

Developing a Research Agenda for Adult Palliative Care: A Modified Delphi Study

Rebecca Sullivan BPsych(Hons)¹

Anna Ugalde PhD, BA(Hons)² 0000-0002-2473-8435

Craig Sinclair PhD, BA/BSc³ 0000-0003-2734-2951

Lauren J. Breen PhD, FT, BSc(Hons)^{1*} 0000-0002-0463-0363

¹School of Psychology, Curtin University, Perth, Australia

²School of Nursing and Midwifery, Deakin University, Melbourne, Australia

³Rural Clinical School of Western Australia, University of Western Australia (Albany Centre), Albany,
Australia

*School of Psychology, Curtin University, GPO Box U1987, Perth, Australia, 6845.

Lauren.Breen@curtin.edu.au

Tel: +61 8 9266 7943

Fax: +61 8 9266 2464

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Abstract

Background: Little is known about research priorities in adult palliative care. Identifying research priorities for adult palliative care will help to increase research quality and translation.

Objective: The aim was to identify the views of health professionals' research priorities in adult palliative care in order to lead to the development of a palliative care research agenda in Australia.

Design: A modified three-round Delphi survey.

Setting/Subjects: Palliative care researchers and clinicians in Australia were invited to participate.

Results: A total of 25 panellists completed Round 1, 14 completed Round 2, and 13 completed Round 3.

Round 1 resulted in 90 research priorities in 13 categories. Round 2 showed consensus agreement on 19/90 research priorities. Round 3 resulted in the top 10 research priorities of the 19 achieving consensus in Round 2. Panellists agreed that research is needed on the transition to palliative care; improving communication about prognosis; increasing access to palliative care for indigenous communities, people who wish to remain at home, and people in aged care; addressing family caregivers' needs; promoting patients' and families' decision-making; improving cross-cultural aspects of palliative care; determining the effects of assisted dying legislation; and improving bereavement care in rural, remote and Aboriginal populations.

Conclusions: The expert panellists identified the top 10 research priorities for adult palliative care. These research priorities identified are the most urgent topics requiring attention in order to increase the quality of life of patients requiring palliative care and their family members.

Keywords palliative care, research priorities, Delphi, research agenda

Background

The barriers to high quality palliative care research are widely documented and include ethical concerns regarding participant randomization, consent, and recruitment; small sample sizes due to passive recruitment methods, gatekeeping, and attrition; and a lack of funding, time, and resources for clinicians to engage in research [1-7]. Although randomized control trials are the gold standard for evidence-based research, they are not widely used in palliative care, often due to methodological issues. Attrition in palliative care research is high, due to patient fatigue, missing data, and considerable mortality [4,8] and randomization protocols often do not allow participants to receive interventions reflecting their preferences [8].

The identification of research priorities in adult palliative care is desirable, in order to increase research capacity, quality, and evidence; promote translation of knowledge into practice; prevent research duplication; and enhance funding competitiveness [6]. Globally, these identified research priorities could be used to build research capacity, leverage funding, better identify patient needs, maximize patient recruitment and retention, enable international comparative studies, maximize research translation, and overall contribute to more effective service development, to meet emerging needs [9,10, 15]. However, there is little known about research priorities in adult palliative care.

Research priorities have been determined for paediatric palliative care in Canada [12] and the United States [13] but these are unlikely to generalize to adult palliative care because of three differences between the two settings—paediatric palliative care addresses a broader spectrum of diseases whereas cancer dominates adult palliative care services, children tend to receive palliative care earlier in the disease trajectory than do adults, and there are far fewer children requiring palliative care compared to adults [14]. Two other studies determined research priorities for palliative care and combined adult and paediatric services across Africa [10] and in the Australian state of Victoria [15]. Thus, we aimed to gain consensus on the research priorities of palliative care clinicians and researchers with a view to establishing a prioritized research agenda for adult palliative care in Australia.

Methods

The study was approved by the Curtin University Human Research Ethics Committee (HRE2017-0432). A modified three-round Delphi survey, adapted from Delphi studies of research priorities in paediatric palliative care [12,13] was employed to identify palliative care researchers' and clinicians' research priorities in order to establish a consensus-based research agenda for Australian adult palliative care. The Delphi technique is an appropriate method to identify research priorities and enables efficient access to a broad range of experts, with the aim of achieving consensus via a process where the successive stages depend on the results from the previous round [16].

Panel Recruitment

Panellists were identified as current experts in palliative care research and/or practice in Australia. The research team identified potential panellists (N=146), purposively selected as experts to optimize data validity [17], from websites of national and state palliative care associations, university profiles, and lists of presenters at recent palliative care conferences. Several palliative care organizations also advertised the study to members. There is no consensus on the optimal sample sizes for Delphi studies, with sample sizes ranging from 10 to 1000+ [16,18] and response rates varying substantially from 15.8% [19] to 97.1% [20]. To ensure

a minimum sample size of 10 in Round 3, accounting for 50% retention rates between consecutive rounds [21], we aimed to contact at least 80 panellists in Round 1.

Questionnaire Administration

Potential panellists were invited with an individual link to the Round 1 questionnaire and only panellists who completed each round received invitations for subsequent rounds. The questionnaires were hosted online on *Qualtrics*. After providing informed consent, Round 1 panellists were asked a series of demographic questions and to provide their top five priority areas for adult palliative care research in Australia. These responses were collated for use in Round 2. Round 2 panellists were asked to rate each of the 90 items on a four-point scale: (1) very important/urgent priority; (2) moderately important/intermediate priority; (3) somewhat important/low priority; or (4) not important/not a priority. There were two open-ended questions to allow panellists to provide feedback regarding the scope of the questions and identify any missing priorities. In accordance with a similar study, consensus was defined as being achieved if the percentage of items scoring 1 (urgent priority) or 2 (intermediate priority) was >85 % with a mean score <2 [13]. Round 3 panellists were asked to rank their top 10 research priorities from those achieving consensus in Round 2. Round 3 rankings were collated into a total prioritization score for each item. Panellists had three weeks to complete Rounds 1 and 2, and two weeks to complete Round 3, and received a reminder email one and two weeks after distribution of each round. Each questionnaire could be completed in one or more sittings to allow panellists to deliberate on responses [16]. Panellists who participated in all three rounds were offered the chance to enter a draw to win one of four \$25 gift vouchers.

Statistical Analysis

Statistical analyses were conducted using *IBM SPSS Version 22.0*. Less than 1% of the data was missing; a Little MCAR test showed it was missing at random ($df=.293$, $p=.864$) and therefore was replaced using expectation maximization. Means and standard deviations were calculated for each item. Due to the small sample size and unevenly distributed sample, Mann Whitney *U* tests were used to explore differences in panellists' Round 2 ratings according to gender, role (researcher or clinician); location (metropolitan or rural); or discipline (medical and nursing or allied health), and median split for experience (>/<) 17 years working in palliative care; >/< 19.5 years since graduation. Effect sizes were interpreted according to Cohen's (1988 [22]) conventions. Due to the exploratory nature of the study and the small sample size, Bonferroni corrections for multiple comparisons were not made.

Results

Item Generation, Rating and Ranking

Panellist characteristics are summarised in Table 1. The Round 1 survey was completed by 25 panellists who generated 125 priorities. These were analyzed by two authors (RS and LJB) using conventional content analysis [23] to systematically code, count, and categorize responses; to remove ambiguous or duplicate statements; and achieve consensus via discussing discrepancies in opinion. This process resulted in 90 research priority statement items grouped into 13 categories. The means and standard deviations for each category and item are shown in Table 2.

A total of 14 of the 25 Round 1 panellists completed Round 2 (response rate=56%). Of the 90 items generated in Round 1, 19 reached consensus in Round 2. A total of 13 of the 14 Round 2 panellists completed Round 3 (response rate=93%) and 19 of the 90 items (21.11%) achieved consensus as high

priorities. The category with the lowest mean rating (i.e., the highest rating of importance/urgency) was ‘*communication between health care professionals and patients/families*’, followed by ‘*community education and capacity building for end-of-life care*’ and then ‘*bereavement care*’. Two categories had a mean overall priority rating of 2 and with all items rated 2 or more—‘*staff training and development*’ and ‘*symptom management*’—and were therefore considered to be of the least importance/urgency. The 19 items were presented to panellists in Round 3, to rank their top 10 (see Table 3).

Rating Comparisons According to Panellist Characteristics

Mann Whitney *U* tests indicated no significant differences in responses according to gender, role, organisation location; or discipline, years working in palliative care, and years since graduation. Items in the category of ‘*integration of palliative care*’ were rated significantly lower (higher priority) by panellists working in multidisciplinary teams (*Mean Rank* 5.44, *n*=9) than those not in a multidisciplinary team (*Mean Rank* 11.2, *n*=5) (*U*=4.00, *p*=.013, two-tailed) with a “large” (*r*=.67) effect size. Items in the category of ‘*communication between health care professionals and patients/families*’ were rated significantly higher (lower priority) by panellists working on sites with inpatients (*Mean Rank* 10.9, *n*=5) than those working on other sites (*Mean Rank* 5.61, *n*=9) (*U*=5.50, *p*=.021, two-tailed), with a “large” (*r*=.62) effect size. Items in the category of ‘*family and carer wellbeing*’ were rated significantly higher (lower priority) by panellists working on sites with inpatients (*Mean Rank* 10.7, *n*=5) than those working on other sites (*Mean Rank* 5.72, *n*=9) (*U*=6.5, *p*=.032, two-tailed) with a “large” (*r*=.57) effect size.

Open-Ended Responses

Five panellists responded to the open-ended questions in Round 2. Two panellists commented that the questionnaire represented an exhaustive list of all relevant research priorities. Three provided additional priorities. One suggestion centred on paediatric palliative care, which was not in the scope of our study, and the remaining two suggestions concerned integrative care packages for people with dementia and research on barriers to care for people with neurological conditions.

Conclusions

This study provides evidence to inform a prioritized research agenda for palliative care in Australia. Panellists identified urgent research priorities concerning integration of palliative care, communication, specific populations, family and carer wellbeing, models of care, and bereavement care, all of which feature in the literature [24-31]. Panellists identified two research priorities concerning communication between health care professionals and patients/families. Communication surrounding prognosis can be problematic, and there are recommendations to increase research on the development of tools to understand family decision-making typologies; develop methods for consensus-building among multidisciplinary teams, patients and family members when views differ; and determine optimal approaches to supporting and guiding family members when making decisions [11]. Determining optimal timing and processes for communicating the transitions into palliative care was also identified in our study and was a research priority for Victorian palliative care [15]. As the conditions and needs of palliative care patients change over time, research in systems and communication regarding progression into palliative care may help to make transition as seamless as possible for patients/caregivers [11].

Panellists identified one research priority centred on family and carer wellbeing as well as three other priorities that involved carers/other family members. Family caregivers are pivotal for successful

patient outcomes and improving quality of life, but often face unmet needs and a lack of support despite the philosophy of palliative care as ‘family-centred’ [32]. These unmet needs stem from numerous factors such as financial disadvantage, social isolation, inadequate symptom management, lack of information regarding their role, discomfort with confronting death and dying, and exclusion from information and care-planning. Considering rates of depression and anxiety are as high as 44% for family caregivers, and that nearly 50% of caregivers are below population norms on physical health [32], there is a significant need for research to find ways to identify caregivers who would most benefit from palliative care and/or other services, and to match the most useful components of palliative care to those with specific needs [33].

Panellists identified two research priorities concerning models of care, with an emphasis on palliative care in the home and in aged care settings. Most patients wishing to remain at home and requiring palliative care services are not likely to have their needs and preferences met without significant family caregiver input [32] and therefore research could help to identify ways to support family members/caregivers to care. Our study suggests that Australian services, caregivers, and families may benefit from research that promotes preparedness for the transition to palliative care.

Panellists identified three research priorities concerning Indigenous and culturally-diverse populations. Disparities in quality of life for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) people diagnosed with chronic illness, groups in comparison to Anglo-Australian populations, are well recognized. Cancer is the second leading cause of death in Aboriginal and Torres Strait Islander people, and is more likely to be diagnosed as terminal in Indigenous populations than Anglo-Australian populations [34] and clinical levels of depression in cancer survivors are significantly higher for ethnic minority groups in Australia (11% Arabic, 9% Chinese, 9% Greek) compared to Anglo-Australians (2%) [35]. Aboriginal and Torres Strait Islanders remain under-represented in the palliative care population due to a lack of understanding of palliative care, poor availability of services, and the burden of chronic disease outranking palliative care as a priority [36]. Barriers and challenges to access include language barriers, unfamiliarity with healthcare systems, socio-economic status and lack of financial resources, discrimination and cultural incompetence of health professionals, structural barriers within the health system, and lack of access to CALD or Aboriginal and Torres Strait Islander health care providers [35,36]. A study in Canada identified key challenges for palliative care specific to rural indigenous populations to increase the relevance, access, and comprehensiveness of palliative services specific to their needs [37].

Panellists identified two research priorities concerning bereavement. Bereavement care is an increasing area of interest and sophistication in palliative care [38]. However, the provision of tailored supports is hampered by questions concerning who to support, for how long, and to what end, given funding and staffing constraints [39]. Research addressing these issues would be complemented by research to strengthen the community’s capacity to support the dying and the bereaved [40].

Study Limitations

The panellists were very experienced palliative care clinicians and researchers (averaging over 20 years working in palliative care) and there was a high retention rate from Rounds 2 to 3 [20]. However, the sample was small, non-random, and participation rates were lower than similar studies using the same methods of identifying and inviting panellists [41]. There was small representation by panellists from

medicine/nursing disciplines (and rural locations), which means that the identified priorities might not reflect the goals of the two main disciplines in palliative care. The identified research priorities identified may not be definitive or in fact constitute current research gaps, as they may have been investigated but not successfully disseminated. Further Delphi or other studies would be useful to provide a more comprehensive picture of expert opinion, both in Australia and in other countries. Although we sought to develop a holistic picture of health professionals' perspectives for urgent research in adult palliative care, the perspectives of patients and their family caregivers were not represented. Investigating these stakeholders' perceptions in palliative care research will help identify goals for progress so that interventions can target and be tailored to the specific needs of the patient and family members [15,42].

Clinical Implications

This study is the first to systematically generate research priorities for adult palliative care in Australia, based on researchers' and clinicians' perspectives of urgency, gaps in knowledge, and potential for impact on the quality of life of palliative care patients and their families. The study offers guidance for adult palliative care research, nationally and internationally, that could be conducted to address the priorities identified for adult palliative care in Australia, particularly in the areas of communication, integration of palliative care services, carer and family needs, new models and packages of palliative care, Indigenous and cross-cultural populations, and bereavement care. These priorities provide an evidence-base to guide palliative care research that is oriented towards the needs of the researchers and clinicians so that research is strategic, clinically-relevant, and addresses neglected areas.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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Table 1. Summary of panellist characteristics.

Characteristic	Round 1 (N=25) N (%)	Round 2 (N=14) N (%)	Round 3 (N=13) N (%)
Gender			
Male	6 (24)	4 (29)	3 (23)
Female	19 (76)	10 (71)	10 (77)
Role			
Researcher	15 (60)	8 (57)	8 (62)
Clinician	10 (40)	6 (43)	5 (38)
Location			
Metropolitan	23 (92)	13 (93)	12 (92)
Rural	2 (8)	1 (7)	1 (8)
Site			
Inpatient	7 (28)	4 (29)	3 (23)
Other (e.g., home-based, university)	18 (72)	10 (71)	10 (77)
Discipline			
Medicine and nursing	6 (24)	2 (14)	1 (8)
Allied health (e.g., occupational therapy, psychology, radiation therapy, social work, spiritual care, pharmacy)	19 (76)	12 (86)	12 (92)
Member of a multidisciplinary team			
Yes	17 (68)	8 (57)	8 (62)
No	8 (32)	6 (43)	5 (38)
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Age (years)	53.12 (10.64)	54.14 (10.86)	54.85 (10.96)
Years working in palliative care	22.72 (10.88)	21.38 (9.71)	21.50 (10.13)
Years since graduation	16.36 (9.81)	17.08 (8.74)	17.75 (8.77)

Table 2. Means and Standard Deviations for Each Category and Item (Round 2).

Category and Items	<i>M (SD)</i>
<i>Family and Carer Wellbeing</i>	2.02 (.75)
Identifying the factors that impact on family carers' wellbeing and ability to care.	2.00 (.76)
Determining how family carers can be better supported (i.e., respite, financial, psychosocial).	2.14 (.95)
Determining the economic impact of caring on family carers.	2.00 (.88)
Understanding the economic and social costs experienced by families and communities associated with caring for people with life limiting illness in the community.	1.93 (.92)
*Determining how to routinely and formally identify and address family carers' needs for support during the palliative care trajectory so that it is part of standard care.	1.79 (.89)
Developing strategies for family members to manage family dynamics when a family member is receiving palliative care.	2.14 (.86)
Investigating the impact of community-based palliative care on informal carers' quality of life/wellbeing.	2.00 (.88)
Determining how to support and prepare families (particularly children) better for death.	2.14 (.77)
<i>Communication between Health Care Professionals and Patients/Families</i>	1.67 (.61)
Improving the communication interface between health professionals and patients/families.	1.86 (.77)
*Improving the communication of accurate information about prognosis upon diagnosis to patients.	1.64 (.75)
*Improving involvement of patients and significant others in decisions regarding care in the last week of life.	1.50 (.65)
<i>Community Education and Capacity Building for End-of-Life Care</i>	1.80 (.38)
*Providing public education about palliative care and its role in our society.	1.43 (.65)
*Investigating the benefit to society of being able to talk openly about death and dying.	1.79 (.58)
*Determining the role of palliative care in assisting the discussion of death and dying in the community.	1.71 (.73)
Determining community attitudes to palliative care.	2.07 (.73)
Determining how community attitudes to palliative care predict engagement in palliative care.	2.14 (.66)
*Determining how community attitudes to palliative care relate to attitudes to euthanasia and physician-assisted suicide.	1.64 (.63)
Understanding how to build capacity for end-of-life care in a variety of Australian communities.	1.86 (1.10)
*Exploring cross-cultural approaches to terminal illness, death and dying and how these can inform palliative care.	1.79 (.58)
*Understanding how communities rally and mobilise to support people at home during advanced, progressive disease.	1.79 (.70)
<i>Health Economics</i>	2.00 (.96)
Assessing cost-effective models of palliative care in Australia.	2.00 (.96)
<i>Integration of Palliative Care</i>	1.91 (.64)
*Determining how hospitals and GPs can work with palliative care to identify and address the needs of older people experiencing multi-morbidity that results in a life-limiting condition.	1.71 (.61)
Determining how to integrate palliative care with existing healthcare services.	1.79 (.80)
Determining how coordinated advance care planning processes can be implemented across different healthcare and community contexts	1.86 (.77)
Understanding barriers to achieving effective collaboration between informal care offered in communities and care provided through formal services.	2.07 (.92)
Determining how to integrate palliative care with primary care so that people who indicate a wish to remain at home can do so for as long as possible.	1.93 (.92)

*Understanding the processes that support dying people and their networks in achieving a death at home.	1.79 (.89)
Determining how to establish network-centred care so that dying people and their family carers are best supported.	2.00 (.96)
Establishing effective and efficient coordination between disciplines and services to simplify information and sources of information.	2.07 (.83)
*Developing communication between active treatment and palliative care so the transition to palliative care is less of a surprise to patients and families.	1.71 (.83)
Improving integration with regional and remote areas.	2.14 (.95)
<i>Models of Care</i>	1.90 (.70)
Identifying barriers to accessing palliative care pathways.	2.00 (.96)
Investigating how the palliative care sector can re-orient towards a public health approach.	1.86 (1.03)
*Establishing palliative care packages for those wishing to remain home but have significant care needs outside of usual available provision of care.	1.86 (.86)
Identifying barriers to service delivery so that best-practice palliative care can be delivered for all who need it.	2.14 (.95)
*Investigating how the aged care sector can identify and provide for the potentially lengthy end-of-life support to the aged who may have multiple co-morbidities but no clear diagnosis for palliative intervention.	1.64 (.75)
<i>Needs of Patients and Families</i>	2.10 (.82)
Identifying what matters most to patients and family carers.	1.79 (.97)
Developing instruments to assess the holistic needs of clients and families e.g., psycho-social, spiritual, financial, etc.	2.21 (.97)
Determining the holistic needs of clients and families e.g., psycho-social, spiritual, financial, etc.	2.00 (1.04)
Developing outcome measures of quality of life, prognosis etc.	2.36 (1.15)
Integrating outcome measures of quality of life, prognosis etc. into usual care.	2.43 (.85)
Investigating if supporting the needs of patients reduces their distress.	2.21 (1.19)
Assessing psychological distress of dying people (e.g., existential distress, death anxiety).	1.93 (1.07)
Developing interventions to reduce psychological distress of dying people (e.g., existential distress, death anxiety).	1.71 (.99)
Investigating discrepancies between patients' wishes regarding the location and style of their death and what occurs.	2.29 (.82)
<i>Outcomes of Palliative Care</i>	2.09 (.75)
Determining the mechanisms or key ingredients of palliative care that make it work.	2.50 (.94)
Determining which patients will benefit most from different forms of service delivery – specialist palliative care versus other supports.	2.14 (1.03)
Understanding how palliative care (experienced by 20%) might contribute to end-of-life care for all.	2.14 (.86)
Comparing the outcomes from early commencement of palliative care versus late entrance to palliative care in the community.	1.93 (.92)
*Exploring the experiences of people who die without receiving palliative care.	1.71 (.91)
<i>Specific Populations</i>	1.99 (.71)
Exploring end-of-life decision-making in Parkinson's Disease.	2.14 (.95)
Determining how to offer targeted support for the children of the dying.	2.00 (.96)
Developing evidence-based palliative care support services to marginalised groups in society e.g., disability, dementia, diverse cultural communities, people living in rural, remote and isolated regions, the homeless.	1.79 (.97)
Expanding knowledge of Diffuse Lewy Body Disease to improve diagnosis and reduce untreated psychiatric and physical symptoms and suffering for patients and carers	2.43 (1.02)
Determining how to expand hospice and palliative care to people with non-malignant diseases.	1.93 (.92)
Improving dyspnoea and secretion management in Motor Neurone Disease.	2.14 (.86)
*Improving palliative care for indigenous communities.	1.71 (.83)

Understanding the experience of living with life-limiting illnesses for vulnerable populations e.g., rural and remote, Aboriginal and Torres Strait Islanders, culturally and linguistically diverse populations.	1.86 (.95)
Identifying when chronic conditions become “end-stage” for palliative care.	1.93 (.92)
<i>Symptom Management</i>	2.26 (.69)
Exploring analgesic pharmacology to improve outcomes in palliative care.	2.43 (.85)
Determining appropriate prescribing of opioid analgesics to improve outcomes in palliative care.	2.29 (.91)
Exploring ways to improve medication adherence to promote symptom management.	2.50 (.76)
Exploring ways to improve treatment of neuropathic pain.	2.21 (.89)
Exploring palliative care patients' and carers' experiences of being palliative.	2.07 (.92)
Understanding what patients want to enhance their quality of life.	2.00 (1.04)
Establishing evidence for best-practice symptom management in palliative and end-of-life care for all health professionals using the palliative approach.	2.29 (1.07)
Developing clinical trials to test palliative care-specific medications for symptom management e.g., pain, nausea, dyspnoea, fatigue, delirium.	2.29 (.91)
<i>Alternative Interventions</i>	2.31 (.74)
Exploring the usefulness and adverse effects of cannabinoids.	2.00 (.96)
Determining the contribution of creative arts in palliative care.	2.57 (.76)
Establishing an evidence-base for alternative therapies in palliative care.	2.36 (.84)
<i>Bereavement Care</i>	1.88 (.43)
Enhancing bereavement risk assessment during the palliative phase to determine the factors during the period of care that can predict adverse outcomes for family carers	2.00 (.68)
*Assessing the impact of assisted dying legislation on family decision-making and bereavement outcomes	1.64 (.75)
*Determining how to increase access to bereavement services that are already available	1.64 (.75)
*Improving bereavement care in rural, remote, and Aboriginal populations.	1.71 (.91)
Investigating how to provide evidence-based and cost-effective bereavement care.	1.79 (1.05)
Identifying predictors of poor long-term bereavement outcomes for family carers.	1.93 (.73)
Identifying where bereavement care is best situated – palliative care, bereavement services, etc.	2.21 (.80)
Identifying bereavement services that are already available and how they align with current understandings of grief and bereavement.	1.93 (.73)
Understanding anticipatory grief and ambiguous grief in palliative settings.	2.14 (.77)
Identifying determinants of the lack of community-based bereavement support for families when their loved one dies of a non-cancer diagnosis.	1.79 (.89)
<i>Staff Training and Development</i>	2.24 (.66)
Determining how health professionals gain knowledge and understanding of palliative care.	2.14 (.77)
Exploring the understandings of palliative care held by healthcare professionals and practitioners outside of specialist palliative care, particularly oncologist and GPs.	2.29 (.82)
Developing and testing interventions to support health professionals working in palliative care.	2.36 (.93)
Identifying training needs of community pharmacists to be part of the palliative care team.	2.21 (.80)
Identifying palliative care healthcare professionals' understandings of the needs of grieving people.	2.36 (.84)
Identifying ways to optimise educational methodologies to increase knowledge and skills	2.14 (1.03)
Determining palliative care healthcare professionals' risk and protective factors in vicarious trauma and burnout.	2.21 (.89)
Developing strategies for health professionals to manage family dynamics when a family member is receiving palliative care.	2.07 (.92)

Identifying ways in which clinicians, in particular hospital-based clinicians, can improve their skills and knowledge of providing adequate palliative care to the patients that they care for.	2.07 (1.00)
Exploring compassion fatigue in palliative care and oncology health care professionals.	2.43 (.85)

Note. *Items achieving consensus as “very important/urgent priority”.

Table 3. Prioritised Research Agenda for Palliative Care in Australia.

Rank	Research Priority	Category	Round 2 Rating	Rated “very important/urgent priority” in Round 2 <i>N</i> (%)	Ranked in top 10 in Round 3 <i>N</i> (%)
1	Developing communication between active treatment and palliative care so the transition to palliative care is less of a surprise to patients and families.	Integration of palliative care	1.71	6 (42.86)	9 (69.2)
2	Improving the communication of accurate information about prognosis upon diagnosis to patients.	Communication between health care professionals and patients/families	1.64	7 (50)	9 (69.2)
3	Improving palliative care for indigenous communities.	Specific populations	1.71	6 (42.86)	7 (53.8)
4	Establishing palliative care packages for those wishing to remain home but have significant care needs outside of usual available provision of care.	Models of care	1.86	7 (50)	7 (53.8)
5	Determining how to routinely and formally identify and address family caregivers’ needs for support during the palliative care trajectory so that it is part of standard care.	Family and carer wellbeing	1.79	6 (42.86)	8 (61.5)
6	Investigating how the aged care sector can identify and provide for the potentially lengthy end-of-life support to the aged who may have multiple co-morbidities but no clear diagnosis for palliative intervention.	Models of care	1.64	7 (50)	7 (53.8)
7	Improving involvement of patients and significant others in decisions regarding care in the last week of life.	Communication between health care professionals and patients/families	1.50	8 (57.14)	11 (84.6)
8	Exploring cross-cultural approaches to terminal illness, death and dying and how these can inform palliative care.	Community education and capacity building for end-of-life care	1.79	4 (28.57)	9 (69.2)
9	Assessing the impact of assisted dying legislation on family decision-making and bereavement outcomes.	Bereavement care	1.64	7 (50)	9 (69.2)
10	Improving bereavement care in rural, remote and Aboriginal populations.	Bereavement care	1.71	7 (50)	7 (53.8)

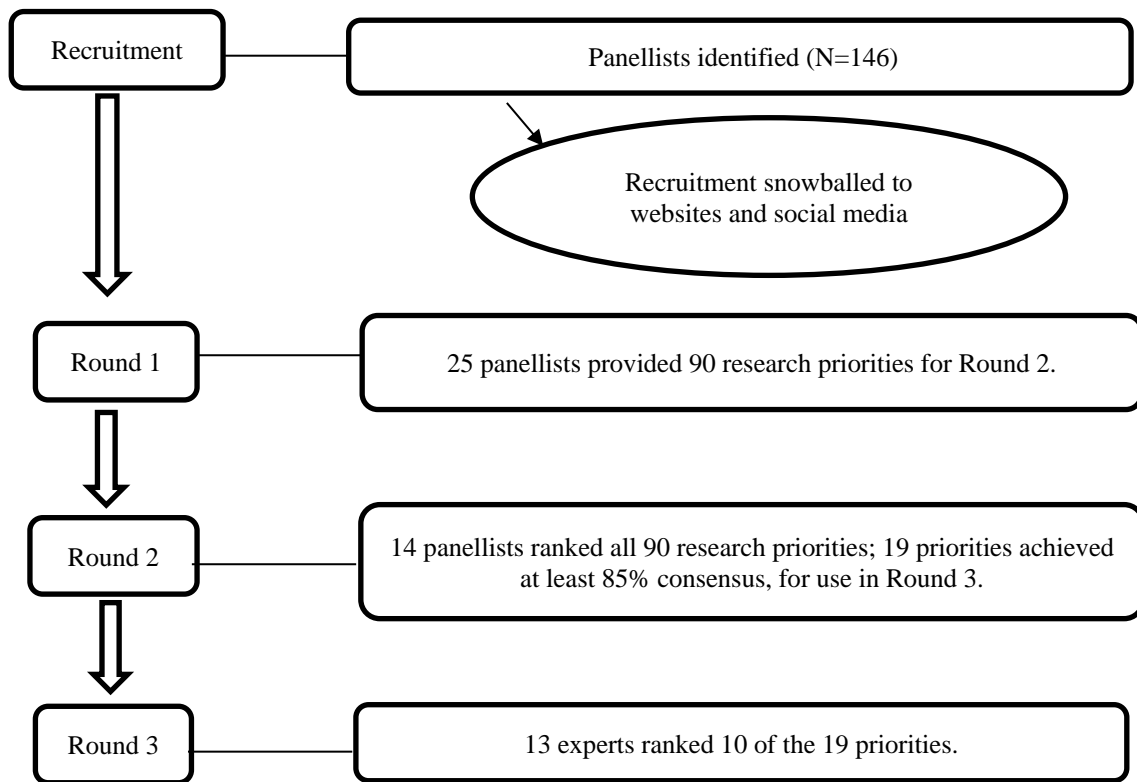


Figure 1. Flow chart of the modified three-round Delphi survey.