

# **JOINT SELECT COMMITTEE ON END OF LIFE CHOICES**

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA  
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS  
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
FRIDAY, 2 MARCH 2018**

**SESSION FOUR**

## **Members**

**Ms A. Sanderson, MLA (Chair)  
Hon Colin Holt, MLC (Deputy Chair)  
Hon Robin Chapple, MLC  
Hon Nick Goiran, MLC  
Mr J.E. McGrath, MLA  
Mr S.A. Millman, MLA  
Hon Dr Sally Talbot, MLC  
Mr R.R. Whitby, MLA**

---

**Hearing commenced at 1.33 pm**

**Mrs RONDA CLARKE**

**Outreach Services Project Officer, Aboriginal Health Council of Western Australia, examined:**

**Ms MEL SHELLEY**

**Manager, Policy and Strategy, Aboriginal Health Council of Western Australia, examined:**

**The CHAIR:** On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am Chair of the joint select committee. Our other committee members are Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal policy officer; Hon Colin Holt; Hon Nick Goiran; Reece Whitby and Hon Robin Chapple.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and highlight any gaps that might exist. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege, however this privilege does not apply to anything you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Could you please both introduce yourselves for the record?

**Mrs CLARKE:** Before commencing with the evidence and introduction, I would like to acknowledge the traditional Whadjuk people of the Noongar lands on which this hearing is being held. I would also like to acknowledge elders past, present and future. My name is Ronda Clarke and I am a Nyigina woman from the Kimberley region of Western Australia.

**Ms SHELLEY:** My name is Mel Shelley. I am the manager of policy and strategy at the Aboriginal Health Council of Western Australia. Thank you for the opportunity to be here today.

**The CHAIR:** Do you have any questions about your attendance today?

**The WITNESSES:** No.

**The CHAIR:** If you are ready, Mrs Clarke, you can make your statement.

**Mrs CLARKE:** I would like to thank the committee for the opportunity to speak today. It is important first to note that I am one Aboriginal voice here today, and there are many Aboriginal voices across WA. I attend today on invitation of the committee on behalf the Aboriginal Health Council of WA, which is also referred to as AHCWA. I have prepared a statement to read to the committee today and will commence with the background of AHCWA as the peak body of the Aboriginal community-controlled health services in WA.

The Aboriginal Health Council of WA is the peak body for the 22 Aboriginal community-controlled health services across WA. The Aboriginal community-controlled health services are located across geographically diverse metropolitan, rural, remote and regional locations. They represent the most effective model of comprehensive primary health care for Aboriginal people and their communities. To borrow from the words of an Aboriginal Noongar woman and former experienced Aboriginal health worker from the Whadjuk Ballardong tribes, which is the Perth and wheatbelt regions, whom AHCWA consulted in preparation for today's hearing, our Aboriginal community-controlled health service routinely provide early intervention, prevention and a broad range of health services to Aboriginal people from womb to tomb.

---

With Aboriginal community-controlled health services based within our local Aboriginal communities, they are in a unique position to identify and respond to the local culture, health and other needs of Aboriginal people of WA, and their surroundings and communities. Aboriginal-controlled health services deliver services in response to complexity of health, early intervention and prevention, and social and emotional wellbeing issues across the life span. AHCWA, as the peak body, exists to support and act on behalf of our 22 member services, which are our community-controlled health services, actively responding to the individual and collective needs of AHCWA members. AHCWA is established under a constitution and is supported by a strong governance framework, including a board, comprising Aboriginal representatives from across our member services and each of our seven regions covering the state. We come together as one to respect, welcome and understand the social and cultural needs; to network; provide support; advocate; to influence policy; monitor performance; build capacity and improve and strengthen the social and emotional wellbeing of Aboriginal people and their communities. Aboriginal-controlled health services have been operating in WA since the early 1970s and, as the peak body, AHCWA draws from the collective voices of our member services to advocate for and on behalf of Aboriginal people across WA, to enjoy the same value of health and wellbeing as all Western Australians. AHCWA advocates for Aboriginal leadership, self-determination and cultural diversity to achieve these objectives.

Aboriginal people's life expectancy is approximately 10 years lower than that of non-Aboriginal people. Aboriginal people of WA are 1.4 times more likely to be hospitalised than non-Aboriginal people in WA. Chronic disease, injury and poisoning are leading causes for hospitalisation for Aboriginal people. Incidents of injury and poisoning contribute to permanent impairment and lead to long-term disability and disadvantage, carer burden, and reduced opportunities for employment and education. Assault is a leading cause of injury for Aboriginal people. The statistics I have mentioned show that evidence of the health inequities between Aboriginal and non-Aboriginal people is well documented. Governments know what the issues are, where the health gaps occur and where services should be delivered.

[1.40 pm]

What these statistics and reports do not often show, though, is the social and other factors that contribute to Aboriginal people's health disadvantage and the gap in their life expectancy. Thirty-nine per cent of the gap in health outcomes is tied to social determinants. The continuing impact of intergenerational trauma, racism, social exclusion and loss of land and culture are contributing causes to these social determinants and health inequities. Therefore, in order to deliver effective and appropriate health services to Aboriginal people across the lifespan, it is AHCWA's view that health services must fully appreciate and understand the unique needs and differences of Aboriginal people across metropolitan, rural and remote communities throughout WA. Health services must understand and incorporate the cultural needs of Aboriginal people by understanding and embracing the holistic concept of health held by Aboriginal people. This holistic concept of health recognises the importance of connection to land, culture, spirituality, ancestry, family and community and how these affect the individual. Our member services, which are our Aboriginal community-controlled health services, constantly report that mainstream health services do not provide health services that are culturally secure and lack the cultural understanding and knowledge that is so important to building trusting relationships with Aboriginal people from the outset. Aboriginal community-controlled health clients report experiences of racism and cultural bias when accessing mainstream services. These experiences are often compounded when it comes to end-of-life matters and decisions by Aboriginal people.

---

The model of care delivered by our Aboriginal community-controlled health services is unique. One of the key strengths of the model is the experienced Aboriginal health workers and practitioners who provide the health services to Aboriginal people within their communities. The Aboriginal community-controlled health service holistic model of primary health care delivers whole-of-life care that involves responding to the needs of the whole person. This includes family and significant others in healthcare decisions and treatments. This whole-of-life, whole-of-family approach ensures delivery of culturally secure health services. The Aboriginal community-controlled health services are unique and expert in engaging Aboriginal people in health care and treatment.

Today I have brought along the Aboriginal community-controlled health service model of care and how we view this service. The Aboriginal community-controlled health service model of care is modelled and underpinned by eight fundamental dimensions that are central to the health and wellbeing of Aboriginal people in their communities. These dimensions are the foundation and cornerstones of Aboriginal health and wellbeing. A disconnection from the eight dimensions can cause an individual to experience an imbalance in their overall health and wellbeing, not only from the medical point of view, but also from an Aboriginal and a cultural point of view. The Aboriginal community-controlled health services in WA acknowledge the importance of timely, assessable, affordable, acceptable, approachable health care for Aboriginal people and their communities, one that is strongly aligned and connected to country and cultural heritage, and recognise the importance and the important role that family and community play in the overall physical, mental and spiritual wellbeing of an Aboriginal person and community.

The person: “I am Aboriginal. I am a traditional owner of this country, a descendant from a proud people. I am culture and culture is me. I am country and country is me. I am the bush and the bush is me. I am the river and the river is me. My family is me and we are one; we are community.”

Physical: the physical refers the capacity of physical health and development. It is the human biological wellbeing of oneself—mind, body and spirit. For Aboriginal people physical wellbeing is intertwined with the spiritual, emotional and family dimensions. Our physical being supports our essence and shelters us from the external environment.

Spiritual: the spiritual is identified as being the most essential requirement for health. It provides the capacity for faith and wider communication. Health is relevant to unseen and unspoken energies. The spiritual essence of a person is their life force. This determines us as individuals and as a collective who and what we are, where we have come from and where we are going.

Family: this is important. Family is the prime support system providing care, not only physically, but also culturally, spiritually and emotionally. For Aboriginal people family is about the extended relationship, rather than the nuclear family concept, and the capacity to belong and be part of a wider social network support system. Family provides us with the strength to be who we are and links us to our ancestors—our ties with the past, the present and the future. Understanding the importance of family and how family can contribute and assist in the healing process for Aboriginal people is vital and important to the holistic wellbeing of Aboriginal people.

Emotional: the capacity to communicate, to think, to feel, to acknowledge that the mind and the body are inseparable. Thoughts, feelings and emotions are an important component of the body and the soul—how we see ourselves in the universe, our interaction with which is uniquely Aboriginal, and the perception that others have of us.

Community: on country and connection of community; cultural heritage; our law and culture; the sustainability of traditional customs, practices, values and beliefs; social networks and support systems; family and community; a sense of belonging; a place to stand; self-determination; leadership and empowerment. It is our authority and our control.

---

Culture: Aboriginal culture is one of the oldest living cultures in this world. It is complex, diverse and it dates back 50 000 to 65 000 years. Culture is an Aboriginal person's awakening; it is the window to one's soul. It depicts who a person is, gives their behaviour and how they live their lives. It encompasses values, beliefs, customs and practices that are central to the health and wellbeing of an Aboriginal person. Culture is to be respected.

Language: as you can see, we have only got one language there today, but the Aboriginal language is diverse, with over 363 different language groups and dialects in Australia. There are over 90 language groups and dialects within WA. It is the importance to communicate and understand and engage effectively. Understanding the Aboriginal language is a vital part of culture and heritage.

Country: last but not least is country. "I am one and linked to the land and the country to my birth, my ancestry, my culture and my identity." Aboriginal lore and spirituality are heavily intertwined with the land and being on country. A disconnection from country, culture and family contributes to an unhealthy state of mind, body and soul.

Culturally secure services at all stages of healthcare treatment is a key imperative for ensuring culturally secure and appropriate end-of-life discussions, services and healthcare treatments and responses for Aboriginal people. Although there are limited number of palliative care services available for Aboriginal people in WA, these are generally mainstream services and do not employ Aboriginal health workers and practitioners or necessarily understand Aboriginal people's cultural needs.

[1.50 pm]

The Aboriginal community-controlled health services are delivering a range of palliative and end-of-life services as part of the holistic healthcare model without proper resources and funding to do so. While AHCWA acknowledges that certain hospitals and hospices do attempt to provide culturally secure services—for example, by embracing the cultural aspects of family and tradition—these are ad hoc and occur more through good luck than coordinated culturally secure management. Basic rules of hospitals and palliative care services, including numbers of visits, times of visits and requirements around what can or cannot be brought in for patients, represent barriers for Aboriginal people in gaining access to and receiving culturally secure health and end-of-life services. Most importantly, these rules represent barriers for Aboriginal people to make informed end-of-life decisions and choices.

Having to come away from home and country is also a major factor which impacts the delivery of end-of-life services to Aboriginal people. The stress and anxiety of being away from country, home and family and community may lead individuals to make their own end-of-life choices—for example, not staying in Perth for dialysis or treatment, returning to home to be with family and on country for end of life.

The view of wanting to die whole may also be an issue where potentially life-lengthening treatments or palliative care may be refused due to cultural beliefs and views of Aboriginal people wanting to leave life in their whole body. In AHCWA's view, these issues are relevant factors in mainstream health services not sharing relevant information or opportunities with Aboriginal people about the stage of dying that they are at, but rather continuing treatment or palliative care to retain the person in the healthcare setting. The information and approach to the end of life and end-of-life choices, such as advance healthcare planning and palliative care services, are not culturally secure and are tailored for a mainstream healthcare response, which reflects a one-size-fits-all healthcare delivery. This approach is a barrier and not culturally appropriate for Aboriginal people.

---

In conclusion, today, and as I have shown you through our Aboriginal community-controlled health services model of care, culture and cultural security is essential to the rights, values, beliefs and expectations for Aboriginal people. Culturally secure health services across the life span are not only necessary, but critical to the planning, development and implementation of all aspects of health service delivery, including services and approaches for assisting Aboriginal people to make informed end-of-life choices.

Aboriginal people share a variety of beliefs and views, and these will be different depending on language, skin group and country, or where you are in a region. This requires an individualised approach to each person and family in the context of their cultural background, beliefs, views and experiences. Our Aboriginal community-controlled health services are at the forefront in this regard, providing whole-of-life and whole-of-person health care across the life span. And, as I have discussed, Aboriginal leadership and self-determination are at the core of our Aboriginal community health services model.

Aboriginal community health services are best placed to deliver health, palliative and end-of-life care and treatment services to Aboriginal people and their communities, yet are often prevented in these efforts by financial constraints and barriers put before them by mainstream health service and palliative care providers. Aboriginal community-controlled health services are one of the most overly scrutinised and accountable health service providers in Australia, yet recognition for the significant achievements and improvements to Aboriginal people's lives, health and social and emotional wellbeing continues to go unrecognised and unfunded. Meaningful dialogue with AHCWA, our Aboriginal community-controlled health services, Aboriginal people and community is essential to developing end-of-life services and resources in WA. AHCWA and our member services, which is our Aboriginal community-controlled health services, must be at the forefront of any discussion, and AHCWA would be honoured to facilitate a bringing together of all our Aboriginal community-controlled health services to develop culturally secure approaches for end-of-life healthcare matters with and for Aboriginal people. Mainstream health services must also be educated about and accept and embrace the whole-of-life, including end-of-life, health choices and views of Aboriginal people.

Thank you. Any questions?

**The CHAIR:** Thank you very much, Mrs Clarke. That was very thorough and it does address a lot of the questions that we had. Directly relating to palliative care, you have said that a lot of your members do deliver palliative care. Are you able to identify which of those members are and what aspects of palliative care? You may want to take this on notice and get back to us if you are not able to now.

**Mrs CLARKE:** That is something that we would have to take on notice, I think, to work out which ones actually do. We do it in our model of care in all our Aboriginal-controlled community health services, so it is a day-to-day running. But to actually say completely palliative care, it would be best if Mel could answer.

**Ms SHELLEY:** There were probably a couple of points further but one was that Aboriginal community-controlled services are, because of the approach, as Ronda has pointed out, providing palliative care as part of their services. One of the things I think is important in preparation for today in contacting our member services and talking to our Aboriginal health care providers is that the terms "end of life", "palliative care" and "advance health planning" are not terms that people are using or familiar with. Aboriginal people are not using those languages. Whilst they are providing services, they are doing it as part of that combined model. If you want specifics naming the services, we would have to take that on notice.

---

**The CHAIR:** Thank you. Can you describe to me, Mrs Clarke, what you mean by “culturally secure”?

**Mrs CLARKE:** Culturally secure as in culturally appropriate, can I say, in a hospital setting? Can we do this as an example in a hospital setting? You would have an Aboriginal client that is in there, the triage team are talking to him, he does not have a carer with him, they are going to amputate his leg and he might need palliative care or something afterwards. He is just sitting there—English could be a second, third or fourth language—and has not understood a word that they have said to him. He is saying, “Yes, yes, yes” because he does not know what they are saying and the next minute he wakes up and has no leg, does not know where he is or what is happening and has no carer and support for him. Culturally, there should be someone there to explain in his terms, not in the main hospital terms, to bring it down to a grassroots level of what actually is going to happen to him and his care.

The other thing for Aboriginal people is not always do they want to know what the end result is. A doctor could be telling him, “You’ve got one to six months to live.” Not necessarily are they listening to that because they do not understand it. To them, how you would explain it as a doctor is not how an Aboriginal person would explain it, and maybe a family member or someone close to them or a carer would explain it in different terms than you would explain it.

**Ms SHELLEY:** If I could add to that, culturally secure is, essentially, the model of care that Aboriginal community-controlled provide. In my own experience, the term gets bandied around a lot in mainstream health services and people use that term without really understanding what it means. It means, ultimately, Aboriginal people providing Aboriginal services for Aboriginal people. The model of care, which is what Ronda has taken you through today, is essentially emphasising that point—that all parts of the person’s health and end-of-life choices as well. It is about recognising the importance of that culture in Aboriginal people in contributing to the development of, for example, legislation, resources and the healthcare approaches.

[2.00 pm]

**Mrs CLARKE:** Can I just add, when you come into an Aboriginal community-controlled health service, we do not just treat the cut on the leg. That cut could have many of those elements that come around it, so we are treating all the elements, not just a five-minute consult where you are in, you are treating the cut, and you are out. The same thing would happen for end-of-life care. There are spiritual, cultural and all sorts of issues there that need to be addressed when you doing it.

**Ms SHELLEY:** I wonder if I could just indulge you to add a couple more important points. One of the things in the research to prepare for today and with the services that we spoke to—the committee would be aware, no doubt—is that Aboriginal people often die from accidents and they often die from cardiac failure as a result of chronic disease. So they die suddenly; they do not often have a planned death. That is significant in terms of that combination of a whole-of-life and cultural approach to health care that Aboriginal community control take. Where people might, for example, be brought to Perth for dialysis or other treatments, they might choose to return to country without having any discussion about end-of-life choices or their palliative care. I think those are some of the particular issues around end of life that need to be considered about the way that Aboriginal people might go about that or understand that.

**The CHAIR:** With regard to mainstream services, you made the point that there are a number of rules and barriers to mainstream services for Aboriginal people. I think you gave us some examples around times and what people can bring in and out. Can you give us some concrete examples of what those rules and barriers are?

---

**Mrs CLARKE:** There are times—visiting times for Aboriginal people. We are not on a time clock. It is about yarnning, getting together, and it is family. It might not just be mum is visiting me; it will be mum, and it could be the sisters, and the aunties. Sometimes in some areas they will say, “Excuse me”. I have been there myself when there has been a few of us. We are loud. We are out there. That is Aboriginal people. We do it out in the open. Family is an important aspect and without family, it is like we lose that connection. When visiting hours are there, those restraints are different. You have to remember, with colonisation, smoking was introduced—tobacco—so there are a lot of people that smoke and maybe they are not allowed to smoke in a health profession, but that is what they want to do. They want to be able to walk out the front and be able to smoke, to be out in the open so they are not closed up in a confined space. Or they want to meet someone outside, which is not normal for a hospital setting. They would say, “Oh, you can’t do that” which makes it hard for an Aboriginal person. There is the different aspects of who and when and when they can have a carer and when they cannot.

There are restraints when you are coming from say Balgo to Perth, and it could be a life-threatening thing. You do it on a regular basis, but we would never do it—we would not fly someone from Sydney to New Zealand and back again, but we do it across Western Australia and the distances are bigger. We do not consider the cultural aspects or whether the family could travel, the dynamics, the funding; that is not there. Could those end-of-life choices be done closer to home, on country, with family rather than bringing them to a metropolitan area where they have never been before or they have never been on a plane? You have to remember with the RFDS, a lot of people that have been in that position have gone on an RFDS plane and they have never come back to country, so a lot of people relate to, “I’m not getting on that plane. I’m never going to come home if I get on that plane.” It is understanding those dynamics as well. In a hospital setting, it is making sure that their culture—if they do not want to have a male person there, is there someone they can speak to who is female? It might be a cultural thing. It could be another thing that they are saying they are sung to death. Their sickness might be end of life but, to them, they believe that they need a connection. I know we are in the twentieth century and telehealth could help in some areas, but it is having that connection with family. Maybe the video link up—there are areas we could work on in a health setting and in a mainstream setting to help with that cultural component.

**Hon ROBIN CHAPPLE:** Thank you very much indeed. I worked with the Nyikina Mangala up your end of the woods. Anyway, it was great. We quite often find, and touching on what you have said, say for example there was a woman out at Jigalong called Fannie who had I think about 12 aged people with dementia she was looking after on country. She was doing it for free—for nothing—and providing a really good service. WACHS comes along and sort of says, “Well, we don’t think you’re providing the right service.” So overnight, these people were transferred to Perth, never to see Jigalong again. The mob is completely upset because connection to country, the most important thing, has been broken. I just do not think we, broadly as a society, understand that connection. Also, the connection of dying on country is incredibly important. I was very privileged in the 70s to work with the Pintupi people out in the desert. We used to regularly take women to Alice Springs because they were going to have a breeched birth. They would walk 250 kilometres across country. It did not matter whether they died on the way, because it was more important to be on country for the birth and for their child than to be in an Alice Springs Hospital. That is a bit of an observation from myself, but I am hoping to lead you into some commentary around that.

**Mrs CLARKE:** That is wonderful. It is good that you have acknowledged that. It is great because there is not always an acknowledgement out there of what is happening. It is getting it right in both the mainstream and an Aboriginal community-controlled health setting. We are under scrutiny 24/7 on how we provide our services and what we do. We do do primary health care services and preventive



health and we already do look after that palliative care. A classic example is someone might come down to Perth because they have been referred, because WACHS have said, “No, they need to go to Perth; it’s life-threatening.” That person might want to but the other thing is the reason they do it is because I can understand from their point of view, as a GP, that they are trying to help that person for an extended period of time, but it is respecting that culture to say if that person does not want to do that, then respect the culture in saying they do not want to go to Perth. Do not put them on a plane to go to Perth. A classic example is here in Perth, a man from the lands came in. He had a very bad, ulcerated foot. He just wanted it bandaged, cleaned up, and wanted to go away. The doctor wanted him to go to hospital and have it amputated. It took an Aboriginal health worker to say, “No, he’s not going to do that. This is what he wants: he wants to go back home and he wants to die whole. He doesn’t want you to send him to the hospital.” It is understanding those processes, and acknowledging and accepting that there are different processes for Aboriginal people.

**Ms SHELLEY:** If I could just add to that, further to your point, you mentioned WA Country Health Service and our Aboriginal community-controlled services work collaboratively with them but I think some of the issues are particularly around patient journeys. Our Aboriginal community control—our doctors and our qualified health practitioners—might make an assessment of a patient that they have known maybe all of their life and are treating them for lots of different things, as we have described, about what is in the best interest of that patient or their client, as they are referred to. They might recommend that they are flown, for example, to treatment in Perth. WACHS generally might be holding the bucket of money for patient journeys and make a decision that, “Oh, no. We’re not going to fly them; we’ll put them on the bus.” This can be people with chronic illnesses who are very unwell, including people who are mentally unwell with psychoses. They are sedated in order to be able to travel on a bus. It is an issue for our Aboriginal community control in terms of looking at end-of-life care and wanting to support people with dignity in that process, whatever their cultural needs or beliefs are. Our community control are doing the work and often, the end-of-life process or that stage of death is taken away from them because they do not have the financial resources. They are not holding the bucket of money for patient journeys. They are not able to coordinate those flights. There is a major issue around those treatment services and patient journeys, and resources for that, which contributes directly to the issues we have discussed today.

[2.10 pm]

**The CHAIR:** What you have alluded to is the refusal of medical treatment.

**Mrs CLARKE:** In some cases—not all cases.

**The CHAIR:** And, I guess, the respect and acknowledgement that people can make that decision, based on a whole range of circumstances, not just medical circumstances, but they require, in many instances, some support in order to be able to make the decision when interfacing with the mainstream services, so they are not flown to Perth to have an amputation that they do not want.

**Mrs CLARKE:** Or life threatening if they are—you know, they come to Perth and they have been diagnosed with cancer. Some of them do not want to have the treatment, and some do, but it is having that support there, and some of them do not understand the terminology because of the way it is explained to them.

**The CHAIR:** In your experience, is that generally respected, when an Aboriginal person comes to Perth and is diagnosed with a terminal illness, that they —

**Mrs CLARKE:** Not always. In some cases, yes, some do understand, and you have to give merit and acknowledgement to those that do, but generally no.

---

**Ms SHELLEY:** I think one of the other experiences of our member services is in that process of negotiation where there might be no choice but for a person to come to Perth or a mainstream hospital where predominantly there is most likely not going to be Aboriginal health practitioners or workers to provide the service. Our community-controlled service who have been treating that patient potentially up to that point are blocked from being engaged in that negotiation or the discussions about their treatment and care options or their advice is not valued equally as that of a specialist or other mainstream health provider. Those are barriers across the whole of life, not just at the end of life, but it is particularly significant when you add the complexities and multiple issues that arise for people in terms of their cultural beliefs about dying and death and all of that, as we have discussed in our model of care.

**Mrs CLARKE:** And it is the terminology—end of life. You do not speak about it. There are certain things with Aboriginal culture that you just do not do, and there are things that women do that are women's business, and there is men's stuff that is men's business, and it is respecting that. But having those eight elements and looking at the whole eight elements is one of the bigger pictures and it is acknowledging that it is not just one little element. For some people coming down for terminal, they could be looking after four or five grandchildren, and they are going to go home to look after those grandchildren, and put those grandchildren first before their own health. If it is a terminal patient down here, and they have a cultural obligation because there is a death in the family, they will go home, whether they need dialysis or not, to meet that cultural obligation, and it is understanding that culture is a big thing for Aboriginal people.

**Mr J.E. McGRATH:** Some of us are city members, so we have not had a great experience with what the Aboriginal people are enduring up in the communities. Who would make a decision that someone has to come to Royal Perth or to Geraldton or somewhere like that? You have got someone on a community. Do they have visiting doctors? How are they looked after, these people?

**Mrs CLARKE:** That is something that we would have to come back with, because there are many people who have decisions in that making. Mel, do you want to answer first?

**Ms SHELLEY:** Perhaps to clarify, our Aboriginal community-controlled health services—there are 22 across the state, and they are predominantly in some of the major Aboriginal communities. Most often they are the services that are treating Aboriginal people in communities, so they might be involved in some process of treating a person and referral and discussion about that, but from that broader cultural perspective, there might be family members and others, and doctors who are contributing to any discussions about transport. It is important to restate that we are here on behalf of the information from our member services. We are a member service-driven organisation, and we act on their advice, and they report to us that the experience they have is that often when they are making recommendations for healthcare treatment in relation to end of life or otherwise, that advice is not often taken on. It might be that the person is in hospital and the hospital makes the decision in Broome or wherever without consulting with the Aboriginal community-controlled health service or the specialist they might be seeing in the community already. They find out later that the person has been transferred to Perth, for example, or from one of the communities down to Broome or whatever it is. So that is some of the gaps, I guess, in the disconnect for that kind of integrated response to the health issue. I do not know whether that answers your question.

**Mr J.E. McGRATH:** So once they leave the community and they go to the Broome hospital, or Derby or wherever, that is where the connection ends and then they either come back to the community or they are brought down to Royal Perth, but those decisions are made at the hospital they are taken to.

---

**Mrs CLARKE:** At the hospital WACHS level. I have to admit that we are, as Aboriginal community-controlled health services, trying to work with WACHS as much as we can. Sometimes it is hard; it is a frustrating set of rules and sometimes those rules do not encompass our whole eight elements.

**Hon ROBIN CHAPPLE:** If I may, can I provide an example that I think you would appreciate? For 30 years, we had a gentleman called Randy Spargo.

**Mrs CLARKE:** Yes, I know Randy.

**Hon ROBIN CHAPPLE:** He was working throughout the Kimberley and out in the desert. He is a doctor, very well respected, and he would be 80-odd now. He knew everybody out there. He knew which family they came from; he knew their relationships; and he knew their wishes and their culture. He was not filling in Medicare forms the way he was supposed to, so after 30 years of working with the mob, WACHS comes along and removes him, and replaces him with a doctor who now goes to Jigalong two days a week, and has no relationship with the people—totally inappropriate—and that is, unfortunately, because it is driven by a bureaucracy down here that has no competency and no relationship with the mob out there.

**Ms SHELLEY:** That is a really relevant story, and one of the things the Aboriginal Health Council has done is—because it works in reverse when people are down here in Perth. The doctors are doing their best, say, in Royal Perth Hospital, but they might not know where that person is connected, and where the medical service is in their own community. The Aboriginal community-controlled health services—in fact Ronda is one of the key project officers that have led the way on a new project which we are patenting. What we are referring to is the mapper project. We have presented on that to the Western Australian community health executive. It is actually about being able to provide opportunity for doctors in Perth, when they have a community member there as a patient, to be able to link back to this online mapper data system and get all sorts of information that will help with that seamless or more integrated approach to health care, including end of life.

**Mrs CLARKE:** It is about getting the right care, at the right time and in the right place. That is what it is all about, and making that connection.

**Hon NICK GOIRAN:** You mentioned that you have 22 Aboriginal community-controlled health services. Does that mean you have 22 members—they are the 22 members?

**Mrs CLARKE:** Yes, they are the 22 members.

**Hon NICK GOIRAN:** Which of those services are in or near Albany?

**Mrs CLARKE:** We have got one, can I tell you, and that is SWAMS—South West Aboriginal Medical Service.

**Hon NICK GOIRAN:** Is that in Albany itself?

**Mrs CLARKE:** No, it is in Bunbury, and it accesses the WACHS Aboriginal arm, which actually services Albany. It is very hard for funding, to set up an Aboriginal community-controlled health service in Albany. It is not something that AHCWA can do; we have to be invited in from the Aboriginal community, for them to come to us, and then we could go to help support in that way, if that is what they wanted. I do know at this stage that they are looking at putting one down closer, and in the wheatbelt there is also a gap, and they would like to see something there.

**Hon NICK GOIRAN:** Which of the 22, then, are in or near Broome?

**Mrs CLARKE:** The peak body for the Kimberley is KAMS, which is the Kimberley medical service.

**Hon NICK GOIRAN:** Where is it?

---

**Mrs CLARKE:** It is in Broome. And then you have BRAMS, which is Broome, and then you have Derby. For the Kimberley, then you will have Nindilingarri, which is Fitzroy Crossing, and it is not a clinic, but it is a social and emotional wellbeing healing centre; Yura Yungi, which is Halls Creek; OVAHS, which is in Kununurra; and Ngnowar Aerwah, which is in Wyndham.

[2.20 pm]

**Hon NICK GOIRAN:** Thank you.

**Ms SHELLEY:** KAMS particularly in the Kimberley leads the way in terms of regionalisation. KAMS is like the peak, and the other services sit under them.

**Mrs CLARKE:** They deliver to, and one of our members is, Bidyadanga, Beagle Bay. So KAMS delivers to those remote areas, Balgo, all of those.

**Hon COLIN HOLT:** Are there any Aboriginal medical services that are not a member of your organisation?

**Ms SHELLEY:** Yes, there are.

**Hon COLIN HOLT:** Who are they?

**Ms SHELLEY:** I cannot say off the top of my head. I can take that on notice if you do not mind.

**Hon COLIN HOLT:** Yes. The second question I have is around, obviously, cultural awareness. How are you interfacing with the universities for doctors to come out of graduation and have some sort of awareness of what is going on?

**Mrs CLARKE:** Can I say that we are certified cultural safety trainers. We do accredited cultural safety training face-to-face. We do not do online. Can I tell you I have done the online, and everybody in this room can say they do it—we all do it—and it is tick tick, tick tick. Do we read it? No. “Tick tick; let’s get to the end; I don’t have enough time to do this.” Okay! We have set up and advertised AHCWA with WAGPET so that doctors that are international can see what AHCWA does and what an Aboriginal community-controlled health service delivers. We have also got an MOU with Rural Health West where we are delivering cultural safety training. We go out to the universities. I am one of those trainers that goes out. We do six modules, all different modules. Our main module, which we make compulsory, is the history so that people can understand, which is not taught and is now slowly coming into the curriculum system. We have just done a big group at the Department of Health in the genomics section, and they were amazed at the difference of face-to-face to an online.

**Ms SHELLEY:** Can I just add, our member services host registrar general practitioners under the general practice Aboriginal and Torres Strait Islander training program, which is through the commonwealth government-funded initiative, and we work with WAGPET as Ronda said. Some of the issues, though, that are creating barriers are that the commonwealth government funding model—the modified Monash model—is creating gaps in terms of the registrar’s salary and what services are funded to pay. That means that registrars are less keen, and our services cannot afford to match the gap between what the commonwealth funding is and what then the registrar’s salary is. So we work in partnership with that program at the commonwealth level to be able to host general practitioners in the rural and remote areas so that they get that entry into these locations as part of their registrar GP training. The evidence from our clinical services team and the data they have collected shows that there is an increased likelihood, and we have increased access to GPs once they get through the process, that they remain or return to those communities to work for our services. So there is proof that that works.

---

**The CHAIR:** I am conscious of the time, because we have other witnesses coming in. We did not get to a number of our questions, particularly around advance care plans and voluntary assisted dying. We may send those to you for a response, if that is all right.

**Mrs CLARKE:** That would be great. Thank you.

**The CHAIR:** Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days of the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. The committee will write to you with the questions taken on notice, and in addition we will include the proposed questions that we were not able to get to today due to time constraints. Thank you very much for your attendance today.

**Mrs CLARKE:** Thank you for having us.

**Hearing concluded at 2.23 pm**

---