

Chapter 9

Research and data

9.1 This chapter looks at research and data collection efforts in relation to palliative care needs in Australia. It outlines the current state of research and areas for improvement, including the need for a more strategic and coordinated national research agenda and priority areas for further research. The chapter examines some current research initiatives and also considers funding arrangements. Data collection is covered, including the need for clinical services to collect evidence in a systematic way in order to inform research and best practice in palliative care. Finally, the chapter will briefly look at issues around the evidence base for palliative care medicines, including complementary medicines.

A nationally coordinated approach to research is needed

9.2 Witnesses told the committee that palliative care needed to be nationally prioritised on Australia's research agenda, with appropriate funds and targeted research programs.¹

9.3 The Clinical Oncology Society of Australia (COSA) and Cancer Voices Australia (CVA) advocated in their submission:

An increased commitment to research implementation to ensure research findings are translated into clinical practice.

Establishing strategies to monitor and record all types of palliative care activity in Australia.

An emphasis on palliative care research in health and medical research funding mechanisms within Australia.²

9.4 Associate Professor Jennifer Philip, Co-Deputy Director of the Centre for Palliative Care, emphasised that a well-coordinated and strategic approach to palliative care research was necessary. She stated it was important that 'good care is underpinned by good-quality evidence and also that we are not wasting resources or, perhaps even worse, wasting people's precious time by giving them either ineffective or futile interventions'.³ She told the committee that a coordination approach, for example, through the Palliative Care Clinical Studies Collaborative (PaCCSC)⁴ was a

1 For example see Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 18.

2 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 2.

3 Associate Professor Jennifer Philip, Co-Deputy Director, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 52.

4 Discussed further at the end of this chapter.

good initiative.⁵ Professor Philip also said that Canada and the UK were the countries Australia should be looking at benchmarking itself against in terms of research.⁶

9.5 Professor Patsy Yates, President Elect of Palliative Care Australia (PCA), commented that overall Australia was 'doing pretty well' when compared internationally in terms of palliative care research:

It has really only been in the last decade or so that we have started to see that develop in Australia. Some of that was due to some of the investment that was put in about 10 years ago for some dedicated money to build capacity in the palliative care research sector. I think that has really paid dividends in terms of enabling some really important research to be done.⁷

9.6 However, Professor Yates noted that further development of research evidence was needed in order to better inform areas of practice such as symptom management and models for coordinating patient care at the end of life. She noted that PCA has been engaging with specialist palliative care services to assist them to measure outcomes and use data to drive and improve their practice, stating 'services have taken to that fairly well but they still have a long way to go'.⁸

What is the current state of research?

9.7 The committee heard that there were several palliative care research initiatives underway and other smaller research projects. Information-sharing and networks of clinicians and researchers have also been set up, although fairly informally.

Examples of current work

9.8 The Centre for Palliative Care is an academic research and education centre, which is a collaborative centre of the University of Melbourne, based at St Vincent's Hospital. Associate Professor Mark Boughey, Co-Deputy Director of the Centre, told the committee that it had played 'a fairly significant role in the development of research activity' in the field of palliative care.⁹ Its submission stated:

The Centre has a state-wide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally. The Centre plays a pivotal role in the development and implementation of training and education programs for health professionals from a variety of disciplines, while undertaking cutting-edge research to set benchmarks and improve practices in palliative care.¹⁰

5 Professor Jennifer Philip, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 53.

6 Professor Jennifer Philip, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 56.

7 Professor Patsy Yates, President Elect, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

8 Professor Patsy Yates, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

9 Associate Professor Mark Boughey, Co-Deputy Director, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 52.

10 Centre for Palliative Care, *Submission 110*, p. 1.

9.9 The Amaranth Foundation, which offers support and information to carers and families dealing with terminal illness and promotes a model of care that emphasises the psychosocial aspects of palliative care, said that the research it had published had attracted some attention:

We have had people come to us and say that when they were doing some research and literature searches—because we have just started publishing—that we are the only ones doing this type of work. We have had difficulty with—and respect to people who might be here in the audience—acceptance by the area health service. I have actually been drilled to within an inch of my life as to my professional competencies, my motivation and why we do what we do.¹¹

9.10 Mrs Julianne Whyte, Chief Executive Officer of the Amaranth Foundation, described to the committee some of the research projects she had undertaken, how some of the findings differed from existing healthcare literature, and how this had informed the Foundation's approach to palliative care:

...I was really lucky and fell into some amazing research positions that looked at care-planning needs of patients in rural and remote communities requiring palliative care. These were research opportunities funded under the Department of Health and Ageing Local Palliative Care Grants rounds 4, 5 and 6. I worked with the Commonwealth carer respite centres and the Riverina Division of General Practice, which is now the Murrumbidgee Medicare Local, and also in a private capacity as a social worker in that time. In that time we did quite a lot of research, literature and qualitative and quantitative assessment of what people really wanted in palliative and end-of-life care in the community. We really did not go into the acute care setting, but looked at what was happening in the community in rural and remote New South Wales.

From the work that we did back then, it has been over six years and we have worked with over 400 families. We really felt that we had a good grip on what people were saying were the problems and the issues that they had. What we found, too, was that a lot of stuff is out there about the delivering of bad news, how to communicate with people and what is needed by people; but what I found in my personal experience was that there was not a lot of translation from the research into the practical skills on the ground. There were no people doing what the research said people wanted. That was a bit of a struggle. Our final research project was the round 5, which was looking at mental health, dementia and palliative care. We took a mental health approach to that and looked at how people with a mental illness, whether pre-existing or as a result of their diagnosis, fitted in and managed the palliative care and end-of-life care journey.

We found quite an amazing mismatch between what the research said and people's personal lived experience—the whole aspect of distress, despair, demoralisation, suicidal ideation and how people responded to that within

11 Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 12 July 2012, p. 35.

the healthcare system. Within the existing medical healthcare system but also from the mental health perspective. We found that the mental health and the acute care system rarely talk to each other. There was a real mismatch between what people were given on what people really wanted.¹²

9.11 Mrs Whyte is currently undertaking her PhD on the competency standards of social workers within end-of-life care. She has also started lecturing social workers and psychologist on psychological responses to palliative care at Charles Sturt University.¹³

9.12 Other organisations such as the Pharmacy Guild of Australia are currently undertaking research into the extended role of pharmacy in the palliative care setting.¹⁴

Networks and information sharing

9.13 When asked about what information-sharing networks were present in the palliative care community, Professor Jennifer Philip acknowledged that there was no formal network, but 'an informal network in terms of people [who] are mates and at the same time competitive' for research dollars. She spoke about a network in Victoria which has received funding from the Victorian Cancer Agency to enable greater information-sharing, although this is still in its infancy.¹⁵

9.14 Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group told the committee that the group she represented had 'self-organised':

Dr Hynson:...essentially we are a group of individuals who try to get together when we can, call each other when we can and do things by email. We have been the point of contact for the National Standards Program, NSP. We have also put together a blue booklet for general practitioners on palliative care for children with cancer and we are hoping to do the same for non-malignant conditions. If we had a small amount of funding to meet once a year, to have a few teleconferences and perhaps a project officer to help us with some of those things, we could really leap up exponentially and leverage that goodwill that is already there. It is a great group.

Senator SMITH: It strikes me that it is quite a representative group across the country.

Dr Hynson: We have all had to work very closely because we are all fairly isolated in our own states. Older members of the group have nurtured the younger ones, so there is a real spirit of bringing through the next

12 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 27.

13 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 12 July 2012, p. 27.

14 Mr Harvey Cuthill, National Councillor, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, p. 4.

15 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53.

generation and sharing. There is not a spirit of competition at all; it is very much about collaboration.¹⁶

What are some future research priorities?

9.15 Witnesses told the committee that research needed to continue in areas such as drug interventions and symptom interventions. Although these are probably the most well-researched aspects of palliative care, there are still evidence gaps.¹⁷ For example, Professor David Currow, Professor of Palliative and Supportive Services at Flinders University, spoke about evidence gaps around delirium and the risks and benefits of anti-psychotic medications:

...which are prescribed thousands of times each day for people who are acutely confused. We do not have any evidence that their benefit over and above good nursing care is there and, in fact, for some people they may be detrimental. We need to answer those questions and that may have important consequences for other parts of health care, particularly aged care, the acutely unwell as people come in from trauma or people in the post-operative setting.¹⁸

9.16 Psychosocial interventions were identified as a particular area needing further investigation:

...what really are effective ways of helping someone to look after someone at home, what is the most effective way to manage a person who develops a delirium at home when we know that is often a time when families will find it too difficult and bail out and take that person to hospital, even though it may well be in the very last period of time of life. I think some of those psychosocial interventions are a particular area. In Australia we have quite a lot of expertise in those but it has not been in a coordinated way, it has been around a couple of key people who have tried to do things bit by bit.¹⁹

9.17 Dr Hynson told the committee that further research on children receiving palliative care was needed. At the moment, she and her colleagues in paediatric care seek advice on symptom and pain management from those providing palliative care to adults. She noted the limitations of this approach, given the dearth of evidence in this area: 'A lot of the medications we use are not approved for use in children. We are doing it because we are having to push the boundaries in terms of extrapolating practice from adult practice into the paediatric world'.²⁰

16 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, and Senator Dean Smith, *Committee Hansard*, 4 July 2012, p. 30.

17 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 54.

18 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 66.

19 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 54.

20 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 30.

9.18 Another area identified for research related to the information needs of parents who have a child diagnosed with a terminal illness. According to Mrs Fiona Engwirda, State Council Member and Consumer Representative for Palliative Care Queensland, the best pathway to enable swift referral and access to appropriate services should be the subject of further research.²¹ The role of families in palliative care was another suggestion for further research.²²

9.19 The Medical Oncology Group of Australia told the committee about a project it hoped to have funded, involving the delivery of care using telemedicine:

At its most basic, if you have a little Skype camera sitting on your laptop at home, you can interview a patient. From a regional cancer centre a specialised nurse, for instance, would be able to interview a patient and a carer, look at what pain levels they have, look at the medications they are taking, make suggestions about altering those and then check back in with that patient 24 hours later to see what has happened. A group of us in Australia are working on some national guidelines for cancer pain management and trying to pull together all the evidence and turn that into a program—if this, do that; if that, do that.²³

Recommendation 15

9.20 The committee recommends that the Commonwealth government increase its support for paediatric palliative care research.

Funding for palliative care research

9.21 The committee heard that grant funding for palliative care research largely came from the Commonwealth Government.²⁴

9.22 Professor Jennifer Philip emphasised that sustained funding was required in an area still in 'relative infancy' so that research programs could be built and more postgraduate positions could be created to be able to compete for grants.

It does take a little bit of time to get to that level, to evolve those centres of experience and excellence in order to be able to do that. So I think the notion of having some sustained funding for a period of time is important.

Having said that too little of the cancer dollar is going to palliative care, it is also true that the major area where palliative care research funding comes from is from cancer. Yet we know that people with heart disease et cetera also have requirements for palliative care. Those bodies probably need some encouragement for them to start considering directing some of the

21 Mrs Fiona Engwirda, *Committee Hansard*, 2 July 2012, p. 28.

22 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53. See also Centre for Palliative Care, *Submission 110*, p. 2.

23 Associate Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 42.

24 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 25.

research dollars towards palliative care research, because it is important for that group of patients as well.²⁵

9.23 She noted a Canadian research model around palliative care which has been aimed at developing key research areas through five-year periods of funding:

...thereafter they have been able to create ongoing funding streams themselves, getting competitive grants. It has attracted a number of postdocs and has built capacity and world excellence in those areas. So it is an interesting model that may be of interest to the committee.²⁶

Cancer research funding and palliative care

9.24 The committee heard calls for palliative care to be integrated as a fundamental part of cancer care, including from a research perspective.²⁷ Professor Philip observed that not enough of the cancer research budget was currently being directed to palliative care:

We know that in other countries, particularly the US and the UK, palliative care research takes up less than one per cent of the cancer research budget. We do not have the figures for Australia, but we do know that between a quarter to a third—and, in some places, even higher—of people who are diagnosed with non-skin cancers will die from cancer. So, currently, an incommensurate amount of the research dollar is going to palliative care. Cancer Australia have agreed that they will audit their research output with respect to palliative care, so I think that is going to be done in the next round.²⁸

9.25 She said that in terms of National Health and Medical Research Council funding, she could recall at least two specifically targeted rounds in the last 12 years with palliative care as a priority. (From one of those funding rounds, Professor Philip had received a PhD scholarship.)²⁹

9.26 The committee notes that Cancer Australia collaborates with the NHMRC in administering the Priority-driven Collaborative Cancer Research Scheme. The Scheme is an 'annual national research project grants funding scheme which brings together government and other funders of cancer research to collaboratively fund cancer research in Australia'.³⁰ Funding bodies set priorities each year for that round of grants.³¹

25 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, pp. 52–3.

26 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53.

27 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 2.

28 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 52.

29 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, pp. 53–4.

30 Cancer Australia, Priority-driven research <http://www.canceraustralia.gov.au/research-data/research/priority-driven-research> (accessed 2 October 2012).

31 Cancer Australia, Research priorities for 2012 <http://www.canceraustralia.gov.au/research-data/research/priority-driven-research/research-priorities-2012> (accessed 2 October 2012).

9.27 Ms Kate Swetenham from SA Health commented that grant funding is inherently unstable and that in an ideal world it would be good 'to have some positions bolted to the floor with some ongoing funding so that you can retain that research culture'. She added:

I think it is unsettling and nerve wracking for people who take on contract positions to near the end of their contract. Then they start to look elsewhere even though there might be a degree of comfort that this is likely to continue or develop into something else. Then you lose that critical mass that you have through their involvement and have to retrain someone else into it. So you are constantly experiencing downtime which impacts negatively on your ability to get things done in a timely fashion.³²

Data collection

9.28 Evidence from submitters and witnesses pointed to the need for consistent data collection practices to become embedded in the clinical environment and for systems to be set up to enable the accurate measurement of this data. The committee heard about the significant gaps in data collection and the consequences of this in terms of quality of care and services.

Lack of good data

9.29 Mr Peter Cleasby, President of Palliative Care New South Wales, commented that in New South Wales, palliative care data is not good and is 'contaminated by a range of different artefacts within the hospital system in particular'.³³

9.30 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre for Blue Care, expressed frustration that it was 'almost impossible to get good figures about how many people transfer from a residential aged-care facility into a hospital and actually die in the hospital; or do they come back?' She said that determining the advantages and disadvantages of transferring patients was constrained by this lack of data:

There is often a myth about the enormous volume of people being transferred from residential aged care into public hospitals to die, but we do not know the figures. We know how many people get transferred, but we do not know what happens to them once they are transferred—whether they come back. It is often appropriate to transfer somebody from residential care into a hospital—I am not saying that you should never do that—but until we really have a handle on the volume of that work and why those people are transferred and do not come back, it is hard to solve that problem.³⁴

32 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 27.

33 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, p. 48.

34 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, Blue Care, *Committee Hansard*, 2 July 2012, p. 4.

9.31 Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, advocated the development of industry benchmarks and the strengthening of compliance with the 13 standards set by Palliative Care Australia. However, he acknowledged that a lack of good data available for external analysis made this task difficult.³⁵

9.32 The Clinical Oncology Society of Australia and Cancer Voices Australia suggested establishing a web portal for palliative care data and a mechanism for the collection of this data.³⁶

The role of the Commonwealth in supporting data collection

9.33 The Department of Health and Ageing appeared before the committee and outlined what funding had gone towards improving data collection in palliative care:

As part of the National Palliative Care Strategy we fund projects to improve data collection and, indeed, we have funded AIHW, the Australian Institute of Health and Welfare, over a number of years to improve national data on palliative care provision. We currently have a project over the years 2011-12 to 2013-14 which is focusing on developing performance indicators for the National Palliative Care Strategy, publication of annual compendium reports on palliative care data and associated work, and supporting a data subcommittee of the palliative care working group, which is the group of all Commonwealth, state and territory officials. Nevertheless, this is an iterative process and data in these areas is improving...Certainly the goal is to progressively improve the comprehensiveness, quality, comparability and consistency of palliative care data more broadly.³⁷

The role of clinical services in contributing to the evidence base

9.34 Several witnesses told the committee that it was crucial that clinical services delivering palliative care should build in measurement, data collection and evaluation of outcomes in order to contribute to growing the evidence base for the best interventions and management approaches.

9.35 For example, Professor David Currow, Professor of Palliative and Supportive Services at Flinders University, acknowledged it was 'very tempting' for specialist services to focus only on clinical matters, but he stressed that:

...if we do that we do not progress the research evidence base that will improve the models of care and the clinical care we offer, and we will not progress the education that needs to be provided to colleagues who are currently in practice and for whom this was not part of their training.³⁸

35 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

36 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 1.

37 Ms Alice Creelman, Assistant Secretary, Cancer and Palliative Care Branch, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 44.

38 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

9.36 In South Australia, full tertiary palliative care services (designated as 'level 6 services') are required to provide research evidence and input into education programs across the undergraduate and postgraduate curricula.³⁹

9.37 Associate Professor Rohan Vora, President of Palliative Care Queensland, was a strong advocate for mandatory data collection and measurement of patient outcomes:

This is absolutely vital and we need to be funded to be able to do that to get some meaningful data. At the moment, each service has to try to find somewhere within it, along with service provision, someone who is actually going to collect this data and down clinical time to do it.⁴⁰

Current data collection work

9.38 While noting the real need for better palliative care data collection, the committee was pleased to hear about some existing initiatives to drive improvement in this area.

Palliative Care Outcomes Collaboration

9.39 The committee heard about the Palliative Care Outcomes Collaboration (PCOC). Its submission outlined its role:

Palliative Care Outcomes Collaboration (PCOC) is an excellent example of a national and voluntary programme using benchmarking to measure outcomes in palliative care. PCOC assists palliative care providers to improve patient outcomes by enabling their clinicians to accurately assess the quantity of care they provide to their patients.

PCOC obtains and reports on information regarding patient care and symptom management. This information supports clinicians in their treatment decisions, assists managers in their service planning and informs policy makers in funding and planning services.

Participating palliative care services submit their data sets biannually to PCOC, enabling PCOC to develop state and national data sets. These datasets are analysed and reported to services, providing them with feedback of their performance, recognition of their achievements and opportunities for quality improvement in their delivery of patient care.

With the primary aim of enhancing palliative care delivery in Australia, PCOC works to support palliative care services by providing education, report analysis and participation in research and quality improvement activities.⁴¹

9.40 Blue Care appeared before the committee and stated that the work of the PCOC had been compromised to some extent by a lack of willingness from large

39 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 22.

40 Associate Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 24–5.

41 Palliative Care Outcomes Collaboration, *Submission 111*, p. 1.

organisations to participate in data collection for PCOC. They described the 'extra administrative burden' felt by some organisations in Queensland which hampered good data collection.⁴²

9.41 Professor David Currow responded to these observations, acknowledging that embedding data collection practices into clinical care would naturally take time:

...we are asking for a data naive clinical community to very rapidly collect data at point of care and start to compare with each other in a benchmarking process. That is a difficult issue for any community. If we look across clinical care, we can look to emergency medicine, intensive care, some of the surgical subspecialties, neonatal care and, to a lesser extent, maternal and child health as the only other areas that are really taking on data collection at this sort of level of granularity.

It is not particularly onerous and we have seen small, relatively poorly resourced teams not only come on board; most importantly, their key success factor has been embedding this into their day-to-day clinical work. This is not esoterica out here; it is actually practical stuff. It is stuff that we say to the community we do well—things like, 'What is the pain control like for this person today?'⁴³

9.42 Professor Currow described how the PCOC had succeeded in getting the palliative care sector engaged in reporting of data:

Within a very short space of time, 2006 to 2012, to have this up and running, where we estimate that 80 per cent of all people referred to specialist palliative care services are covered, is a tremendous engagement of the sector.

We have seen lots of services who can now say, 'We've collected the data for the first time systematically. We've seen a problem. We've put a program in place to address that problem and we've seen our outcomes improve.' There were lots of people who said, 'You can't measure outcomes in palliative care.' Clearly we can and they are patient centred outcomes: 'What is your symptom control like? What are we doing to better maintain your level of function in the face of inexorable decline?' And, yes, there are a couple of very notable services across the country that are not participating, but they are the exceptions now.⁴⁴

9.43 He acknowledged the reticence of some services to participate fully in the work of the PCOC, noting that some groups within the Collaborative 'have really been challenged by some of their results':

Prof. Currow:...This is not a comfortable place for every service to be. If we look at a median, half the services are going to be below the [median]. So the investment has been to work alongside services to look at how the

42 Associate Professor Deborah Parker, Blue Care, *Committee Hansard*, 2 July 2012, p. 4.

43 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 65.

44 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 65.

quality of that care can be improved, and that is what we are starting to see now.

...

Senator MOORE: Has there been any attempt to link this data to funding? Would you be afraid that, if you gave data and it did not look good, you might not get funding?

Prof. Currow: It is a voluntary program at the moment and it has been deliberately voluntary for a couple of reasons. You have absolutely identified the major one. There is another large service provider that is participating in yet another state, and they were already collecting much of this data and their funding was contingent on it. They have had to look at how they collect their data so that they are actually reflecting patient centred responses.⁴⁵

Mortality reviews

9.44 Associate Professor Rohan Vora described to the committee a process developed on the Gold Coast known as a mortality review for expected deaths. These reviews are normally done for unexpected deaths, but not usually for expected deaths. Mortality reviews examine the 'quality of death'.⁴⁶ Associate Professor Vora explained:

Mortality reviews are usually there to see whether you should have informed the coroner or done something different to avoid death. We have introduced a different type of mortality review and continue to do that. Mortality reviews, we believe, should also include expected deaths—that should be audited for quality of care, carer support and bereavement follow-up plans.⁴⁷

Committee view

9.45 The committee considers that building the research and evidence base for palliative care in Australia is crucial to improving service delivery and quality of care. There is a need for a more strategic and coordinated research agenda, underpinned by adequate funding. In this regard, the Committee notes that the government in 2011 commissioned the Strategic Review of Health and Medical Research in Australia, chaired by Simon McKeon AO. This review has a number of terms of reference relevant to the preceding discussion, including 'current expenditure on, and support for, health and medical research in Australia by governments at all levels', 'ways in which the broader health reform process can be leveraged to improve research and translation opportunities in preventative health and in the primary, aged and acute care sectors', and 'the degree of alignment between Australia's health and medical research

45 Professor David Currow and Senator Claire Moore, *Committee Hansard*, 2 July 2012, p. 65.

46 Associate Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 32.

47 Associate Professor Rohan Vora, President-Elect, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 10.

activities and the determinants of good health'.⁴⁸ The committee notes that the NHMRC and Centre for Palliative Care were submitters to this process, which is ongoing.

Recommendation 16

9.46 The committee recommends that Cancer Australia, in reviewing the distribution of research funding, discuss with funding bodies the capacity to ensure that appropriate levels of funding are being provided to palliative care research.

9.47 The committee also supports a systematic approach to data collection and measurement. It acknowledges the good work of the Palliative Care Outcomes Collaboration and considers that improvements in data collection and evaluation would not only lead to better translation of clinical evidence into best practice evidence, guidelines and standards, but increased efficiencies in terms of resource allocation and costs to the health system through better knowledge of what works well in palliative care.

Recommendation 17

9.48 The committee recommends that governments encourage care providers to provide data to the Palliative Care Outcomes Collaboration and consider making the reporting of this data a condition of public funding.

9.49 The committee notes the recommendation of the Centre for Palliative Care:

Develop a nationally funded framework for palliative care research that:

1. Provides funding for the development of research programs specifically addressing symptom management, psychosocial support (including family carers and bereavement), and health service evaluation.
2. Invests in capacity building by developing a critical mass of palliative care researchers.
3. Creates a “whole of health” approach to palliative care research that incorporates cancer care and non-malignant diseases.
4. Focuses on strategies to translate research into practice in specialist and generalist settings.⁴⁹

Recommendation 18

9.50 The committee recommends that the Australian government develop a nationally funded framework for palliative care research, as outlined by the Centre for Palliative Care.

48 Strategic Review of Health and Medical Research in Australia, Terms of Reference, http://www.mckeeonreview.org.au/9937/Terms_of_Reference/ (accessed 2 October 2012).

49 Centre for Palliative Care, *Submission 110*, p. 3.

Evidence base for medicines

Palliative Care Clinical Studies Collaborative

9.51 The Palliative Care Clinical Studies Collaborative (PaCCSC) was first funded in 2002–03.⁵⁰ Administered by Flinders University⁵¹ and led by Professor David Currow, the Collaborative's focus is multi-site clinical drug trials to gather evidence to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the Pharmaceutical Benefits Scheme (PBS).⁵²

9.52 Professor David Currow explained to the committee that the PaCCSC's funding from the Commonwealth currently runs until mid-2014. He said there had been 'a fantastic return on investment' from this collaborative work—for example:

We were delighted last year, for example, to have three sites where the Australian Council on Healthcare Standards—and these were not sites that were just palliative care; they were across the range of clinical care—singled out the palliative care units for the quality of the work that they were doing as the most highly commended on site, and that was because of the Palliative Care Clinical Studies Collaborative. So there are direct collateral benefits that patients, their families and staff will experience because of that investment by the Commonwealth.⁵³

9.53 The committee heard from Professor Currow about the work that had been done over the last decade by the PaCCSC on the evidence base for medicines used in palliative care. In 2000 from a national survey, a number of medications were identified as critical to community based palliative care. Work was done to have some of these medicines listed for subsidy on the PBS in 2004. However, for other medications in widespread use, not enough evidence for their effectiveness had been identified:

The Commonwealth then put out a tender for an organisation to lead national, collaborative, multisite research for clinical trials at a level of quality that would inform both registration with the Therapeutic Goods Administration and importantly subsequent subsidy, were they to be positive studies with the Pharmaceutical Benefits Advisory Committee [PBAC].

I want to go on record as saying that, as those studies were developed, the TGA [Therapeutic Goods Administration] and the PBAC offered to every

50 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 67.

51 The PaCCSC comprises Flinders University/Southern Adelaide Palliative Services, Sydney Cancer Centre, Sydney South West Area Palliative Care Service – Liverpool Palliative Care Services, WA Centre for Cancer and Palliative Care, Centre for Palliative Care Research and Education/Queensland University of Technology/Mater Health Service and the Peter MacCallum Cancer Institute.

52 'Increased access to palliative medicines in the community', Department of Health and Ageing, <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program-prio2> (accessed 14 September 2012).

53 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 67.

company, every new triallist, the opportunity to talk about the design. We have done that ahead of these ever going to ethics committees and their input has been absolutely invaluable in refining that process. At the moment, there are 12 sites across Australia who are participating in these studies. They cannot be done in other populations. We cannot take information from a population of people who are relatively well and extrapolate it into [these] populations who are frail, on many medications and need to have evidence developed for them. Two of those studies have already been completed and are being reported at the moment. Importantly, some of these findings will be able to be extrapolated to other areas of health care.⁵⁴

Complementary medicine

9.54 In discussion with the Medical Oncology Group of Australia, the committee heard that complementary medicines are widely used in palliative care and that there was a lack of research around the evidence for these substances, such as herbs and vitamins, which have sometimes been recommended to patients by general practitioners. Associate Professor Frances Boyle, Former Executive of the Medical Oncology Group of Australia, told the committee of the risks involved in mixing these therapies with chemotherapy drugs:

It is almost impossible then to work out what the interactions might be with chemotherapy drugs. Many chemotherapy drugs are made from plants and for that reason they have the potential, in the liver, to interact and change each other's metabolism. We have the greatest respect for medicinal plants. We cure a lot of cancer with them—but by knowing what the active ingredient is and purifying it rather than by having something that you are taking orally, with poor labelling. The other thing, of course, is that there is increasing evidence that things like meditation, relaxation and so forth are beneficial to cancer patients. I do not think that the herbs and spices really fall into the same category as many of the other mind-body type things where there is clear evidence of benefit. We encourage patients with advanced cancer to become involved in those things.⁵⁵

9.55 Ms Kay Francis, Executive Officer, added that the Medical Oncology Group of Australia held significant concerns about the lack of regulation of complementary medicines:

Ms Francis:...The media are constantly hyping up all of these quite often bogus treatments and recipes for a 'solution' to cancer or any number of diseases. But we have a totally unregulated market. It is absolutely extraordinary, when we have such an effective health system and controls in place in all other areas of drug access in this country.

Senator FIERRAVANTI-WELLS: Your comments do not appear to deny that there should be complementary medicines—

54 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 66.

55 Associate Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 44.

Ms Francis: No, not at all.

Senator FIERRAVANTI-WELLS: There is a role for them but it is part of a more holistic and a more—

Ms Francis: Exactly. We need to have, whether it is the Therapeutic Goods Administration or some other new body that needs to be established in the Department of Health and Ageing, I think it is time at a federal level that we address this.

Senator FIERRAVANTI-WELLS: I think there is now quite a high usage of complementary medicines in Australia.

Ms Francis: I think that something like 75 per cent of patients across the board in Australia use some form of complementary medicine, regardless of their condition.⁵⁶

9.56 Professor Boyle noted that the National Health and Medical Research Council (NHMRC) is now looking more closely at complementary medicines and that 'there are a number of groups around the country who would have the appropriate scientific rationale and background to do appropriate research in that area'.⁵⁷

Committee view

9.57 The committee notes that complementary medicines are in widespread use around Australia. It acknowledges the concerns of expert clinicians from the field of cancer care regarding the lack of evidence and regulation of these alternative therapies. The committee welcomes the work being done by the NHMRC⁵⁸ into examining 'alternative therapy claims' and supports further research being conducted into the interactions of complementary medicines with evidence-based drugs used specifically for cancer care and palliative care.

Recommendation 19

9.58 The committee recommends that the NHMRC publicly report the results of its work on alternative therapy claims in relation to palliative care.

56 Ms Kay Francis, Executive Officer, Medical Oncology Group of Australia, and Senator Concetta Fierravanti-Wells, *Committee Hansard*, 2 July 2012, p. 44.

57 Associate Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 44.

58 See 'Complementary medicines', National Health and Medical Research Council, <http://www.nhmrc.gov.au/your-health/complementary-medicines> (accessed 14 September 2012).