

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 23 July 2015

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Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

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#### Witnesses

Ms Frances Diver, Deputy Secretary, Health Service Performance and Programs,

Ms Jackie Kearney, Manager, Continuing Care, Health Service Programs, and

Ms Pauline Ireland, Director, Health Review and Regulation, Department of Health and Human Services.

**Necessary corrections to be notified to  
executive officer of committee**

**The CHAIR** — I declare open again the Legislative Council legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. Together with my colleagues, I welcome from the Department of Health and Human Services Ms Frances Diver, deputy secretary, health service performance and programs; Ms Jackie Kearney, manager, continuing care, health service programs; and Ms Pauline Ireland, director, health review and regulation. Thank you very much for being here today and for your submission to the inquiry.

I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with proof versions of the transcript in the coming days. The transcript will ultimately be made public and posted on the committee's website.

We have allowed an hour and a half for your session today, and I understand you have a presentation of approximately 30 minutes. We look forward to hearing from you, and thank you again for being here.

**Ms DIVER** — Thank you. Thanks very much for the opportunity to present to the committee. I have here a presentation of about 30 sides which I can talk you through. I think you have either been provided with copies or will be provided copies at the end of my presentation. I also have a little pack of take-home material in case you do not have enough. It covers a range of our documents. It is a package of some of the things I will be referring to.

It is probably worth explaining up-front our roles in the Department of Health and Human Services so you can get a sense of our expertise and the information we can provide for you. As deputy secretary of health service performance and programs I pretty much have the interface with public health services both in policy and programs as well as the performance of the health sector, including the regulation of the private hospitals. Jackie works very closely with the palliative care sector and has detailed knowledge of that sector. Pauline, as a lawyer, has the legal expertise in relation to some of the acts and how they interact with healthcare provision. That gives you a sense of who we are.

The other opening point I would make is that, as many of you will know, we operate under a devolved governance arrangement in Victoria in terms of our health service provision. The Department of Health and Human Services has a role in setting policy, funding and performance, and is a system leader. The actual health service delivery occurs out there under the direction of boards that take responsibility, with chief executive management and clinicians, for the day-to-day care. So really our comments and the information we provide will be about what the department is doing, the shape of the sector and what some of the policy frameworks are. I can see that you have lots of very expert clinicians coming to fill you in on all of the clinical components, but we can certainly talk to the policy aspects, if that helps.

The presentation is designed to give you an overview of the current state of play for the palliative care service system. I can talk a little bit about the advance care planning initiatives and what we are doing in the advance care planning space, and we can talk about the legislative framework. I will probably very quickly hand over to Pauline when we get to those tricky questions.

### **Visual presentation.**

**Ms DIVER** — I will begin by setting the scene. This is not new information but it is important to start with. People are living longer and chronic disease has become a greater feature of the casemix of patients within the healthcare system. That changes the way we need to shape our healthcare system to better meet the needs of people with chronic illness. Around 39 000 people die every year in Victoria — roughly 100 per day. About half of those people are at the end of a chronic disease, and half of all deaths occur in hospitals. That gives you an idea of the kind of demand we have in the healthcare setting. The ageing population, the success of treatment and the remaining people having a larger proportion of chronic disease means that end-of-life care perhaps needs to change for people with chronic disease.

This slide really just covers off a shifting focus on health care. In the past it has been treatment-oriented, cure-oriented and episode-focused. That is still important for a large number of people who have a one-off illness or a one-off treatment requirement, but with a larger component of chronic disease care we need to shift

from a cure focus to a care focus. End-of-life care is similar in that way. Given that context of an ageing population and the chronic disease component of the casemix that hospitals are treating, we need to move to a person-centred focus arrangement for healthcare delivery.

What is palliative care? I am not sure if others have covered this this morning. This is the World Health Organisation definition. Palliative care is an approach to improving quality of life. It is person-centred. It is not just for cancer-related conditions; it is for any life-threatening conditions. It is really about relieving suffering and improving the quality of life towards the end of that trajectory. It includes not just physical care but also the psychological and spiritual aspects of care.

The role of palliative care. What does palliative care do? If we think about it, palliative care is an approach — that is a definition — but palliative care you describe as a model of care. The palliative care sector has a number of ways in which they deliver their work, so palliative care could be actual direct care: doctors and nurses and allied health professionals, as well as volunteers, providing direct care to consumers. The palliative care sector might also be involved in coordinating care, particularly in a community-based setting, sometimes in an inpatient setting. That is coordinating the GPs, the specialists, the oncologists and a range of healthcare providers.

The palliative care sector clinicians also have a leadership role in working with generic health workers to provide consult liaison services. That might be a palliative care physician working with the Royal District Nursing Service, it might be working with a general practitioner to provide consult liaison services. There is also an education and training component of course, and there are a number of particular services that are dedicated towards education and training. And then of course the palliative care sector is involved in undertaking research about caring for the dying and also caring for families and consumers.

One point I would make is that the palliative care sector, whilst it is a relatively small sector with a specialised workforce, not all palliative care actually occurs within the palliative care sector. Palliative care also provide input into care in the generic health system. That is particularly important given that large numbers of people are dying of chronic disease and they need a palliative care input as well.

How do we provide palliative care? Palliative care is provided in hospitals, so we have hospital-based wards and hospices. Palliative care patients might be in an acute bed in a big general hospital, but they also might be in a specialist palliative care bed. A significant component of palliative care is provided in people's homes. By 'in homes' we mean residential homes but also in aged-care facilities as well as disability facilities. Palliative care might be provided to an elderly person who is in a residential aged-care facility. We do not necessarily need to move the resident out of that facility and really provide in-reach support into residential aged care to support those services to care for the person who is dying.

We also have hospital-based consultancy services. Within one hospital there might be a palliative care physician who is providing support within the hospital, but in regional areas it might be, for example, Latrobe Regional Hospital providing support out to Sale and Bairnsdale and to the smaller regional health services. In addition, there are some statewide palliative care services. Paediatrics is a very small field in palliative care but obviously very important, and there is a statewide palliative care service, Very Special Kids, and I would imagine that you are going to hear from Very Special Kids at some point during your hearings.

We also fund a statewide grief and bereavement service, an important component of the service in terms of helping people once their family member has died, so dying is not the end of the episode of care I guess. And then there are day hospices for respite care — places where people who are part of the palliative care program can come and receive some care and support during the day. That is particularly important for giving carers a break from their responsibilities for caring for people with palliative care needs.

Most of the hospital-based services are funded and governed through health services. For example, Monash Health would have a palliative care service contained within their health service, but there are also a number of non-government organisations that are also funded to provide palliative care, particularly community-based services. We have inpatient palliative care services in 31 locations across Victoria and we have community-based palliative care services — there are about 38 of them. So we have a mixture of health service-governed care and non-government organisations and government care in the community.

Patterns of palliative care use in Victoria. I will just show you a little bit of data; I will not use too much data. We are happy to provide any follow-up information. This data comes from pretty much the hospital datasets — that is the best way to describe it. The first graph on the left talks about community palliative care episodes. There is a gap in the middle and that is related to the data not being available during that period because we were upgrading the data system. The community palliative care episodes come from the Victorian Integrated Non-Admitted Health (VINAH) dataset and it really records the number of episodes of palliative care that have been provided in the community. You can see there is a huge increase in the palliative care service provision. There has been increased investment in community palliative care over time, showing a significant increase in access to that service.

The graph on the right is really about inpatient stay. What that is showing is there is a significant increase in separations — a separation is a discharge from hospital, so it is just a period of time someone spends in hospital. But what you are seeing there is the average length of stay declining. That is important and helpful, and what it probably reflects is the increased access to community palliative care — patients are able to leave hospital and have significantly more complex care occurring in community-based settings.

These are a couple of interesting pieces of data. The first one on the left is interesting, and it is about the location of hospital deaths. The top line is all deaths in hospital. What it is showing is that we are actually having a decline in people dying in hospital, which is a good thing I think. The second part though is that of those dying in hospital what you can see is less are dying in acute beds and more are dying in palliative care beds. That is by design, and that is showing that the policy is working and that is where we want to head. The graph on the right shows the number of separations, or the number of episodes of care in a hospital, where a palliative care specialist has been involved in that episode of care, so showing that there is an increase in palliative care physicians providing input into general patients in acute hospitals.

I think I mentioned before the patterns of disease. More people living with chronic illness means that we have a change in casemix out there. What this graph on the left shows is who is receiving palliative care. In some ways palliative care has been often associated with cancer services, but in fact there are a large number of chronic diseases for which palliative care becomes important. It might be progressive neurodegenerative disorders or it could be respiratory disorders or cardiac disorders, renal disorders. What that is showing is that there is a small but steady increase in the non-cancer patients receiving palliative care. That shows that for both the inpatient component and the community component.

We have talked about how many people die, where they die and the fact that less are dying in acute beds and more are dying in palliative care beds. This is interesting, which is, 'Where do people want to die?'. That is the key. It is all very well where they die, but did we actually meet the community's expectation? We do have some data from our community palliative care services. Roughly half of the people who said they wanted to die at home ended up dying at home. Over 90 per cent, so nearly all the people who wanted to die in hospital, got to die in hospital, and of those who wanted to die in their residential aged-care facility 87 per cent did.

I guess the critical issue with this, and it is something we need to understand a little more, and we do not necessarily have the full data on this, is why do people who want to die at home not end up dying at home. That can be for a number of reasons. I cannot tell you how often it is, and I think clinicians would probably be in a position to make a comment on this.

Some people think they want to die at home and then when it comes towards the end of their life, their needs may be very complex. Their carers may find it more complex to look after them at home and some people choose to then die in hospital, so they may spend the last few days or few weeks of their life in hospital. Whilst early on in their palliative care journey they may have identified it as a desire to die at home, in fact when it comes to the end of their care, they may actually make an active choice to die in hospital.

But there also may be issues about access to the appropriate levels of support, and we are unable to disentangle that. It is something that we intend to do to try and get a better sense of, 'Are people not being able to die at home through lack of support and lack of services or is it because they are choosing to die in hospital?'. That is obviously a critical issue for the community.

In terms of comparison with other jurisdictions, we think that our volume of patients who are able to die at home and say they want to die at home is roughly the same as other jurisdictions, but we do note WA appears to have a higher proportion of patients that are able to die at home, so we are talking to WA about what their

model of care is and we are quite interested to know how they are managing that and if there is anything we can learn from WA.

Probably the other thing that I would just comment on is in terms of length of stay, so I have said there is reducing length of stay in hospitals in palliative care beds. Just to give you a sense, our average length of stay for a community palliative care service is about 100 days, so community palliative care looks after people for quite an extended period prior to the death. The trajectory for patients at the end of their life can be quite different. So it can be a gradual decline or there can be stability and then a decline and then getting better and then plateauing and then having a decline. So there is a different pattern and a different journey for individuals along their end-of-life journey.

Satisfaction with care. We do have a couple of tools that measure satisfaction with care, and I am sure we have included some of that information in the pack, but pretty much patients who are receiving palliative care, for those that are in the system, they are identifying that they have very high levels of satisfaction with their care, noting that there are some outcomes, particularly the treatment of problems, including pain, nausea and vomiting that we monitor and we also monitor their experience including the respect and the kind of psychosocial needs that are associated with palliative care patients.

This is a survey. We conduct a Victorian palliative care survey. This was June 2014. The survey was sent to about 8000 people. We got about a 30 per cent response rate and it covers all inpatient and community-based palliative care services. The survey identified a number of areas for improvement, and I guess the areas for improvement tell us something about what we are already doing reasonably well — they are not included in the areas for improvement. But some of the things that were talked about were minimising the financial burden, the level of training provided to carry out specific care — that was for carers, so carers wanted additional training support. Planning ahead for funeral arrangements was identified, and ongoing support to minimise the psychological burden, and that was both the clients and carers. They were identified as the main opportunities for improvement.

I have described the palliative care system a little bit and some of the consumer and carer interests. But of course there are challenges associated with the system. Responding to demand is a never-ending issue for the healthcare sector of course, with our ageing population and the rising rates of chronic disease. Responding to palliative care needs is similar, so there is an overall demand issue. Then there is responding to people's end-of-life care preferences, so meeting individuals' and the community's expectation.

There are also some challenges around increasing the knowledge across the whole health sector about caring for people when they are dying, because we cannot expect the small palliative care sector to respond to the whole of the population's end-of-life care needs, so there is a need to grow not only the palliative care expertise but also the generic health workforce expertise. We see a significant challenge as also making sure that we are responding to the non-cancer group of patients. We have seen some increase in that, but we expect that we need to do some more work in that area. And really the ongoing challenge of making sure that we are listening to consumers and listening to the carers about their end-of-life care needs and wishes.

Advance care planning is one way that we undertake that work, so advance care planning I will talk a little bit about. It is a process really for planning for future health care. It is a mechanism by which consumers can engage in conversations with healthcare professionals and really have their wishes reflected in their future needs. We have had an advance care planning strategy for Victoria since 2014. It has been modelled on the national framework for advance care directives that was developed by the Australian Health Ministers' Advisory Council and endorsed in 2011. The framework was developed to support the harmonisation of advance care planning terminology across all the states and territories, so terminology which you will find you will come across — the same words have different meanings.

Victoria has been undertaking a program of promoting advance care planning across health services for some time. That has reached a certain level of maturity. I am sure you will hear more about advance care planning from Bill Silvester, who I think is presenting to the committee later this afternoon. Our history of advance care planning started back in the early 2000s, and Professor Silvester was a lead promoter of advance care planning. There is considerable evidence about the benefits of advance care planning and improving the quality of life at end of care, ensuring that the individual's wishes are known and respected at the end of their life care, improving client and carer satisfaction, and also the opportunity to reduce symptoms associated with anxiety and depression and post-traumatic stress. Research at the Austin has identified those specific outcomes.

Our first approach to advance care planning was the Respecting Patient Choices program that was promoted by the Austin. That work was piloted in the early 2000s. Whilst we have evidence that advance care planning is effective and we know that we have benefits, what we do not really have is evidence about what is the right way to implement it across Victoria. Whilst we have quite a lot of local initiatives, we do not necessarily say it has to be implemented in one particular way, and that is consistent with our approach to locally governed health services who determine the best way to implement particular programs across their individual services.

For example, Respecting Patient Choices has been strongly promoted at the Austin, and Bill Silvester has done a fantastic job of engaging with the primary care end at the Austin to implement that approach. Professor Charlie Corke at Barwon Health, whom you may hear from across your inquiry, has developed a particular tool at Barwon Health, MyValues, which enables people to create their own values profile on their end-of-life care. So we have different tools across the system, and we think that is a good thing because it allows services to develop processes that will respond particularly to their community. Another example of that would be Northern Health. With a particularly strong culturally diverse community, it has developed an approach that has a very simplified approach to ensure that those people from those communities can engage in advance care planning.

Our advance care strategy, which I am sure is in your pack, 'Have the conversation', was released last year. It has four particular components, which was making sure that health services establish their own internal robust systems, so get their systems sorted; make sure that their approaches are evidence based; increase the workforce capability, so this is about training and development for the workforce — it is all very well promoting consumers to have that conversation but we have to have the workforce that is able to have the other side of the conversation. So it is both workforce training but also enabling individuals to have that conversation.

We have an expert panel that provides advice to us on the implementation of the strategy, and we have surveyed health services to have a look at how they are going with the strategy and assess their progress against year 1 and identify any areas where they need help. This is almost impossible to read — not by design! This really reflects that there is variation across our entities about how mature they are in implementing advance care planning. If you think about it, at the far right we have 16 per cent 'embedded in usual care'. That is where we want everybody to get to. At the other side, at the far left, we have 'in the initial planning phase', and about a quarter of our services were still in the initial planning phase in October last year when we surveyed health services. Then in the middle there are some services 'establishing systems and developing policies' to 'increasing workforce capability, becoming part of usual care'. We undertook that survey as a baseline really, then we will re-survey services over time to see if they are increasing in their maturity and what are the gaps and where do we need to help services and identify opportunities for them to help themselves to move over to embedding advance care planning in usual practice.

The key findings from that survey are that 70 per cent of health services have resources to support advance care planning; 40 per cent of services have an electronic alert system, which is fantastic; where there is not an electronic alert system, 45 per cent of services also have a paper-based alert. That just means something on the front of the medical record that would indicate that there is an advance care plan. Forty-three per cent are using best practice standards.

Interestingly and importantly — I think this is a very important component of what health services are now doing — about a quarter of services are reviewing the outcome of advance care planning when they do their morbidity and mortality reviews. So within a hospital clinicians and different clinical streams will have a morbidity and mortality review for all deaths or morbidity associated with a hospital admission. Whilst that group is doing that clinical review, they are now also including whether or not the death of a patient was consistent with the advance care planning that was undertaken. That is something that has the capacity to really reinforce the self-learning within individual clinicians to see if in fact they are taking notice of patients' wishes.

Eighty per cent of services are providing training for their staff. Seventy per cent of services have a nominated clinical leader. Clinical champions for these kinds of programs are obviously crucial, and these programs are best led clinically. Seventy per cent of health services are focusing on delivering advance care planning for key patient groups, so making sure that culturally and linguistically diverse groups or particularly vulnerable groups are able to access these services.

There are a number of programs in place that the department has funded to support the implementation of advance care planning, and we have funded the Australian Medical Association to develop a package of

resources by doctors for doctors to help doctors with having the conversation. We are also working with the Royal Children's Hospital on development of particular resources for children, particularly for their families, enabling clinicians and families to have conversations about end-of-life care for children who have life-threatening illnesses. We have also funded the Health Issues Centre to undertake some work — and I expect the Health Issues Centre is a group that you will hear from in due course — to really help us shape our communication with consumers. The Health Issues Centre is really able to help us work with consumers and hear from consumers about how these conversations will be had. They are providing significant support in shaping those integration materials.

Advance care planning does not just happen in hospitals. That is a very important point. Advance care planning is something that has to happen. Hospitals have to work in partnership with others, in particular with general practice. It is not just at the end; the conversation needs to start early. Medicare Locals, which now do not exist but have turned into primary health networks, which are kind of the local coordinator of primary care, are a particularly important focus for services, and Barwon Health has had particular success in engaging general practitioners to undertake advance care planning conversations. Residential aged-care facilities are obvious places because a significant number of people in residential aged-care facilities will need to express their end-of-life care choices, particularly avoiding the transfer out of residential aged-care facilities into hospitals at end of life.

I have talked about the challenges in really developing the system further. I have described the broad system of how palliative care works, the changing casemix of the profile of community illnesses, the investment in palliative care and particularly in community palliative care, and increasing access to palliative care, then I have talked about some of the challenges in the palliative care sector and the general health sector in terms of improving end-of-life care. Now I will move on to some of the complexities around some of the legislative framework as well as some of the broader organisational issues.

There is an issue about the transferability and the recognition across the jurisdictions. Each jurisdiction has its own particular approach, and there is a different set of legislative arrangements in each of the jurisdictions. Communication skills for clinicians but also empowering communities — so this is not just about individual patients; these are broad community conversations that need to be had around end-of-life care, not just for people who are facing life-threatening illnesses. There is integrating all of this work into organisational and clinical practices, and then I have mentioned the complex legislative arrangements.

The existing legal framework in Victoria — I am sure you will become familiar with all of these — is the Medical Treatment Act, the Guardianship and Administration Act, common law, the Powers of Attorney Act and the Crimes Act. Each of these have a particular focus on protecting consumers or enabling consumers to ensure that their wishes are able to be respected at the end of life.

I will move on to a comparison with the other states and territories. All states and territories have statutory processes for appointing a guardian. All allow for a competent person to be appointed as a substitute decision-maker. Victoria and Tasmania are the two states that do not have advance care directives in law. You would be aware that the government has made a commitment to put advance care directives into law, and that is something that will be undertaken following the development of an end-of-life care policy and work will proceed after that to look at what is the best mechanism for putting advance care directives into law. How advance care directives are enshrined in law varies across all of the jurisdictions, and of course it is important to note that no jurisdiction has statutory recognition of voluntary euthanasia or physician-assisted death.

I probably should at this point also make clear the advance care planning and advance care directives. Advance care planning is where individuals are able to have a conversation about their future needs. Advance care directives are where individuals are able to talk about future needs whereas advance care planning is really values and wishes and desires, but advance care directives provide much more direction about future conditions rather than present conditions. It is advance care directives that the government has made a commitment to look at in future — what the legislative framework will be for advance care directives.

In terms of the legislative arrangements, there is lack of awareness of existing legal frameworks amongst clinicians and the community. That is a particular issue about confusion over the existing arrangements that are in place, and I guess that is one of the reasons we have particularly supported the AMA to develop materials for doctors. It is not only supporting the conversation but clarifying clinicians' responsibilities and rights. There is the ambiguity in the Medical Treatment Act, which allows patients to refuse medical treatment under specified

circumstances using a prescribed form, and there is some confusion for individuals about the use of the Medical Treatment Act.

If I keep going I will come to probably my last slide. I guess this is our framework for thinking about end-of-life care decision-making. Most people would like to be included in the decision-making process about their health care in general but also specifically in relation to their end-of-life care. Many people, but not all people, would like to have an advance care plan, some people would like to have an advance care directive and then there is a very small component of people who would like access to voluntary euthanasia. That is kind of a way of thinking about it. There is a broad need for everybody to be engaged in their health care delivery. There are some who would like to be more specific about their end-of-life care. There is an even smaller component that sees the need for having advance care directives — and that is where the future policy direction will go — and only a very small component of people may want access to voluntary euthanasia. There ends my presentation!

**The CHAIR** — Well done, and thank you very much for that most comprehensive outline of the framework within which you operate, which will be most helpful for the committee when it is considering these issues. If I could start the questioning and take you back to the presentation by Professor Hal Swerissen. You would be familiar with the work the Grattan Institute has done.

**Ms DIVER** — Yes.

**The CHAIR** — What is your view of the suggestion he has put forward, one about greater public awareness and education, but also about having key trigger points in the system where there are prompts for people to have an interaction with their health care professional or someone about these issues?

**Ms DIVER** — I think that goes to the issue of broader community conversation in a culture that perhaps is not so used to talking about death and dying — increasing the capacity for the community to have that broad conversation. That is really where some of the work of the Health Issues Centre is helping us out with — how we shape the conversation in the community. That then has to be matched with the capacity of healthcare professionals to have that conversation. We would probably point to the primary care sector as being the place that would most likely need to have that conversation, and we would say that general practitioners have a particularly strong role in that, general practitioners being funded by the commonwealth. The commonwealth is currently doing a review of the MBS schedule. Perhaps there are opportunities there where the commonwealth needs to look at the way that GPs are remunerated for having these conversations. Obviously an advance care planning conversation is a longer conversation. It requires a relationship between the consumer and the GP. So I think there is an opportunity in primary care in particular for that to occur. That is one point.

The next point would be, I guess, trigger points that the Grattan work would identify. Do 5.4 million Victorians need to have an advance care plan? Probably not. If there is a broad community conversation where there is awareness, then there is a smaller section of the community that needs an advance care plan. That would be particularly for people with chronic diseases who would need to have an advance care plan or for whom it would perhaps be important for them to engage in conversations with their general practitioner, and then of course people who are facing a life-threatening illness. Particularly in those circumstances, advance care planning becomes more important. Probably if you are getting at that kind of broad, ‘What’s the trigger?’, we would say that something probably in general practice in general but then triggered by perhaps the establishment of a chronic disease or the establishment of a life-threatening illness.

**Mr MELHEM** — Just on that last graph you have, where did you get that information from? Is it based on a particular survey, surveying people at that stage of their lives? Can you take us through that, because I am interested in particular in the smaller dots and what prompted this discussion?

**Ms DIVER** — Yes, sure. What I should say is that this is a conceptual framework. It is not to scale. There is no weighting of size. It is a conceptual framework to say that there is something that applies to everybody and the issue of voluntary euthanasia is an issue that applies that is of significance to a small number of people, for which there may or may not be work that needs to be done. Then there is work at a broader level where everybody needs to be engaged in decision-making about their health care. So it is really a conceptual framework to say there is work that can be done to improve end-of-life care — a small amount of work for a lot of people can actually deliver significant benefit as well. So it is really a conceptual framework. It does not reflect the size of the communities that require that kind of intervention.

**Mr MELHEM** — To follow-on from that, what are the community expectations of the end-of-life care and decision-making process?

**Ms DIVER** — What are communities' expectations about end-of-life care?

**Mr MELHEM** — Yes.

**Ms DIVER** — We have surveyed people who are receiving palliative care services and they have told us what the opportunities for improvement are, but they are probably reflecting the improvement on the service system. Whilst the consumers who are receiving care through palliative care services are generally satisfied with their care, what they have talked about is the need for the respect of their experience, the recognition of the role of their carers, attending to their symptoms — so treatment of nausea, pain and those sorts of things — but also having access to psychological and emotional support needs as well as recognising their end-of-life care in terms of where they receive the care, either at home or in the community. I am not sure whether you want to add anything, Jackie?

**Ms KEARNEY** — Yes. Just thinking about people's care broadly across the healthcare system, particularly in hospitals, there has been significant research not just in end-of-life care but in a range of healthcare decision-making that most people want to be involved in decisions about their own health care. It sounds obvious but it does not always happen in hospitals and it does not always happen in healthcare. What we know is that people just do not want to have discussions about their health care, they want to know about what their prognosis is, what the treatment involves and what the illness trajectory is going to be like. They actually want quite a lot of detail to be able to then make decisions about what matters to them.

There is also research that suggests that most people do not always get all the information they need. There is some research that suggests that doctors think they are giving the right level of information to people, but when you interview the people who got the information you find that the doctors are not giving them what they need or they do not give them enough. That is perceptions about doctors not wanting to give information that might be bad news but people actually saying in the research, 'We need to hear that information. That information is important to us to realistically assess what is going to matter to us over the next 12 months, 6 months, 6 weeks'.

**Ms DIVER** — I think what that is saying is that consumers are increasingly saying that they want to be a partner in the decision-making around their health care and we need to equip consumers to be able to have those conversations and clinicians need to be equipped to be able to be a partner. That is broadly across the health system but it becomes particularly important in palliative care where we are talking about people's particular desires around end-of-life care.

**Ms FITZHERBERT** — Ms Diver, I was interested in what you said about confusion in the community about the provisions of the Medical Treatment Act and I was just wondering if you could elaborate on that a little.

**Ms DIVER** — I will just hand over to Pauline.

**Ms FITZHERBERT** — If I could elaborate on that: how do we measure that, how do we know?

**Ms IRELAND** — It is about the framework as a whole, of which the Medical Treatment Act is a part. I know you have just heard from Loane Skene, who has probably taken you through the whole legal landscape. But essentially you start from the common law where the competent adult has the right of personal autonomy, bodily integrity, the right to make informed decisions about their health care and the right to refuse medical treatment. You have got the Medical Treatment Act, which was designed from a policy point of view to give concrete legal expression to the right that exists in common law already, which is for a competent adult to refuse medical treatment.

It allows that for a current condition a person can, under the Medical Treatment Act, either refuse all treatment for that condition or particular kinds of treatment. For example, if they have cancer and really do not want to have chemotherapy, that is their right — they can refuse that treatment. It also makes provision for when a person who was competent legally to make decisions becomes incompetent. If while they are competent they appoint an agent, the agent can make all medical treatment decisions that they could make and stand in their shoes when they become incompetent. So effectively the agent is meant to be the expression of that person's

wishes and desires. The whole idea underpinning the appointment of an agent is that they need to be someone the person really knows who gets where they are coming from — what their values are, what kind of decision they would make in those circumstances — —

**Ms FITZHERBERT** — If I could just interrupt — if it is not impolite — to say it is not so much what are the provisions, but — —

**Ms IRELAND** — Yes, I was going to get to guardianship, because you have the Medical Treatment Act, with a particular framework, then you have got the Guardianship and Administration Act, which provides a substitute decision-making framework. So there are different provisions where people can appoint people — under the Medical Treatment Act, as an agent. Under the current Guardianship and Administration Act, you can appoint a plenary or a limited guardian who can make certain kinds of decisions. There can also be court-appointed guardians for people who cannot make decisions of that nature. You can appoint an enduring guardian. There are further changes to the law that are going to come into effect on 1 September which actually streamline the process around appointments of all kinds of attorneys. So there are different mechanisms to appoint different kinds of people.

Under the Medical Treatment Act there are particular prescribed forms. The one thing the Medical Treatment Act gives people, if you like, is an offence of medical trespass for doctors who refuse to or do not implement the decisions of a duly appointed agent for a treatment for a current condition that the person has indicated they do not want. Under the guardianship framework, if you appoint an enduring guardian, that person must make decisions in the best interests of you as the appointor, but there are provisions in that act where ultimately a doctor could decide that the decision of the enduring guardian not to consent to treatment is not the right decision and could actually not follow that decision, and ultimately if there is a dispute about that, it can go to VCAT.

So you have lots of different layers of appointments and you can overlay them with other forms of attorney that people can appoint. We live in a complex world, and when people can no longer be legally competent to make decisions for themselves about all kinds of things there are frameworks that kick in. On one level there is quite a lot of choice. People can choose an agent under the Medical Treatment Act, an enduring guardian or soon to be an enduring attorney under the new Powers of Attorney Act, a limited guardian, a plenary guardian for different purposes — for financial matters, for healthcare matters, for lifestyle decisions. The picture I am trying to paint — and I am sorry if I am doing it rather clumsily — is that it is a confusing landscape.

**Ms FITZHERBERT** — I totally get that it is confusing, but what is our evidence that people find it confusing? I can look at it and say, ‘That is confusing’ — we can assume that — but is there some sort of survey — —

**Ms IRELAND** — Certainly medical practitioners and those who are dealing with patients find it very confusing. In fact there was a survey conducted recently, in 2014, by Professor Ben White, who examined doctors’ knowledge of the law in this area and in particular what their legal duties and obligations were for withholding and withdrawing life-sustaining medical treatment. That survey found that many doctors do not possess sufficient legal knowledge to determine, for example, how to implement patients’ wishes or whether an advance care directive presented to them is valid. They are not sure of their legal obligations under different kinds of instruments. That is the evidence we have got from a clinician’s point of view.

**Ms DIVER** — Can I just add to that, it becomes particularly important in the context of a broader range of healthcare professionals meeting to deal with end-of-life care rather than just palliative care specialists. Obviously physicians who are dealing with this all day, every day have a clearer sense, but once you get into the territory of general practitioners and more broadly physicians being supported to do end-of-life care, it is a very complex field for them to also get themselves involved in. I think that is also part of the issue where it is broadened from a specialised group to the generalised profession.

**Ms FITZHERBERT** — I took a note of what you said before, which is that there is confusion in the community. You said that in relation to the Medical Treatment Act, so I was trying to get a sense of how we can — —

**Ms KEARNEY** — Yes, and I am hoping that you will hear from the Health Issues Centre, because of the preliminary findings of the study they are doing at the moment, interviewing people who have been substitute

decision-makers and asking them questions about what that has meant for them and what have been the challenges for them in terms of thinking about making decisions on behalf of somebody who is not competent to do so. The feedback that they are getting, I think, is really important in terms of understanding what it means for people who are in other people's shoes and the idea that it is a confusing space. They are not sure what their powers are under the particular agency that they have been appointed under. Can they make decisions about treatment or can they just make decisions about withdrawing treatment? Can they make decisions about future conditions or do they have to make decisions about current ones? How do you get support to think through those decisions? If you have an opportunity to talk to the Health Issues Centre about what they are finding, I think you will find it is a really important story to hear from consumers and people in that situation.

**Ms FITZHERBERT** — Thank you.

**Ms SYMES** — Just going back to you, Ms Ireland, in terms of the different powers or different appointments that you can accept from someone, with the Medical Treatment Act I get that it is the agent. Are there any medical-related ones under the guardianship act?

**Ms IRELAND** — Yes, there is a whole part of the Guardianship and Administration Act which is specifically about substitute decision-making for people who cannot make medical decisions for themselves; whether it is episodic, for example, because they have got mental illness and at times will have capacity and at other times will not; or whether it is permanent, for example, because they have an acquired brain injury. So the Guardianship and Administration Act sets up a regime about consent to medical treatment in those sets of circumstances, and if you like, there is a hierarchy of substitute decision-makers under the act. At the top of the hierarchy, if someone happens to have appointed an agent under the Medical Treatment Act, they are the decision-maker. If there is a court-appointed guardian, they are probably next in line, or a personally appointed guardian.

The hierarchy starts off with people who are either appointed by the patient themselves or a competent authority like a court or a tribunal, and then it goes down the hierarchy to family members. So if you have a spouse or partner, they would be the decision-maker. If you do not have a spouse or partner, I think it would go to children and then parents and the like. That is to ensure that there is no gap. There is no-one who is not legally able to make medical treatment decisions on behalf someone who cannot make those decisions, because even though custom and practice of health professionals is to work with families, at common law, next of kin, for example, do not have the power to make medical treatment decisions. There is a whole framework under the Guardianship and Administration Act. It even goes to providing treatment in emergency circumstances. For example, unless someone has appointed an agent under the Medical Treatment Act — —

**Ms SYMES** — How common is that?

**Ms IRELAND** — Sorry?

**Ms SYMES** — How common is it? My general experience is that most people in the community understand power of attorney, and a lot of people that have ageing parents get made power of attorney. That is really fairly commonly understood, whereas I am less familiar with 'agent'. Do people take it up in advance of crisis situations?

**Ms IRELAND** — I do not think we have any data on that. I have just asked my colleagues about it.

**Ms DIVER** — We can perhaps take that one on notice and see if there is any additional information we can get.

**Ms SYMES** — My question would be the practical experience of people. If you go and apply to be power of attorney, is that an opportunity for people to be advised, 'Because you are getting power of attorney, do you know that there is a whole other health aspect that perhaps you might want to consider?'.

**Ms IRELAND** — Certainly it is, and bodies like the law institute provide advice for solicitors. So if people go to a solicitor, and hopefully the solicitor is good at what they do, they would be saying, 'Right, if you want to think about a power of attorney, what about other kinds of decisions?'. Especially if they are ageing and maybe if they have an illness as well, a good lawyer would take people through what the options are for them in terms of ensuring that they are able to express their wishes and appoint the kinds of people or a person who can make

the decisions for them when the time comes that that is required. A good lawyer would understand the entire legal landscape and walk people through it and choose the right mix of tools, if you like, for them.

**Ms SYMES** — On the withdrawal of medical treatment, does that apply to pain relief as well?

**Ms IRELAND** — No, the Medical Treatment Act does not include palliative care in the definition of ‘medical treatment’. For example, there are court cases on PEG feeding — tube-feeding into the stomach. That is regarded as medical treatment; it is not palliative care.

**Ms SYMES** — For instance, if a doctor is giving high levels of pain relief and the agent thinks that is actually detrimental because it is affecting the person’s cognitive abilities, that agent has no power to — —

**Ms IRELAND** — No, they do. The agent should be making the decisions about medical treatment for the person. They stand in the shoes of the person, and there should be an informed discussion about treatment options and what kind of treatment is required. If you are talking about pain relief, that would be medical treatment and so that ought to be part of the discussion because the agent is standing in the shoes of the patient.

**Ms PATTEN** — That is not considered palliative, that is considered — —

**Ms IRELAND** — Yes, that is right. Although are you getting to the point of: when is it possible to provide high levels of pain relief?

**Ms SYMES** — No, just in terms of withdrawing — —

**Ms IRELAND** — I think I should just correct the record because pain relief is part of palliative care, and I thought I said it was not. Let me check my act. I will just check my definition for you, just so I get this right.

**Ms SYMES** — Because it is very clear that you have the right to refuse treatment for chemo et cetera, but I just was not sure how far that extended.

**Ms IRELAND** — ‘Palliative care’ is defined as including ‘the provision of reasonable medical procedures for the relief of pain, suffering and discomfort’ and ‘reasonable provision of food and water’. I guess what I was trying to get to is: the question is what is reasonable in all the circumstances, and that is part of the discussion that will be had.

**Ms PATTEN** — I have got a question about palliative care. But just before that, could I just ask you to elaborate on Mr Melhem’s question about this graph, because what we are hearing from other witnesses and other submissions is that there is a large percentage of the community that is very interested in having an opportunity for physician-assisted dying, yet this is suggesting otherwise.

**Ms KEARNEY** — As Frances said, this is conceptual, but in thinking about the conceptual framework, it is based on some research and some evidence. Because we do not have voluntary euthanasia anywhere in Australia, in thinking about this conceptual framework we looked at how often voluntary euthanasia was used overseas. That is how we came to that. No matter where you look in the world where voluntary euthanasia or physician-assisted deaths are legislated, it is still only a very small percentage. There is no comment on the view when you interview people and ask them the question in Australia, and it is 70 per cent. That is not what we have looked at. We have looked at what actually happens where it is law.

**Ms PATTEN** — Thank you. That really clarifies that.

**Ms DIVER** — Probably the other reason for having a conceptual framework in this way is to say that voluntary euthanasia is an issue, but it does not remove the need for the other three components, which is important for probably a much larger number of people in reality.

**Ms PATTEN** — Of course. Thank you both very much for that. I turn to palliative care and particularly care at home. In all of the evidence we have been hearing from the Grattan Institute and from Palliative Care Victoria, most people want to die at home and they want to be able to do that. In your evidence you say 51 per cent of people who want to die at home do die at home. I am wondering if you could elaborate on what measures you are taking to enable more people to die at home?

**Ms DIVER** — We spend about \$120 million a year on the palliative care sector, and about \$60 million of that would be on bed-based services, which are the expensive end, and the remainder on community-based services. Over time, the balance of those services is that we have been investing more in community-based services than we have in bed-based services. But often care for an individual is a combination of community-based care and inpatient care, so they might need to come in for a week for maximising pain relief or symptom control to enable them to go back out into the community.

Many patients will experience both aspects of the palliative care sector. Partly it is about growing the capability and capacity of the community-based sector to provide those services, and more and more people are able to experience that. I guess the issue that we are probably not really clear on is that of the 49 per cent who said they wanted to die at home, why did they not die at home? I think that is a piece of work that we need to do as a department to get a better understanding of what are the barriers for people dying at home, and how much is it about access to services, or is it about the reality of when people get closer to death they perhaps decide they do not want to die at home? We cannot answer the question for the 49 per cent, and we agree that it is a piece of work that we need to do to help inform the development of our end-of-life care framework over the coming months.

**Ms PATTEN** — Following on from that, I think there was research done for Palliative Care Victoria around the CALD community. A very large sector of that community has no concept of palliative care at home. Is this something that the department is actively working on?

**Ms DIVER** — We funded Palliative Care Victoria to do some work with the CALD communities, to really engage with them and have the community conversations.

**Ms PATTEN** — But according to their evidence that funding has ceased now?

**Ms KEARNEY** — The funding for the project has ceased, and I think that what Palliative Care Victoria has provided is a series of products for us to go on and use, so a lot of work was done over how you have the conversation, how you engage communities in discussions about palliative care, and what death and dying means in different communities. I think there is a piece of work; it is now about how you take that and use it and share it with community palliative care services to engage in that discussion.

Equal to that is the work that is happening in places like Northern Health, where Dr Barbara Hayes, a palliative care physician at Northern Health, has been working with her CALD communities not so much in a discussion about what does palliative care mean but what does talking about death and dying mean for you and your community. The lessons we learn from that project are going to have knock-on implications for how we work with all of our palliative care services and how they work with their CALD communities. Our next stage is to do some implementation. The science of implementation and getting that embedded in day-to-day practice takes time, but we are developing some implementation strategies around that.

**Ms DIVER** — There is probably a point to be made there about the way services are delivered in the community and organised locally and governed locally. That is fantastic for delivering really responsive services, but sometimes it means that some things are reinvented in each service. That is why we use peak bodies or statewide bodies. There is the Centre for Palliative Care at St Vincent's, which has a statewide function, and Palliative Care Victoria is the peak body. We fund those services to do work that can then be rolled out across the state. Whilst we fund a particular piece of work, a particular initiative or a project — we may fund the Centre for Palliative Care at St Vincent's to develop something or Palliative Care Victoria — because those services are no longer being funded and developed it does not mean that the project has ended. That just means they have given us the product and now it has gone out to the 38 community healthcare services to actually implement.

I guess I am making the point that because the funding has ended does not mean we are not committed to implementing it, and the resources are already in the agencies from our point of view to implement it, and that is where we need to embed it in regular service delivery and not be dependent on small pots of money. It is actually just part of usual practice, and that is where we are aiming for.

**Mr MULINO** — Thanks very much for your detailed submission. It is very interesting. I have a couple of follow up questions on dying at home. Your research indicates that 51 per cent of people who want to die at home do manage to die at home?

**Ms DIVER** — Of those whom we surveyed who were receiving palliative care services at the beginning of their episode of care, yes.

**Mr MULINO** — What was the total proportion who wanted to die at home of the total population surveyed?

**Ms DIVER** — For the proportion who wanted to die at home, 51 per cent actually did. So how many wanted to die — —

**Mr MULINO** — Of the total proportion surveyed?

**Ms KEARNEY** — I do not think we know off the top of our heads.

**Ms DIVER** — Can we take that on notice?

**Mr MULINO** — The only reason I raise that is that the Grattan Institute gave us a number — that about 70 per cent of people want to die at home — so I would be interested to see how comparable it is to that number.

**Ms KEARNEY** — Can I just add something to that as well, because I think this is an important component? We ask people not just the question of where would you prefer to die but also where would you prefer to be cared for. We know that 93 per cent of people who nominate to be cared for at home are cared for at home. So I think we have got a bit of work to do, as Frances said, because while we know most people are cared for at home for most of their stay in a community palliative care service, there comes a time when 49 per cent are not. What we do not know is whether or not that is because they opt to either go to hospital or somewhere else or potentially to a hospice. Because that very end-of-life dying process is just not what they expected and the carers are not quite prepared, they opt to go somewhere else.

**Mr MULINO** — I agree. Drilling down to that 49 per cent is really interesting.

**Ms DIVER** — We will go back to our data and have a look to see if we can give you that information and to see what else we can give you from that survey, but we do not have it today.

**Mr MULINO** — That is fine. The other thing, which, again, I am happy for you to take on notice, is whether you have a sense as to whether that proportion of people is trending over time, because I think it is an interesting contextual piece of information.

Regarding the last bit on this issue, I am just interested in whether you have done any thinking or modelling on some of the costs. I am not looking at this from the perspective of saving money, but in my mind there seems to be the potential here that if we are moving from what might be a high-cost option to a potentially lower cost option that is actually more in line with what people want, it might be better because it is more in line with what people want and also because it might free up resources to fund some of the services, which you mentioned earlier, that clients and their carers and families want more of. It just seems like an area where there might be some real policy gains in the future if we can get things right.

**Ms DIVER** — Certainly community-based care can often be less expensive than hospital-based care, but we should also recognise that the people who are in hospital-based care have much more complex needs; that is why they are in hospital. A proportion of them may be able to be cared for in the community, and there is an opportunity to possibly push that down the line and substitute hospital care for community care, but many of the people are in hospital because they need to be in hospital because the care cannot be provided at home. Does that make sense?

**Mr MULINO** — That makes total sense.

**Ms DIVER** — Of course we want to grow community palliative care, we want to grow access to community palliative care and we want to have the least intrusive and most cost-effective health care, and it is good where we can do that in community palliative care. But if I just moved my \$60 million out of inpatient health care to the community, I am still going to have \$60 million worth of care needed to be delivered in hospitals. There is a complexity issue.

**Mr MULINO** — It is a different cost make-up.

**Ms KEARNEY** — That is right. But certainly, as within all health care, not just in palliative care, the whole system and all the reform directions are geared towards early intervention and community-based care and the least intrusive options close to home. In those circumstances, mostly, they are more cost effective than expensive end hospital care, but of course we still need to fund hospital care as well.

**Mr MULINO** — Of course. I guess to the extent that it is based on perhaps a lack of awareness of options and other barriers that may be things we can address through better policy settings, it might offer scope for resources to be shifted to other services that are in the community.

**Ms DIVER** — Yes. I think that one of the issues that will give us more capacity to do community-based palliative care is the opportunity for consult-liaison health care, so it is actually general practitioners and RDNS or residential aged-care facilities or generic healthcare workers providing end-of-life care with input from palliative care physicians, rather than patients being completely nested within the community palliative care setting for the whole of the end-of-their-life care. It is about at what point they shift from generic services into specific or specialised palliative care services. At the moment 100 days is the average length of stay. Is that the right length of stay? Should we skill up the general work force to be able to provide more care so that more people can access the specialised end and more people are accessing some of their care through the general healthcare setting?

**The CHAIR** — I want to ask a question about the advance care directives. I think earlier, Ms Diver, you said that Victoria and Tasmania are the only states that do not have advance care directives in legislation currently.

**Ms DIVER** — Correct.

**The CHAIR** — My understanding of how they work at the moment is that an advance care directive can only be made for a current condition.

**Ms DIVER** — Yes.

**The CHAIR** — Leaving aside Tasmania, can you describe what exists in other states in their legislative frameworks?

**Ms IRELAND** — I will have a bit of a go at it. I do not pretend to be an expert but we certainly have got some information for you. I will just clarify one point though; in New South Wales the advance care framework is at common law rather than in legislation.

**The CHAIR** — Okay.

**Ms IRELAND** — That came out of a 2009 case, which was based on guardianship law quite similar to Victoria's. It possibly has some applicability in Victoria. South Australia has the most comprehensive and most recent legislation. We are talking about advance care planning with directives about care to be given in advance. Some elements of those are binding and some are non-binding, and there is a whole framework about ensuring that health professionals take on board patients' wishes in the whole circumstances. I think South Australia has the most well-developed legislative framework from what we have seen, but certainly Queensland, the Northern Territory, the ACT and WA all have legislation in this space, specifically, that goes beyond what we have in the Medical Treatment Act.

**The CHAIR** — How do some other jurisdictions deal with the issue of people's changing views as they go through the care process? We heard evidence earlier today that someone may think something today but in six months they may think something different.

**Ms IRELAND** — Interestingly — and I am just remembering this, so it is something I will take on notice and correct if it is wrong — I think in South Australia once you have made your advance care directive, it cannot be changed. I was surprised when I read that, and I want to double-check that, but basically it was intended to be a binding long-term advance care directive. I would be surprised though — what you can give, you can revoke as an ordinary principle, so I really need to check that, and it may be only restricted to limited circumstances.

This is a conundrum which the law faces in this area generally about how to capture people's views when they are thinking in advance and they cannot foresee all the circumstances that will come to pass or even how they might feel at that time. The law has to provide for flexibility, but there is also a tension there because health practitioners will want certainty. They will want to know what legally they can and cannot do and whether they are entitled to rely on a valid document.

I think one of the challenges is to learn from and understand the laws that are in place in the jurisdictions that have moved to head down this path. All of the laws are going to have the same issue, which is that you do not want to build a bureaucracy around constantly filling in forms and changing forms if someone has changed their mind, and then have people thinking, 'Have I got the most up-to-date representation of the patient's wishes and am I actually allowed to act on that patient's wishes?'. That is from a clinician's point of view or a hospital's point of view?

Of course, as a judge in New South Wales said, when working through guardianship law, there was a chap who was a Jehovah's Witness who actually made an advance care directive, not under very specific legislation, but he filled out a form, had an agent or a guardian who understood his views, which were communicated, and the hospital actually went to court to seek a declaration of whether or not they could act on that patient's views, because this was about withholding dialysis, which was life-sustaining. The judge found that, yes, in all the circumstances, the hospital could act on that advance care directive as reinforced by the agent who had a good understanding of the particular patient's wishes.

The judge said that when clinicians and hospitals are not sure, they should come to court to get a ruling on this, and that is very good and fair enough in tricky cases, but it is not something that is sustainable for a health system on a day-to-day basis, so we are going to be carefully looking at the legislation in place in other jurisdictions and trying to do the best thinking we can about mechanisms for capturing and accurately reflecting patients' views so that people can make advance care directives. Some of the overseas research that Jackie has dug out has indicated that one of the best ways of doing this is by capturing people's views and values, because those things may change over time but not to the same extent as someone trying to foresee how they might feel in advance, and the scenario might arise 10 or 20 years later about how they would deal with a particular set of circumstances. So they are the kinds of things that will be taken into account in working through how to implement the government's policy commitment.

**Ms KEARNEY** — Do you mind if I just add a bit more to that —

**The CHAIR** — Please.

**Ms KEARNEY** — because I think the idea about expressing your wishes and views and values about what matters to you is an important discussion to be having because that is what this is conceptually trying to say, particularly around advance care planning. I understand that you are hitting the road tomorrow and heading out to Barwon?

**The CHAIR** — Next week.

**Ms KEARNEY** — Next week? I hope you get to meet Associate Professor Charlie Corke at Barwon Health. He has been doing a lot of work looking at people's values in advance care planning. The research that he has been undertaking has shown a couple of things including that while people's decisions about the treatment that they may want may change, their values and wishes stay pretty constant throughout their lives. It is important that those values and wishes are expressed and known in order for doctors to make decisions about treatment, not for people to make decisions about treatment, and I think that is a really important piece of work. In thinking about that, most people want to be involved and many people would like to be able to at least record what matters to them.

**Ms IRELAND** — Could I just add to that, in terms of what happens now under the Medical Treatment Act? Under that act, forms need to be filled in and they are supposed to be put on the patient's record. A copy is supposed to go to the hospital CEO, but I personally wonder — and I do not know whether we have any data on this — whether even that is routinely done or capable of being done in an environment where people are trying to make things work. They are busy clinicians, making decisions about treatment. Sometimes this is occurring where decisions need to be made fast, so the challenge is around not having a bureaucracy and trying to find and

fill in lots of paperwork and create lots of paperwork while ensuring a direct and simple means of communicating people's views and values to inform those decisions.

**Ms FITZHERBERT** — I have a question about the increasing numbers of people using palliative care, as you outlined in the presentation, which was good. Are there any projections on what the future needs will be that you are able to share?

**Ms DIVER** — Yes, we look at our forecasting models, and in the context of the ageing population and population growth we are anticipating about a 4 per cent increase in palliative care over the next four years. So we are looking at about 4 per cent per annum.

**Ms PATTEN** — I would just like to return to your advance care planning strategy. We heard from the Grattan Institute about the triggers that the Chair mentioned, and particularly the ones where residents enter into aged care —

**Ms DIVER** — Yes, that is a good trigger.

**Ms PATTEN** — and possibly when they went into hospital and were likely to die within 12 months. The Grattan Institute talk about the fact that this should be, not mandatory, but highly important, and I wonder whether, in your strategy, advance care planning would be part of an audit process or part of a performance indicator in how you assess the services.

**Ms DIVER** — Certainly we are starting to collect that data on hospitals so that we can see that I think there was capacity for an electronic alert in about 40 per cent of health services, and then there was a mechanism to have an alert and the medical record — a paper-based alert — for those who do have advance care plans. I think this will become particularly important for particular cohorts of patients in hospitals. It is not all patients in hospitals, obviously, but particular cohorts, and I think we will find that in particular specialty streams, particularly with chronic disease or the elderly, that will become part of routine practice.

But I think it was that table I showed where on the right there was the 'fully embedded into usual care' category, and the ones who were starting and not quite getting there. I think that as the system matures over time we will see that, and there will be particular chronic disease programs where we may mandate that as part of the program, but we are less about mandating then saying, 'This is a good idea. Here is the evidence. This is working' and having clinicians take it on and embed it in their practices. Rather than saying, 'This is compulsory, and everyone should do it', we are more likely to take the approach of, 'This is a good idea. Here's the evidence, here are the guidelines, this is who's doing it and here's the data — see who is doing it'. People can then benchmark and compare their performance. It is through that mechanism and local ownership that we are likely to see a greater uptake of those kinds of practices.

**Ms PATTEN** — So you may see it as a performance indicator.

**Ms DIVER** — Yes, we will be able to measure it over time.

**Ms KEARNEY** — From 1 July this year we have had a flag in our hospital dataset that allows hospitals to record patients who arrive at hospital with an advance care plan or who develop an advance care plan while they are in hospital. I think that is a really important bit of data so we can start seeing over time increases in advance care planning. That also allows hospitals to identify electronically or through the data whether or not a patient has a substitute decision-maker so that there are really clear measures that we have got about how hospitals are asking those questions.

**Ms DIVER** — Having the data is the first step. Next is sharing the data — that is, giving them feedback on how their individual performance at health service is going. Working out the right proportion of patients at health services that should have an advance care plan — it is not always equal. I am not sure that everybody at the Royal Women's should have an advance care plan, but I am pretty sure that most people at Royal Melbourne should have an advance care plan. It is about getting the right benchmarks for the right-sized health service. Having that data in place provides the opportunity for us to get some reasonable measures — benchmarking — and ultimately, when we are confident in the data, to be able to get the right incentives in place for services to work on improving their performance in that area.

**Ms SYMES** — Just picking up on a point that you raised in your introduction, which was about palliative care being provided for in residential facilities, I assume you mean aged-care residential facilities.

**Ms DIVER** — Yes, residential aged care and disability services.

**Ms SYMES** — In relation to the aged care, how common is that? If you have an underlying terminal illness and you are going into an aged-care facility because of your age as well, are most aged-care facilities looking at palliative care, or is it that you are getting a different type of care, so our palliative care gets directed towards those who are not in aged care?

**Ms DIVER** — Increasingly residential aged-care facilities are providing palliative care services. We think of a residential aged-care facility as their home — the place where people live. The increased investment in community palliative care to provide in-reach services to go in and support the residential aged-care facility to care for people who are dying becomes important. The other part that was referred to was the trigger of going into a residential aged-care facility where people can express their wishes. If we get that intervention right — if we are getting advance care planning happening on admission to a residential aged-care facility — the person can indicate their desire to either stay in the residential aged-care facility and die there or return to hospital. That is obviously a mechanism by which we can make sure that people who choose to die at a residential aged-care facility have the community palliative care resources then put into the residential aged-care facility for that to occur. Having said that, there are some aged-care facilities that do find it beyond their capability to provide palliative care, and some of their patients move into inpatient palliative care facilities.

**Ms SYMES** — What about the difference between city and country?

**Ms DIVER** — We can have a look at our data to see if we can give you that comparison. My pick would be that country would be doing better than city, particularly in public health services. That is my complete anecdote. Some of our small rural health services provide a mixture of residential aged care and a few acute beds. The capacity for those health services to care for people in place — dying in place — is probably stronger than in some of the metropolitan areas. I think we would say that makes sense. It operates as an integrated facility. Many of those small rural health services that have clients known to them over a long period of time are probably much better because it is an integrated service. You have a residential aged-care ward here and an acute ward there. It is same-same. So they can provide the care as opposed to the metropolitan area where you are shifting from residential aged care to a facility.

Health services and the residential aged-care sector have put a lot of effort into establishing partnerships, not just for dying in residential aged care but in general for the whole issue of the risks for patients of transferring constantly between residential aged care and hospitals, trying to get the care in place and have hospitals provide in-reach to residential aged care for broader than just end-of-life care. There is a lot of work going into that. We would say we think it is improving. Is it completely there? No; there is still a way to go. Some residential aged-care facilities would find it challenging, and perhaps we need to work a little bit more with them to provide that care, recognising that residential aged-care facilities have their own pressures around the number of qualified staff that they have.

**Ms FITZHERBERT** — Just really quickly, speaking earlier about capacity in the palliative care system, I assume that is measured in beds?

**Ms DIVER** — Yes, we can measure it in beds, and we can also measure it in numbers of patients' beds. For community palliative care we can measure the length of stay in palliative care and also episodes.

**Ms FITZHERBERT** — In terms of the capacity of the system to take people, are we at capacity? Do people have to wait? What sort of need is there versus what exists to support it?

**Ms DIVER** — Interestingly there have been some reports of a bit of under-occupancy in palliative care beds, which is a good sign, we think. Therefore there would be pretty good access to palliative care, although some palliative care patients also receive their care in acute facilities. It would be mixed in different areas and at different times, so where patients are not able to be accommodated in a palliative care bed they would be accommodated in an acute hospital. That is how the mix would work. In terms of waiting times for community palliative care?

**Ms KEARNEY** — Again, in community palliative care it varies from region to region. In your pack you have a table looking at how Victorian palliative care services stack up against other palliative care services across Australia. About 95 per cent of people get access to community palliative care within 48 hours. It can vary from region to region, and it also varies throughout the year. Like most other hospitals and health services there is often a peak over the colder winter months. Generally speaking, however, people get access within about 48 hours unless there is a really big, intense demand.

**Mrs PEULICH** — My apologies for being late and not being able to be privy to your presentation, but I have a quick question. In terms of the advance care plans and in relation to end-of-life choices, what capacity is there for flexibility for changes to those plans, and how often does it occur that individuals do change their minds about the nature of those care plans? Does the system accommodate the flexibility for individual choices changing?

**Ms DIVER** — Advance care plans are really documents that reflect wishes, desires and values, and they are able to be changed very easily — there is flexibility. None of us could comment on the frequency of that. Some of the clinicians that you talk to would probably be in a better position to comment on the frequency.

**Mrs PEULICH** — Is there any data?

**Ms DIVER** — No, we do not have any data. I do not imagine that we would have any data on that. A clinical perspective would probably give you that sense. An advance care directive is a different instrument — which we do not have in Victoria — that is embedded in legislation. Pauline spoke a little bit earlier about approaches to that need to maintain flexibility for consumers who want to make changes and how you reflect an individual's preferences. We had a bit of a discussion about the difference between specifying values and then specifying particular treatments and the capacity for those advance care directives to fully reflect somebody's values or the specific things they do not want by trying to anticipate needs a long way into the future.

That is work that would need to be undertaken in Victoria, learning from the other jurisdictions what they have done in relation to advance care directives in terms of trying to get maximum flexibility but also reducing bureaucracy associated with advance care directives on how consumers would use them. That is work not yet done, but as we mentioned before, there is a commitment to implement advance care directives. We are at the moment in the stage of developing a policy framework, and they will be considerations for the policy framework.

**Ms IRELAND** — In relation to what we do have in Victoria under the Medical Treatment Act in terms of refusal-of-treatment certificates for a current condition, we would not know how often they get changed, but anything you can grant you can change; however, they are specific forms under the act. People would probably need to go and get advice. It comes back to a question I answered previously about what problems people are having with the administration of the framework we have got — a lot of the time people might be going to clinicians and hospitals for advice, and the framework is quite complex because it reflects the complexity of having substitute decision-making in people's lives. A lot of the time to do this, to set it up well and even to change it, it is probably advisable for people to go and see a lawyer who understands the framework. The problem of that is that it makes it less accessible for people, so in terms of developing further legislation around advance care directives these are some of the issues we have to examine carefully.

**Mrs PEULICH** — Is there an additional layer of complexity in relation to people from multicultural and CALD backgrounds?

**Ms DIVER** — Yes.

**The CHAIR** — Thank you very much, Ms Diver, Ms Kearney and Ms Ireland, for your detailed presentation and the information you provided the committee in the pack. It is greatly appreciated. As I advised earlier, a transcript will be provided to you for your review. I trust that as we progress through this process we can engage with the department further as questions arise.

**Ms DIVER** — Absolutely. We are very happy to answer any questions or return. Thank you very much.

**Witnesses withdrew.**