance planning; presented common critiques of advance care planning (e.g., advance care directives written in legalistic jargon) and invited suggestions for improving practices; and asked participants to reflect on and share their practices for capacity assessments and supporting clients who have conditions that may affect capacity.

**Stage 2) End-of-course survey:** Participants completed a short online survey to provide reactions to the course content and indicate their satisfaction with the training. A link to the Qualtrics survey was embedded at the end of the online course. The ten survey questions included Likert scales and free-text comment boxes to elaborate on their responses. Survey questions included: the extent to which the course content was appropriate and relevant to participants' professional practice; participants' confidence in their ability to apply information and resources in their practice; reflection on the concept and attributes of a 'dementia-capable' legal practitioner; and the perceived value of compiling their own Dementia-Capable Toolkit. Survey questions also explored the feasibility of measuring behaviour and practice changes and improvements in client care, including feasibility of: follow-up contact with clients to seek their views on the extent to which lawyers demonstrated 'dementia-capable' attributes; and audits of advance care planning

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<sup>23</sup> Claire A Surr and Cara Gates, 'What Works in Delivering Dementia Education or Training to Hospital Staff? A Critical Synthesis of the Evidence' (2017) 75 *International Journal of Nursing Studies* 172.

<sup>24</sup> K DeSouza, SW Pit and A Moehead, 'Translating Facilitated Multimodal Online Learning into Effective Person-Centred Practice for the Person Living with Dementia among Health Care Staff in Australia: An Observational Study' (2020) 20(1) *BMC Geriatrics* 33.

<sup>25</sup> Michael J Annear et al, 'Dementia Knowledge Assessment Scale (DKAS): Confirmatory Factor Analysis and Comparative Subscale Scores among an International Cohort' (2017) 17(1) *BMC Geriatrics* 168.



documents against best practice recommendations.<sup>26</sup> Demographic details were also collected.

**Stage 3) Follow-up survey:** Participants were invited to complete a short online survey four months after completing the training. The Qualtrics survey link was provided by email. The eight survey questions used Likert ratings to elicit the extent to which participants applied course knowledge and skills in practice and provided free-text comment boxes for participants to give examples or elaborate on their responses. It also re-administered the DKAS items. A four-month period was chosen to provide adequate time for practitioners to apply the course learning and ensured completion of data collection within the grant funding timeline.

Survey responses were analysed using descriptive statistics. Content in discussion posts and open-text comment boxes was analysed qualitatively. A thematic analysis was undertaken using course topic areas as the framework for organising the data. Illustrative quotations were selected to highlight key points and patterns. Data were collected anonymously.

### 3. Results

Twenty-eight participants enrolled in the courses and 20 (71%) engaged with the course materials.<sup>27</sup> Of these, three-quarters (n=15) registered their completion to receive a certificate, which could be used as documentation in support of practitioners' annual CPD reporting. The remaining participants recorded activity in the courses but did not seek a completion certificate. No activity was recorded for eight participants. Some of these participants had to withdraw from the evaluation project due to COVID, work pressures and unexpected family circumstances.

#### 3.1. Demographics

Almost three-quarters (72%) of participants were female. Most participants (83%) reported they were between 30 and 49 years of age. Over half (55%) of participants had 10 years or more of legal practice experience, while 28% were early career professionals with up to four years of practice experience. Most participants worked in small to mid-sized organisations; 55% worked in a small organisation of between two and nine lawyers and 33% worked in organisations with 10-49 lawyers. Two-thirds (67%) of participants were working in New South Wales at the time of completing the course, with the remaining participants working in Victoria. There was a mix of metropolitan (55%) and regional (45%) practitioners. The

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<sup>26</sup> Australian Government, Department of Health, *National Framework for Advance Care Planning Documents* (2021) 36 <<https://www.health.gov.au/sites/default/files/documents/2021/06/national-framework-for-advance-care-planning-documents.pdf>>.

<sup>27</sup> By comparison, an online dementia course for health professionals (international medical graduates and practice nurses) had 33 people consent to participate; 27 (82%) completed the online course and six either withdrew or did not complete: see Michael W Bentley et al, 'Behavioural Change in Primary Care Professionals Undertaking Online Education in Dementia Care in General Practice' (2019) 25(3) *Australian Journal of Primary Health* 244.

most commonly reported fields of legal practice were Elder Law/Seniors Law (44%) and Wills/Estates (39%).<sup>28</sup> Table 1 in the Appendix provides full demographic data.

### **3.2. End of course feedback**

The end-of-course survey was completed by 18 participants and the results are detailed in Tables 2 to 4 in the Appendix. When asked about their overall level of satisfaction with the course, 89% of participants reported they were extremely or very satisfied. All participants agreed or strongly agreed the content of the courses was useful and relevant for legal practitioners. Nearly all participants reported the courses contained new information and resources they were not previously familiar with. The concept of a 'dementia-capable' legal practitioner made sense to all participants as a way to describe relevant knowledge and skills for lawyers and all but one reported they felt confident they would be able to implement the course content into their legal practice.

In regard to the online platform, most participants (94%) agreed or strongly agreed the courses were easy to navigate. They found the links to resources and further readings to be the most useful features, followed by the opportunity to contribute to comment boxes and discussion posts where views and experiences could be shared among participants.

Participants valued the "good mix of material, including journal articles, videos, and useful websites and summaries" (Participant 9), the "easy to follow resources that will be useful to give to clients" (Participant 8) and the inclusion of medical and client/consumer perspectives in the courses (Participant 4). When asked to offer suggestions for improving the courses, several participants recommended further content on the experiences of diverse populations, including Aboriginal and Torres Strait Islander people and people from CALD backgrounds, and incorporating more expert insights in brief audio-visual clips. Additional hypothetical client scenarios were also recommended "so that less experienced lawyers can participate more easily" (Participant 17).

All but one participant responded to the prompts to create their own Dementia-Capable Toolkit as they worked through the course content. The majority (61%) of participants reported they had downloaded and saved resources from the course as well as searching for and saving additional resources when they were prompted to do so. One participant commented: "I have collated a dementia toolkit and feel that I can put what I have learnt into practice. Importantly, I am excited about sharing my knowledge" (Participant 16).

The following quotations illustrate views on the benefits of dementia-related training for lawyers:

"It's important to be aware of the ... effects of dementia so that a practitioner can properly assist a client and fulfill their role without making incorrect assumptions about a dementia diagnosis." (Participant 1)

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<sup>28</sup> Three participants selected the option of 'Other' for this question. These other areas included: "Provide advice and deal with matters re victims of crime, property law, guardianship, NDIS, personal injury, disability, aged care, admin law"; "Disability, Personal Injury, Medical Negligence, No-fault compensation, NDIS, Aged Care"; and "Trust and Estate practitioner, succession and legal planning."

“... the concept [of a dementia-capable legal practitioner] is very important in recognising the skills necessary to provide legal advice to people with dementia. Further, this will provide a basis for practitioners to lead reforms in this area, whether by improvements in law, collaborating with health professionals and educating the community.” (Participant 16)

“A heightened understanding of dementia [and] recognition of characteristics I need to demonstrate in my work. An understanding of the wave of issues which are going to confront legal practitioners and the community generally as our community ages.” (Participant 18)

### **3.3. *Four-month follow-up survey***

Ten participants returned a four-month follow-up survey, a 67 percent return rate based on the number of participants who registered completion of the courses. All but one reported they had been able to apply the course information and resources in their practice. Participants cited examples such as: the courses “informed my thinking as I approach not only elderly clients but also younger clients with elderly family members” (Participant 9); and they had shared Dementia Australia resources with clients (Participant 7). The participant who had not applied the course content explained this was due to moving into a management role with reduced client contact. Over half of participants reported that the course content had informed or influenced how they work with clients, either a great deal or a moderate amount. One participant commented they now had “a huge awareness of how dementia can affect clients differently and how it can affect younger people too” (Participant 8). All participants agreed it is important to investigate the longer-term impacts of CPD training, including on lawyers’ practices (eg, how they work with clients with dementia), client experiences (eg, how satisfied are clients with their lawyer), and client outcomes (eg, legal documents meet best practice standards). Most participants reported a strong willingness to take part in further evaluation activities, such as participating in a review of templates or documents they used to assess against recommended practices and inviting clients to share their views and experiences as recipients of legal services. One participant commented on a need for a culture change in the legal profession: “Sharing knowledge and expertise is essential to best practice but something not usually done well by many lawyers. Assessing client satisfaction is also essential to gauge whether we are delivering relevant outcomes for clients.” (Participant 9)

The re-administration of questions from the DKAS indicated mostly correct responses, suggesting retention of key facts about dementia. However, several participants incorrectly answered that dementia is a normal part of the ageing process and that the sudden onset of cognitive problems is a characteristic of common forms of dementia.

### **3.4. *Insights from in-course activities***

The completion of questionnaires, polls and discussion posts in the courses provided insights on lawyers’ views about the knowledge, skills and attributes needed to work effectively with clients living with or at risk for dementia. Posts were submitted

anonymously and quotations are therefore not reported with reference to a participant number.

### *3.4.1. Dementia: Facts and Foundations*

The activities in this course elicited lawyers' self-perceived gaps in knowledge, areas for improvement and how to strengthen person-centred approaches for clients with dementia.

#### *Principles of Dignity in Care*

Participants were asked to review ten Principles of Dignity in Care, which underpin national clinical practice guidelines for people with dementia.<sup>29</sup> These guidelines highlight the importance of legal advice and support for people diagnosed with dementia. In a poll, participants were asked to select the top three principles relevant to legal practice. The principles that elicited the most votes were: enable people to maintain the maximum possible level of independence, choice and control; listen and support people to express their needs and wants; and treat each person as an individual by offering a personalised service.

In a discussion post, participants elaborated on why these principles are important. Those who chose 'treat each person as an individual' explained:

"I think that it is really important to make sure each client has documents drafted that are bespoke to them and their circumstances – not just filling in a few blanks on a standard form, which can be all too common with documents like POA [Power of Attorney] and Enduring Guardianship."

"Solicitors shouldn't make assumptions about the relationship a client has with their family and we shouldn't assume that they will want their adult children to act as attorneys/guardians."

A participant who chose enabling independence, choice and control wrote: "Often people want a power of attorney to start straight away, however once I have gone through with them why it can be better to wait until 'loss of capacity' and remind them that they are still able to make their own decisions, people feel relieved and more in control of their own lives."

Another participant stressed the importance of enabling "people to express (and give effect to) their needs and wants; diminished capacity can complicate day-to-day life, but it shouldn't prevent someone from living it how they choose."

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<sup>29</sup> Guideline Adaptation Committee (n 9). The 10 Principles of Dignity in Care are: zero tolerance of all forms of abuse; support people with the same respect you would want for yourself or a member of your family; treat each person as an individual by offering a personalized service; enable people to maintain the maximum possible levels of independence, choice, and control; listen and support people to express their needs and wants; respect people's privacy; ensure people feel able to complain without fear of retribution; engage with family members and carers as care partners; assist people to maintain confidence and a positive self-esteem; and act to alleviate people's loneliness and isolation.

### *Problematic assumptions and language*

Participants reflected on situations, behaviours and language that revealed negative attitudes and assumptions about older clients and people with dementia. A common example lawyers encountered was adult children trying to speak for their older parents:

“... when an adult child attends an appointment with a parent and answers for them and talks over them. I then try very hard to talk to the older person and direct eye contact and questions to them.”

“It can seem easier to communicate with the adult child, but I do my best to overcome this and take instructions from the client.”

Participants reviewed recommendations from Dementia Australia’s Dementia Language Guidelines,<sup>30</sup> which advocate for ‘person-first’ language. For example, use of the term ‘person living with dementia’ respects the dignity of the person, and emphasises that they are a person first and their diagnosis should not be regarded as the defining aspect of their life. In regard to problematic use of language, participants commented:

“I have heard family members state ‘He has dementia.’ As a statement intending to mean that the person lacks capacity purely because of a diagnosis of dementia. I have to explain that a person with dementia can still have capacity to make decisions for themselves.”

“It seems common to refer to people [as] ‘suffering’ from dementia which I think reinforces this idea that a person with dementia is no longer able to live any kind of normal life, and therefore simply incapable of engaging in any kind of legal processes in a meaningful way.”

“I read a wide range of medical and legal expert reports which do not use individual first language at all. Often there are references to the person ‘suffering’ or ‘lacking functioning’. I think the main reason is that in court cases, experts are required to comment on medical diagnoses and substantiate levels of impairment, and this is contrary to dementia-respectful language. I don't know how this can be rectified.”

### *Dementia knowledge*

Participants correctly answered a majority of questions from the DKAS.<sup>31</sup> In a discussion post to reflect on their score, they identified facts they previously did not know, including some risks factors for dementia (eg, high blood pressure) and protective measures: “I also didn't know that leading a healthy lifestyle meant you were at less risk of developing dementia - I assumed it could happen to anyone despite their level of fitness and health.”

Many participants reported they were surprised to learn about some of the modifiable dementia risk factors that occur through early, mid and later life (eg, lower levels of

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<sup>30</sup> Dementia Australia, ‘Dementia Language Guidelines’ (2022)  
<<https://www.dementia.org.au/resources/dementia-language-guidelines>>.

<sup>31</sup> Annear et al (n 25).

childhood education, smoking, exposure to air pollution, hearing loss, depression). They suggested law reform or advocacy initiatives that could help to reduce these risk factors:

“Supporting legislative / economic reforms that address some of the bigger risk factors - eg. access to education for disadvantaged groups, reforms that reduce smoking and alcohol consumption or increase access to better quality food. Reforms that address unnecessary high level noise exposure that causes hearing damage.”

“Greater education of the community as to the causes of dementia, ensuring older people have ready access to services that provide for aging in the home along with social interaction and exercise, maintenance of health services and services to assist those on reduced incomes access healthy food.”

“Encouraging lawyers to undertake dementia awareness training, that may lead to creating champions to share and build awareness about the issues.”

### *Overall reflection*

At the conclusion of the Dementia Facts & Foundations course, participants were asked to reflect on the most important or most surprising piece of information they learned from the course. The majority of participants noted learning about the various types of dementia stood out for them, as well as legal issues for people with younger onset dementia, such as impacts on employment, and behavioural changes, such as aggression and spatial disorientation, that may create legal risk situations for people with dementia. The need for awareness of risk factors for dementia, and adopting a holistic view, were also raised.

“I didn’t realise how one dimensional my experience has been to the huge range of dementia related considerations. It has led me to review my own inclinations and potential prejudices which to at least some extent I had not been aware of. ... There is no one piece of information which stands out. Rather the weight of the totality of what I have been exposed to in this course will have a profound impact on my level of awareness.”

“I didn’t know very much about the different types of dementia and that the term really encompasses a broad variety of symptoms beyond cognitive issues. I also had no idea how preventable it is by ensuring you lead a healthy lifestyle.”

### *3.4.2. Planning Ahead: Focus on Advance Care Planning*

The activities in this course explored lawyers’ perspectives and experiences in relation to clients’ rights to plan ahead for serious illness and the end of life, current practices in this area, including assessing and supporting clients’ decision-making capacity, and ways to improve the uptake and quality of advance planning.

#### *Uptake of advance personal planning*

In a poll, most participants reported they were not surprised by data on the uptake of advance planning instruments (eg, wills, enduring powers of attorney) among Australians, including the lower rates of uptake of advance care planning (eg, appointing an enduring

guardian and making an advance care directive) among people with dementia and other health conditions.<sup>32</sup> When asked to consider barriers that might prevent people who are living with a chronic illness from engaging with advance planning, participants discussed a lack of awareness of available legal instruments, the complexities of legal requirements, the cost involved, cultural factors, and a fear of losing control.

“The process appears too complicated. A lack of understanding as to the importance of the documents, or thinking they don’t have substantial enough assets to need them.”

“Some clients are uncertain about making the document as they are hesitant to hand over control of their decision making to someone and find the issue of facing a loss of capacity confronting, other clients are concerned that there is no-one in their lives that they would trust to make appropriate decisions for them.”

### *Professional experiences of advance planning*

Discussing their own experiences of facilitating advance planning with clients, participants generally noted that they encouraged all planning mechanisms to be completed, including financial and health-related instruments. However, even where clients were enthusiastic to engage in the process, some barriers still arose:

“[A]ll too regularly clients start with an initial burst of enthusiasm after a referral from, for example, a financial advisor. They then lose enthusiasm and momentum ... this i[s] all the worse when tough decisions are needed. Too many seem to feel they are too busy to finalise this and despite encouragement drag their feet. A lack of cross disciplinary collaboration often impedes the process and certainly results in poorer and slower outcomes.”

Participants were asked to reflect on their experience of working with older clients who do not have anyone they wish to appoint as a medical or financial decision-maker in the event of loss of capacity.<sup>33</sup> Several participants described common situations:

“I have encountered this issue on many occasions – especially where the client will expect that I would automatically take the role. ... [T]hey will not complete the documents and ‘hope’ that they will never lose capacity. Usually I give them some

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<sup>32</sup> The online course summarised research data from studies that included: Amy Waller et al, ‘Are Older and Seriously Ill Inpatients Planning Ahead for Future Medical Care?’ (2019) 19(1) *BMC Geriatrics* 212; Jamie Bryant et al, ‘Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities’ (2022) 12(e3) *BMJ Supportive & Palliative Care* e319; Sarah Jeong et al, ‘“Planning Ahead” among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey’ (2015) 24(1–2) *Journal of Clinical Nursing* 244; Ben P White et al, ‘Prevalence of Advance Care Directives in the Community: A Telephone Survey of Three Australian States’ (2019) 49(10) *Internal Medicine Journal* 1261; Karen M Detering et al, ‘Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study’ (2019) 9(1) *BMJ Open* e025255.

<sup>33</sup> This discussion activity followed a summary of literature on older people who do not have trusted legal representatives: see eg, Andrew B Cohen et al, ‘Older Adults without Desired Surrogates in a Nationally Representative Sample’ (2021) 69(1) *Journal of the American Geriatrics Society* 114.

suggestions and allow them time to think over their decision before taking instructions – commonly they will end up with a long-term friend or accountant.”

“In most cases that I have come across they do not make any documents. They leave it for the determination of the NSW Trustee and Guardian – whilst we try to inform clients why this is not always in their best interests when people believe they are all alone they feel they do not have any choice and don’t often appreciate you prying into their lives too deeply to try to find someone who could help them.”

### *Criticisms of current processes*

Participants were presented with criticisms relating to advance care planning, including: documents are not reviewed or updated; instructions included in documents are vague or not tailored to the person’s medical circumstances; documents are not accessible when needed to make decision; a person’s recorded wishes may be overridden by healthcare providers; and difficulties associated with the variation in laws relating to advance care planning across the states and territories.<sup>34</sup> These critiques resonated with participants’ experiences:

“[A]ll of these criticisms are valid and far too prevalent. A major part of the problem is a lack of skilled lawyers prepared to invest the time needed to become very competent in this area of law which is still not recognised as an area of specialisation by the NSW Law Society ... Too often it is attempted by lawyers with limited experience and interest in this very important area of practice.”

“Of the factors mentioned, often [a] client’s biggest concern is that any wishes they have (documented or not) will be overridden by their treatment providers when the moment arises. ... I always advise clients to have discussions with their family / decision makers / doctors about these wishes and document them there, rather than with lawyers.”

“I think we all need to stop relying on templates and start developing documents that are specific and clear enough to make the client’s wishes known, understood and acted upon.”

### *Areas for improvement in advance care planning*

Participants were asked to review the ten principles of best practice set out in the National Framework for Advance Care Planning Documents, as well as recommendations for legal practitioners when assisting clients in advance care planning processes.<sup>35</sup> Almost all

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<sup>34</sup> The critiques of advance care planning were consolidated from relevant literature, including: Mark I Friedewald and Peter A Cleasby, ‘Advance Care Directive Documentation: Issues for Clinicians in New South Wales’ (2018) 42(1) *Australian Health Review* 89; R Sean Morrison, ‘Advance Directives/Care Planning: Clear, Simple, and Wrong’ (2020) 23(7) *Journal of Palliative Medicine* 878; Nadia Moore et al, ‘Doctors’ Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study’ (2019) 9(10) *BMJ Open* e032638; Laura I van Dyck et al, ‘Understanding the Role of Knowledge in Advance Care Planning Engagement’ (2021) 62(4) *Journal of Pain and Symptom Management* 778.

<sup>35</sup> Department of Health, ‘National Framework for Advance Care Planning Documents’ (2021). The recommendations include: raising clients’ awareness of their rights to engage in advance care planning; using



participants rated their current advance care planning processes as ‘good’ or ‘excellent’. When asked which of the recommended practices stood out as areas for improvement, most participants noted the recommendation that documents be uploaded to a client’s My Health Record. Participants also supported the recommendations relating to reviewing and updating documents as necessary, and encouraging clients to discuss their wishes with others.

“Adding their documents to their Health Record. Giving a copy of the ACD to their support person now – not just in the future when the need arises.”

“Encouraging clients to think about their future medical wishes etc in terms of their values – rather than it being a tick list of medical treatment options.”

### *Supporting clients to make their own decisions*

The concept of supported decision-making was explored, encouraging the understanding that people living with conditions that affect cognition should be put in the best position to make their own decisions. The Law Society of New South Wales Capacity Guidelines recommend the four strategies of: building trust and confidence; accommodating sensory changes; accommodating cognitive impairment; and strengthening client engagement.<sup>36</sup> When asked which of these strategies was a particular strength in how they currently worked with clients, most participants selected building trust and confidence, followed by strengthening client engagement, and accommodating cognitive impairment. Fewer participants had experience with accommodating sensory changes. When asked to consider any changes or improvements they may make to address the strategies they had not selected, participants noted the following:

“I think I could (and should) make an effort to ensure the environment in which I am taking instructions is appropriate to the client's circumstances. This is particularly important at present where a lot of meetings take place via video conference [due to COVID considerations], although I am much more inclined to arrange a face-to-face meeting with older clients as they tend to prefer this, and it’s much better for getting an understanding of the client’s situation and ensuring they do not have someone influencing their instructions.”

“We deal with many older clients, it would be good for us to provide a simple summary in dot points to a client with mild cognitive impairment and to perhaps arrange subsequent appointments to confirm understanding. We do ask questions that are simpler and at a slower pace and in an open ended way to gauge understanding.”

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appropriate templates for ACP documents; encouraging clients to use values-based languages to express their wishes; ensuring that documents don’t have conflicting directions; encouraging clients to discuss their wishes with key others; informing clients that advance care planning documents can be uploaded to My Health Record; reminding clients to review and update their advance care planning documents as necessary; and directing clients to resources that can help them and key others.

<sup>36</sup> The Law Society of New South Wales, ‘When a Client’s Capacity is in Doubt: A Practical Guide for Solicitors’ (2016) 1, 19-22 (Appendix C).

### *Medical assessments of capacity*

Lawyers have a professional responsibility to determine whether a client is able to give competent instructions, in accordance with relevant legal tests.<sup>37</sup> In the event of uncertainty, a medical opinion may be sought to inform the lawyer's determination. In response to information regarding cognitive assessments and working with health professionals,<sup>38</sup> participants were asked to share their experiences of seeking to refer a client for a medical assessment of their capacity. The majority of responses indicated difficulties with the process, with only two participants reporting a cooperative relationship or positive outcome.

"I review a large volume of medical assessments in relation to common law claims. Sadly, some assessments are poorly written, ableist, misogynistic, not trauma informed at all. A well drafted instruction letter is important but equally, selecting a suitably qualified health professional. Unfortunately, I am very pessimistic due to the bad experiences with report writers. Further, in the medico-legal space, costs are frankly outrageous."

"I am a regional practitioner. I have had to do this on only a few occasions and it has been a positive outcome due to the strong level of collaboration between myself and the medical practitioner. The [l]awyer needs to lead the process and the result will depend on the level of commitment shown by the lawyer to the engagement of the medico in the form of clear instructions and setting out clear expectations of what is expected in the medical report and potential follow up. An exhaustive letter of instruction is the key. The [Law Society] templates are a strong starting point."

### *Improving health and legal sector connections*

Participants reviewed the American Bar Association's *Advance Directives: Counseling Guide for Lawyers*,<sup>39</sup> which is designed to help bridge the gap in legal and medical approaches to advance care planning. They were then asked to provide their reaction to the guidance in the document. Participants believed the guide was thorough and provided "[a] good summary of the issues to go through with the client so their wishes can be properly documented in a tailored way." However, participants also noted the need for improvement

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<sup>37</sup> Ibid (Appendix A); Law Council of Australia, *Best Practice Guide for Legal Practitioners on Assessing Mental Capacity* (June 2023), <https://lawcouncil.au/resources/policies-and-guidelines/best-practice-guides-for-legal-practitioners-in-relation-to-elder-financial-abuse-and-assessing-mental-capacity>.

<sup>38</sup> For example, the course explained several tools that health professionals may use to assess patients: the Mini-Mental State Examination (a common test used to screen for cognitive impairment); the General Practitioner Assessment of Cognition (designed for primary care practitioners to screen for dementia); the Kimberly Indigenous Cognitive Assessment (a dementia assessment tool for use with older Indigenous Australians living in rural or remote areas); and the Rowland Universal Dementia Assessment Scale (recommended when assessing cognitive function in people from culturally and linguistically diverse backgrounds). The course content noted that these assessment tests are not determinative of capacity to make a specific legal decision, but legal practitioners may need to weigh up information from health professionals in their consideration of a client's capacity to instruct in relation to a legal matter.

<sup>39</sup> Commission on Law and Aging and American Bar Association, 'Advance Directives: Counseling Guide for Lawyers' (2018), [www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/ad-counseling-guide/](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/ad-counseling-guide/).

relating to broader consideration of LGBTQI+ and CALD groups, as well as special consideration of the circumstances of individual clients.

“[S]pecial consideration for cultural diversity, special needs or language difficulties or limitations should be specifically considered.”

“As mentioned by others, consideration of other factors including cultural, LGBTQI+, language, etc.”

“The guide is useful for gather[ing] information about a client’s situation although the client requires that the lawyer carefully draft the documents to suit the situation so that the conditions are clear (in the event of any family conflict).”

### *Improving substitute decision-making*

Participants were asked to reflect on their current practices when assisting clients to appoint healthcare decision-makers. Almost all participants responded that they ‘always’ or ‘often’ discussed the qualities of a suitable decision-maker with their clients, however, challenges were also noted:

“[T]he client doesn’t necessarily explain to their appointed decision maker exactly what the duties and responsibilities are. Often when the decision maker attends our office to sign the document and accept their position, it is the first time they are hearing about the content of the document and exactly what their role entails.”

“[I]t is important to take into consideration the cultural backgrounds, linguistic capabilities, historical life experiences (such as DV [domestic violence]). But as a legal practitioner, you do not have time to exercise caution or consider these aspects – this could be due to the length of experience of the practitioner, awareness of cultural diversity and diverse cultural values etc. In such circumstances, it is quite easy or prevalent that a family member or the substitute decision maker dictate or take charge of the situation altogether. Availability of interpreters, possible lawyer-health professional involvement will benefit the older person involved. Extensive training to lawyers is an important aspect.”

### *Dementia-specific directives*

Participants were asked to reflect on the merits of a dementia-specific Advance Care Directive (ACD) that prompts individuals to record their wishes for care at mild, moderate and severe stages of illness.<sup>40</sup> While there was strong support for the use of a dementia-specific directive, participants noted some disadvantages. For example, clients may have co-morbidities that present complexities for recording their health-related wishes, the stages of progression of dementia may occur differently for some people, and the language in a directive template may stigmatise dementia.

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<sup>40</sup> This course content was based on: Barak Gaster, Eric B Larson and J Randall Curtis, ‘Advance Directives for Dementia: Meeting a Unique Challenge’ (2017) 318(22) *Journal of the American Medical Association* 2175.

“If used early enough this is a good document. It has alerted me to the limitations of my own current practice. I would recommend it to appropriate clients.”

“As a starting point, it is a useful document. However, the challenge is that it may oversimplify things and that it is not consistent in language with respect to dementia language guidelines.”

“I like the idea of tailoring someone’s documents to their medical diagnosis, however it could be problematic because not everyone’s condition is going to follow the same trajectory, which may result in an overly complicated document as we try to account for every possible outcome.”

#### **4. Discussion**

The findings from this pilot project provide useful data to inform the design, delivery and evaluation of online learning initiatives for legal practitioners. Participants’ responses to the course activities also contribute insights into the role of the legal profession and lawyering practices in advancing the objectives of Australia’s National Dementia Action Plan.

##### **4.1. Online training and evaluation method**

To be successful, continuing professional education must be acceptable and appropriate to the intended audience.<sup>41</sup> The pilot evaluation of the online dementia training demonstrates that the course content and mode of delivery met these criteria, with a majority of participants rating high satisfaction with the courses and relevance of the content to their professional practice. The evaluation provides data on engagement and completion rates for online learning for legal practitioners, as well as the proportion who may seek a certificate of completion for CPD purposes. The study also demonstrates the feasibility of the evaluation model. Survey methods have notoriously low response rates for time-poor professionals like lawyers,<sup>42</sup> however, reasonable response rates were achieved for the surveys administered immediately on completion of the online courses and at a four-month follow-up period.

There is a dearth of empirical research to evaluate continuing professional education for legal professionals, in contrast with research examining continuing education for health professionals.<sup>43</sup> A 2021 systematic review of online and other technology-enabled dementia

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<sup>41</sup> Claire A Surr et al, ‘Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature’ (2017) 87(5) *Review of Educational Research* 966.

<sup>42</sup> Yair Listokin and Raymond Noonan, ‘Measuring Lawyer Well-Being Systematically: Evidence from the National Health Interview Survey’ (2021) 18(1) *Journal of Empirical Legal Studies* 4; Kathryn Birtwistle, *Access to Digital Records upon Death or Incapacity: Survey Results* (Research Report No 15, New South Wales Law Reform Commission, 2019) <<https://www.lawreform.justice.nsw.gov.au/Documents/Publications/Other-Publications/Research-Reports/RR15.pdf>>; Ries et al (n 5).

<sup>43</sup> Rima Sirota, ‘Can Continuing Legal Education Pass the Test? Empirical Lessons from the Medical World’ (2022) 36(1) *Notre Dame Journal of Law, Ethics & Public Policy* 1. Sirota observes (at 2) that ‘no evidence-based reason has emerged to support the conclusion that CLE bears *any* relationship - much less a causal one - to better lawyering.’

training for health and social care practitioners identified 21 studies.<sup>44</sup> Most reported that the training interventions were effective in improving knowledge and attitudes, however few studies measured post-training behaviour changes. Our pilot evaluation found that, following completion of online training, there was strong reported confidence in being able to implement the course content and nearly all practitioners reported actual use of knowledge and resources gained from the training. Longer term follow up is needed to determine the uptake of recommended strategies and resources when assisting clients who live with dementia. This pilot indicates that practitioners endorse the need for longer term evaluation of continuing professional development, including gaining client perspectives on whether and how lawyers' training translates to improved client experiences of legal advice. This promising finding suggests that practitioners may be willing to be part of innovative studies to build an evidence base for what constitutes "good lawyering" for clients who live with dementia or other neurocognitive conditions.<sup>45</sup>

#### **4.2. The National Dementia Action Plan and the legal profession**

The results of this study inform consideration of how the legal profession can contribute to the goals of the National Dementia Action Plan, which seek to build dementia capable workforces, encourage dementia-friendly service provision and reduce stigma and discrimination.<sup>46</sup> Access to dementia-focused training is important to support the development of dementia capability in the legal profession. Improved knowledge and confidence among practitioners will support their ability to work effectively with clients with or at risk for dementia. For example, study participants endorsed the benefits of learning up-to-date factual information about dementia and the use of respectful language when communicating with and about people who live with dementia. A developing body of research calls attention to the stigmatising effects of language used by professionals and elicits the terminology preferred by people with lived experience of dementia.<sup>47</sup>

The National Action Plan calls for improving post-diagnostic supports for people with dementia, including comprehensive advance planning to prepare for future periods of decisional incapacity and the end of life.<sup>48</sup> Advance care planning, including appointing an enduring decision-maker and making an advance directive to document values and preferences for health-related interventions, can empower people with dementia and improve the care they receive.<sup>49</sup> A recent Australian study found that 60 percent of people

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<sup>44</sup> Kevin Muirhead et al, 'Establishing the Effectiveness of Technology-Enabled Dementia Education for Health and Social Care Practitioners: A Systematic Review' (2021) 10(1) *Systematic Reviews* 252.

<sup>45</sup> Recent research into domestic violence lawyering offers an informative model: Jane Wangmann et al, 'What Is "Good" Domestic Violence Lawyering?: Views from Specialist Legal Services in Australia' (2023) 37(1) *International Journal of Law, Policy and the Family* ebac034.

<sup>46</sup> Australian Government, Department of Health and Aged Care (n 4).

<sup>47</sup> See eg, Emma Wolverson et al, 'The Language of Behaviour Changes in Dementia: A Mixed Methods Survey Exploring the Perspectives of People with Dementia' (2021) 77(4) *Journal of Advanced Nursing* 1992; Andrea Gilmore-Bykovskiy et al, 'Nomenclature Used by Family Caregivers to Describe and Characterize Neuropsychiatric Symptoms' (2020) 60(5) *The Gerontologist* 896.

<sup>48</sup> Australian Government, Department of Health and Aged Care (n 4) 37.

<sup>49</sup> Annelien Wendrich-van Dael et al, 'Advance Care Planning for People Living with Dementia: An Umbrella Review of Effectiveness and Experiences' (2020) 107 *International Journal of Nursing Studies* 103576.

with dementia had some form of care planning documentation, but the legal status was questionable as half the documents had been prepared by someone else on behalf of the person, such as a healthcare provider or a substitute decision-maker.<sup>50</sup>

While some commentators have questioned the role of lawyers in advising clients on advance care planning,<sup>51</sup> comprehensive legal advice on advance planning rights must include guidance on health-related planning. In the American context, Orsatti has highlighted how lawyers assist their clients, including by ensuring that documents comply with applicable statutory requirements, educating clients on the responsibilities of legally appointed decision-makers and encouraging clients to discuss their care wishes with key others, including their named decision-maker(s) and healthcare providers.<sup>52</sup> The findings from the current study endorse the value of training for legal practitioners to enhance the strategies they use to improve the uptake and quality of legal aspects of advance care planning.

The National Action Plan calls for ‘prioritising supported decision-making’ whereby people with dementia are supported ‘to exercise their own preferences in the context of making legal and day-to-day decisions.’<sup>53</sup> Informal carers, legally appointed representatives and professionals all have important roles to support people with dementia in making decisions. Sinclair and colleagues conducted interviews with Australian health and legal professionals to explore how they conceptualised and carried out supported decision-making for clients with dementia.<sup>54</sup> A range of practical techniques were described, mainly focused on accommodating cognitive impairment by allowing more time for explaining and discussing information and speaking in a clear and direct manner. Participants in the online dementia training shared similar examples and indicated that sensory changes also require accommodations, particularly for clients who may have impairments in vision and hearing, as well as cognitive changes.

Our study also reinforces the need for improving capacity assessment processes, especially procedures and resourcing for obtaining formal medical reports. Purser et al have called for better medico-legal collaboration to ensure timely and appropriate assessments for clients, particularly in relation to will-making, enduring powers of attorney and making legal documents as part of advance care planning.<sup>55</sup> Client experiences of capacity assessments are an emerging area of research in Australia<sup>56</sup> and will provide valuable insights to inform future updates to dementia training for legal practitioners. For example, a pilot study of

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<sup>50</sup> Bryant et al (n 31); preparation of care planning documents by a third party raises questions as to whether they accurately represent the values and preferences of the person living with dementia. See also Detering et al (n 31) for data on the low uptake of statutory ACP documents.

<sup>51</sup> See eg, Sean Morrison (n 34).

<sup>52</sup> Grace W Orsatti, ‘Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives’ (2022) 50(1) *Journal of Law, Medicine & Ethics* 157.

<sup>53</sup> Australian Government, Department of Health and Aged Care (n 4) 43.

<sup>54</sup> Sinclair et al (n 12).

<sup>55</sup> Kelly J Purser and Tuly Rosenfeld, ‘Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment’ (2014) 201(8) *Medical Journal of Australia* 483.

<sup>56</sup> Karen Sullivan and Kelly Purser, ‘Developing and Piloting the Consumer Experience of Capacity Assessment Tool (CECAT)’ (2022) 29(5) *Psychiatry, Psychology and Law* 752.

consumer experiences recommended a need for better communication and preparation for what to expect during a formal assessment of decision-making capacity.<sup>57</sup>

Lastly, but importantly, the study findings suggest opportunities for the legal profession to advocate for legislative and policy reforms aimed at dementia prevention, especially public health measures that support healthier environments and lifestyles.<sup>58</sup> At a personal level, participants expanded their understanding of risk factors they could change in their own lives. Lawyers can also advocate for conditions in the legal profession that promote practitioner well-being and reduce the lifestyle-related risk factors for dementia.<sup>59</sup>

#### **4.3. Strengths and limitations**

The online training evaluated in this pilot study was designed in accordance with the features of effective web-based training, which overcomes pedagogical critiques of continuing legal education initiatives that do not suit the needs of adult learners.<sup>60</sup> The participants who took part were drawn from both specialist and generalist backgrounds and metropolitan and regional settings. However, the demographic profile of the participants raises some limitations. Any non-compulsory professional training initiative involves self-selection and attracts individuals with some degree of pre-existing interest in the topic. More female practitioners than males engaged with course materials and completed the surveys. Over half of participants had 10 years or more in practice and were able to draw on their professional experiences in completing and providing feedback on the course activities. Novice practitioners with little direct client experiences may benefit from additional training activities, such as role plays or simulations.<sup>61</sup>

The number of participants for the pilot was limited by the funds available to cover the course costs, however, the sample size was in line with other pilot studies of dementia education initiatives.<sup>62</sup> The training was provided at no cost to participants to avoid any financial barriers and to recognise the time that practitioners would take to complete all the course activities and complete surveys for the evaluation process. Of the practitioners who consented to take part in the study, just over 70 percent engaged with the course materials, which was slightly lower than the engagement rate reported in dementia training initiatives for health professionals.<sup>63</sup> The engagement rate was likely affected by a number of factors, including COVID-related and other unanticipated disruptions to practitioners' professional

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<sup>57</sup> Ibid.

<sup>58</sup> Joyce Siette et al, 'Advancing Australian Public Health Initiatives Targeting Dementia Risk Reduction' (2022) 41(2) *Australasian Journal on Ageing* e190. These authors highlight the 'structural enablers of healthy behaviour such as system level changes through policy, legislation, and taxation.'

<sup>59</sup> Michael Jay Badger et al, 'Concerns About Cognitive Impairment and Older Lawyers' (2015) 25(2) *Experience: the Magazine of the Senior Lawyers Division, American Bar Association* 30; Debra S Austin, 'Drink Like a Lawyer: The Neuroscience of Substance Use and Its Impact on Cognitive Wellness' [2014] (15) *Nevada Law Journal* 826.

<sup>60</sup> Sirota (n 42).

<sup>61</sup> Brandy Schwarz, Mike Richardson and Kathlene Camp, 'Impact of a Short-Duration Experiential Learning Activity on DPT Students' Attitudes toward Patients Living with a Dementia' [2023] *Gerontology & Geriatrics Education* 1; Moehead et al (n 18).

<sup>62</sup> See n 21.

<sup>63</sup> See n 27.

and personal lives. Providing free access to the courses might also have been a factor since participants who enrolled but did not engage with the training were not out-of-pocket for fees. Finally, within the timeframes for this pilot project, the four-month follow-up period was adequate to elicit preliminary data on survey response rates and practitioners' reported use of course knowledge and resources. Longer term follow-up with both practitioners and their clients is recommended for future research into the use and impacts of continuing professional education and training.

#### **4.4. Next steps**

In light of the overall positive feedback, it was not necessary to revise and re-evaluate the courses and they are currently available for general enrolment. The data collected through the course activities revealed complexities that lawyers encounter in practice, however these comments did not indicate areas for amendment in the courses themselves. The comments either endorsed the need for ongoing practitioner training (such as provided in the online courses) or for other changes, including legislative reforms, additional policy and practice guidance from legal professional societies, and improved practices by medical professionals, such as in capacity assessments. We have secured ethics approval to continue to collect data from the course activities and feedback surveys. We have also undertaken a related project to explore in more detail what the concept of dementia capability means for legal professionals, people living with dementia and their support persons. The dissemination of the results of that project will be an opportunity to further invest in the rollout of the online training courses.

### **5. Conclusion**

The coming decades will see at least a doubling of the number of people in Australia who live with dementia.<sup>64</sup> All levels of government are committed to strengthening public understanding of dementia, improving workforce capabilities and fostering dementia-inclusive communities, where people living with a diagnosis and those who support them have access to high quality services. Research into unmet needs among people with dementia and carers reveals legal concerns, including a need for advice on planning ahead to reduce the burden of uncertainty and prepare future decisions.<sup>65</sup> The legal profession has a critical role to play and practitioners need knowledge, skills and resources to work effectively with clients who live with, or are at risk for, dementia. The online training courses that were evaluated in this pilot project were aimed at two key topics: dementia facts and foundations for legal practitioners; and legal dimensions of advance care planning. The findings were positive both in terms of the suitability of the training and the feasibility of the evaluation model. Wider-scale delivery of a range of training initiatives will assist in building dementia capability in the legal profession and foster practitioners who can become

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<sup>64</sup> Australian Government, Department of Health and Aged Care (n 4) 6.

<sup>65</sup> Betty S Black et al, 'Unmet Needs in Community-Living Persons with Dementia Are Common, Often Non-Medical and Related to Patient and Caregiver Characteristics' (2019) 31(11) *International Psychogeriatrics* 1643; Elise Mansfield et al, 'Prevalence and Type of Unmet Needs Experienced by People Living with Dementia' (2022) 87(2) *Journal of Alzheimer's Disease* 833; Elise Mansfield et al, 'Prevalence and Type of Unmet Needs Experienced by Carers of People Living with Dementia' [2022] *Aging & Mental Health* 1.



'dementia champions'<sup>66</sup> to lead practice changes and advocate for systemic law reforms to support a dementia-inclusive society.

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<sup>66</sup> Margaret Brown et al, 'What Are Dementia Champions and Why Do We Need Them?' (2018) 17(4) *Dementia* 397.

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## Appendix

**Table 1: Demographics\***

<b>Gender</b>	
Female	13 (72%)
Male	4 (22%)
Did not answer	1 (6%)
<b>Age</b>	
30-39 years	7 (39%)
40-49 years	8 (44%)
50-59 years	2 (11%)
60-69 years	1 (6%)
<b>Years of Experience as a Legal Practitioner</b>	
0-4 years	5 (28%)
5-9 years	3 (17%)
10 years or more	10 (55%)
<b>Size of Firm or Organisation</b>	
Sole practice	1 (6%)
Small organisation (2-9 lawyers)	10 (55%)
Mid-size organisation (10-49 lawyers)	6 (33%)
Large organisation (50 or more lawyers)	1 (6%)
<b>Current State/Territory of Work</b>	
New South Wales	12 (67%)
Victoria	6 (33%)
<b>Area of Legal Practice</b>	
Wills/Estates	7 (39%)
Elder Law/Seniors Law	8 (44%)
Other	3 (17%)

\*The demographic data were collected in the end-of course feedback survey, which 18 participants completed.

**Table 2: Satisfaction with online courses**

Level of Satisfaction	Number of Participants
Extremely satisfied	11 (61%)
Very satisfied	5 (28%)
Moderately satisfied	2 (11%)
Slightly satisfied	-
Not at all satisfied	-

**Table 3: Relevance of courses**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Neither Agree nor Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
The content covered in the course is useful and relevant for legal practitioners	13 (72%)	5 (28%)	-	-	-
The course provided new information and resources that I wasn't familiar with before doing the course	9 (50%)	8 (44%)	1 (6%)	-	-
The course introduced the concept of a 'dementia-capable' legal practitioner. When introduced, the concept made sense to me as a way to describe relevant knowledge and skills for lawyers	9 (50%)	9 (50%)	-	-	-
It was easy to navigate through the online course	9 (50%)	8 (44%)	1 (6%)	-	-
I feel confident I will be able to implement knowledge and skills from the course into my practice	9 (50%)	8 (44%)	1 (6%)	-	-

**Table 4: Features of online courses**

<b>How useful were the following features:</b>	<b>Useful</b>	<b>Somewhat Useful</b>	<b>Not Very Useful</b>
Questions to self-assess your knowledge and attitudes	12 (66%)	5 (28%)	1 (6%)
Links to resources and further readings	16 (88%)	1 (6%)	1 (6%)
Comment boxes/discussion posts to share views and experiences	12 (67%)	6 (33%)	-

