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TRANSCRIPT OF PROCEEDINGS

O/N H-1037310

THE HONOURABLE R.R.S. TRACEY AM RFD QC, Commissioner MS L.J. BRIGGS AO, Commissioner

IN THE MATTER OF THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

DARWIN

9.03 AM, THURSDAY, 11 JULY 2019

Continued from 10.7.19

DAY 34

MR P. GRAY QC, counsel assisting, appears with MR P. ROZEN QC, MR R. KNOWLES and MS B. HUTCHINS

COMMISSIONER TRACEY: Yes, Ms Hutchins.

MS HUTCHINS: Commissioners, the first witness we will call today is Ms Lisa Backhouse. I note during the course of her evidence there will be a number of photographs shown which show graphic content which may be disturbing to some people. Further, a number of the photographs that are subject to a non-publication direction. The photographs that will be made available to the media will be moved into the relevant space in the usual way.

COMMISSIONER TRACEY: Yes, thank you for that warning and I would ask anybody who is in the courtroom or watching this hearing online to note what has just been said and if need be to absent him or herself from viewing the evidence of the first witness. Yes, Ms Hutchins.

MS HUTCHINS: I call Ms Lisa Backhouse.

<LISA MAREE BACKHOUSE, SWORN [9.04 am]

<EXAMINATION-IN-CHIEF BY MS HUTCHINS

MS HUTCHINS: Ms Backhouse, you've prepared a statement for the Commission.

MR BACKHOUSE: Yes, I did.

MS HUTCHINS: Operator, please bring up WIT.0221.0001.0001. Ms Backhouse, is this a copy of your statement?

MS BACKHOUSE: Yes, it is, and please call me Lisa.

MS HUTCHINS: And Lisa, is it true and correct to the best of your knowledge and belief?

MS BACKHOUSE: Yes, it is.

MS HUTCHINS: I tender that statement.

COMMISSIONER TRACEY: Yes. The witness statement of Lisa Maree Backhouse dated 3 July 2019 will be exhibit 6-20.

EXHIBIT #6-20 WITNESS STATEMENT OF LISA MAREE BACKHOUSE DATED 03/07/2019 (WIT.0221.0001.0001) AND ITS IDENTIFIED ANNEXURES

MS HUTCHINS: Thank you, operator, please bring up general tender bundle, tab 20. Lisa, your statement today relates to your mother, is that correct?

MS BACKHOUSE: That's correct.

MS HUTCHINS: And what is your personal and professional background?

MS BACKHOUSE: I have a background in media. I spent 20 years as a journalist working for the ABC, Channel 9 and Channel 10. I then moved into the corporate sector where I manage corporate affairs and reputation for organisations.

MS HUTCHINS: Thank you. I understand today you would like to read from your statement. In your own time, could you please commence from paragraph 8.

MS BACKHOUSE: Yes, thank you.

We all think our mums are special but Christine was a stand out. Kind, funny and completely dedicated to her beloved girls. She never once raised her hand or voice. Instead, she made up stories and songs and created a wonderland of dolls, books, baking and road trips just for ice-cream. She nurtured, guided and protected, committing herself to us absolutely.

I apologise.

MS HUTCHINS: Lisa, if you need to take a break at any time please just let us know.

MS BACKHOUSE: Thank you.

As was the norm this those days Christine left her career as a nurse and midwife when motherhood came along. She was the ultimate caregiver, both as a parent and in her chosen profession. Such is life's cruel irony that years later this strong capable and fiercely independent woman would be relying on so many others to provide for her most basic needs.

In her mid-fifties Christine suffered the first of what would be many strokes; small vascular episodes that would see her capacity slowly and painfully diminish along with her mobility and cognition. It began what would become a long grieving process as the woman I knew so intimately, excruciatingly ebbed mentally, physically and emotionally away. In her 70s she was officially diagnosed with vascular dementia and entered a care facility in Brisbane.

Over the decade that Mum has spent in aged care, I have experienced the good, the bad and the downright unacceptable. I have tried to work in partnership with facility managers, have been through periods where we have fought openly over my mother's care and have been reduced to tears by the

compassion and benevolence shown by countless carers, nurses and nurse managers.

On the afternoon of 20 November 2018 I was in a work meeting when I received a telephone call from the nursing home. Phone calls were not uncommon. Mum had a long history of falls including a previous broken leg, numerous hospital visits for suspected concussion and countless incidents where she had been found on the floor after "sliding" off her chair.

This day I was told that an ambulance had been called and Mum was on her way to hospital having been found alone on the floor with a suspected broken leg. The fall had been unwitnessed.

Due to Mum's issues with falls, a sensor mat was located next to her bed. A sensor beam was located next to her chair on the other side of the room however it does not appear to have been switched on. I don't know how long Mum was lying on the ground in agony after the fall, and whether she had crawled across the room with her broken leg to trigger the sensor mat before being found. I try to block that from my mind.

In the months leading up to this incident I had been increasingly concerned about the number of times Mum was found on the floor by nursing home staff. Staffing levels had reached such a low level that carers were unable to perform basic duties. Early in 2018 I had a series of conversations with staff at the facility about checking on Mum more frequently during the afternoons. I recall on one particular day I asked a carer during a conversation in the facility's hallway to please check on Mum in her room to try and prevent her being found on the floor. I was told, "I'm sorry but I just don't have time".

Mum's level of agitation had been rising and the nursing home was pushing strongly to increase her medication but I believed greater care for her basic needs and behavioural interventions would improve her comfort and reduce her agitation. In late 2016 Mum was assessed by the Dementia Behaviour Management Advisory Service. Around February 2017 I engaged a private nurse to visit her for two afternoons a week for two hours to provide extra support and care which I paid for myself.

Advanced dementia can bring many challenges including rising physical agitation in overwhelming situations such as hospital visits. Hunger and tiredness exacerbate the condition. On the peak hour drive to hospital last November I mentally dug in for what I knew would be a long, difficult night.

I'm sorry.

Mum was surprisingly calm on my arrival but the nursing staff were not. They had just finished changing her into a hospital robe and replacing her incontinence aid. There were hushed voices from behind the curtain and a

discreet cautious sharing of information; tentative, in breach perhaps of some unspoken policy, but the furrowed brows and low tones illustrated the gravity of concern. The incontinence aid was removed from the waist with the explanation, "I'm so sorry but I need to show you this. It's important that you are aware".

I stood for a moment gaping at the item which clearly had been in use for an unacceptably extended period of time; an item that in its current condition breached all levels of basic hygiene and human standards. The ambulance officers had noted the strong odour on entry to Mum's room in their paperwork. I was able to view this paperwork following a Freedom of Information search. Approximately two weeks earlier I had complained to the centre manager about Mum's incontinence care. The manager had provided assurances that better processes were in place and had left a voicemail message for me by way of a follow-up on the morning of Mum's fall.

A subsequent investigation by the Aged Care Quality and Safety Commission found that no tangible action had taken by the facility to address the serious issues regarding Mum incontinency care between the time I contacted the facility manager and the day of Mum's fall. I believe that Mum's fall was directly attributable to the state of her incontinency care as she was trying to mobilise due to discomfort. The Commission also found the centre did not appropriately implement fall prevention strategies with a further three unwitnessed falls in the month of November alone.

X-rays taken in hospital revealed Mum's left leg was smashed in two place. I use the word "smashed" because the lower break, near the ankle, was a smattering of small bones floating like pieces of a jigsaw puzzle. The upper bone, just under the knee, resembled a snapped tree branch.

I can only imagine the pain this must have caused. Add the fear and uncertainty that comes with dementia and the all-night stay in the emergency department was bound to end badly; ambulance officers were forced to restrain Mum for the return trip to the nursing home as the sun rose.

Despite relaying the doctor's concerns regarding the severity of the broken leg, her care at the nursing home was dreadfully deficient over the following days. Around 23 November 2018, finding her in pain, agitated, lying half out of bed and soaking in urine, I confronted staff who were gathered chatting in the nurse's office. I asked when she last received pain relief and was told she was given Panadol at 8 am, some three hours earlier. Panadol, for a freshly smashed leg which was yet to be set in a substantive cast. There was a container of water sealed tightly and well out of reach. Her sheets were wet through and she was visibly distressed.

The weeks that followed during November and December 2018 and January through February 2019 were a blur of hospital reviews, X-rays, pressure sore

management, care meetings, hunting for a new nursing home, and paperwork. Given the immediate challenges and long-term uncertainty, I resigned from my job to give Mum my full focus.

I discovered how difficult it is to secure a place in a nursing home, especially if your relative is at the higher end of care and will by necessity take resources away from others. After many calls, tears and what felt like downright begging, a kind-hearted soul in a nearby centre took pity and Mum was offered a bed. We moved her the week before Christmas; a huge ordeal for a dementia patient for whom routine and familiarity are so crucial. The full leg cast would now mean she was completely immobile forcing further change. It would turn our lives upside down but I was so grateful for a fresh start. I believe Mum was too.

Mum's level of agitation can spike during any given day. If tired, hungry, scared or confused she can become overwrought and is capable of lashing out. This behaviour is not uncommon to dementia patients and she receives medication aimed at both reducing anxiety and managing her distress. During these times she requires a great deal of patience, kindness and competency.

After just three months in the new facility I received a call from the centre manager noting an unfortunate incident that she must bring to my attention, and a difficult call to have to make. Mum had been hit by one of the carers. It had been reported by a witness, the staff member stood down and a full investigation was underway. The investigation concluded that there were mitigating circumstances, nevertheless, disciplinary processes were still followed. Just a few weeks later, the phone rang ominously again.

The manager of the new centre is professional, thoughtful and empathetic and this was clearly a tough conversation. "I'm so sorry to have to call you about another incident. I'm afraid your mum has been hit again". The words ran off me like water on an oily surface. It was a different carer than previously. It had taken the second carer who witnessed the incident a full day to report it. She had been in tears when she did so. I was told the carer would be stood down, and the matter reported to police. I was told my mother had been hit with intent and force twice on her upper leg. I simply cannot describe the feeling of devastation and powerlessness that this has delivered. I had moved her to guarantee her safety and instead delivered her further into harm's way. I had earlier adorned her room with pictures from her youth, a smiling beautiful woman embracing the possibilities of life in the hope the carers would see that person when they attended her. I immediately sought permission to install a surveillance camera, infra-red and voice-activated, not to spy but to act as a deterrent. Short of moving into the facility and sleeping by her bedside I just don't know what else to do.

I have proceeded with pressing an assault charge against the carer, not because I'm vindictive but because I don't want her to work again in the aged

care sector, and this is my only choice. There is no regulation for care workers in Australia. No national register to guard against this type of behaviour, not even a blue card or equivalent. Without any way to check employment history and dismissals, this carer can walk into another centre tomorrow with no record of the event to follow her. Nurses and other health professionals are regulated under the Australian Health Practitioners Regulation Agency but this does not currently extend to carers.

The carer has been charged with one count of serious assault over the second incident and has been dismissed by the facility.

On 17 May 2019 despite increased awareness and attentiveness by the aged care facility following recent events and the presence of a surveillance camera in her room, Mum was left unattended on the floor for a period of 43 minutes at 1444 hours following an alert from a sensor in her room.

I had noticed that Mum was on the floor in the motion-activated video that was recorded by the surveillance camera and contacted the facility. I was informed that staff had not attended to Mum earlier because they were assisting the family of a recently deceased resident. The video footage shows that Mum is soiled and was trying to mobilise. She is not able to use the call bell to request help independently.

The facility management has apologised and staff have been counselled regarding this incident. However, this is indicative of a much wider systemic issue – that of failure of staff to attend in a timely way following sensor or call button alerts. I have experienced this personally innumerable times and across different centres. It is also a common complaint of other residents and family members.

Mandating call time response rates, that is, residents must be attended within a specified period of time following an activation and this being monitored by the Aged Care Quality and Safety Commission as part of the facility's accreditation process is the only way to ensure that residents are not left to languish for any reason.

Adequate staffing levels should be provided to allow for a contingency including the management of priority situations without the safety and wellbeing of other residents being compromised.

This issue goes directly to the need to mandate staff to resident ratios to ensure adequate numbers of staff are available at all times. Without this being enforced, facilities are able to not replace staff who are unwell or fail to attend shifts resulting in cost savings to the providers to the detriment of residents' safety and wellbeing.

Given the profit nature of the aged care sector it is fundamental that regulation be introduced to prevent a budget focused culture which overrides the basic care needs of residents.

On the week beginning 2 June 2019, Mum was left for periods of up to 10 hours overnight without being checked. This is despite processes at the facility which outline that residents must be checked two hourly throughout the night. During one of the coldest nights of the year, Mum had inadvertently removed her bed covers while falling asleep. Wearing just a thin nightie, the surveillance camera in her room records her trying to get warmth at 2.44 am by pulling a pillow over her legs. She is not covered until 7.35 am in the morning when the first staff member enters the room since 9.17 pm the previous evening. Exclaims, "Oh my God, you're cold" and immediately reaches for the bed covers. This incident was extremely distressing to witness and once again triggered an overwhelming powerlessness to ensure basic humane care for my mother.

I have a surveillance camera in Mum's room which I purchased at a well-known technology outlet in a local shopping centre for a reasonable cost. It allows me to view live footage on my mobile telephone through an app and it also sends notifications directly to me when motion is detected allowing me to remotely view the camera's feed. It is through the surveillance camera in Mum's room that I have been able to identify two serious issues in Mum's care as outlined in paragraphs 31 to 38 above. These issues presented in less than a month of having the camera installed and activated.

While I am permitted by the facility to do this, the installation of the camera in Mum's room at the aged care facility has been contentious. The facility provider has told me that it has since up updated its national policy so that moving forward family members can put cameras into their room provided the facility manages the data it collects, and that the family members must watch any footage in the facility with a staff member present. This nervousness about the ownership and storage of the data and its use is extremely disappointing. Technology has now advanced to a point where relatives can connect with their loved ones 24 hours a day from any location. This should be encouraged as it provides peace of mind and comfort to both residents and their families. The technology can be used to assist with the care of residents, particularly regarding issues such as fall management. I believe passionately that if you have a vulnerable loved one in an aged care facility in this country today, you should immediately install a surveillance camera. In my experience, the more a facility tries to hide, the more they have to hide. You will very likely be shocked by what you see. I certainly have been.

The Royal Commission should consider recommendations aimed at preventing aged care providers from banning or restricting the use of surveillance cameras in residents' rooms if the resident and/or their family, if they're cognitively impaired, believe it is in their best interests. Further, providers

should not be allowed to insist that they hold the data with the footage only able to be viewed with a staff member or at the facility. Providers should welcome the transparency that the technology is able to deliver and work in partnership with relatives in the best interests of residents.

In December 2018 following Mum's fall, I made an official complaint with the Aged Care Quality and Safety Commission in relation to the first residential care facility. The four categories of complaint included incontinency care, fall management, pain management, and nutrition and hydration.

Just months earlier in 2018 I had sat with an official from the Commission during that same centre's accreditation process. I had laid out a raft of concerns including incontinence care, understaffing and poor processes leading to worrying outcomes for residents. I was told that the Commission would work with the facility to remedy the identified issues, including understaffing. However, once the accreditation process was complete standards quickly deteriorated resulting in the situation Mum faced in November.

The commission's six-month-long investigation following the fall identified failings in all four areas of complaint. Even so, I understand there is no direct consequence for the facility provider. This is despite Mum suffering pain, indignity, loss of mobility and probably a significant reduction in life span as a result of this incident.

The Commission's response to the complaints outline a raft of remedies such as provision of further training and check sheets for staff to follow. I have no doubt that remedies such as those offered by the provider and accepted by the Commission will quickly disappear in the task-focused flurry of an overstretched sector where the chasing of profits consistently overrides care needs. It is beyond belief that further training should need to be provided to registered nurses on basic issues such as appropriate medication for severe pain. The failure of qualified staff to provide adequate care is a serious concern and should at the very least be referred to the Australian Health Practitioners Regulation Agency.

There are fundamentally inadequate consequences for providers who fail to meet proper standards in their care of residents. The Commission places its emphasis on working with facilities to improve standards. This approach has been a total and absolute failure. Punitive action is required to ensure the sector uniformly meets its obligations to residents. Just as the Banking Royal Commission revealed the failings of ASIC to hold the financial services sector to account, a renewed emphasis must be placed on the culture and resources within the Aged Care Quality and Safety Commission. Stronger powers should be bestowed on the regulator to allow for a broader range of punitive measures such as financial ramifications including fines and penalties for providers who

fail to deliver adequate care, especially where it results in harm. We need a policeman on the beat, not a social worker.

This is particularly important as legal redress is severely limited, restricting the ability of residents and families to hold providers to account for negligence and non-compliance issues which cause harm and suffering. Society's ability to lift overall standards in the sector is currently severely compromised.

Breaches to workplace health and safety legislation, for example, allow for penalties of up to three million dollars for corporations, or $600,000 and five years' imprisonment for officers. Should not the boards of aged care facilities be held personally and criminally liable where harm is caused to those under their care?

The aged care sector has undergone a monumental shift over the past decade but reform has not kept pace. When Mum entered the system the majority of residents were low care. The facility was essentially a supporting living arrangement where meals, laundry, cleaning and medical services were provided but normal life continued to a substantive degree. By the time Mum was deemed high care the centre had also morphed, much like a frog in boiling water, into a secure dementia facility where the doors no longer opened without code access, and hoists, electric hospital beds and medical paraphernalia were the norm. The situation had effectively reversed with the majority of residents high care patients and around half suffering some form of dementia. Their needs are greater than ever before and the work of the carer so much more important.

The vast majority of carers are loving, compassionate and diligent people who bring a wealth of pride to their work. They have extremely hard jobs and they do it well under the circumstances. However, they desperately need more training and better qualifications to meet the increasing demands and the complex needs of residents.

The workforce must be professionalised to improve standards and quality of care and, yes, that means regulation and appropriate funding and remuneration. It means developing proper career pathways to attract and retain the best employees. It is expensive and it's going to become more so as the baby boomers enter the system but change must come and it must come quickly.

Politicians are great at kicking the can down the road delaying public policy imperatives such as mandating minimum staff to resident ratios. Ask any family member of an aged care resident and they will tell you that you can shoot a cannon down the empty corridors on weekend and afternoon shifts in particular. I have observed that residents are often left sitting in chairs all day long, more often than not in soaking incontinency aids, lying on the floor unable to mobilise after falls, unable to reach fluids, or with spills covering

them. Sometimes, they have pressure sores and infections that go unnoticed in the busy task-focused environment. Even the best facilities operating a staff to resident ratio of around one to eight. That means the most basic care needs such as bathing, dressing, feeding and toileting are just being met. Sometimes not. There is no playtime for true care where humanitarian and comfort needs are also met in a proactive way.

Thank God there's a Royal Commission. The collective sigh of those navigating the aged care sector was audible around the country; change is coming. But as we know, there must be political will to adopt change and a community momentum to force politicians to act, especially when the financial cost of such change is high. Witness the banking Royal Commission. Hardly a day passed when we did not hear or watch stories showcasing victims of greed and systemic cultural issues. It was high drama and great TV. Some three months into the Aged Care Royal Commission and it was deathly quiet by comparison.

While we know that abuse, neglect and poor care of the elderly is rampant in our society, victims and their families are often reluctant to speak out. Having a loved one in aged care makes you dreadfully vulnerable and exceptionally cautious. Your actions could impact your mum or dad. There could be repercussions and they may suffer quietly behind closed doors. Victims of the sector are also generally traumatised; feelings of betrayal, guilt and lack of control can paralyse absolutely.

Some will say: what of the families? Where is their responsibility for the care of their relatives? Please don't judge us without walking a day in our shoes. We are already crippled with self-loathing, in most situations, forced into a world we are poor and constantly struggle with. My parents were divorced, and I was a lone carer with no siblings, two small children and recovering from breast cancer when mum began her journey of deterioration. Now, her high physical around the clock needs are simply too great to be managed at home.

Older Australians like mum have given of their bodies, minds and spirits to grow a future for their families and communities and have laid the foundations of a society we enjoy today. Growing old should be a dignified experience where self-respect can be maintained. The next generation must have confidence that their basic physical, psychological and human needs will be met and hopefully exceeded when they are at their most vulnerable.

The current situation is heartbreaking at best, criminal at worst. When we look back in years to come, much like the orphanages of yesteryear, this will be our country's greatest shame.

MS HUTCHINS: Thank you, Lisa. I wish to take you, now, to a number of photographs that you've provided to the Royal Commission to illustrate the story that

you've just now told. Operator, please raise general tender bundle tab 13. Lisa, do you recall when this photo was taken?

MS BACKHOUSE: This was taken in the lead-up to the fall in November 2018. I can't pinpoint the exact time. There were numerous falls that mum sustained and injuries that she suffered in the years leading up to the November incident.

MS HUTCHINS: And in relation to the November incident, Operator, please bring up tab 15. Is this the incontinence pad that you referred to in your description of the event?

MS BACKHOUSE: Yes, it is.

MS HUTCHINS: And how long had your mother been using incontinence pads like this?

MS BACKHOUSE: For a period of a couple of years. Her physical health had declined steadily as her disease progressed. She had become gradually incontinent over a number of years and had been using incontinency aids for a period of time.

MS HUTCHINS: And have you found, with the use of the surveillance camera in your mother's room, that this is a matter you are able to keep an eye on?

MS BACKHOUSE: Yes. The surveillance camera, I felt, when I originally installed it, would be a deterrent to try to prevent harm such as future abuse to mum. What I didn't realise and has been an enormous advantage, is my ability to become a joint carer for her. I am able from any location at any time of day to check to see whether she is asleep, whether she is up, whether she is being cared for, and, quite often, I find that I am bridging the gap at the nursing home in her care. For example, two nights ago, she had slept from lunchtime on one day right through until 5 am the next morning.

By the time you get to 5 o'clock the next morning in a nursing facility such as the one mum's in, the communication has broken down to a point where the morning staff coming on at 5 am have no idea that she has been asleep since midday the following day. So I find I am able to make a call to the nurse and say, "Mum's awake. She needs to be up. She needs fluids. She hasn't had anything to drink since lunchtime yesterday, and it's now 7 o'clock in the morning. Can you please get her up? Feed her; get her some fluids." So I found that I have been able to assist, whether I should have to or not. It gives me comfort knowing that I can do that, and that she is not going to slip through the net and fall through another crack.

MS HUTCHINS: Operator, please bring up tab 18. In your statement, you make reference to an incident where you found your mother before – after the fall, but before the cast has been put onto her leg. Is that what this is the photograph of?

MS BACKHOUSE: That's correct.

MS HUTCHINS: Yes and did you take this photograph?

MS BACKHOUSE: I did. I took it because I was horrified.

MS HUTCHINS: Yes. And, Operator, go to tab 16. What does this photograph show?

MS BACKHOUSE: This is a photo of mum following the fall when she had had her leg set in the substantive fibro cast. It shows the extent of the break, from the tip of her toe right through to the top of her – her thigh and, obviously, the pain and discomfort that she was having to endure and lack of mobility permanently following the fall.

MS HUTCHINS: Yes. How long was she in the cast for?

MS BACKHOUSE: She was in the cast approximately eight weeks.

MS HUTCHINS: Operator, please bring up tab 19. What does this picture show?

MS BACKHOUSE: That's a pressure wound that mum sustained on her heel as a result of the cast that was discovered after eight weeks when the cast was removed. That's only just healed, just in the last one or two weeks – some six months following the incident.

MS HUTCHINS: And, Operator, please go to tab 22. So what does this picture show?

MS BACKHOUSE: This is an image that I captured from the surveillance camera in mum's room. This is mum on the floor, after the sensor beam activated, for 43 minutes before staff came and discovered her situation. I only discovered it about an hour after the event when I checked in on my camera on my phone, and I was shocked to see what had happened and quite dismayed that this is with a surveillance camera in her room.

MS HUTCHINS: Operator, I will ask you to please move through a series of stills that are taken from the security camera on this occasion. Please go next to tab 22, then to 23. Next, to tab 24. What was the reaction of the facility when you raised this instance with them?

MS BACKHOUSE: The manager was very professional. She responded immediately to my concerns. She checked the sensor activation to see whether, in fact, it had activated, which it had. She apologised and explained that there were, on that day, what she believed were extenuating circumstances. There'd been a death of another resident and staff had been attending to that, but, even that, she didn't feel was acceptable and, clearly, it's not acceptable.

MS HUTCHINS: And, Operator, please now go to tab 30. These stills, again, were taken on the security camera from your mother's room.

MS BACKHOUSE: That's right.

MS HUTCHINS: Yes, and these stills relate to the event you described in your evidence just now about the night that was cold and your mother had lost her sheet; is that correct?

MS BACKHOUSE: That's correct.

MS HUTCHINS: Yes. Operator, I will ask you to please move through a number of these stills. Next, to tab 31. What does this image show?

MS BACKHOUSE: This image broke my heart.

MS HUTCHINS: And is that her pillow that she's trying to use to - - -

MS BACKHOUSE: Yes, it is.

MS HUTCHINS: - - - put on herself. Yes. And at tab 33, please, Operator. And tab 44 – sorry, 34. So were you, again, alerted to this situation by looking at your app on - - -

MS BACKHOUSE: Yes, that's right. I would have had no idea.

MS HUTCHINS: And did you mention that the app would send you notifications if there was movement in the room?

MS BACKHOUSE: It has two settings. You can watch all vision live, or you can set it to send you a notification if there's motion in the room.

MS HUTCHINS: Yes.

MS BACKHOUSE: And then – yes, so that you're aware if, you know, when mum returns to the room, I'm aware when she's back in the room.

MS HUTCHINS: Yes, thank you. Operator, please go to paragraph 58. Sorry, to tab 30, and now to tab 35. When was this picture taken?

MS BACKHOUSE: This was taken in the last six months at the new facility. This is mum, you know. Really very loving, kind, adoring woman who loves babies, loves children and loved life.

MS HUTCHINS: Thank you. Commissioners, I have no further questions.

COMMISSIONER TRACEY: Ms Backhouse, thank you for your deeply moving testimony and, also, for your very constructive suggestions about what needs to be done to improve the lot of those who're patients in the aged care system. We will take on board your suggestions, and I must say, speaking personally, the idea of cameras in rooms with ongoing immediate access to relatives has many attractions.

MS BACKHOUSE: Thank you, Commissioner.

COMMISSIONER TRACEY: Thank you very much.

MS BACKHOUSE: Thank you.

<THE WITNESS WITHDREW [9.45 am]

MS HUTCHINS: Commissioners may I request that we stand the Commission down for a short five-minute adjournment?

COMMISSIONER TRACEY: Yes, there will be a short adjournment.

ADJOURNED [9.45 am]

RESUMED [9.51 am]

COMMISSIONER TRACEY: Yes, Mr Rozen.

MR ROZEN: Commissioners, the next witness is Associate Professor Peter Neil Gonski, who I formally call; I see he is seated in the witness box. If Professor Gonski could be sworn or affirmed in please.

<PETER NEIL GONSKI, AFFIRMED [9.51 am]

<EXAMINATION-IN-CHIEF BY MR ROZEN

MR ROZEN: Thank you, Commissioners. Associate Professor Gonski, can I ask that you state your full name for the transcript please.

ASSOC PROF GONSKI: Peter Neil Gonski.

MR ROZEN: Thank you. And have you made a statement for the Royal Commission dated 27 May 2019?

ASSOC PROF GONSKI: Yes, I have.

MR ROZEN: It's WIT.0197.0001.0001. The first page of that should be on the screen in front of you, Professor Gonski. Have you had a chance to read through that before giving evidence today?

ASSOC PROF GONSKI: Well, I wrote it so I have read it, yes

MR ROZEN: Okay. Is there anything that you would like to change?

ASSOC PROF GONSKI: Nothing, no.

MR ROZEN: Okay. And are its contents true and correct?

ASSOC PROF GONSKI: Yes it is.

MR ROZEN: I tender the statement of Professor Gonski.

COMMISSIONER TRACEY: Yes. The witness statement of Associate Professor Peter Neil Gonski dated 27 May 2019 will be exhibit 6-21.

EXHIBIT #6-21 WITNESS STATEMENT OF ASSOCIATE PROFESSOR PETER NEIL GONSKI DATED 27/05/2019 (WIT.0197.0001.0001)

MR ROZEN: If the Commission pleases. Professor Gonski, you hold the position of senior staff specialist geriatrician at South Eastern Sydney Local Health District.

ASSOC PROF GONSKI: That's correct.

MR ROZEN: And you're a doctor by training, a general physician.

ASSOC PROF GONSKI: I started as a general physician because there was no aged care faculty. Subsequently, I have approved as a geriatrician when it all started – when aged care all started and became a subspecialty of the College of Physicians.

MR ROZEN: All right. I want to ask you little bit about that, if you could, please, because the Commission is particularly interested in the role of geriatricians in aged care generally. So what period are you talking about as that period of transition or change?

ASSOC PROF GONSKI: So I became a geriatrician in 1991. I trained previously as a general physician, which is basically a whole lot of subspecialties in one, so

looking after the whole patient or person. And subsequently it was evident that aged care was going to be the future of medicine and a number of us decided that it was time to make it into a subspecialty which we did and so I became a geriatrician in '91 on those grounds. And subsequently we have been able to put together a training scheme so that there is a proper subspecialty in aged care and geriatrics which are really the same things, but people call them different things but it's geriatrics really, and we have now got more trainees than any other subspecialty across Australia.

MR ROZEN: When you talk about subspecialties, another subspecialty might be paediatrics, for example. Is that what - - -

ASSOC PROF GONSKI: Yes, so people train in – as a basic trainee in being a physician and then they subspecialise in things like cardiology, respiratory, gastroenterology, and aged care, neurology, etcetera.

MR ROZEN: Right.

ASSOC PROF GONSKI: So paediatrics is – although it's under the same college, it's a separate training scheme.

MR ROZEN: And, as you have indicated, you also have a teaching role in the Faculty of Medicine at the University of New South Wales; you are conjoint associate professor there. That is in geriatrics, I take it?

ASSOC PROF GONSKI: Okay. So that's in – it's actually in geriatrics, but it's actually also in community medicine. So I'm in the School of Public Health and Community Medicine, and I think it stands well there because geriatrics is very much a community-based subspecialty.

MR ROZEN: You said a moment ago that you have more trainees than any other subspecialty; what do you put that down to?

ASSOC PROF GONSKI: People are getting older and the requirements of – of geriatricians. Basically, this has only been in the last few years that we have basically got more than any other subspecialty. It used to be cardiology, particularly, and respiratory and gastroenterology, but everyone has obviously realised that people are getting older, there's much more chronic disease. Every year there's more and more – people are getting more and more chronic diseases. We often have young people with chronic diseases but we mainly look after older people with chronic diseases and it was obvious that in – even in every subspecialty that geriatrics has to be a part of it because older people are the people who get ill.

MR ROZEN: Is there a growing awareness, do you think, in the medical profession about these matters and about the need for there to be more geriatricians?

ASSOC PROF GONSKI: Yes. If I go back to when I started, I was very unaccepted. You know, cardiologists were very accepted, gastroenterologists were

very accepted amongst other peers but no one really knew what geriatrics was on about, what we were trying to do. They really – and they treated us as such. But we held our heads up and said that this is going to be the future and now they totally rely on us, and if you look at emergency departments, we have the biggest number of admissions through emergency departments for medical problems, and the subspecialist is only grateful that we are there and we are ready to take patients who previously would have been under their care.

MR ROZEN: All right. We will come to a number of examples of that presently, I think. I would like to ask you some questions about the geriatric flying squad model of which you have been an integral part in establishing in Sydney. We have had some evidence in the Commission about this before; Professor Henry Brodaty, you may know, gave evidence in Sydney, in the Sydney hearings and spoke particularly about the success the flying squad model has had in reducing hospital admissions, and I want to ask you some questions about that. We also heard some evidence in Perth from a nurse practitioner, Josh Cohen, who is involved in the Calvary palliative care processes and organisation. He also spoke about the overlap between some of the work they do and the work of the flying squad. So I will touch on that as well when we talk about palliative care later. But if we can start at the beginning. How long has the Geriatric Flying Squad model that you've been involved with, how long has that been in existence?

ASSOC PROF GONSKI: Well, look, our department has been going for 20, 25 to 30 years and we've always provided services to people at home and in aged care facilities. But it was apparent to me that people deteriorating quickly in aged care facilities particularly, but even also at home, they didn't want to go to hospital. Many of them didn't need to go to hospital if we could provide similar services in – where they lived. So we took the model that, if someone deteriorated acutely in an aged care facility, unless they really, really required hospitalisation like they broke their hip and they obviously were going to need an operation or they hit their head and they obviously were going to need a CT brain scan then maybe we could provide our service to them.

So about nine years ago I was able to get funding to put together a half time geriatrician and nurse practitioner to do this work on an eight to five basis Monday to Friday. Subsequently we have been able to attract a lot of funding and I've been able to now provide the service 8 am to 10 pm, seven days a week, and we've also been able to get through that same funding, been able to start the very similar flying squads in other parts of our district. So, we now run three flying squads.

Now, flying squads, in the way the words are, they mean a lot of different things to a lot of different people. What we are providing is a very rapid assessment of acutely deteriorating people in aged care facilities and we also do it in a different team to the people who are actually deteriorating at home. Obviously, it's difficult, more difficult in the home because you don't have all the infrastructure like nursing staff, as you do in aged care facilities. So it really, really works well in the aged care facilities. A little bit more difficult in the community, but it can work, and as we

progress over the next few years, I would hope that it's going to be one – it's also going to be as good as and as important to people as the ones that we provide in the aged care facilities.

MR ROZEN: Right. I'll just stop you there for a moment if I could, and if I could direct your attention to page 6 of your statement please. If that could be brought up on the screen, the middle paragraph. The number one:

> *Residents having chronic medical problems. Geriatrician registrar consultation.*

If I can just deal with this topic first before moving to the flying squads because, if I'm understanding correctly, what you are describing in this paragraph is different from the flying squad notion. Am I correctly understanding that? This is where residents in a residential care aged care facility have a chronic medical problem, rather than an acutely deteriorating resident; is that right?

ASSOC PROF GONSKI: Yes. So – you do have to see the older person, in that they have problems on – chronic problems. They have subacute problems which are - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - in between the acute and the chronic. So you do have to see it, and you have to provide services where they are and at those different timeframes. So we - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: We provide – we feel that we provide a holistic approach to all older people in all settings at all times. So acute, subacute and chronic to people that live in homes, community, aged care facilities or who are in hospital.

MR ROZEN: You said a moment ago – if we can turn then to the operation of the flying squads. You said that the rationale – if I understand you correctly, it's the central rationale, isn't it? It's to provide medical care, clinical care at the most appropriate location. Is that sort of the - - -

ASSOC PROF GONSKI: That – so – so for - - -

MR ROZEN: - - - central idea? And at an appropriate level.

ASSOC PROF GONSKI: For older people, one has to provide the right care at the right time in the right place - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and so – and everyone is different. Every individual is absolutely different. So, basically, you do have to provide it to them. The best place is in their own home and that may be – that home may be an aged care facility.

MR ROZEN: Yes.

ASSOC PROF GONSKI: But people do much better in their own homes. I'm not saying that people shouldn't go to hospital, and we should not deny the fact that we do need acute hospitals, we really do, but there are a lot of people who don't need the services of acute medical treatment, and if they do, we can provide a lot of that treatment in their homes and their aged care facilities. Then they can stay in their own room, in their own bed, their families can visit. It is much better for them, and there's a good study which is always talked about, and that was the one of Professor Gideon Caplan, who is one of my colleagues - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - who showed that if you treat people in their own homes, you have less chance of acute confusion, that is, delirium, less chance of problems like constipation, less problems with medications, less problems with falls. So, primarily, this is a benefit to the person and their families. The hospitals see it as a reducing the number of people coming to emergency and to their – into their hospital beds which I'm very happy we've been able to do significantly, but that's the secondary benefit. The primary benefit is to treat these people in their own place of residence.

MR ROZEN: Yes. As you've said, it's – to an extent, it's horses for courses. You wouldn't be treating a broken hip, for example, in a residential aged care facility.

ASSOC PROF GONSKI: No.

MR ROZEN: You recognise that there are, obviously, some conditions that need treatment in a hospital setting, but the point, as I understand it, is that it's to reduce the number of unnecessary hospital transfers.

ASSOC PROF GONSKI: Correct.

MR ROZEN: Yes.

ASSOC PROF GONSKI: For the benefit of the resident.

MR ROZEN: Yes, and you identified a number of those benefits at the bottom of page 6 of this statement, if I could just take you through those. So this is under the heading:

To Acutely Deteriorating Resident, Geriatric Flying Squads.

If that could be brought up, please. At the final paragraph on that page there, you say:

> *Prior to the advent of our geriatric squads, residents who acutely deteriorated in aged care facilities were sent to acute emergency departments if GPs could not attend rapidly which is and was often the case.*

If I could just pause there for a moment. The Commission has heard a lot of evidence about GPs not attending at residential aged care facilities or not as frequently as a number of witnesses have said is desirable. You're nodding your head. Is that something that is part of your experience in this field?

ASSOC PROF GONSKI: Well, if you look at it overall, one would say yes.

MR ROZEN: Yes.

ASSOC PROF GONSKI: I mean there are many very good individual GPs who often do attend - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and attend very quickly, and some of them have actually made their lives of only looking after people in aged care facilities.

MR ROZEN: Yes.

ASSOC PROF GONSKI: But on the whole, GPs are very busy people, and they – most of their work is in their clinical practice, and for them to suddenly stop everything, walk out of a full waiting room and go down and look after an acutely deteriorating resident is just an impossibility - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and it's not good for anybody. But we have a team who can do that work and who do do that work and do it very well. So why not call them.

MR ROZEN: I will come to that in a moment. You – back – going back to your statement, you say:

> *Referral emergency departments requires ambulance transport, a lengthy stay in emergency department for assessment and, often, subsequent acute hospital inpatient admission for four or five days.*

And you note that that can be very unsettling for the resident, leading to increased adverse events such as delirium, falls, medication errors and so on. And we saw in the case study we heard yesterday, Professor Gonski, the potential that exists for

miscommunication as well. So we heard evidence yesterday of an elderly resident who had been transferred to hospital, having broken her hip, having surgery there, being returned to the residential aged care facility with a discharge report that identified the need for a review within a fortnight by the GP. The evidence the Commission heard is the GP was unaware of that discharge report. It hadn't been provided to him. Ultimately, the staples weren't removed from the wound until an infection had set in, and the – in the end, the staples had to be removed back at the hospital, so another transfer. I take it that's exactly the scenario that the model is designed to avoid.

ASSOC PROF GONSKI: Well, that would be one of the scenarios, yes.

MR ROZEN: Yes.

ASSOC PROF GONSKI: That would be a fairly unusual case, but, yes, that's definitely something that we could deal with very easily, yes.

MR ROZEN: When you say it's an unusual case, in the sense that the GP wasn't informed of the discharge information, is that the unusual feature of it or - - -

ASSOC PROF GONSKI: Well, I think that's very variable across districts. I mean, I think some districts do that extremely well, and others don't do it well at all, but I think, more importantly, I mean, there's a whole lot of things about that case, not that I actually know the case. But, really, you would have expected that someone in the aged care facility, a nurse or someone, would have – they often help with showering, dressing. They would have – someone would have twigged that if there was a dressing there, that it should be removed at some stage.

MR ROZEN: Yes.

ASSOC PROF GONSKI: That if there were staples there, they should have been removed. So that's why it's a very unusual case. But, certainly, if the GP wasn't told about it, well, that's another communication error. So that's just, sort of, a lot of times where one could have overcome such a problem.

MR ROZEN: Yes.

ASSOC PROF GONSKI: We call them lots of, sort of, misses - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - which, in this case, I believe caused the person to deteriorate significantly.

MR ROZEN: Yes. Yes. All right. Thank you. I might come back and ask you a couple more questions about that case study presently, but if I could just go back to

what you said about the funding because I think it's important for the Commission to understand this. The flying squad is part of a local area health district; is that right?

ASSOC PROF GONSKI: Yes. So we have, in our district, which covers, basically, the eastern side of east and southern side of Sydney.

MR ROZEN: Yes.

ASSOC PROF GONSKI: We have a number of – three major acute hospitals - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and two rehab/palliative care hospitals. In the three acute ones, each of them have their departments and each of their departments have relationships with community. In our department, we run community and hospital together. So there's complete interaction and integration which, I feel, is extremely important. So within our department, we have about 22 different teams which include things like dementia outreach programs, community nursing, etcetera, etcetera, but one of those teams is the geriatric flying squad, and that is the one that provides services to the aged care facilities. So it's only one out of a whole big department, but it is one of our stars because of what we've been able to do, and people have realised the benefits of it. So, basically, if you go right down to – it's one team in a department of many teams which is part of a hospital community which is part of a district, yes.

MR ROZEN: Three acute hospitals. How many residential aged care facilities are there in the district?

ASSOC PROF GONSKI: Well, we cover 60. We actually go beyond one of our districts because one of our districts was unable to provide a team to their aged care facilities. So we now provide that.

MR ROZEN: Okay. But it's a geographically limited service that's provided to a particular geographical area only; is that - - -

ASSOC PROF GONSKI: So each of our three flying squads covers about 20 - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - to 30 aged care facilities.

MR ROZEN: Right. And are all the aged care facilities in the district part of the program, if I can call it that? Are they all - - -

ASSOC PROF GONSKI: Now they are - - -

MR ROZEN: Right.

ASSOC PROF GONSKI: - - - only over the last 12 to 18 months, thanks to significant funding we've been able to get from the primary health network that worked very closely with us which basically looks after the general practice and primary health of the community in our district. So they realised that they could not provide after-hours services through their GPs to aged care facilities - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and they do get after-hours funding from the Commonwealth. And they, in their wisdom, said to us, "Why don't we provide you with some funding, and you provide the service," which we do.

MR ROZEN: Right.

ASSOC PROF GONSKI: Now, we don't provide the service for simple problems. Like, we're not taking over after-hours GPs at all.

MR ROZEN: Yes.

ASSOC PROF GONSKI: We're only looking at the ones that, potentially, would be deteriorating and going into an acute facility.

MR ROZEN: I see, and does a residential aged care facility in the district have a choice about being involved in the program? In other words, is it an opt-in program?

ASSOC PROF GONSKI: It's definitely opt-in because - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - you have to work with these people closely.

MR ROZEN: Yes.

ASSOC PROF GONSKI: Every one of ours opts in.

MR ROZEN: Okay. Is that something that's developed over time? Where the – and earlier on, were there some that weren't in the program - - -

ASSOC PROF GONSKI: Definitely. Definitely.

MR ROZEN: Yes.

ASSOC PROF GONSKI: And the reason was we were doing things in their aged care facility that they'd – never been seen before.

MR ROZEN: Yes.

ASSOC PROF GONSKI: We were putting drips up. We were giving intravenous antibiotics. We were putting subcutaneous fluids in. We were doing all – we were using syringe drivers for morphine. We were doing all that, and for them, they say, "Look, we can't even look after our residents on a daily when they're – when they're fairly well."

MR ROZEN: Yes.

ASSOC PROF GONSKI: "How can we be expected to, now, be running these things?" However, with very good education and us, our teams being there on the spot all the time until everyone is comfortable with what's going on, handing over back to the GP, all our – nearly all of our aged care facilities are on board to carry all that. And some of them absolutely – I mean, I walk into aged care facilities and they say, "We love your flying squads," you know? So they've really changed from, "Is this going to be more work? Isn't it easier for us just to send a resident to ED, rather than" - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: And now it is, "Let's call the flying squad and see what they can do for us."

MR ROZEN: And the – let's talk a little bit about the practical operation of the squad. You deal with this at the top of page 7 of your statement. If we could go to that. You say:

> *Members of the team including specialist nurses and aged care specialists receive referral from the aged care facility staff. Where possible, after liaison and communication with the GP when the resident has deteriorated.*

I just ask you a little bit about the relationship with the GPs because that's important too, isn't it? Most GPs that do work in residential aged care facilities do it on a contract basis, rather than being employed by the facility itself. So how does the relationship work? You've got the facility. You've got the flying squad, and then the GP is also, presumably, an important part of the arrangement; is that right?

ASSOC PROF GONSKI: Well, the GP is very important.

MR ROZEN: Yes.

ASSOC PROF GONSKI: They're much more important than the flying squad until the flying squad are referred - - -

MR ROZEN: Yes.

ASSOC PROF GONSKI: - - - and get in there, and start doing their management plan but the GP is involved all the time. The fact is the GP can't be there,

particularly after-hours and on weekends and therefore we are a team that can provide that service. Now, initially, we talked to all our GPs and we had to get them on board to show them what we were doing and how we were helping them because they weren't going to accept us until they actually saw the benefit for their patients and for themselves. They realised – a lot of them realised we were not going to take their work; we were just going to enhance the benefits to the residents. So we have about 180 to 200 GPs in our district – in our immediate district where I work, and we were able to get nearly all of them on board because we want the aged care facilities to call them first and see whether they want us to come out.

But if they can't get them, or they're not available for some other reason, then we want to know that we can get down there because this is for the resident. This is for the health of the resident. So we basically got GPs to sign off that they are happy to refer any of their patients to us if we can't contact them. There were a couple at the beginning that really wanted to look after their residents. They are people who are very holistic GPs who said, "I look after all my patients all the time 24/7". Unfortunately we got into situations where we couldn't contact them 24/7, and therefore those patients had to go to hospital because we did not have, basically, the GPs referral acceptance that we were going to get involved. In fact, in the early days they were quite negative towards us.

Now, I think a couple of those – a couple have really improved their thoughts and now are happy for us to get involved because they realise that they can't be available 24/7 and they don't know when their particular patients are going to deteriorate. So it's a learning curve. It's certainly – one has to be a team. They have to realise that we are part of their team now with this acute deterioration. Otherwise, the patient – their resident wouldn't even be in the aged care facility, it would be in the hospital. So we see it as a big team. The most important part are the staff and the families in the aged care facilities. That's number 1. Number 2 is the GP and number 3 is us trying to get in there and helping them get through this acute event. Sometimes people improve. Some people go on a palliative care pathway but it's just to get them over this very acute event.

MR ROZEN: If I could ask you then, if we can talk about a hypothetical fact scenario which we might use to illustrate the operation of the flying squad. Would attendance at a residential aged care facility for a resident with a particularly difficult pressure sore that the facility is finding difficult to cope with – difficult to manage, would that be the sort of circumstance that might trigger the involvement of the flying squad?

ASSOC PROF GONSKI: Well, initially, no. Initially, it should be seen that this is a deteriorating pressure area or wound.

MR ROZEN: Yes.

ASSOC PROF GONSKI: And there are other people you can get involved. For example, we have nurse consultants – clinical nurse consultants in wound care who

may go down and have a look, or they may use teleconferencing to have a look through – on a screen. We have geriatricians who routinely go down and look at chronic problems related to aged care people, such as wounds, such as pain, chronic pain, such as depression, such as dementia. So we have got ways of doing that. So they would have been the first person to call, either a clinical nurse consultant or a geriatrician to come and have a look and go from there. If things get really out of hand or it's a weekend or something and the person is starting to look really unwell from possibly that pressure area, that would be the time to call the Geriatric Flying Squad.

MR ROZEN: Right. Just before I come to that, are you saying that part of the service that's offered is a sort of regular visiting type service rather than a responding to emergencies; is that right?

ASSOC PROF GONSKI: Okay, so – look, I just want to say that every district does their own thing, in fact different parts of district. For example, we have a district where what we do is we respond to GP referrals. So if the GP is worried that someone is getting very depressed and the GP wanted my expertise in depression, I would then go down and see that person. In the location right next to us, the St George area, what they have is they have allocated their nursing homes to – or aged care facilities to their geriatricians, so amongst possibly six or nine geriatricians each of them may have, say, three aged care facilities that they go in regularly and they walk in and they say, "Well, who do you want me to see here?"

So there's different ways of doing it and I don't want to say mine is better or vice versa. And I think you really have to work out – I mean, it also depends on workforce, you know, we are lucky enough to have a good team and we have a number of geriatricians working with us as they do. That's not always possible in other districts. So you have to work around your workforce. Some people may have nurse practitioners who do a lot of what we do. Other places don't have any. So workforce is incredibly important but you have to work out what your district can provide but it does need to be, again, providing people care, specialist care, that is what this is, at the right time and the right place. That's the two important things.

MR ROZEN: So what will be a typical trigger for a call to the flying squad?

ASSOC PROF GONSKI: So, in that situation, you know, they know that there's a pressure area, maybe they've been treating it in different ways. Suddenly the person gets incredible pain in their left leg or they start getting redness around it, which likes like an infection, cellulitis; that would be a typical call to a geriatric flying squad.

MR ROZEN: Okay. So the call comes into a particular number. Does it have to be triggered by the facility; is there any capacity for a resident or a family member of a resident to request the attendance of the flying squad?

ASSOC PROF GONSKI: We require that the family go through the facility. The facility are looking after their family member. They need to know what's going on.

For us just to arrive and say, "Here we are, what's going on here?" is not really a good communication line. It's much better if the person – and we know that there's staff in the aged care facilities 24/7 so they can talk to them. They need to talk to them and for our aged care facilities it wouldn't take much to just trigger that phone call to us, get the referral and we will be down within two to four hours.

MR ROZEN: We heard evidence yesterday in this case study of a concern on the part of a daughter that her request for involvement by the Austin outreach service, which I suspect is a little bit similar to the model you are talking about, there was pushback from the facility from her perspective. I take it that you would say part of the answer to that type of problem is the relationship needs to be built up so that there's a level of trust between the facility and your organisation but also between the facility and residents and their families so that everyone sort of heading in the one direction in terms - - -

ASSOC PROF GONSKI: Definitely. Definitely.

MR ROZEN: All right.

ASSOC PROF GONSKI: And, look, it's like everything. We don't all see things the same way. What I see as an acute situation, someone else might see it as a subacute situation or vice versa.

MR ROZEN: Right. So the call comes in and, as you say, at the top of page 7 of your statement, there's an expectation of attendance within four hours. Is that a maximum period or a desirable period? How does that work?

ASSOC PROF GONSKI: Well, look, no one set that. We set that ourselves; that's our own KPI. But you know, if it's not four hours, then if it's an acute deterioration, well, they should be probably seen by someone and if no one is there then they need to probably be put in an ambulance and go up to the hospital, which is hopefully – not that – hopefully that doesn't happen.

MR ROZEN: Right. And the multidisciplinary nature of the teams that you have, can you just explain to the Commissioners what that involves. Headed up by a geriatrician?

ASSOC PROF GONSKI: So it's headed by a geriatrician, and we have three nurse practitioners who work with that geriatrician. We have a registrar who helps that team when the geriatrician is away but a number of other flying squads have registrars who are becoming geriatricians, who look after the medical side of things with their nurse practitioners. Some people don't have nurse practitioners, they might have nurses who have had a lot of experience in aged care. Ours is a very strong team of a half-time geriatrician and three nurse practitioners.

MR ROZEN: All right. Those nurse practitioners, we have heard quite a bit of evidence about the great potential that exists for nurse practitioners playing a bigger

role in aged care clinical care. Do they have particular training and expertise in geriatrics?

ASSOC PROF GONSKI: Well, they have specialised nursing training, well above registered nurses. I mean, they spend time doing extra study and they become nurse practitioners.

MR ROZEN: Yes. And what is the – from your perspective, what's the benefit of having nurse practitioners as part of the team?

ASSOC PROF GONSKI: Well, I'm overwhelmed by their knowledge and their expertise. It's quite interesting, when I'm on call, I get a call from them and they give me a full assessment and management plan and have – already about to put the management plan into play, and it is very, very, very rare that they need to say to me, "This person needs to go to hospital." I can put the phone down and five minutes later get a similar situation where the phone call comes from the emergency department where someone got through the system and got into the emergency department, a very similar scenario of the problem, possibly not even as good an assessment and they're up there in the emergency department, with not as good a management plan in many circumstances.

Nurse practitioners, they have got experience, they've got education behind them but also they're learning on the job all the time. For ours, they communicate with us all the time either to the geriatrician who looks after the flying squad with them or after-hours with the geriatrician who is on call, they will communicate with us with each person they see and we are giving them suggestions as well. So they're learning on the spot all the time. So my nurse practitioners who work with me, they have got an incredible experience and for me, they are just, as far as the acute assessments are concerned they're probably as equal to, if my geriatricians went down there.

MR ROZEN: You are a fan of the nurse practitioner?

ASSOC PROF GONSKI: Look, it's a personal thing because, obviously, we are lucky enough to have three excellent nurse practitioners who work in an excellent team. You know, you don't always get that. People are people and sometimes you don't get good nurse practitioners, you don't get geriatricians, you don't get good of anything. But we are very, very lucky to have a very great team.

MR ROZEN: And when there is a visit out to a facility to deal with a stubborn pressure sore that we've been talking about, what equipment would the nurse practitioner have with them when they go to the facility?

ASSOC PROF GONSKI: So they have – obviously have a phone. They have an allocated car so they can get there. Some of us believe that one day we will need a helicopter not a car because of – and that makes us the flying squad but – because of the traffic around Sydney. But, look, they've got a car. In the boot of the car, they carry a lot of equipment. They carry an ECG machine. They carry an ultrasound

particularly to measure bladder retention, urinary retention. They have intravenous fluids in their boot. They have cannulas, they have some medications. So they have a lot of equipment. They also have pathology equipment that they can actually do point pathology tests.

So basically they can get the kidney function, the white cell count, all that sort of thing right there and then so they don't have to call a pathology in. They can't do X-rays at this point but we can sometimes call X-ray – there are X-ray people who come in and do mobile X-rays in the facility. But to have all that equipment there and then, they can tell us if someone is short of breath what their ECG shows, whether they're having a heart attack. They can tell us what their – if their kidney function has deteriorated and what they're going to do about it. They can tell us that this person is starting to get a bad infection because their white cell count has gone up. It's just all there. It's just a great service.

MR ROZEN: And the nurse practitioner can prescribe medication as needed?

ASSOC PROF GONSKI: So they have – they cannot prescribe all the medication that doctors can prescribe but they can certainly prescribe the medication that we use on a day-to-day basis. They have antibiotics; they have morphine and they – and they can prescribe those so that maybe they can start someone on certain treatment that night or whenever they're seeing the person and then private pathologists can provide the pharmacy from then. But they carry it all with them so that – or they're lucky enough, obviously, that they can also get into the car and maybe go to the hospital and get it and come back again and do that and put it in. So they've done that as well. Which, obviously, you need to work with your emergency department after-hours pretty well. So a lot of it is a lot of communication and teamwork.

MR ROZEN: Yes.

ASSOC PROF GONSKI: Certainly, our ED would be so grateful to hear that that particular resident of an aged care facilitate is not coming to their ED today, so they will be delighted to help out. So you need to have all this equipment so it's there and then, but you also need to have relationships so that you can get it because, often, you're working after-hours which is always very difficult times.

MR ROZEN: Yes, and you say in your statement that in 90 per cent of cases, the resident will remain in the aged care facility, their home, as you say, and receive appropriate care. And I take it, as you said earlier, that's a – that's considered to be a positive outcome of the involvement of the - - -

ASSOC PROF GONSKI: That's best practice.

MR ROZEN: Yes.

ASSOC PROF GONSKI: But I – could I just say that that 90 per cent are of our referrals, not of total people.

MR ROZEN: Yes.

ASSOC PROF GONSKI: So we don't take referrals of people who've fallen, fractured – who look like have a fractured hip. They have to go up to hospital and have an X-ray.

MR ROZEN: Right.

ASSOC PROF GONSKI: So we don't – that's not a referral to us. A referral is basically a phone call to say, you know, this is a problem, and we say, well, we can deal with this now. Most of our – so I would be saying that we actually, today, would be getting – 50 per cent of the people who are deteriorating in aged care facilities, we get calls for. Of those, we can keep 90 per cent in the facility.

MR ROZEN: Yes.

ASSOC PROF GONSKI: So the other 50 per cent are the ones who do need some type of hospitalisation because of a CT scan needed, because they've got a fractured hip, because they've vomited so much blood and we can't – and there's no way we're going to be able to stop it in the aged care facility or something. So there's also – of the 50 per cent that do go, we could probably prevent 50 per cent of those. So what I'm saying is that we can still do better, I think.

They're the 50 per cent who get through the system. It could be because the flying squad is so busy and, in my whole life, I've only heard that once, and that was about two nights ago where we got a call from the flying squad to say they are so busy they cannot take another referral tonight. So if there's another referral, they will possibly have to go up to ED. So there're a couple that we might, in the future, be able to stop coming. So what my thought is that we stop – we get 50 per cent of the referrals, and we stop 90 per cent of those, we could probably stop another 25 per cent getting up there. Of the 25 per cent to make the 100 per cent, they need to be there.

MR ROZEN: Yes.

ASSOC PROF GONSKI: So we're not going to stop everyone, and that would be a bad thing to not allow people to have the care of an emergency department when they need it.

MR ROZEN: Yes, I understand, it's the unnecessary hospitalisations that - - -

ASSOC PROF GONSKI: Correct.

MR ROZEN: - - - you're seeking to stop. Do you have any data that could be provided to the Commission that analyses the work of the flying squad over time where we can see trends?

ASSOC PROF GONSKI: Yes. So we have written one international paper on this and we've also got – we got all time data. I mean, we get it every day.

MR ROZEN: Yes.

ASSOC PROF GONSKI: We can give it to you. But not only from my – the flying squad are part of my department. As you mentioned, I am the director across the district. We have data that we can access from the other two flying squads as well.

MR ROZEN: All right. Perhaps if I could ask for this commitment from you, Professor. If staff for the Commission could liaise with - - -

ASSOC PROF GONSKI: Yes.

MR ROZEN: - - - the service and identify the most useful form of data for us, that would be greatly appreciated. One of the topics we're interested in, in relation to the operation of the service, is the educative role that's performed by the service in aged care facilities because there must be a risk that the involvement of your service as specialist involvement could unintentionally deskill residential aged care facilities from being able to deal themselves with clinical issues. In other words, "We know the service is there. We don't need to attend to these things. We'll just ring up and they'll come in." Is that something you're conscious of, the need to pass on skills when you're dealing with aged care facilities?

ASSOC PROF GONSKI: Well, firstly, we do have fairly strict criteria for referrals. We're not going to be looking after everyday things that general practitioners should be looking for.

MR ROZEN: Treating – yes.

ASSOC PROF GONSKI: So that's really important to set up in the first place.

MR ROZEN: Yes.

ASSOC PROF GONSKI: Second thing is we don't mind them calling us, but we're actually going to skill them because part of our role is to go down there and educate them as to what we're doing it, why we're doing it, how we're doing it, and also remember that we're there for, maybe, an hour, an hour and a half on that 24-hour period. It's up to the aged care facility to run with that treatment for the other 22 and a half hours of the day.

MR ROZEN: Yes.

ASSOC PROF GONSKI: So they need to be skilled, and the only way they can be skilled really – well, there's a number of ways they can be skilled, but, particularly, the best way is for our staff who go down there to actually skill them up and that's what's happened. And over our period of working in these teams, the skill has

increased tremendously to the extent that there's no question that we're going to look after these people in their aged care facility because the staff are actually quite excited and interested that they can do it.

MR ROZEN: Yes.

ASSOC PROF GONSKI: And this is particularly important in palliative care because if we identify someone, really, who should be on a palliative care pathway because they've acutely deteriorated, but they've also been deteriorating over three months, six months to a time where, really, they don't have a quality of life and, suddenly, they deteriorate. Then we instigate – and we do in 25 per cent of our referrals, instigate at – a pathway for end of life.

And it's really important that the staff get involved in that, and I think they really appreciate it, now, that they can actually allow the resident – because they're often attached to these residents in many cases. It's part of their – they're living there. So, you know, the residents are living there, and the staff are very attached to these people. To see them actually dying in the facility is really dying in their home which is what a lot of people want. So, you know, it's a positive aspect, and I don't think we should be seeing it as a negative, "Oh, well, we don't want to know about you." It can't work like that. It has to be a team effort.

MR ROZEN: Yes. We've had cases here, very sad ones, Professor, where – we had one yesterday where residents' family members have desperately tried to get their elderly relatives out of aged care facilities and into dedicated hospices and palliative care providers for the purposes of the provision of palliative care. If I'm understanding you correctly, the model that you're involved in and advocating is to upskill workers in residential aged care facilities to be better positioned to provide palliative care then and there for the residents in what is their home; is that right?

ASSOC PROF GONSKI: Yes. Look, I think it's also important to understand that the – there aren't the facilities in hospices to look after these people as well. I mean, a lot of people live and die in aged care facilities, and hospices cannot provide that service and I don't believe that they should be providing the service because we should be allowing these people to die in their aged care facility.

MR ROZEN: Yes.

ASSOC PROF GONSKI: And bringing the palliative care services or the geriatric services, whichever provides those facilities, whatever – whichever group does it, or both together as a team, whatever it is, and that's specific to the district or the place where people work, it should be provided in the facility. So my attitude with that would be we need to get palliative care into that facility, whether it's through any of those ways. And it's unfortunate where it gets to the situation where a family member has to say, "I want my mother to die in a hospice because they're not getting good palliative care in their home," which is the aged care facility. I think that's very sad. Obviously, some places do not have services, and then it's, possibly, they

may have to die in hospital, they may have to die in a hospice, but if the services can be set up, then that's the best way to provide that care.

MR ROZEN: Two more topics I would like to ask you about. The first is the use of technology and teleconferencing in particular. You refer to this at the top of page 8 of your statement, if that could, perhaps, be brought up on the screen. There's a paragraph – it's number 6, "Video and teleconferencing." You refer to a trial of using televideo-conferencing instead of direct attendance at facilities. When did the trial take place?

ASSOC PROF GONSKI: About two to three years ago.

MR ROZEN: Right. And how did it go? What did you – what were the results?

ASSOC PROF GONSKI: Well, we – I think our nurse practitioners particularly established that it was better just to get in the car and go. Particularly if it was after-hours, they could get there pretty quickly. We do look after a New South Wales state aged care facility called Garrawarra which is about – probably about 30 – well, it's 30 minutes away. So in that situation, they did fit – set up a teleconferencing facility. That went quite well. They still do go out there, and we probably go out there more than we use teleconferencing now, but that's a much better set up because it's really set up as, sort of, a part hospital, part aged care facility. But it does work, and I do teleconferencing work to Norfolk Island, not for acute deterioration, but for people – older people who have got chronic problems such as dementia, and that works extremely well, and that model can be set up in aged care facilities, in people's homes and particularly useful in, obviously, rural and remote areas.

MR ROZEN: Yes. Yes. That's a particular area of interest for the Commission, which is why I'm asking you about that, and the last matter I wanted to ask you about is topic 11 on that same page, down towards the bottom. You talk about research, and you say that aged care facilities are excellent places to conduct research. Can you tell us a bit more about the formal research relationships that you've described there between the University of New South Wales and Montefiore Aged Care. How does that work?

ASSOC PROF GONSKI: Yes. I will indicate I am on the board of Montefiore Aged Care, so I do know about it and I do actually see residents in that facility in Randwick.

MR ROZEN: Yes.

ASSOC PROF GONSKI: But – and you would have heard from Professor Henry Brodaty who set this up and, really, was a pioneer in this. But – you would – in an aged care facility, you often have different types of levels of care. So you may have independent units. You may have lower care people. Although, we don't refer to them like that anymore. We used to have low level and high level, but now it's a mix. But people are obviously lower care, requiring less services, and higher care in

aged care facilities, but they're often – a lot of – a lot of people are residents, and it's – and they're old and they've got a lot of problems, and it's an ideal place to be doing clinical research.

So Professor Brodaty came to Montefiore and said, "We would like to run trials, clinical trials looking at different things such as reducing medications in your residents – using your residents. Would you be able to provide funding to us so that we can set up a program, and we will provide funding from our program, and we'll put them together and we'd be able to do the study." Now, for an aged care facility such as a Montefiore, we've got the respondents. They often want to be involved. I mean, a lot of them have got a lot of time. They're happy to talk to people. The families are quite interested that they're being involved in research, and so it's a really, really good fit and, obviously, because we have the residents at Montefiore, we are providing the clinical data for the research.

Now, not only do we benefit from that point of view, but our residents are benefitting from being in the research trial because the research trial suggested that, you know, we can possibly reduce our medications such as psychotics and things like that, and that benefits people, and if that research can be done with our residents, well, our residents are benefitting and also, obviously, research is benefitting and, obviously, then the community benefits throughout, even, internationally to say, "Oh, well, we reduced all these medications. The people did very well. How about we now do the same thing in another aged care facility?"

MR ROZEN: Yes.

ASSOC PROF GONSKI: So – and this is not a unique situation. It's not common, but it's not a unique situation, and there are other groups, and I've been asked to be involved with other aged care providers to be involved in research, and we've been able to do that. So it's a great team effort. We work very well together. I think, again, just like the flying squads, everyone is a winner. So it's a great model.

MR ROZEN: We will be hearing next week – thank you. We'll be hearing next week from Dr Frances Batchelor from the National Ageing Research Institute. I don't know if you know Dr Batchelor. She does a lot of research in the area of falls and falls prevention. One of the issues that she will refer to in the evidence that she's going to give is one of the challenges of doing research in residential aged care facilities, particularly where you've got high numbers of residents with dementia, and that is the question of consent and obtaining consent. Is that a problem you've grappled with at all or are aware of?

ASSOC PROF GONSKI: Look, you need consent for anybody for anything, and in an aged care facility, you're giving people medication all the time. You're doing things to them. You need consent and you get consent. Some – that person has to have a person who is going to give consent for treatment for day-to-day care, for going out on a home visit, for going on day trips.

MR ROZEN: Yes.

ASSOC PROF GONSKI: So I don't really see it as a big problem.

MR ROZEN: Right. Thank you. Commissioners, they're the questions that I've got for Professor Gonski at this stage.

COMMISSIONER BRIGGS: Professor, thank you for your evidence. I'm particularly interested in the issue of change and change management, and we heard your words about how you worked with the GPs in the district to try and get them over the line. Have you got any guiding principles for how to play with change of management for doctors and for nurses and personal care workers in residential care facilities?

ASSOC PROF GONSKI: Well, I think, firstly, the person – the resident has to be number one and in the centre of care, and what we should be providing is the best practice care for them and that could be at different levels. The important thing about the GP is that they do need to be there. They are the medical link to that person, and you do have to have them working with you whatever you're doing. So the aged care facility has to have a very good relationship with them. We have to have a very good relationship with them, which I'm happy to say we do. It's all about teamwork.

It's incredibly important, and it's all about communication, and it's all about saying to someone "We're going to help you. We're not going to make it more difficult for you. So we are going to help your resident, your patient, but we're also going to help you because you're not going to have to rush down and see this person, but we are going to communicate with you. And when we feel that it's not acute anymore, we're going to actually bow out and, hopefully, you'd be willing to take this on, and if you're not, we've got other ways of maybe looking after this person for you."

So whether it's aged care facility staff, whether it's GPs, whether it's hospital or community staff, it's all the same. It's communication, teamwork. But, from my point of view, it's all about how is it going to benefit them? Because without that benefit, people cannot see why they should be involved. So I was – how I – we went along to the GPs was to say, "This is the benefit to you. This is why you should get on board." And number of GPs, as I allude to earlier on, said, "Well, we look after our residents 24/7. We don't need you." And I said, "Well, that's fine. We won't be involved with your patients," but then, with time, they realised that was just not sustainable. So it's all about teamwork, communication and education, of course, as well, which we do a lot of. That's a really big topic with regard to aged care facility staff because they don't have a lot of education. I'm sure you've heard a lot about that in the past.

COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising?

MR ROZEN: Nothing arising. Thank you.

COMMISSIONER TRACEY: Professor, thank you again very much for taking the time and trouble to come and give your evidence at the Commission. We greatly appreciate that, and we'll certainly take on board the many useful suggestions you've made about how treatment regimes for the elderly can be improved. Thank you very much. The Commission will adjourn until 11.15.

<THE WITNESS WITHDREW

ADJOURNED [10.47 am]

RESUMED [11.19 am]

COMMISSIONER TRACEY: Yes, Mr Gray.

MR GRAY: Thank you, Commissioner. Our next witness is an important witness in a number of respects. If I may, I will make some brief introductory remarks before having Professor Westbrook sworn in.

COMMISSIONER TRACEY: Yes.

MR GRAY: The terms of reference of the Royal Commission at paragraph (a) call for inquiry into the causes of systemic failures leading to substandard care; and at (d) what can be done by government and the sector to strengthen the system of aged care services to ensure that they are of high quality and safe; and at (e) to allow people to exercise greater choice and control and independence in relation to their care; and at (f) for the Royal Commission to inquire into innovative models of care and the increased use of technology. Professor Westbrook will give important evidence in all of these respects. I call Professor Johanna Westbrook. Professor Westbrook is already seated in the witness box.

<JOHANNA IRENE MARY WESTBROOK, AFFIRMED [11.20 am]

<EXAMINATION-IN-CHIEF BY MR GRAY

MR GRAY: Professor Westbrook, what is your full name?

PROF WESTBROOK: Johanna Irene Mary Westbrook.

MR GRAY: Thank you. Professor Westbrook, you have made two witness statements for the Royal Commission, one dated 3 June 2019 and the other today, 11 July 2019; is that right?

PROF WESTBROOK: That's correct.

MR GRAY: I will ask for them to be brought up on the screen in front of you in succession, firstly, the 3 June 2019 statement which I will be referring to as your first statement, WIT.0196.0001.0001. Is that, on the screen, a true copy of your first statement, the one dated 3 June 2019?

PROF WESTBROOK: It is.

MR GRAY: And to the best of your knowledge and belief, are its contents insofar as they relate to facts, true and correct?

PROF WESTBROOK: They are.

MR GRAY: And are the opinions stated in the statement, opinions which you do hold?

PROF WESTBROOK: Yes.

MR GRAY: I tender the statement.

COMMISSIONER TRACEY: Yes. The witness statement of Johanna Irene Mary Westbrook dated 3 June 2019 will be exhibit 6-22.

EXHIBIT #6-22 WITNESS STATEMENT OF JOHANNA IRENE MARY WESTBROOK DATED 03/06/2019 (WIT.0196.0001.0001)

MR GRAY: Thank you. I will now ask the operator to bring up your second statement, the one dated 11 July 2019, WIT.0196.0002.0001. Professor Westbrook, do you recognise that document currently on the screen as a true copy of your second statement, titled Supplementary Statement.

PROF WESTBROOK: Yes.

MR GRAY: And insofar as it contains facts, to the best of your knowledge and belief are its contents true and correct?

PROF WESTBROOK: They are.

MR GRAY: And to the extent that it sets out opinions, are those opinions which truly are held by you?

PROF WESTBROOK: Yes.

MR GRAY: I tender the statement.

COMMISSIONER TRACEY: Yes. The second witness statement of Johanna Irene Mary Westbrook dated 11 July 2019 will be exhibit 6-23.

EXHIBIT #6-23 SECOND WITNESS STATEMENT OF JOHANNA IRENE MARY WESTBROOK DATED 11/07/2019 (WIT.0196.0002.0001) AND ITS IDENTIFIED ANNEXURES

MR GRAY: Thank you. I will ask the operator to bring up your first statement again, at page 0001. With reference to paragraph 4, Professor Westbrook, your qualifications include bachelors and masters levels degrees, respectively, in applied science, medical record administration and health administration; is that right?

PROF WESTBROOK: Yes.

MR GRAY: Followed by a doctorate, DPhil, in epidemiology.

PROF WESTBROOK: It's a PhD, yes.

MR GRAY: PhD. And you have fellowships at the Australasian College of Health Informatics and its American and international equivalent organisations.

PROF WESTBROOK: I do.

MR GRAY: As well as, in the Australian Academy of Technology and Engineering; is that so?

PROF WESTBROOK: That's correct.

MR GRAY: Your full-time position is – and this is with reference to paragraph 3 of your statement, is as Professor of Health Informatics and Patient Safety and as director of the Centre for Health Systems and Safety Research, which is a research centre within the Australian Institute of Health Innovation at Macquarie university; is that right?

PROF WESTBROOK: That's correct.

MR GRAY: Professor, in your statement on page 0002 at paragraph 6 you refer to the six different research streams within the centre.

PROF WESTBROOK: Yes.

MR GRAY: Could you just outline those for the Commissioners, please.

PROF WESTBROOK: Yes, so we have research streams in diagnostic informatics, medication safety, human factors and electronic decision support, data analytics, work and communication patterns in the health care system and particularly, obviously of relevance here, is the aged and community care research that we undertake.

MR GRAY: Thank you. And in addition to the aged and community care research stream, are you also drawing on your knowledge and the research done by your collaborators in the centre on data analytics and medication safety and other matters.

PROF WESTBROOK: Yes. Absolutely. So I would like to mention the workers and key colleagues who have really – I will be referencing their work today – Drs Mikaela Jorgensen, Kim Lind - - -

MR GRAY: Could I ask that paragraph 85 on page 0025 be shown.

PROF WESTBROOK: All right. Sorry. Yes, there they are.

MR GRAY: Please do acknowledge.

PROF WESTBROOK: Yes, so Professor Andrew Georgiou, Kim Lind, Joyce Siette, Mikaela Jorgensen, Amy Nguyen, Magda Raban and Amina Tariq have contributed to various research which I will be referring to today.

MR GRAY: Thank you. Can I just briefly ask about relevant advisory positions. You've mentioned these again on page 0001 of your statement at paragraph 3. You're on the World Health Organisation 3rd Global Safety Challenge in what capacity?

PROF WESTBROOK: So I provide advice to that group, the current global challenge in terms of trying to improve medication safety around the world, and I provide advice to the evaluation working party for that.

MR GRAY: Thank you. And this is a recently concluded stint on an advisory board but there's reference in paragraph 3 also to the Digital Health Quality and Safety Governance Committee at the Australian Digital Health Agency. In brief compass, what was the scope of that advisory work?

PROF WESTBROOK: So that was in my capacity as being a board member of the Australian Digital Health Agency, and I chaired the committee which really was looking at potential clinical safety issues relating to the use of digital technology but particularly My Health Record at that time.

MR GRAY: Later in your evidence I will be returning to the topic of My Health Record and asking you some questions about that program. Before asking you to

delve into the detail of your statements, and the studies referred to in them, I want to ask you about some of the overarching themes that are discernible from your evidence as a whole. Firstly, on page 0002 at paragraph 7 of your statement, you refer to an overarching theme of your career. Could you please outline that for the Commissioners.

PROF WESTBROOK: So really my research has been in undertaking and designing large-scale multi-method evaluations in the health care system to look at how we can improve service delivery, how we can improve patient safety, and I've got a particular interest and expertise in looking at the use of information and communication technologies, where it can be helpful to leverage information and improve safety, and also where it can actually create other problems as well.

MR GRAY: Okay. Thank you. You refer elsewhere in your evidence to a central principle in data analytics. And you refer in this respect to collecting data once for its potential use in multiple applications and for multiple purposes.

PROF WESTBROOK: Yes.

MR GRAY: Would you please expand on that.

PROF WESTBROOK: Yes, I think this is something that we don't do particularly well and certainly we don't do it well in the aged and community care sector. So we tend to collect the same information in multiple different places in different datasets and this really limits our ability to use that data or improve the quality of that data. So the idea is really we should be looking at what are the core pieces of information that we need to deliver good client care, to be able to monitor the quality of care across the sector, to be able to evaluate whether the services we are providing are beneficial, to be able to evaluate policy reforms. So we should work out what information we need and have that entered once and then have that information available to be analysed and manipulated so we can answer a range of different questions from that information.

MR GRAY: And that analysis and manipulation of the data once collected, you are speaking of that being an automated computer-assisted process.

PROF WESTBROOK: Absolutely. I mean, what we've got to do is take advantage of the great capabilities that computers have to be able to take information and manipulate it in different ways to link it with other information so it can give us the answer to a different question.

MR GRAY: Thank you. You've referred in various places in your evidence to the state of progress of that endeavour in the health sector, and you've drawn a comparison between the state of progress in the health sector and the state of progress in the aged care sector. What are your thoughts on that?

PROF WESTBROOK: So a lot of our research is in the acute care sector. I've spent a lot of time looking at medication safety and electronic health record systems in hospital systems. And then in contrast, when we moved into looking at the aged care sector I think we realised that there was just so much more additional work that needs to be done, that the sector really isn't using the great potential of information technology. And also that it potentially therefore has the ability to really make a significant improvement in quality and safety.

MR GRAY: Thank you. I will ask the operator to now bring up page 0003 and on that page, in a passage in paragraphs 10, 11 and 12, you refer to the focus of attention within the centre on the aged care sector, and a grant that was received from the Australian Research Council.

PROF WESTBROOK: Yes.

MR GRAY: In combination with a particular provider, a large provider.

PROF WESTBROOK: Yes.

MR GRAY: Would you please, by way of overview, tell the Commissioners a little bit about that development in the centre's work.

PROF WESTBROOK: Okay. So what became very clear to us when we did research in the aged care sector is there is enormous amounts of information that are collected in all sorts of different places and what we wanted to do was undertake research with a large provider to demonstrate to them how they could better use that information by using information technology, by linking their datasets, by analysing that data and then feeding it back, particularly with the aim of being able to target areas where you might want to focus quality and safety initiatives, to show the staff how they could better use data in their day-to-day care of clients, as well as for the organisation to have a much better idea of actually what is going on, and are their services making a difference; actually trying to link information about what's being provided with particular outcomes.

MR GRAY: And this led to a number of studies being performed by researchers within your team in the centre?

PROF WESTBROOK: Yes.

MR GRAY: And you refer in detail to a number of those studies that are of relevance to questions that the Royal Commission has posed to you; is that right?

PROF WESTBROOK: Yes, that's correct.

MR GRAY: So we will come to those in detail in just a minute. Before we delve into the detail of those, you alluded to this in your last answer but at paragraph 13,

you say very pithily that the aged care sector is data rich but information poor. Could you just explain that distinction you make between data and information.

PROF WESTBROOK: Yes. So data is, you know, numbers and you know – we do lots of collection of items of information but really it doesn't become meaningful information until you start bringing it together in some sort of holistic way. And at the moment we have got lots of different data collections going on but as a sector we really aren't able to use that data so it's not providing us with any real information about what is going on and I think it's come up time and time again that we really don't have good indicators about what is the quality and safety in the sector. And yet that data itself is sitting in these data silos available ready to be used but it's just not being used and brought together in that way.

MR GRAY: So this is squarely in the territory of data analytics, I take it.

PROF WESTBROOK: Yes, absolutely. Of data linkage and data analytics. Yes.

MR GRAY: When you were referring a little earlier to one of your overarching themes which is about collecting data once to use it multiple times, do you have to have in mind the uses that you are going to put the data to in order to collect it right?

PROF WESTBROOK: Well, certainly you do need to have that initially but you also should be designing it so that it will be able to answer future questions because we don't know what those may be. But if you design a system well and you are able to connect pieces of information together, then you can often answer a whole range of questions that perhaps you hadn't anticipated that you would want to answer down the track.

MR GRAY: I just want to ask you about the starting position that we find ourselves in, in the aged care sector. If we go over the page please, operator, to page 0004, at paragraphs 14 and 15. Perhaps, operator ,if you could please put up the photograph on the other side of the screen at page 0005 in the middle of the page. If we could call out that photograph. Could you please explain to the Commissioners what your team has found in relation to the current state of the collection of data and the mode of collection of data or modes thereof in aged care.

PROF WESTBROOK: Okay. So I think there are two issues here. One is because we can't – even though we are collecting lots of information and lots of data, we can't bring it together to answer specific questions ,then we tend to be relying upon lots of ad hoc paper-based audits where people have to go in and specifically look for information. But also, in order to communicate information to the various people that need it in the sector, that we're relying upon things like faxing and this is really quite shocking. Sometimes it's stated that the aged care sector is keeping the fax business going. But here we could see particularly in terms of medication charts that this seems to be one – traditionally, one of the core ways in which medication charts are communicated to, for example, community pharmacies.

And I think this – these were a series of photos that were taken by one of our PhD students who was studying it which demonstrate the potential risks that communicating information in this way can pose because these are high-volume documents and, you know, identification information can often become dislodged from the – you know, the original document. So I think that's really just demonstrating the state of some of our information communication in the sector.

MR GRAY: Thank you. In your statement you refer to the risk of pages getting shuffled in between different faxes, handwriting being difficult to decipher.

PROF WESTBROOK: Yes, and pages getting lost and not knowing whether a particular page relates to a particular patient or not, yes.

MR GRAY: We will come to this in a minute but this is not just a hypothetical problem, is it?

PROF WESTBROOK: No, this is a real and common issue.

MR GRAY: On page 3, in paragraphs 16 and 17, you do refer to there being substantial uptake of electronic data systems by the aged care sector, subject to various qualifications you make about whether that is occurring in a holistically thought out manner.

PROF WESTBROOK: Yes. Yes.

MR GRAY: You've – in your supplementary statement, your second statement – given the Commission some detail on what we know about the take-up of electronic record-keeping systems in residential aged care facilities. And you've mentioned in that statement that, in effect, there really isn't much hard data that could tell the Royal Commission what the current take-up of electronic record-keeping systems might be in residential aged care. I will just ask the operator to put up the second statement at paragraphs 22 to 25, please, and would you please outline the state of what we know and what anecdote might suggest.

PROF WESTBROOK: That's a different - - -

MR GRAY: No, this is – I beg your pardon. The second statement is WIT.0196.0002.0001, exhibit 6-23 at paragraphs 22 to 25.

PROF WESTBROOK: Yes.

MR GRAY: Thank you. I beg your pardon, paragraph 28 to 31.

PROF WESTBROOK: So, Professor Greg Alexander visited us on a Fulbright scholarship and he undertook a survey of over 800 aged care facilities in New South Wales to try to find out their level of IT sophistication. He only received responses from 130, so it's a reasonably small response rate so it may not be able to be

generalised across the whole sector. But it does give us some interesting numbers in terms of the fact that the vast majority – over 90 per cent of facilities – were using some sort of IT system in order to, you know, administrative functions and funding, to record the details of clients. And most facilities had an IT system that allowed them to record their incidents. But I will mention that often that data is not well-analysed and they really use it for a data collection process.

And he found that over 56 per cent of the facilities had an electronic medication administration system and that has been increasing over time. In talking to a number of IT vendors, which I do regularly and through my research and things, it's clear that they're reporting greater uptake of IT systems in the sector and greater interest, and in those discussions, trying to get an estimate of actually how many facilities have more clinical information systems, I think we have got enough evidence to suggest that probably in the area of medication systems we have got maybe 40 to 50 per cent of aged care beds probably are covered by some sort of medication administration system, certainly not the prescribing function at the moment. But we clearly need some more – better information about the actual uptake but I think we've got enough evidence and my experience has been that facilities are gradually increasing their IT system use.

MR GRAY: Thank you. I will just ask you to comment on a document called A Technology Roadmap for the Australian Aged Care Sector dated June 2017. Operator, please bring up that document at tab 135 of the general tender bundle. And if we go to page 0009, we see something about the object of this roadmap with respect to data analytics in the second last box in the middle of that table under the heading Action. And there's more detail on this matter at original paginated pages 22 and 23 but there's a reference to the setting up of a national data exchange and reporting hub. To the best of your knowledge, what's the progress in that respect? Has there been an exchange and reporting hub established yet?

PROF WESTBROOK: I don't think there has been really any real progress here. I think there's – you could call that as aspirational sentence.

MR GRAY: Thank you. The roadmap is broadly consistent at a level of principle with a lot of the things that you're saying in your statement, isn't it?

PROF WESTBROOK: Yes, absolutely.

MR GRAY: There don't seem to be measurements about the level of take-up or detailed milestones for progression of take-up of the technologies that you're speaking of. Do we need to move to a position where we have measurable milestones and outcomes, in your view?

PROF WESTBROOK: Well my view is that we really need to be starting to put these systems in place and therefore we need some information about where we currently are so we know where we are trying to get to, and how we can support the sector to get there.

MR GRAY: Thank you. Operator, we can take that document down from the screen, thank you. I want to ask you about the specific evidence you give relating to medication management and the use of electronic medication administration records, eMARs. This is a topic that you allude to early in your statement at page 2, paragraph 8 where you say that:

Medication errors are the greatest source of harm to patients –

in the acute setting.

PROF WESTBROOK: Yes.

MR GRAY: And you give some figures as to the estimated cost of medication errors in the acute setting; is that right?

PROF WESTBROOK: That's correct. Well, that also relates to medication errors which occur in the community which result then in people often having to be admitted to hospital as well.

MR GRAY: Thank you. And you refer to your research on the use of electronic medication management systems in hospitals, demonstrating huge improvements in what can be achieved.

PROF WESTBROOK: Yes, yes.

MR GRAY: Can you just outline that for the Commissioners.

PROF WESTBROOK: So this was part of a control – before and after trials that we undertook at two of our major teaching hospitals. They were the first Sydney teaching hospitals to actually implement electronic prescribing systems with administration systems. We measured the error rates prior to the introduction of the system, and then we measured them afterwards, and we compared the intervention wards with the controlled wards, and we found on every ward, there was, at least, a 50 per cent reduction in prescribing errors, and we also found that there was a 44 per cent reduction in the most severe errors as well. So it's pretty compelling evidence internationally that these systems make a significant impact in terms of reducing medication error.

MR GRAY: And later in your statement – this is jumping forward to page 0004, under the heading near the bottom of that page, paragraphs 18 to 37, there's an extensive passage on the messages that can be taken from the acute setting and transferred to the aged care setting; is that right?

PROF WESTBROOK: Yes. Absolutely. You know, we don't have good information about the extent of medications errors in residential aged care because we haven't done the studies. But, clearly, what we do know is that, actually, the medication process can be much more hazardous in residential aged care facilities

because you have both internal and external actors in the process. Whereas, in hospital, you have everybody. You have pharmacists, doctors, nurses all working within the same organisation. For residential aged care, you've got the GP offsite responsible for the prescribing. You've got nurses and care workers delivering, administering the medications, and you have community pharmacists offsite as well. So you just don't have the level of expertise in one location, and you don't have the level of oversight. So, you know, in hospitals you have very experienced pharmacists who is going to capture errors before they occur. You don't have those same safeguards in residential aged care.

MR GRAY: Thank you. Perhaps it's no wonder that you start your discussion of this topic, that the transference of knowledge from the acute sector to the aged care setting - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - with a reference to the most recent report of the Aged Care Complaints Commissioner, and you say that problems and errors associated with medication management are the most common - - -

PROF WESTBROOK: Most common complaint.

MR GRAY: - - - complaint arising from residential aged care facilities.

PROF WESTBROOK: That's correct. That's correct.

MR GRAY: But, as you say, we don't know the true extent of medication errors because – why is that? That - - -

PROF WESTBROOK: Well, because the only things we know about are those where it has actually become apparent and there has been a complaint. There are lots of errors which occur that no one ever knows about. I mean, we know that is the case in hospitals. From our reviews of records, we identify lots of errors in that study which had never been identified, and I'm sure the situation is the same in residential aged care.

MR GRAY: And the gist of your evidence and the recommendations you lead to would change that, I take it.

PROF WESTBROOK: Yes. So, certainly, greater use of information and technology in terms of the medication management process could bring lots of benefits, I believe.

MR GRAY: Could I ask you about the relationship between eMARs, electronic medication administration records - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - and electronic health records more generally. The study of the student or the Fulbright scholar Professor Alexander - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - who surveyed take up of electronic systems back in 2018. Did he look at electronic health records, generally, and eMARs specifically, and what's the relationship between - - -

PROF WESTBROOK: So the terminology moves around a little, but, generally, electronic health records is a broad umbrella term of an electronic system that contains health information, and within that, there may be several modules. So you may have a medication administration module within your electronic health record. You may have a pathology section. You may have a prescribing module, and what happens is that a facility may start off with an administration type part of the system and then they add modules to gradually have a more comprehensive electronic health record. And I think what we've seen in the aged care sector is that, clearly, the system started by being very administrative in order to secure information for funding purposes, and then what they've done is add on various components. Unfortunately, often, the information in one module may not be able to be linked to the others.

MR GRAY: And is the eMAR a module of an overall electronic - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - health record system, but there may be limited interoperability or communication between the - - -

PROF WESTBROOK: Yes. It partly depends - - -

MR GRAY: - - - modules; is that right?

PROF WESTBROOK: - - - upon the way they were set up and whether they're all the same commercial systems so they can talk to each other.

MR GRAY: You say in paragraph 26 on page 0006, that there was an outcome of a particular study conducted by a team within the centre in 2017 which really threw up a very alarming result about the extent of discrepancy between the records of GPs and the records of residential aged care facilities.

PROF WESTBROOK: Mmm.

MR GRAY: Would you please explain that study and the outcome.

PROF WESTBROOK: Absolutely. So as I mentioned before, general practitioners who are external to the facilities come in and prescribe medications. They will often

take note of changes that they make to the resident's medication chart, and then they will go back to their practices and enter that information because the systems in the general practice don't communicate with those in the aged care facility. And we were interested, therefore, to know about how the degree to which the clients' record in the residential aged care facility actually matched the record in the general practice, and what we found was a really high level of discrepancy. So, on average, residents had nearly 10 discrepancies between their record in the general practice and their record at the aged care facility. In general, the greatest proportion of those discrepancies were related to omissions, omissions in the general practice record, so that changes and medications which appeared in the aged care facility record did not appear in the general practice record.

MR GRAY: But even that discrepancy could have, in a given set of circumstances, a serious consequence, I take it.

PROF WESTBROOK: Potentially, it could. So if you take the example of a facility which may ring a general practice and indicate that a resident might need a certain type of medication order, the general practitioner would probably bring up their record of what medications the client is on, and so, therefore, they may not have a complete picture of the medications. And, obviously, that is mainly a problem when, for example, two drugs might interact with each other, and so you wouldn't want to prescribe them, for example.

MR GRAY: Yes, indeed. And just to be clear, are you saying, Professor, that the study indicated that there were 10 – on average - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - 10 such discrepancies for each resident?

PROF WESTBROOK: Yes.

MR GRAY: Professor Alexander's work indicated a point in time estimate based on a sample - - -

PROF WESTBROOK: Mmm.

MR GRAY: - - - and there wasn't a great response rate, as you said. Is there any longitudinal data on trends and improvements in take-up of electronic record keeping systems in nursing homes?

PROF WESTBROOK: Not that I'm aware of.

MR GRAY: And with respect to eMARs, in particular, is that the same point? We don't have the data on what the trend might be?

PROF WESTBROOK: Not really. I know that I – maybe a decade or so ago, there was a survey undertaken, and I can't recall exactly who did it, but I remember seeing it in a report where they indicated, maybe, 10 per cent of facilities at that time. It was well over a decade ago. So the most recent data we really have is from Professor Alexander's survey and from talking to some of the vendors who can provide – they, obviously, know who has the – who has these systems.

MR GRAY: Thank you. I want to refer to a document that the Commissioners have seen before. You refer to it at paragraph 23 of your first statement, and then you go into a lot more detail about it in your second statement. It's exhibit 3-56, RCD.009.009.0049.0290. It's the National Residential Medication Chart.

PROF WESTBROOK: Yes.

MR GRAY: Firstly, Professor, this is a paper chart at present; is that right?

PROF WESTBROOK: That's correct.

MR GRAY: Could you please explain the format and the length of it and how it is, in general terms, used, at present, where it is used.

PROF WESTBROOK: So, at present, it's the document on which general practitioners will order medications for residents. It can be very lengthy. So I think, on average, it's 17 pages. It partly – what happens in some facilities that have an electronic medication administration system is they have reproduced the content and, broadly, the format, and so, sometimes, the actual number of pages will vary depending whether you're just using a paper or whether you're representing electronically which then gets printed. So, yes, that's broadly - - -

MR GRAY: Thank you. And when it is used to chart - - -

PROF WESTBROOK: Yes. Yes.

MR GRAY: - - - a new medication and it needs to be communicated – transmitted in some form to, say, the pharmacist - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - and, presumably, also the residential aged care facility, or it has been transmitted from the aged - - -

PROF WESTBROOK: Yes, from the facility.

MR GRAY: - - - care facility; is that right?

PROF WESTBROOK: Yes.

MR GRAY: And the GP has to be present at the residential aged care facility to fill it out; is that how it works?

PROF WESTBROOK: Yes, that's correct.

MR GRAY: And when that happens, does the entire chart have to be faxed?

PROF WESTBROOK: That's right. So at least 17 pages. Even if those pages are blank, they have to be faxed.

MR GRAY: And that's important because - - -

PROF WESTBROOK: That's important.

MR GRAY: - - - the omission of a medication is a significant matter just as much as the inclusion?

PROF WESTBROOK: Yes. Also, it's important that the community pharmacist see that they have received the entire chart and that they're not missing something.

MR GRAY: Thank you. And with respect to the reasons why this chart was introduced, can I ask you to look at an evaluation report in 2014 which was considering the introduction of this chart. It's at tab 139, please, Operator. And if we go to the foot of page 6, you see the reference there, we could call out under the heading Project, is that your understanding of the reason for – the main reason for the introduction of the chart:

> *To be the main communication tool for medication information between prescribers, dispensers, administrators and reconcilers.*

PROF WESTBROOK: Yes.

MR GRAY:

> *And to initiate supply and claiming of most PBS or RPBS medicines directly from the chart without the need for a written prescription.*

PROF WESTBROOK: Yes. So that meant particularly, which was different previously, was that pharmacists could use the sign chart to dispense medications, whereas, in the past, they needed the chart and they needed a signed prescription as well.

MR GRAY: So this was an important reform. We've heard some evidence that the take-up is not necessarily consistent. Is that – do you have any knowledge about the degree of take-up of this chart for prescribing in residential aged care settings?

PROF WESTBROOK: I don't have any information about that. My understanding is that it's reasonably good, but I haven't investigated it.

MR GRAY: Thank you. Could we just go to some further pages which refer to the option that this chart be implemented in electronic form and what came of that.

PROF WESTBROOK: Mmm.

MR GRAY: If we ask the operator to go to page 10 and, again, at the bottom of the page under the heading that appears at the bottom, if we call that out and then if – Operator, if you could call out the text over the page – go to the text over the page at the same time, the first paragraph. What seems to be recorded here, Professor, correct me if I am wrong, is, in effect, an aspiration that it would have been good if the National Residential Medication Chart could have been an electronic form to begin with, but it just wasn't practical given the state of take-up of electronic systems at the time; is that right?

PROF WESTBROOK: Yes, that's correct.

MR GRAY: So, in that sense, even at the genesis of the development of the chart, it was contemplated that, aspirationally, there might be an electronic form of it?

PROF WESTBROOK: Yes, absolutely. I mean, ideally, that's what they would have wanted to do.

MR GRAY: And in your statement – thank you, Operator. We can put those documents away. In your statement, Professor, in particular your second statement, you refer to some current activity in that space around the possibility of an electronic version of the national residential medication chart.

PROF WESTBROOK: Yes.

MR GRAY: Could you please tell the Commissioners about that.

PROF WESTBROOK: Yes. So, the Commonwealth department is currently running a trial in 12 residential aged care facilities where they have implemented an electronic version of the national resident medication chart, and importantly what they've done in that trial is to combine an electronic prescribing function. Do you want me to go into any more detail?

MR GRAY: Yes. Well, perhaps in a minute. I will just ask you, back at paragraph 23 of your original statement, in particular on page 0006 at the top of the page, you do refer to the process involving the national residential medication chart as containing two specific risks. Would you tell the Commissioners about those risks, please? This is the paper version of the national residential medication chart.

PROF WESTBROOK: Yes. And this, really, is regardless of whether it's the national medication paper chart or any paper chart, the risks are that when a general practitioner comes in and is prescribing using a paper chart, they do not have access to any electronic decision support which they would be very standard in their practice and they're very used to receiving that decision support. And yes, and then we've talked about the second risk is that they then try to take that information and enter it into their general practice records and they're often missing information.

MR GRAY: You also refer to decision support.

PROF WESTBROOK: Yes.

MR GRAY: Could you explain the concept of decision support and how it works.

PROF WESTBROOK: So, most people would be familiar about when you go to your general practitioner, they will electronically enter your medications and at some point, they may receive alerts. So, if you are, for example, allergic to penicillin and the general practitioner starts to prescribe that, they will receive an alert to say this patient is allergic to that medication, it's probably not a good idea to prescribe it. Also, there are lots of drugs that may interact with each other and it will send you an alert to indicate that. And when we are dealing with people with many chronic conditions, many medications – we know that this occurs in this population, there is increasing risk for these types of drug-drug interactions, for example, and so this decision support can be very helpful in ensuring appropriate medication ordering.

MR GRAY: Thank you, Professor. In your statement on page 0007, at paragraphs 30 and 31, you refer to the introduction of eMARs, the electronic medication administration systems, and over the page, you have provided a schematic – this is page 0008 – of, in effect, the information flow involving a medical practitioner's decision to prescribe and then all of the processes which relate to that decision and how that decision gets communicated and implemented, and is this schematic something that applies even if the residential aged care facility has an electronic medication administration - - -

PROF WESTBROOK: Medication, yes. This is an example of a facility that has an electronic medication administration system in place.

MR GRAY: And so, it would be even more difficult if it was a paper-based - - -

PROF WESTBROOK: They would be slightly different. Yes, different steps and - - -

MR GRAY: But it is a complex diagram. I might ask you to take it in three steps. Could we ask the operator, please, to call out the top left quadrant of the diagram first and then, Professor, I will ask you to explain, from initiation by the medical practitioner of a decision to prescribe a medication, do we then – so we are starting in the very top left corner, I take it?

PROF WESTBROOK: Yes.

MR GRAY: Do we then go downwards, and if you could just take the Commissioners through - - -

PROF WESTBROOK: That's right. So, if you imagine that a general practitioner arrives and wants to chart the medications for a new resident, they will do this on paper and then they will give those paper orders to a registered nurse. In this case, that information is then – actually – yes, this information is entered – if they have a medication administration system, they enter that information into the clinical information system. So, there's an electronic version of those orders. But here, what we've got is that it's a paper chart and they fax those paper charts to the pharmacy and they will send them – they might send them a message, an email to say we're about to fax you the charts. So, this is actually, sorry, with a facility that doesn't have them.

MR GRAY: Thank you.

PROF WESTBROOK: Yes.

MR GRAY: And there seems to be then a step further down at the pharmacy. I will just ask the operator to call out the bottom left quadrant of the diagram.

PROF WESTBROOK: So, here, the pharmacy will receive a paper fax and if it's a paper fax what they will then do is they will then transcribe all those orders into their dispensing system, and then they will organise for the medications to be packed. So, examples there are the Webster packing system which is a medication dose administration system. If it is an electronic – they've seen an electronic version which is scanned to them, they still have to transcribe all that information into their dispensing system before they can actually then pack those medications and send them off to the aged care facility.

MR GRAY: Thank you. And then there seems to be an arrow across the bottom where the pharmacist updates residents' medication records into an integrated data entry interface and then a process that goes back up the diagram.

PROF WESTBROOK: Yes, so they might add a few instructions. So, if it's an electronic medication administration system available, they might add some instructions to the staff at the aged care facility, for example, about how the medications should be administered.

MR GRAY: And then operator, if you please call out the top right-hand quadrant of the diagram this time. These are then consequential steps that occur - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - at the facility.

PROF WESTBROOK: Yes so - - -

MR GRAY: And then there's, in effect, a feedback to the original part of the diagram as well. Is that right, Professor?

PROF WESTBROOK: That's right. So, for example, if the pharmacy has transcribed information which then forms part of the medication administration chart then the RN needs to check that there have been no errors in that transcription process. Also, then if the – the facility may use mobile devices, so the information then has to be uploaded on to mobile devices.

MR GRAY: Thank you. If we call out the top left-hand corner again, the information goes back into a reprint of the original medication chart. Is that right?

PROF WESTBROOK: Yes. Yes, and then it will have to be signed – the orders will have to be signed by the GP.

MR GRAY: And at any step in that complex flow of information there could be a slip or an error or an omission.

PROF WESTBROOK: As is apparent, there are multiple places where information may be missed, miscommunicated, mistyped, yes.

MR GRAY: I will ask the operator to bring out tab 136. Now, Professor, thank you very much for preparing this document. This is, in effect, a textual description of much of the schematic that you gave us earlier.

PROF WESTBROOK: Yes, and this is sort of the most recent, because there have been some, you know, broad improvements but here this outlines what happens when you have a medication administration system in place, it goes through that process and captures a few extra steps. Do you want me to briefly outline them?

MR GRAY: Yes, please do.

PROF WESTBROOK: Okay. So once again we have got the GP who hand writes the medication chart. That information is then entered by a registered nurse into the electronic medication administration system. She or he will then print that chart. The GP will have to sign every order. That chart, a minimum of 17 pages, will be then scanned or faxed to the community pharmacy. The community pharmacy then transcribes those orders into their dispensing system. And their dispensing – then they can dispense those medications. This process, the chart needs to be reprinted at least every four months but obviously clients often have changes between that time.

MR GRAY: Just stopping you there and asking the operator to keep that there, what's iCare?

PROF WESTBROOK: So iCare is a clinical information – a commercial clinical information system and it has one of its modules as an electronic medication administration system.

MR GRAY: Thank you. It's one of various brand names.

PROF WESTBROOK: One of various brand names that are out there.

MR GRAY: Thank you. Please continue.

PROF WESTBROOK: Yes, so that's broadly the process. And then on the right-hand side in red it just gives an indication of what happens when a phone order is needed. So, the facility will ring a general practitioner in their offices. They will discuss the conditions. Then the GP may decide that a medication order is required. That order has to be witnessed by two staff which includes a registered nurse. That is written on the paper chart in a designated part of the chart. And then once again the full medication chart is then faxed or scanned to the community pharmacy. It's transcribed again so that it can be entered into the dispensing system and then the medications are dispensed and sent to the facility.

MR GRAY: Thank you. And you've also put an asterisk alongside each of those process steps that involves, in effect, paper, scanning, faxing, transcription and so forth, and in addition to that there are phone calls.

PROF WESTBROOK: Yes. And so, it takes enormous amounts of time, of following up and checking information. One of the great advantages of having an electronic medication administration system is that at least there is a printed version which is able to be read very clearly, which is certainly better than having handwritten medication charts. And also, a lot of the medication administration systems have some sort of reporting functionality. So, for example, it will report clients who have missed their medications, omitted medications and provide a report on the reasons for that. So, it does provide some benefits in terms of better monitoring of the administration of those medications to clients.

MR GRAY: Thank you. If we just pick up on the advantages of electronic medication administration record-keeping systems, you refer at paragraph 34 of your statement, at page 0009, to a study on some of the advantages that you just, I think alluded to in your last answer, really. Could you expand on that study and demonstrate – we will go to the graphs in just a minute and will demonstrate the advantages that you found in that study.

PROF WESTBROOK: Yes, so this is part of the research that we did with our ARC linkage grant, and this is really exciting because as we started to see more aged care facilities introduce these medication administration systems, we suddenly realised that we had medication data that was electronically available and so the potential of that to be able to extract that data and to be able to develop, you know, profiles of what medications that residents are actually receiving across facilities and answer a

lot of missing questions – or questions that we didn't have the answer to. So, we worked with a large aged care provider who has 71 residential aged care facilities, all who have implemented this system. We extracted that data and we were able to give them information about what are the types of medications your residents are actually receiving.

We could produce information about the proportion of residents that had polypharmacy, the proportion of residents who were on antipsychotics at any period in time, you know, and we could break that down by age group. So, we were able to show, for example, that 30 per cent of people over 95 years of age were on 10 to 14 medications in a day. So, it's enormously powerful, once you have this data electronically available and its really important to be able to feed this back to individual facilities, so they can actually look at what is happening, because it's very hard for them to have an overview of what is happening among their residents.

MR GRAY: So, what you've been speaking about is identifying trends in an aggregated sense at a particular organisation.

PROF WESTBROOK: Yes.

MR GRAY: And, in addition, are there also benefits for the individual resident in terms of identifying risks of deterioration for that person or other risks of polypharmacy for that individual?

PROF WESTBROOK: Well, absolutely. So – and this is where we want the research and the work to go, is to – you can have alerts to identify, for example, residents who have been on certain medications for a long period of time and they haven't been reviewed. That would be possible to build into these systems. You could have reports that were generated for individual clients at the facility level so that they could be easily reviewed by the care staff there to identify, for example, who are all the residents that have been on antipsychotics for greater than 12 months and they haven't had a review. So, it really provides a way to use data to better target quality improvement activities without having to undergo really laborious audits of data.

MR GRAY: And just returning from the advantages for tailoring individual care - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - to the service provider level aggregation of the data and the analysis of the data at that level, you mentioned a number of potential things that could be done by way of that analysis, and do they also include identifying, perhaps, where a particular service provider might be showing anomalous behaviour compared to what would be expected with regards to, say, the rates of prescription of antipsychotics?

PROF WESTBROOK: Absolutely. So, part of our work, and I think it's later on in the statement, is producing graphs which actually represent, you know, a number of facilities where we can compare their rates of use of particular medications to see where there might be facilities that are over or underusing particular medications, for example, and how those might change - - -

MR GRAY: And that's just one example you - - -

PROF WESTBROOK: That is just one example, and I think it is also important to note that this information also needs to be shared with the general practitioners who – I mean, you know, these are the people who are prescribing these medications as well. So, it's information to be shared for the facilities, but, also, an opportunity for the facilities to share this information with the general practitioners who are servicing the facility.

MR GRAY: I will ask the operator to put up the graphs that you just alluded to.

PROF WESTBROOK: Mmm.

MR GRAY: They're on page 0010 which pick up the very example of percentages of use of antipsychotics. And, Professor, this is information about the actual administration of antipsychotics as opposed to merely their prescription. Is that right?

PROF WESTBROOK: That's right. So, these are clients who actually received antipsychotic medications.

MR GRAY: And what's the source of this data and how do we read these graphs?

PROF WESTBROOK: Okay. So, this data is based on 71 residential aged care facilities who had a medication administration system in place. We extracted the data, and then we've presented it here in terms of each of the dots represents one facility, and we've – this is what's called a funnel chart, and it puts in 95 and 99 per cent confidence intervals which gives us an indication of where a facility might fall outside the boundaries that we might expect.

Importantly, what we can do with this data by linking the medication data with other client data is to risk adjust it so that we can take into account the different mix of clients at different facilities which can be really important. We can represent the information in different ways. So, the top graph A is showing the rates of antipsychotic drug use among those facilities which are – were – and, at that time, labelled high-care facilities. They're the round circles, and then the crosses represent those facilities that had been designated as low-care facilities. So, you can look at that, and you can see, for example, that there is one high-care facility which seems to be, you know, a particular outlier.

And then the second graph is the same data but presented in a different way. So, here, we were looking at, you know, is there a difference between those facilities in major cities versus regional areas in terms of their use of antipsychotic medications. And there are many other permutations that you could prepare with this data, and it can be really powerful in terms of saying, well, where should we be focusing our limited resources in terms of potentially targeting interventions, and because this information is always there, it means that if you introduce an intervention, you can then go back and look and see whether it was effective in creating change.

MR GRAY: Thank you very much. Can I now just take you back to the national residential medication chart and ask you, again, about this activity around converting it, possibly, to an electronic form.

PROF WESTBROOK: Mmm.

MR GRAY: Firstly, just – I'll ask you a question in a general way, and then I will ask you to go to the project that's currently underway. Can the national residential medication chart, at present, automatically interoperate with the electronic management –you're your pardon, electronic medication administration record keeping systems that exists? Presumably, it needs to be in electronic form before that could be happen – before that could happen as a first step. Is that right?

PROF WESTBROOK: I'm not entirely sure that I understand the question.

MR GRAY: I'm sorry. We've currently just got a paper chart.

PROF WESTBROOK: Yes.

MR GRAY: And so, it can't speak with, can't operate together with - - -

PROF WESTBROOK: With a prescribing system.

MR GRAY: - - - any electronic prescribing system or - - -

PROF WESTBROOK: No. No.

MR GRAY: - - - medication administration record keeping system.

PROF WESTBROOK: No.

MR GRAY: In order to have a chance of being able to operate seamlessly, you'd need, in the first place, to have an eMAR, electronic medication administration record keeping system.

PROF WESTBROOK: System – yes.

MR GRAY: Thank you.

PROF WESTBROOK: That would be helpful.

MR GRAY: And assuming that the entire sector moves to eMARs, that doesn't necessarily mean that there's going to be interoperability with an electronic version of the medication chart. Is that right?

PROF WESTBROOK: No, I - - -

MR GRAY: More work needs to be done.

PROF WESTBROOK: Yes. I – to really comprehensively manage the medication process, we need an administration chart, electronic administration chart, and we need an electronic prescribing system, and they need to be interfacing.

MR GRAY: And what's this activity that is currently underway? Could you explain by reference to your second statement at paragraph 18 to 26. You refer there to a trial and some involvement by your centre.

PROF WESTBROOK: Yes. So, as I previously mentioned, the Commonwealth is currently undertaking a trial of an electronic version of the national resident medication chart, and they are incorporating a prescribing function as part of that. So, they have, as I understand it, three vendors who are participating in this trial across 12 facilities, and, recently, they called for a project to be undertaken to evaluate whether this has made a difference in terms of patient safety, but also in terms of workflow, etcetera. And KPMG were successful in securing that project, and they asked us to partner with them in terms of undertaking the evaluation of the clinical component which, in essence, is going to evaluate whether, having this system in place with the electronic chart and the prescribing function, actually reduces medication errors and improves safety.

MR GRAY: I will ask the operator to put up tab 137 now and perhaps put it alongside tab 136 on the same page. They'll probably be too small to read, but 137 is on the left-hand side. Is that a simplified schematic of the process once one has both an electronic national residential medication chart and an electronic prescribing function that are interoperable?

PROF WESTBROOK: Yes. Yes.

MR GRAY: And it compares quite well in terms of being a little more simplified - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - than the diagram that you explained to the Commissioners earlier, which is on the right-hand side.

PROF WESTBROOK: Absolutely. So, now, what happens when a new resident comes in, the GP can prescribe automatically into the residential aged care system, and then that becomes the medication administration chart, the facility can see it, the pharmacy can see it. So, the pharmacy no longer has to transcribe it into their dispensing system. They can view the chart, and then they can dispense medications.

MR GRAY: In your second - - -

COMMISSIONER BRIGGS: And can I just ask - - -

MR GRAY: Of course.

COMMISSIONER BRIGGS: - - - does – can the GP also have the supports that they normally have for writing prescriptions in their own offices as part of this?

PROF WESTBROOK: So, this is a prescribing system which is at the facility, and I would anticipate that it would have some sort of decision support. It depends on the different commercial systems. They have different levels of decision support, but there would be no technical barriers for it to have the same level of decision support that they have in their practice that they're used to.

COMMISSIONER BRIGGS: And would you agree it would be sensible if they did?

PROF WESTBROOK: Yes. It would be extremely sensible if they did.

MR GRAY: Thank you, Commissioner. Another point that's been raised as a potential concern, as I understand it, is that this might act as a disincentive against GPs visiting residential aged care facilities.

PROF WESTBROOK: Yes.

MR GRAY: Has that been raised in – during - - -

PROF WESTBROOK: That has been - - -

MR GRAY: - - - this project?

PROF WESTBROOK: - - - raised with me. So when I discussed this with a number of aged care providers about the potential benefits for it, they have consistently sort of raised this as a potential concern, but they also recognise, for example, that, you know, no longer, now, do we need a RN to be devoting their time to taking a paper chart and transcribing it into the medication administration system. So, you know, there are lots of time advantages as well, but they have highlighted to me they are concerned about whether GPs will just stay in their practices, access the electronic system and not come to the facility.

MR GRAY: Yes. Do you have any thoughts about what the answer might be to that?

PROF WESTBROOK: I don't know the answer to that. It's certainly something that perhaps you might want to keep an eye on.

COMMISSIONER BRIGGS: I think there is another side to this, and that is that, for many years, GPs have been complaining about the process of prescribing in aged care facilities and how complicated it is.

PROF WESTBROOK: Exactly.

COMMISSIONER BRIGGS: And this might, in fact, keep more of them coming back to the - - -

PROF WESTBROOK: Well – exactly - - -

COMMISSIONER BRIGGS: - - - aged care facility.

PROF WESTBROOK: I think that is a reasonable argument too.

MR GRAY: Could we just briefly return to the topic you mentioned right at the start of your evidence which is My Health Record.

PROF WESTBROOK: Yes.

MR GRAY: Could you just tell the Commissioners in brief terms where it's at in terms of interoperability with the kinds of eMAR related medication administration record related information you've been speaking about.

PROF WESTBROOK: Okay. So maybe just to briefly put it in context. My Health Record is designed to provide a summary overview of your healthcare at any point time so that if you turn up to the emergency department, it can be accessed, and you can see an event summary from your last GP visit. You will have your PBS medications listed there, etcetera. So, in aged – in the aged care sector, it has many potential benefits. So, for example, if a resident had been returned from hospital and the facility had not received a discharge summary, that discharge summary would be available in My Health Record which they could call up and have a look at. That is particularly useful, say, if medications had been changed and things.

Part of the problem at the moment is that not many aged care facilities are – have access to My Health Record, or even those that are registered are not using it. There are some other areas of the sector, I think, that could really benefit. So if you're looking at community care clients at home or instances where we have pharmacists coming into to do medication reviews, I think it could potentially be very useful for them to be able to access a client's My Health Record which would include a record of all the drugs that had been – their PBS, data, for example, their general practice

data. That information would be available to them, and it also reduces the burden on the clients to have to try to remember all their drugs and things. So that's one example of, I think, in community care, it could be particularly useful as well. It is not a system that is designed to interoperate with existing everyday clinical information systems.

MR GRAY: Thank you. I want to go to another area of potential application for data analytics which you mentioned in your statement – your first statement at paragraphs 38 to 45 which is pressure injuries.

PROF WESTBROOK: Yes.

MR GRAY: And you refer to the fact that, as of the 1st of July, under the now mandatory national quality indicator program, the reporting of pressure injuries defined in the way they're defined in that manual for that program must occur.

PROF WESTBROOK: Mmm.

MR GRAY: And there's an obvious role for electronic record keeping and reporting in this respect. Would you please outline to the Commissioners your evidence on that point?

PROF WESTBROOK: So, this, also, was part of the large study that we undertook with a range of facilities. So, with pressure injuries, care workers are documenting every day if they see a – if they identify a pressure injury, how those are treated, and they document that within the electronic system. So, once again, we thought, well, that information is sitting there. Let's see if we can devise a model for extracting it and to be able to calculate rates of pressure injuries. And that's in fact what we did. So, we took data from the clinical records of 60 facilities and we were able to calculate pressure injury rates, which would fulfil the requirements of the indicator data that have been set up by the Commonwealth. Clearly, as is always important, you have to have good quality data and we are reliant upon the quality that goes into the system, but I think that's where we need to put continued efforts to improving that quality.

MR GRAY: Is this the point you made right at the start of your evidence about collecting the data in a way that it can be used for the purposes you need to use it for?

PROF WESTBROOK: Absolutely. But also, it's – so for example, as part of the indicator work of the Commonwealth, they specify that the pressure injuries need to be classified in certain ways, by stage, etcetera, and we can build those classifications into these clinical information systems. In the study that we had, we had to do quite a lot of manipulation to the data, but it was actually there, but it would be improved by improving the functionalities of these systems. But I think what we were able to clearly demonstrate is that we could calculate pressure injury

rates, that we could also do some more sophisticated things with them, so we can actually – do you want - - -

MR GRAY: I will ask the operator to put up the graphs, Professor, so you can explain them.

PROF WESTBROOK: Okay.

MR GRAY: Please go, operator, to 0013 and we will start with the funnel graphs - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - at paragraph 44. And then we will go to the trend graphs, the scatter graphs with trend lines at the foot of the page. Starting with the funnel charts, Professor, if you could please go on.

PROF WESTBROOK: So here we took a similar approach to that which I showed you with the medication charts. We were able to report the pressure injury rate for each of the 60 facilities, so each dot represents a facility, identify where facilities fall outside the confidence intervals which might suggest that they have particularly high or particularly low rates. But importantly we can also risk adjust these data. So, we can take into account the age and gender profile of the residents at each of the facilities. We also adjust it for things like whether the clients had diabetes or not because obviously if you've got a facility where you have lots of people with diabetes who are particularly at risk of pressure injuries that needs to be adjusted for.

And so here we can demonstrate the differences that when you have unadjusted rates, which is in graph A, and then you adjust those to take into account the different mix of clients at the different facilities. And the importance of adjusting the data taking into account these factors is that you are able to make more meaningful comparisons. So, it's highlighting to you where the differences may be real. And so, I think that means that these are more meaningful comparisons to be made between facilities.

MR GRAY: Is this the sort of information that could be used for targeted information if you have a service provider who seems to be performing particularly badly?

PROF WESTBROOK: Yes. I think performing particularly badly or performing particularly well. I mean, a high rate may be that they may be incredibly good reporters and they're doing a very thorough job to identify the real rate of pressure injuries. The low rates may be facilities who actually are not doing a very good monitoring and surveillance job. So, it works both ways, but it gives you a basis – an evidence base to actually target quality and safety - - -

MR GRAY: It's a cause for inquiry - - -

PROF WESTBROOK: Absolutely. Yes.

MR GRAY: Could we go to the trends that you are able to identify by reference to the examples at the foot of the page, paragraph 45.

PROF WESTBROOK: So, in this table, what we have done is we've taken a number of individual facilities and we've plotted their pressure injury rates over time. And because we're using this data which is constantly available, we can look at trends over time. We can look at how those change. We can feed this information back to facilities, so they know where they are sitting, and they can target their own investigations.

MR GRAY: I think a minute ago I said scatter chart. The top one is a scatter chart. This one is just a single facility.

PROF WESTBROOK: Yes, these are single – each – each box represents a facility over time – their pressure injury rates over time.

MR GRAY: And you can see from this sort of analysis whether they're improving or deteriorating in their performance.

PROF WESTBROOK: Exactly. Whether there is a change. And it also means the facilities, if they get this data, they implement some sort of program. They can then use the same data and say, yes, it's making a difference or it's not. One of the challenges for these facilities is they often – they get no feedback about whether they're making a difference or not. So, this can be really important information for them.

MR GRAY: Thank you. Could I ask now about the work that the centre has done in community aged care and, in particular, around quality of life, and then I will ask you to wrap up your evidence with your recommendations about future innovation. But could you please tell the Commissioners about the work that the centre has done in community aged care, if you could outline the series of studies - - -

PROF WESTBROOK: Okay.

MR GRAY: - - - in that space and then use that as an entry point into the topic of quality of life.

PROF WESTBROOK: All right. So, there has been considerably less work overall done in community aged care clients. But they also – many providers will have electronic systems where they collect information about the types of services that they're delivering. And so, we sought to look at that data to see if we could actually use it to see what we could do with it. And so, one of the most important things that we did was to actually look at the relationship between the types of services that clients were receiving in community care and - - -

MR GRAY: I beg your pardon, Professor, page 0014, paragraph 48.

PROF WESTBROOK: Yes, thank you. And looking at what are some of the important outcome indicators for community care. And really, they're designed to try to support people stay in their own homes. So, what we are interested to see is was there a relationship between the type and volume of community care services that clients received and whether it actually delayed entry to a residential aged care facility. And here, we have the work of Dr Mikaela Jorgensen where she followed over 1100 clients over a 12-month period and she looked at the services they received, and what she found was that those clients who received more hours of community care services significantly delayed their entry to residential aged care.

Also, we were able to look at the types of services they received and those who delayed entry to residential aged care services were more likely to also receive social support services, which is very interesting. So that's one of the few studies that actually demonstrate that these - - -

MR GRAY: 0015 please, operator.

PROF WESTBROOK: These services are actually delivering on the outcomes that we hoped these services would, and I think it does have implications when we know there are over 130,000 people waiting for home care support. Potentially, we could be missing the opportunity to keep them well for longer in their own homes by providing these services to them.

MR GRAY: This leads to the topic of – I'm going to skip over the next heading and I'm going to ask you to comment on quality of life because I know that in the community care setting there has been research in the centre on quality of life.

PROF WESTBROOK: Yes.

MR GRAY: Could you outline that for us and then perhaps pick up that economic point that you made about the value of investing in community care in terms of saving money by avoiding people having to enter permanent residential aged care.

PROF WESTBROOK: Okay. So, improving quality – maintaining and improving quality of life is one of the most important outcomes that we should be aiming for in aged and community care, and we were interested in being able to demonstrate how we could measure that in a large population of - - -

MR GRAY: Page 0017 please, operator.

PROF WESTBROOK: - - - people receiving community aged care. So we worked with a large provider of community aged care services and we suggested to them that they start to measure a quality of life for all their clients and also a social – the level of social participation of their clients because there's really good research evidence that if you allow people to actively engage in their community, they have reduced

rates of mortality, they use less health services and they have better quality of life. So – and it's something that we can actually do something about reasonably easily.

MR GRAY: Could I ask the operator to put up the tool that measures participation, the actual activities of participation. That's on page 0019.

PROF WESTBROOK: So, this is an example of the survey tool that we chose for this particular project. That's a social participation tool. And then we also had a quality of life tool which is called the ICECAP-O.

MR GRAY: Page 002 – I beg your pardon, Professor, 0020.

PROF WESTBROOK: Do you want me to go into that tool?

MR GRAY: Yes. What is the ICECAP-O measuring?

PROF WESTBROOK: Okay. So, it's – it's called – it's a preference-based quality of life tool. It's particularly targeted to older population and it's quite brief, as you can see. And it's shown to have – be well accepted and is also has being shown to be reasonably good for people even with mild cognitive impairment. What we did in this project - - -

MR GRAY: .....

PROF WESTBROOK: - - - was actually – so we got all clients who were receiving community care services to be interviewed with their case worker and complete these two surveys together. And we recorded the information and we had it embedded within their electronic information systems, and our original aim was to have these outcome measures of quality of life and social participation and once it was in the system that we could link it to the types of services they were receiving so we could actually see whether the services that they were providing over time were making a difference to quality of life and outcomes. Interestingly, what we found was that was slightly unexpected was the actual process of sitting down and having this discussion and completing these surveys became an intervention in itself and we started to investigate that as well.

So, we interviewed clients and case workers about what was the experience of doing this survey, and the clients and case workers were overwhelmingly positive about it. So clients reported that the fact that they just are so rarely asked these types of questions about their lives, about what's important to them; it gave them an opportunity to say things like you know, "Yes, I am lonely and, you know, I find it depressing sometimes that I can't do the things that I used to do and these are the things that I really love doing". For the community case workers, they came back and said how valuable that they had found these discussions and the information that was being revealed to them.

MR GRAY: I will just ask the operator to put up 0021 at paragraph 70, for example. You lead into that paragraph saying here is one example of the use and effect of this process.

PROF WESTBROOK: Yes, that's absolutely right. And so, it started to change the nature of the conversation between the case workers and the clients. So, they started to focus their attention on what services they could provide which actually supported things like social participation. I link them up with other ideas about other services that they might become more engaged with. And, really, I've never had a research project where the results have been so overwhelmingly positive. And the case workers have really been instrumental in ensuring that the organisation continues to have these assessment tools in as part of their regular assessment for clients.

MR GRAY: Now, this is in the community context but what's your view on whether there is transferrable to the residential care context.

PROF WESTBROOK: Well, clearly, I think the same approach could be used. You might choose different measures in the residential aged care setting but it's just so incredibly important to provide people with a voice and to report quality of life because at the end of the day that's what we're trying to improve for these people.

MR GRAY: A lot of your evidence has been – with the exception of this wellbeing and quality of life study with that overwhelmingly positive outcome, a lot of it has been about the residential setting. I want to ask you briefly about service providers that are also in the community care setting and whether the electronic record-keeping is interoperable.

PROF WESTBROOK: So, unfortunately, what tends to happen is that while there might be – the one provider might provide both community care service and have a number of residential aged care facilities, they often have separate information systems and, ideally, what we should have is an information system which allows us to follow clients through their journeys from when they might receive community care services to later when they enter into residential aged care facilities because it will enable us to start understanding overall what is the impact of the services and the care we are providing for these people over time. What things seem to make a difference or not.

MR GRAY: Professor, I won't ask you to explain the analysis of the quality of life information but is the same data analytics methodology available to measure the quality of life outcomes and to see whether there are service providers that are doing well or poorly on that metric?

PROF WESTBROOK: Yes. So – absolutely. So, once again, these providers are providing services, and while they might get individual feedback, they don't really know if they're making a different to these people's lives. And so, by looking at their – the population of their clients, looking at their wellbeing, quality of life

scores, they can actually see how their service is performing in terms of improving the quality of life for their clients versus other facilities.

And we've also been able to look at what happens when you reassess clients over time, so we've now got over 200 people who have been assessed twice after going through this process, and we can see that, of those, around 36 per cent of them actually improve their – have improved their quality of life, 21 per cent have maintained their quality of life, and 44 per cent have had a decline in quality of life. Interestingly, what we've seen, even though these are preliminary results, is that those who improved and maintained their quality of life were more likely to have a greater number of hours of community care services. So, once again, we're starting to generate evidence which suggests the value of providing these types of services to people and their clients in terms of making a difference to their quality of life.

MR GRAY: And in respect of the 44 per cent, we're, of course, talking about a cohort who are in their older years.

PROF WESTBROOK: Yes. Yes.

MR GRAY: So, do you need to do more research into what the control group might be without those quality of life interventions in order to really draw conclusions about the significance - - -

PROF WESTBROOK: Exactly.

MR GRAY: - - - of that 44 - - -

PROF WESTBROOK: Exactly, but once we have these outcome indicators, they're in the system and then we can link them to all sorts of other data .... we can answer those questions, and we can see which services might make it more of a difference than others for particular populations, for example.

MR GRAY: Earlier in your evidence, quite a long time ago now, you mentioned the fact that a lot of the data is collected for funding purposes.

PROF WESTBROOK: Yes.

MR GRAY: Does the funding model, in particular, ACFI in the residential context provide any incentive for the collection of quality of life information presently?

PROF WESTBROOK: Not that I'm aware of, no.

MR GRAY: Now, just – Commissioners, I see the time, but if I could have another five minutes, I think we can - - -

COMMISSIONER TRACEY: Yes, of course.

MR GRAY: Thank you. In your statement, the first one at paragraph 75, and then in your second statement at paragraphs 4 to 7, you refer to the work done, in particular, by Professor Julie Ratcliffe at Flinders University about incorporating quality of life assessments into an overall economic evaluation. Now, just pausing there, there are a lot economic evaluations that can be done, cost-benefit analyses of various interventions in health or aged care. You alluded to one earlier in your evidence about the cost savings of intervening by investing more in community care so as to delay entry into permanent residential care, for example,

PROF WESTBROOK: Yes, though there's been no formal cost-effectiveness study done on that, we've just shown that there is a – it is likely.

MR GRAY: You've provided an input into - - -

PROF WESTBROOK: Yes. Yes.

MR GRAY: - - - what might be an overall cost-benefit analysis. Could you please outline – perhaps – thank you very much, Operator. The operator has put up some of the relevant text of your second statement and the gateway to this issue in your first statement. Would you outline Professor Ratcliffe's work and its potential significance?

PROF WESTBROOK: So, Professor Ratcliffe is a health economist and has done some really valuable work in this area of quality of life scores which can be used in terms of economic evaluations in the aged care sector. Overall, there haven't been very many such studies undertaken in terms of looking at whether different programs might be more cost-effective than others. In order to do those types of studies well, we really need to be using preference-based quality of life tools, which is exactly what the ICECAP-O is.

Because what happens with those tools is that the scoring algorithms used are based on research which has set out to ask older people how do you value different health states and things, and then the scoring algorithms are applied to the quality of life score. So, it's based on research evidence that what older people have said is important to them. The preference-based quality of life tool such as the ICECAP-O can be used to calculate what are called quality-adjusted life years in economic studies. And so, what that allows is that if everybody uses a tool that allows qualities to be calculated, then we can compare various types of economic evaluation studies of different types of interventions.

MR GRAY: Thank you very much. Just while we have the second statement open at this point, I will just ask the operator to show paragraph 8 and the text that follows there. You refer in more detail here to that dividend that arose from the quality of life study about engaging with the older person. Is the gist of your experience from that quality of life study that the very fact of asking the question, in effect, giving a voice to the person who is receiving care is a significant intervention in itself?

PROF WESTBROOK: Absolutely, and I must say it probably was – it shouldn't have been a surprise, but it really was quite a surprise to us, the very strong reaction we had when we interviewed clients. And I think under point 13 there, we talk about some of the direct quotes about things that client said about completing the surveys and what they thought about them.

MR GRAY: So, this is going through, Operator, to the other page. So, if we can show both pages at the same time, thank you. Pages 0002 and 0003. You've just referred, Professor, to some of those quotes in paragraph 13, have you?

PROF WESTBROOK: Yes.

MR GRAY: Yes. Thank you very much. Could we go to your suggestions about future innovation and recommendations. In your first statement, you outline a number of these, in paragraphs 79 to 84. We don't have time for all of them, but can I ask you about your remarks concerning performance rating systems that might be available to the public at paragraphs 83 to 4. And what are your thoughts on the potential use of data analytics to provide greater information so that people receiving care, or their families can make informed decisions?

PROF WESTBROOK: Well, I think there are multiple opportunities here. I think, one, some of the indicator data that we have been able to demonstrate that can be produced to look at variation between facilities and things should – is reasonable to be made public and to allow people to see those indicators. I think, also, we can provide – use that data to provide individual feedback to clients.

So, for example, even being able to present them with a list generated from the electronic system of the medications they are on with, perhaps, a couple of flags which said, you know, do you realise that you have been on antipsychotic for 12 months, and the usual recommendation is that, perhaps, it should be reviewed by your general practitioner. Just to provide them some flags or guidance about things that, possibly, they might want to have reviewed and, certainly, family members may find this very useful to, you know, pursue. So, I think that, as we are able to generate more information, we need to make that information available to people, so they can make more informed choices about where they want to be, but also to engage more actively in their care and management.

MR GRAY: Thank you. So that's, again, that – that's your perspective: the benefits for the individual – tailoring care for the individual and having a look at the service provider-wide performance at the organisational level.

PROF WESTBROOK: Absolutely.

MR GRAY: On that latter point, can I just ask you about some work by Dr Kim Lind in your centre - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - in looking at what's, perhaps, the exemplar of a very broad program of collection of clinical indicator information which is in the US and, to a lesser extent, in Canada. If we could put up tab 140, please, Operator, in landscape. What's this work, Professor?

PROF WESTBROOK: So these are indicators which are used in the US for facilities to report upon, and what we have done or what Kim's done here is that she's gone through and had a look at the data that we've been able to look at in some of these clinical information systems that we've been analysing to try and determine how many of them could we actually calculate from the data that's currently collected in these systems.

MR GRAY: So, if we – just pausing there, if we had some sort of obligation to report the same indicators that a - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - residential aged care facility reports in the US - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - could it be done with information that is just collected administratively anyway by an Australian RACF. Is that the question?

PROF WESTBROOK: Yes. So in terms of we have data from a large – from over 70 aged care facilities that have – are using a particular clinical information system and, having gone through that, we could answer – we could calculate many of these indicators from the data that is currently collected.

MR GRAY: And in unqualified terms, it's the case that Dr Lind concluded that 11 out of 17 of the indicators could be met with existing information. Is that right?

PROF WESTBROOK: Yes, that's correct.

MR GRAY: And four of the others, the information is available in paper or spreadsheet form.

PROF WESTBROOK: Yes or may require linkages. So, for example, to look at hospitalisations or outpatient emergency department, we would have to have a linkage of data between emergency departments and hospitals with the residential aged care facility data, which is technically possible.

MR GRAY: Professor, finally – I don't think we've got time to go through these very important points, but if we bring up your second statement at paragraphs 6 and 7, and I just ask you to speak briefly to the heading, there are four key points that are .... that you're conveying to the Commissioners. Perhaps we've already covered

number 1, implementing electronic information systems, and you've explained the reasons for that.

PROF WESTBROOK: Yes.

MR GRAY: We probably covered number 2 as well, I suspect.

PROF WESTBROOK: Yes, I think the point there I would make is that while we have some clinical information systems that are commercially available, we really need to improve the functionality of those systems.

MR GRAY: Six and seven of Professor Westbrook's supplementary statement. Thank you. Page 6 and 7.

PROF WESTBROOK: Then going - - -

MR GRAY: Sorry, Professor.

PROF WESTBROOK: That's all right. Then going to the third point, it's really about we need a sort of national standard data set. So this idea of working out what information that we need for a range of service – for a range of functions. So whether it is the day-to-day care of clients, whether it's about working out a funding formula, monitoring quality or safety, etcetera. We need to just collect that information once in one system, rather than having parallel systems which is the way we currently have. And the last point is really about how, you know, there's enormous potential for using the data that we have in much more effective ways.

While there may be concerns about, well, what is the quality of the data in our existing systems, I think that the main point I would like to emphasise here is that, rather than spending a lot of time improving the quality of data and standalone audits, that we need to invest that effort into improving the quality of data in the clinical record systems which should be used every day to support the care of clients. So it needs to be of high quality, and then when it's of high quality, it not only serves that purpose, but it allows us to calculate indicator data to look at the effectiveness of services, to look at whether our outcomes are improving in the way that we would hope they would.

MR GRAY: Thank you very much, Professor. Those are my questions for Professor Westbrook.

COMMISSIONER BRIGGS: Thank you, Professor Westbrook. I certainly found your written submission very interesting and your presentation today even more so. So thank you. I will take away your supplementary statement today and read it as well. There was an action plan which was alluded to earlier without terribly much progress in this area and having had a bit of a background in electronic health systems, after 10 years, I virtually gave up. So my question here is if there were to be a concerted amount of effort to introduce effective interlinked electronic systems

in this sector, what timeframe and what level of effort would we need to make that happen nationwide? And I want to include, in the first instance, residential care, and in the second, community care, or if it's the same time span, that's fine too. What do we need?

PROF WESTBROOK: It's a very difficult question to answer.

COMMISSIONER BRIGGS: Yes, it is.

PROF WESTBROOK: So I think if you say, you know, what's the technical capability of being able to do that, we have the technical expertise. We know – we have examples in another sector that we can draw upon. So I think that is there. I think that there are many challenges. There are the challenges to getting the IT vendors to improve the design and the functionality of these systems. They've been very much designed as, sort of, supporting administrative functions, financial reporting and those sorts of things. There really have never viewed these systems as a clinical system, as has been the case for those systems designed for hospitals.

But, you know, I think it depends on the range of incentive programs that might be available, that could – you know, if it's a strong incentive program, I imagine the IT vendors who have commercial interest would come along for the ride. I think there are many challenges in terms of up-scoping the workforce within residential aged care facilities. So we would need to (1) you know, have some expertise in the staff mix that would be able to support any information – clinical information system. To be able to start making, you know, demands and requirements to the IT people that are designing these systems because, at the moment, I think residential aged care facilities have not really been asking a lot of their IT system providers because there's just not the expertise there.

I think for care workers, they are a very different type of workforce to hospital workers. They have different skill base, and so I think, in the design of these systems, we have to look at different types of design features which really support those workers. So, for example, some of the future work that we are hoping to do is this idea of having a dashboard which would be available which basically would have a whole series of – you know, it would be run by algorithms at the back of the system which would say, you know, look, this client, it looks like they're deteriorating.

They've increased their pain medication. They have had a fall. They have stopped participating in activities within the centre, and that that information behind the scenes could provide a flag.
But those flags would need to be, often, very graphically presented so that we wouldn't rely on an RN necessarily to see that, but a care worker, and so – and then we have to empower those people to take action. So having information, of itself, will not lead to changes. We need to have models by which we support people to be able to do something in response to that information.

So, clearly, one element of that is decision support. So having – you know, what happens when you get this type of alert? What action should you take, and what action should you take if you're a care worker, an RN, etcetera. So I think those things can be built into information systems which can support the process. I suppose that's not really answering the question of how much effort would it take, but, I mean, I think there are many people, if you brought them together, have a good idea about what needs to happen. We know there would need to be investment and incentives to drive behaviours in certain ways, and there are schemes in other sectors that have been used to create incentives for the uptake of information technology, and so we could draw on those.

COMMISSIONER BRIGGS: I suspect that if there were to be partnering with some lead players in the field to develop an appropriate system which engaged the staff at all levels of - - -

PROF WESTBROOK: Yes.

MR GRAY: - - - facilities, but also home community care in the usage of those systems, this could be done reasonably quickly.

PROF WESTBROOK: Yes.

COMMISSIONER BRIGGS: And we would learn from that what cultural changes need to occur, but I must say I concur with your view that you need a particular format for personal care workers. I've seen this in use in early learning, and it's a very powerful tool about driving quality, but also engaging children with their families and grandparents. And you could see – or I can certainly see that tablet communication or phone communications that springboard off some of these systems connect with community and broader health services and so on in a very powerful way.

PROF WESTBROOK: Yes, absolutely.

COMMISSIONER BRIGGS: Have you got experience or knowledge of other countries in the world where these systems operate as you think they should operate – and I did notice from your witness statement you are able to quote data from across the world. So some systems must be working more effectively than ours, maybe?

PROF WESTBROOK: So I – I mean, I think that's probably the case that you will find – I think some – there are some large US providers. So I know of some, for example, in the States where, for community care clients, they have very strong electronic record systems where they're able to – and they run algorithms to identify clients who may be at risks, and then they target their visits according to the risk profile of those clients. So I think there are pockets of it. I don't know that there is a national system.

COMMISSIONER BRIGGS: Are these, largely, managed care providers through the health system?

PROF WESTBROOK: I'd have to go back and have a look.

COMMISSIONER BRIGGS: All right. Well, let me say thank you. I found this an incredibly helpful session.

PROF WESTBROOK: Thank you.

MR GRAY: Commissioners, may I ask that, in view of the time we need to get through the program this afternoon, we start at 1.30. I'm sorry that's a very short break.

COMMISSIONER TRACEY: I'm very conscious of that, Mr Gray. Yes, we will. Professor Westbrook, your evidence, as Commission Briggs has already said, has been invaluable, and we're very grateful to you for sharing your expertise with us. The Commission will adjourn until 1.30.

<THE WITNESS WITHDREW

ADJOURNED [1.05 pm]

RESUMED [1.37 pm]

COMMISSIONER TRACEY: Yes. Mr Knowles.

MR KNOWLES: Thank you, Commissioners. We have Associate Professor Michael Murray and Dr Joan Ostaszkiewicz in the witness box now to give evidence in respect of continence care and incontinence management.

<JOAN OSTASZKIEWICZ, SWORN [1.37 pm]

<MICHAEL JOHN MURRAY, SWORN [1.37 pm]

<EXAMINATION-IN-CHIEF BY MR KNOWLES

MR KNOWLES: Professor Murray, can you please state your full name for the Royal Commission?

ASSOC PROF M.J. MURRAY: Michael John Murray.

MR KNOWLES: And you have prepared a witness statement for the Royal Commission. Do you have a copy of that in front of you?

ASSOC PROF MURRAY: I do.

MR KNOWLES: Yes. An that's your witness statement dated 3 July 2019.

ASSOC PROF MURRAY: Yes.

MR KNOWLES: Yes. And that's the witness statement, Commissioners, numbered WIT.0273.0001.0001. Have you read your statement recently, Professor Murray?

ASSOC PROF MURRAY: I have.

MR KNOWLES: Yes. And are there any changes that you wish to make to your statement?

ASSOC PROF MURRAY: There's one change.

MR KNOWLES: Yes.

ASSOC PROF MURRAY: It's page 4 of 27, (d), and it's line 4. The – I've quoted the Australian Institute of Health and Welfare. It's 2012, not 2017. My apologies.

MR KNOWLES: Thank you. Subject to that change, are the contents of your statement true and correct, to the best of your knowledge and belief?

ASSOC PROF MURRAY: They are.

MR KNOWLES: Yes. I seek to alternate the statement of Professor Murray.

COMMISSIONER TRACEY: Yes. The witness statement of Michael John Murray, dated 1 July 2019, subject to the minor amendment, will be exhibit 6-24.

EXHIBIT #6-24 AMENDED WITNESS STATEMENT OF MICHAEL JOHN MURRAY DATED 01/07/2019 (WIT.0273.0001.0001)

MR KNOWLES: Dr Ostaszkiewicz, can you please state for the Royal Commission your full name?

DR J. OSTASZKIEWICZ: Joan Ostaszkiewicz.

MR KNOWLES: And you have prepared two statements for the Royal Commission. Can I take you through them one by one? The first of those is dated 5 June 2019.

DR OSTASZKIEWICZ: Yes.

MR KNOWLES: Yes. And that's the document numbered WIT.0222.0001.0001. You have also prepared a supplementary statement, dated 25 June 2019?

DR OSTASZKIEWICZ: I have.

MR KNOWLES: Yes. And that is document WIT.0222.0002.0001. And, finally, Dr Ostaszkiewicz, you have prepared a corrigendum of today's date?

DR OSTASZKIEWICZ: Yes.

MR KNOWLES: And that is document WIT.0222.0003.0001. Now, the corrigendum, Dr Ostaszkiewicz, sets out minor typographical matters that you wish to correct in your earlier two statements?

DR OSTASZKIEWICZ: That's right.

MR KNOWLES: Yes. Subject to those corrections set out in the corrigendum, are the contents of your two earlier statements true and correct, to the best of your knowledge and belief?

DR OSTASZKIEWICZ: They are.

MR KNOWLES: Thank you. I seek to tender all three of those documents. Perhaps - - -

COMMISSIONER TRACEY: Yes.

MR KNOWLES: - - - each of them might be a separate exhibit.

COMMISSIONER TRACEY: Yes. The first statement of Dr Joan Ostaszkiewicz, dated 5 June 2019, will be exhibit 6-25.

EXHIBIT #6-25 FIRST WITNESS STATEMENT OF JOAN OSTASZKIEWICZ DATED 05/06/2019 (WIT.0222.0001.0001)

COMMISSIONER TRACEY: The second statement, dated 25 June 2019, will be exhibit 6-26.

EXHIBIT #6-26 SECOND WITNESS STATEMENT OF JOAN OSTASZKIEWICZ DATED 25/06/2019 (WIT.0222.0002.0001)

COMMISSIONER TRACEY: And the corrigendum will be exhibit 6-27.

EXHIBIT #6-27 CORRIGENDUM PREPARED BY JOAN OSTASZKIEWICZ DATED 11/07/2019 (WIT.0222.0003.0001)

MR KNOWLES: Dr Ostaszkiewicz, could you tell the Royal Commission your present position?

DR OSTASZKIEWICZ: I'm a research fellow. I work at Deakin University, in a partnership with the Department of Health, for the Centre for Quality and Patient Safety Research, under the Institute of Healthcare Transformation.

COMMISSIONER TRACEY: Yes.

DR OSTASZKIEWICZ: I am a registered nurse as well, and I've been an academic since 2004.

MR KNOWLES: Yes. And you have clinical and academic expertise in the management of incontinence in frail older adults?

DR OSTASZKIEWICZ: That's right.

MR KNOWLES: And you've said at paragraph 5 of your first statement that you have a national and international profile in that area.

DR OSTASZKIEWICZ: That's right.

MR KNOWLES: Yes. And you've also referred to be the recipient of the 2018 Medical Research Future Fund Next Generation Clinical Researchers Program Translating Research into Practice Fellowship?

DR OSTASZKIEWICZ: That's right.

MR KNOWLES: Can you tell the Royal Commission what work you are doing in respect of that fellowship?

DR OSTASZKIEWICZ: Because the fellowship involves translating research into practice, I am using it to implement a project that I'm calling "Translating principles of dignity into aged care". I have two years to do that and I'm implementing – trialling it with – in a co-design with aged care staff at Barwon Health. So for the

first year we will do a design, what it looks like, and then in the second year we will pilot it.

MR KNOWLES: Yes. And you've otherwise referred, at paragraph 6, to some of the very considerable research that you have undertaken into the topic of incontinence?

DR OSTASZKIEWICZ: Yes. Yes. I've been researching this for some time now.

MR KNOWLES: When you say for some time, how long would that be?

DR OSTASZKIEWICZ: Since 2004.

MR KNOWLES: Yes. You are also an active member of the Continence Foundation of Australia?

DR OSTASZKIEWICZ: I am and - - -

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: - - - have been since its foundation.

MR KNOWLES: And when was that?

DR OSTASZKIEWICZ: I think in the 80s.

ASSOC PROF MURRAY: 30 years ago.

DR OSTASZKIEWICZ: 30 years ago.

MR KNOWLES: You are looking to Professor Murray because he is also an active member of the Continence Foundation of Australia? Is that right, Professor Murray?

ASSOC PROF MURRAY: And it's our 30th year celebration, so – yes.

MR KNOWLES: Yes. And you've been the national president for several years?

ASSOC PROF MURRAY: Yes.

MR KNOWLES: Yes. And you've been on the board of the Continence Foundation for nearly 20 years?

ASSOC PROF MURRAY: Yes.

MR KNOWLES: Yes.

ASSOC PROF MURRAY: Perhaps more.

MR KNOWLES: What are your qualifications, Professor Murray?

ASSOC PROF MURRAY: I'm a doctor and a physician. I'm a fellow of the Royal Australian College of Physicians. I'm an associate fellow of the College of Medical Administrators and I've got a fellowship to the Australian Association of Gerontology and the Australian and New Zealand Society of Geriatric Medicine.

MR KNOWLES: And what's your present position of employment that you hold?

ASSOC PROF MURRAY: I'm the divisional medical director and head of geriatric medicine at Austin health.

MR KNOWLES: And you've also had experience, according to paragraph 5 of your statement, of work on boards of aged care providers in the not-for-profit sector over the last 25 years?

ASSOC PROF MURRAY: So for 25, 27 years, I've been on boards of residential aged care facilities, whether it be Lynden Aged Care, BENETAS or a Lebanese ethno-specific residential care facility.

MR KNOWLES: Yes.

ASSOC PROF MURRAY: .....

MR KNOWLES: Now, Professor Murray, you also have referred, at the end of your statement, to having had personal experience of incontinence yourself.

ASSOC PROF MURRAY: I have.

MR KNOWLES: And are you prepared to talk about that today, so far as you are comfortable doing so and it's relevant?

ASSOC PROF MURRAY: Perfectly fine.

MR KNOWLES: Yes. And can you tell the Royal Commission your experience in that regard?

ASSOC PROF MURRAY: Certainly. I was unfortunate to get diagnosed with a metastatic neuroendocrine tumour of the bowel of unknown primary. Fortunately, it wasn't as – they thought it was a more aggressive form, but it was – I was able to have part of my liver resected, part of my large bowel resected, part of my small bowel and some various other bits resected. And although I'm not curable, I've got quite a significant extension. So I've been extremely lucky. But, unfortunately, I do have short gut syndrome and some other minor problems and, therefore, faecal incontinence. I've had a chance to have a lived experience, which, whilst I personally would have preferred not to have, it certainly has given me some additional insights into the importance of continence and the maintenance of dignity

and continence care, which is of relevance to my community and also my residential care experience.

MR KNOWLES: Now, I'm going to ask each of you questions about incontinence management and continence care, particularly in aged care. Obviously, if I ask one of you a question that the other wishes to add something on, please feel free to do so. Dr Ostaszkiewicz, can I ask you, at the outset, how do you define incontinence?

DR OSTASZKIEWICZ: Well, there's urinary incontinence and faecal incontinence and there are established definitions that have been produced by the International Consultation on Incontinence. And they're – both conditions imply an involuntary loss of control of the bladder and bowel. There has been a lot of work done in the area to understand incontinence in – over the last 20 or 30 years. With urinary incontinence, it's divided into subtypes. So there's urge incontinence, stress incontinence, overflow incontinence, mixed incontinence and also a new term called disability incontinence. And so they're very different subtypes. And, of course, people can have a mix of any one or more.

MR KNOWLES: Okay. And are those subtypes dependent upon what is actually causing the incontinence?

DR OSTASZKIEWICZ: Absolutely. Yes.

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: So there's multiple causes for incontinence – physiological causes, but also environmental causes. So as with any other medical condition, it's a matter of identifying a comprehensive assessment undertaken by a multidisciplinary team to identify potential causes. And once you've identified the cause, then you're in a better position to implement targeted treatment, because the treatments vary, depending on the type.

MR KNOWLES: Can you provide some examples of how treatments might vary, depending upon the type of incontinence that a person might experience?

DR OSTASZKIEWICZ: I think, Michael, you might be better to answer this.

MR KNOWLES: Yes.

ASSOC PROF MURRAY: Sure.

MR KNOWLES: Professor Murray - - -

ASSOC PROF MURRAY: Sure.

MR KNOWLES: - - - would you like to answer that?

ASSOC PROF MURRAY: I would be delighted. Depending on the treatment type – depends not only on the modality of treatment that has been effective, but it also perhaps looks at other contributing and – factors, such as medication, medication management. If you've got an urge or urgency-type continence-related problem, then gastrointestinal things – drugs or things that affect the gastrointestinal system, even just simply constipation, in the case of residential care, can have a significant impact on people's continence. Certainly, that has been my own personal experience, but it's certainly well-established in the literature.

Similarly, drugs that are diuretics that promote urine excretion or increasing concentration of sugar in the urine, in the case of diabetes medications, can have an effect on the need to void – the need to void overnight and the urgency at which that needs to be done. In theory, all of us could be incontinent if we've got to go five miles to an appropriate facility. It's really how quickly you can get access to a facility. Sometimes it's literally seconds and it's too late. In other people, they can defer a bit longer. And, therefore, having an assessment and an understanding of that is very important, whether you live in residential care or whether in the community.

MR KNOWLES: Yes. And I take it that it may mean that, in some instances, it's not a case of containment but an actual case of reversal and cure of the condition?

ASSOC PROF MURRAY: Well, you are always seeking to minimise the effect of the continence-related problem and, wherever possible, to cure, but, at the very least, to restrict or to limit the effects of the condition. So you can make at least common - in my case- you want to make it at least common and reduce the likelihood. You know, it improves your ability to participate, it improves your ability to work, to be involved in the community activities. It means you don't have to navigate by bathrooms. You know, it has a substantial effect on quality of life and engagement and – you know, depressive symptomatology, etcetera.

MR KNOWLES: I'm going to come back to that, if I might. Dr Ostaszkiewicz, can you indicate, from your research, whether or not you have a sense of what the level of public awareness is about incontinence, its causes and how it can be treated?

DR OSTASZKIEWICZ: It continues to astound me how little is understood about incontinence in the community, but also amongst healthcare professionals and also at policy level. So it doesn't matter what document I look at in terms of policy, it doesn't mention anything to do with incontinence. For instance, recent guidelines for dementia care, to provide guidance about people with dementia, don't include anything about incontinence and, yet, people with moderate to advanced stage dementia will be incontinent because they lose their skills to manage. So there's broad scale lack of awareness of incontinence as a problem and its causes, and that leads to people accepting it to be a problem of old age and something that you can't do anything about, which is just not the case.

MR KNOWLES: And that leads to my next question of you, and that is how prevalent is incontinence in the community at large and, particularly, though, in older people?

DR OSTASZKIEWICZ: Well, I think CFA puts out the message that one in four people suffer from incontinence in the community, which is extraordinary. The largest percentage of that are young women, not old people, as is generally believed. But there is a group of people that are more at risk, and they're people with disabilities and older people. So it is a very prevalent problem in the general community. And you might like to add to that.

ASSOC PROF MURRAY: Yes. There's a whole range from – from teenagers and children, or children and teenagers, to adults. Particularly in younger people it tends to be associated with specific disease states, whereas older people it tends to be summative, that is, the cause of a number of factors, including mobility, etcetera. And, obviously, effects of child birth, multiple child birth and vascular disease, diabetes, etcetera, all could have an impact on the risk of continence and continence-related problems. So we do certainly see it become more prevalent, especially among men, more prevalent – become increasing more prevalent, so they start to approach the rate of incontinence in women, once they get to their 80s. But it is still quite significant, even in younger people.

MR KNOWLES: Yes. And I think you've said at page 9 of your statement, Professor Murray, in setting out some statistics under the paragraph (d), that 71 per cent of the residential aged care population have urinary or faecal incontinence or both.

ASSOC PROF MURRAY: Yes. It's – we have known, really, for a long, long time that it's a factor in precipitating people's admission to residential care. Certainly, the inability to manage it is a precipitant. And since those early studies were done, we have been very successful in managing people at home. But, of course, if we don't manage people in home with home-based packages well or we don't try and minimise their continence-related problems, they are – they can become significant factors in precipitating admission into residential care. So the very fact we want to keep people out of residential care – and they, indeed, want to be able to be maintained in the community. It's very important that we do have access to continence services, continence nurses, assessment services, et cetera.

MR KNOWLES: Dr Ostaszkiewicz, on a related point to awareness, do you think that there are any problems with the availability of data about incontinence?

DR OSTASZKIEWICZ: Yes. I mean – Dr Murray mentioned 71 per cent. So we have very limited data or information about incontinence in residential aged care facilities. And it's curious that – where you don't have data, because staff actually collect a lot of information, but it's just not publicly reported or released. So the information they do collect is to complete the Aged Care Funding Instrument, and they collect information about the levels of assistance that residents require in order

to use the toilet. And they also collect three days of information about residents' bladder function, i.e., the frequency of voiding and whether or not there's any episodes of incontinence. And they also keep a seven-day bowel chart.

MR KNOWLES: What are those last two sets of data collected for?

DR OSTASZKIEWICZ: So the reason they collect that information is to complete a question about the frequency of incontinence on the Aged Care Funding Instrument - - -

MR KNOWLES: I see.

DR OSTASZKIEWICZ: - - - which is question 5.

MR KNOWLES: Yes,

DR OSTASZKIEWICZ: So those two questions inform the funding category that they will fall into. So, yes, whilst that's collected it's not reported. So we actually don't really know how many people are incontinent. But worse than that, we don't even know anything about their bladder and bowel function. So beyond incontinence, there's a whole lot of other bladder and bowl symptoms that people experience in the community but also aged care.

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: For instance, getting up at night-time to go to the toilet, having to go to the toilet too often, constipation, not being able to pass urine. So we know nothing about the prevalence of these problems in residential aged care.

MR KNOWLES: So while there is data, the first problem that you're indicating is that it's not available?

DR OSTASZKIEWICZ: That's right.

MR KNOWLES: And the second problem is that the data isn't necessarily as sophisticated as it ought to be for proper research purposes.

DR OSTASZKIEWICZ: Not just for research purposes, but also to inform clinical care.

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: Because if we did know, for instance, that people needed to go to the toilet at night, then we would be better placed to develop a care plan to help them to get that assistance.

MR KNOWLES: Yes. And that takes me to the next point. Professor Murray, you refer to person-centred care. Dr Ostaszkiewicz, you refer to the contrast between task-oriented and relation-oriented care. Perhaps can I ask each of you to deal with that particular topic, in respect of good continence care and good incontinence management?

DR OSTASZKIEWICZ: So good continence care takes time. In order to help people to maintain optimum bladder and bowel control, they need high levels of assistance. Most residents of aged care facilities need assistance to reach and use the toilet, and they might need assistance with tasks – toilet – what we call toilet and hygiene tasks. And those tasks can be done very quickly and without any interaction with the person, or they can be done in a way that respects the person's – engages with them. So I've heard of residents talking about feeling objectified, you know, being forced to the toilet, for instance. So there are ways to engage with residents that might help to make them more receptive and more responsive and to feel safe, for instance, to ask for help and to access help.

ASSOC PROF MURRAY: I think one of the really great things about the new standards that have just come in and are really only about 11 days old is the attempts to focus more on consumer dignity, on engagement with a consumer and have them as active participants in the development of care plans and care. You know, standard ones around consumer dignity and choice. And there is no doubt that, in my mind, continence is one of the areas where it really exposes you to the opportunities of great care or, conversely, less-than-great care, because they're – regardless of older people sometimes telling me, "I don't suffer from that indignity any more", when challenged, they tell you they're lying. You know, they really do. They're just trying to hide it and cover it up. Old people are just as sensitive as we are, and we will be when we get older. Somehow, it doesn't get lost.

Maybe grey hair comes, but – but dignity doesn't get lost along with it. So the new standards really are very much aligned to that participant and co-development of a care plan and management. And that's really the critical thing, that you need to undertake in conjunction with a resident, whether they be in residential care or whether they be in community care. And in some ways, community care, because this has, you know, really been a great opportunity in the last decade or so to manage people at home and prevent inappropriate admission to residential care. It is clearly important that we actually deliver good care in the home and try and minimise – or take the "in" out of incontinence to avoid people being admitted into residential care because that's – you know, nobody actually wants that if they can possibly avoid it – they would rather stay where they were. So this collaborative-type model of care is critical.

MR KNOWLES: Yes. In terms of the appropriateness or effectiveness of care, does the figure that you cite in your statement of 71 per cent of people having a diagnosis of incontinence say anything about that as to residential aged care?

ASSOC PROF MURRAY: Well, for me, I suppose it tells us that residential aged care is – has got a lot of people who have got significant disabilities and significant risk. And it really tells you and I, if you have ever had experience of placing a loved one in residential care and all the trauma for all concerned, it's a place where you go where you absolutely need to go and if there are alternatives there wouldn't be. So I think the fact that there is a high rate of disability is not surprising. What nevertheless we still want to do is to say, well, it may be 71 per cent of people go into residential care who have got continence-related problems but how many of those can have their continence well managed to minimise. So I've got continence-related problems but I'm very rarely incontinent and on each and every occasion I'm incontinent it is, for me, a major trauma and a distress and it will – I suspect it will continue to be so throughout my life.

So it's very, you know, why would I want to treat anybody else in any way less than I would want to treat myself. You know, if you can avoid each and every occasion. So even in public health, you know, I've had in my own division – or my own units, on my own wards people saying "Don't worry, dear, you can use your pad" as that's just an easier way rather than toileting and going to the bathroom. You know, they don't really understand how – how psychologically difficult that is. If you have ever been to the football and have a pad on and think I will just use the pad and I won't go to the bathroom, well, it's almost impossible to do, you know, to really be incontinent when you don't absolutely have to be.

So – so I think that if you appreciate that and you sort of have that lived experience you would treat other people in exactly the same way with the same amount of respect that if you can avoid it on each and as many occasions as you possibly can, well, surely you would because that's, you know, the fundamental nature of human dignity and the human lived experience, I would have thought.

DR OSTASZKIEWICZ: If I could add to that, there's an international study that says that 61 per cent of people admitted to residential aged care are incontinent of urine on admission. We don't have that data in Australia, but we do have the data that 71 per cent are incontinent. But what we don't know is of that 71 per cent how many are incontinent because they have a physiological problem with their bladder or because they simply can't get the levels of assistance they need to use the toilet. And there's quite a number of studies now from overseas that suggest that access to toileting assistance is really problematic in residential aged care facilities meaning that a lot of the incontinence is socially engineered or it's disability incontinence.

MR KNOWLES: Yes. And can I ask you, Dr Ostaszkiewicz, what are some of the clinical consequences of inadequate continence care or incontinence management for those with continence problems?

DR OSTASZKIEWICZ: So clinically incontinence can increase the risk of falls. There's limited data on that but there's a lot of anecdotal data and certainly when you talk to staff in aged care, they are well aware of those risks and often put in place strategies to restrict residents' movement so that they don't get up to go to the toilet

in order to protect them from falling. So there's the risk of falls. There's also the risk of breakdown of the skin. So there's a condition called incontinence-associated dermatitis which is from contact with the skin. And I read a paper the other day that that damage to the skin can occur within a couple of hours. And it's worse if a person has faecal incontinence and so when you have incontinence-associated dermatitis it increases the risk of pressure injury. So that's another main one, a clinical one.

Another one is depression. So there's studies showing an association between incontinence and depression in older people and a reduced quality of life. So how that plays out in an aged care facility is usually the resident doesn't want to go out of their room. I've certainly spoken to residents who socially isolate themselves because of the fear of exposure.

MR KNOWLES: Yes. Professor Murray, did you wish to add anything to that?

ASSOC PROF MURRAY: Well, they may also become socially isolated because of the perception of the smell and so, you know, you then don't – you know, you don't go on outings. If you are in community care, you don't visit people. You become a recluse in your own home, so it actually becomes even more difficult. So I think there are significant consequences of poorly managed continence.

MR KNOWLES: Dr Ostaszkiewicz, could you expand on what you mentioned a moment ago about socially engineered and disability incontinence.

DR OSTASZKIEWICZ: So disability incontinence refers to incontinence caused by the inability to reach and use the toilet or a receptacle such as a urinal or some other device and it's usually – it often affects people who are cognitively impaired which is one of the reasons why you would have high rates of disability incontinence in residential aged care because you have higher rates of people with dementia. But it also, of course, affects people who have a functional disability and they're not able to reach, physically, the toilet, i.e., you know, they might have broken their leg skiing or something and suddenly they can't get to the toilet on their own.

So we can really reduce rates of disability incontinence by being responsive to their needs and in people with dementia, we can reduce their rates by being aware of behavioural cues that they may give, that they have a full bladder. Of course, not every person who is cognitively impaired will have behavioural cues, but good staff are very alert to these and they talk about understanding, anticipating when the resident needs that assistance. It becomes problematic when you've got staff who don't know the residents very well, for instance, agency staff or if that information is not communicated.

MR KNOWLES: When you say it can be reduced, by that do I take it that it's not necessarily being reduced to the levels that you think it should be in residential aged care?

DR OSTASZKIEWICZ: This is my main concern. I really think that most – that we have a problem with providing the levels of assistance residents need to reach and use the toilet and be optimally continent. So I did some systematic reviews for my Masters many years ago on toileting assistance programs to look at their efficacy, and all of the studies on toileting assistance programs show that you can reduce rates of incontinence, when the researchers come in and implement the intervention. So the rates go down. But they go down suddenly, it's not over time and the fact that they go down suddenly suggests we are not really dealing with a bladder problem, we are dealing with an access problem.

And then what happens when the researchers leave is the rates go back up again. So we're finding that, you know, yes, we can do something about this, but we are not resourcing places to implement this intervention.

MR KNOWLES: So do I take you it you see that as a question of resources in some respects, Dr Ostaszkiewicz?

DR OSTASZKIEWICZ: Absolutely, yes. Again we don't have any research studies in Australia but drawing on a study from a researcher, Schnelle, from the US, he found that we needed – I think it's three to four – no, one staff member to three to four residents in order to provide two-hourly toileting assistance. Now, we don't obviously staff places at those rates. But the other thing that's interesting is that, obviously, residents need different levels of assistance. So if you can reach and use the toilet on your own, you don't need a staff member to help you, that's fine. But some residents need one staff member, some need two, and some need a lifting machine to reach and use the toilet.

And there's a researcher from the UK that looked at the time difference involved for these three groups. So for a person who just needs one staff member to assist them, it's something like 11 minutes. And if they need a lifting machine and two staff members, it's 33 minutes. So all of us here in this room will probably void four to six times a day and once at night. That's normal bladder function. So if you multiply that by seven, it means that a person who needs assistance from one person would need at least an hour of staff support over a 24-hour period. But if they need a lifting machine to get to the toilet and two staff members that adds up to about four hours of staff time. Well, it's actually eight hours if you are talking about two staff members. So you can see the difficulty of actually providing levels of assistance that people need. So staff find pragmatic ways to deal with this problem because they have to manage it.

MR KNOWLES: And I take it you when referring to pragmatic ways, are you alluding to the use of incontinence products?

DR OSTASZKIEWICZ: There is a high level of overuse and indiscriminate use of incontinence products in aged care and, as Michael mentioned, they're often used as a substitute toilet. Staff do often – they aspire to providing toileting assistance and they make judgments about who they will provide that assistance to, based on

pragmatic considerations such as how many staff there are and whether or not it's safe for the staff member or for the resident to have that help, because some residents resist being assisted to the toilet, and might respond in a distressed manner because they might not understand the nature of the care. So we have all these wonderful policies saying people should be toileted but in practice we are not resourcing places to provide the assistance required.

MR KNOWLES: And can I just – following on from one thing you said earlier, Dr Ostaszkiewicz – ask you, Professor Murray, about consequences and costs of inadequate continence care. More broadly, are there costs of that, that might flow from increased incidents of falls or other medical consequences?

ASSOC PROF MURRAY: We, in all truth, Commissioners, don't have enough data to be sure of a lot of these points. At the end of the day, however, poor continence care and poor disability reduction within the community – so community package dwellers – recipients, is likely to increase the likelihood that they will go into residential care. So we know from experience that once you become faecally incontinent or have difficult-to-manage urine incontinence, you are very much more likely to be placed. So the consequence is obviously very distressing for the individual. It may be distressing for their loved ones, for their carers, et cetera, and it's going to be costly for us as a society, so that's a substantial cost.

There is no doubt that it's better and cheaper to have people where they want to be and almost all, without exception, people want to be in their own environment. So that's a big cost. And there's a big cost right across the board of going into residential care. We know that loved ones face depressive symptomology at the placement of your loved one into residential care which doesn't go away. You continue to be depressed when you place your husband, wife, partner, whatever, into residential care and you stay that way for their entire time. So that's very difficult. So there's the sort of the social trauma and the social engineered costs.

Within residential care, if you can minimise incontinence problems, and reduce it and have a negotiated management plan of product and perhaps toileting, that's negotiated with the individual and with their family, then you may well not get perfectly managed continence but you may get a plan that actually meets the consumer's expectations and is deliverable, so to speak, within that sort of pragmatic and probably clinical reasonable model.

MR KNOWLES: Do you think, Professor Murray, that there are systematic barriers that exist to prevent the provision of good continence care in residential aged care and community care settings?

ASSOC PROF MURRAY: I think there's probably many, many barriers. I think there's barriers of – of what in a sense we have talked about ageism and the belief that continence is a normal part of ageing. I think there's barriers in terms of appropriate assessments, both in the community from a – you know, the access to community nursing to specialist continence nursing to specialist continence services.

There's barriers within residential care. You can't get a continence nurse adviser to go into residential care easily. It's not a funded model. There's very little expertise and knowledge amongst personal care workers within their training around continence, there's almost none. And there's even very little amongst nurses and very little, dare I say, amongst doctors, sadly, around the management of continence.

MR KNOWLES: Why is that, Professor Murray, that there is very little training in respect of continence care for medical practitioners, health practitioners and personal carers?

ASSOC PROF MURRAY: From medical – you know, I've been on government committees for 20 years trying to figure out [why] we can't train people, or why, when we develop programs, they don't want to take them up. For some reason, because they don't see it as important, it's not a – not an exciting area like cardiology or neurology or some other area that people think that is very important, and, indeed ,they are important, but you've got limited course time, and it's actually getting less, not more, so you've got to reduce something, and we tend to spend very little time – and I've taught at two universities, medical schools, very little time teaching them about older people.

Or we incorporate it into older people is – as more an afterthought, but on specific age-related disability, there's very little – I think, in the one I'm most familiar with, I think, we've got about three weeks in your entire medical training. So continence is one of those core geriatric topics of which there's several that's covered within those three weeks, and that would be pretty standard across all of Australia. For nursing, I think, similarly, there are all sorts of challenges about getting nurse – into the nursing training which Joan will probably know more, but I know that, more than 10 or 15 years ago, we tried to do that as part of a government program to try and encourage increased training around aged care in nursing, and it was, unfortunately, unsuccessful.

DR OSTASZKIEWICZ: At my – I'm at Deakin University. I teach third year undergraduate nursing students and we're fortunate in our school that we actually have a unit – a dedicated unit around the care of the older person. So I teach in that unit. So I have about 20 minutes to teach the third-year nursing students about incontinence. I think we are one of the very few universities that has a dedicated unit on care of the older person. Most university schools of nursing thread the education through their program. So it's not really visible. Some years ago, one of our colleagues did a big national consultation to try and elicit information about what content there was on incontinence in undergraduate nursing education – nursing midwifery education, and the result of that consensus consultation study was that nurses were not well prepared at the point of graduation to deal with incontinence. That was in 2008, and so it's probably timely to do something like that again.

MR KNOWLES: How do you see it changing in terms of training, Dr Ostaszkiewicz, in - - -

DR OSTASZKIEWICZ: I guess, over the years, I've come to realise we need to be more clever at targeting accreditation bodies and the drivers of change. So, you know, for instance, if we want to – we need to build in some incentives. So all the nursing and midwifery courses are accredited. So if we build into the accreditation framework a requirement that they address the topic of incontinence and it has to look like this, then that would be one way. I think we have to mandate it. We can't rely on universities just taking it up from a sense of goodwill

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: And it's been driven largely at universities by individuals. So, at Flinders, the person – there was a course, a nursing course that's a postgraduate course, but – and that was driven by the same person that did the national consultation. That course ran for a couple of years, but then it fell over because it didn't get enough staff – students through it.

MR KNOWLES: Just talking about drivers, Professor Murray, do you see funding models as having any influence on the continence care issue and, in particular, whether or not people provide good continence care in residential aged care.

ASSOC PROF MURRAY: If you take a step backwards, I think funding drives lots of things in health, quite frankly. And if it's not assessed, it's not measured, it's probably not going to be done very – you know, as well as we perhaps would like. So there's no doubt that we've all learnt that one of the benefits of safety and quality, and we've had experience of safety and quality in hospitals for 15 years, and residential care is a little bit like hospitals were 10 or 15 years ago, and it's going through a rapid growth cycle to try and catch up, but it's got a substantial way to go.

In my view, the new standards have, in the genesis, the opportunity if they're appropriately interpreted, and expectations are on the part of the Commission, say, that, you know, standard one, consumer dignity and choice means that I have to have engagement with a consumer around their care including their continence care. If you are specifically going to have that expectation, which I think is, quite frankly, very reasonable that the consumers are, obviously, engaged around their care, then it should be no problem for me, when I'm coming out to assess a residential care facility, to ask, well, can you show me? You know, 71 per cent of people are incontinent at least in this residential care facility, can you show me evidence that you have engaged with consumers and you have developed a program that is undertaken in conjunction with their wishes, and that will create change.

MR KNOWLES: And you see that as an improvement on this is a regulatory standard - - -

ASSOC PROF MURRAY: Yes.

MR KNOWLES: - - - that previously existed that simply required that a person's continence is managed effectively.

ASSOC PROF MURRAY: Yes, because part of the problem with the old ACFI – the old funding instrument was – the aged care funding instrument is that, in a sense, you were – there was no re-enablement built in. You got paid for their incontinence. So if they were not incontinent, you didn't get paid, which is putting it somewhat crudely, but, you know, there – what's the driver to try and improve something if you're actually going to cut your funding, and you already feared you've got insufficient funding. So, yes, there wasn't a strong re-enablement built into that sort of process. The new standards that – which were, obviously, done over some years in conjunction with the – and ensure they were involved in their formulation is really much more turned to the consumer perspective, and if they're interpreted properly and – you know, it's early days, obviously, but if they're interpreted properly and if they're assessed properly, then they really do have potential to be game changer within residential care.

MR KNOWLES: Dr Ostaszkiewicz, can I ask you for your views about, firstly, funding models, both ACFI and the proposed new funding model and, secondly, the regulatory standards that we've just heard about from Professor Murray as well.

DR OSTASZKIEWICZ: So when I did my PhD, I did qualitative research and I did look very closely at a micro level of how continence was managed in aged care, and I found that staff were very focused on containing the incontinence, pads and the number of pads people needed – incontinence products, sorry. And, you know, what was the best product in order to conceal the incontinence? But they were not focused on interventions to prevent incontinence, and they were also very focused on collecting information about the frequency of incontinence, but it didn't translate into anything other than being able to inform them so that they could complete the aged care funding instrument in order to get funding.

So, clearly, when you've got a funding framework where people – where organisations get more money for more incontinence, then the assessment that staff do is geared towards trying to find more frequent incontinence which leads to a whole set of, really, I think, unethical practices such as checking residents far too frequently to see if they were wet or dry. So the funding framework was a disincentive or is a disincentive for continence promotion. With the new funding framework, as to the extent that I understand it, and I have read most of the reports about the proposed new funding framework, I can't see that incontinence is recognised as being a problem at all other than – sorry, not at all. It's not built into the funding model. So it's not considered to be a cost driver. And that's problematic because if we don't recognise it as being a problem, then we won't actually fund it, and if we don't fund it, we won't do anything about it. So that's funding.

In terms of the accreditation standards, as you said, the old standard pre-July the 1st this year simply stated that residents' continence needed to be managed effectively. And the problem with that is that it left it up to staff and service providers to interpret what effective continence care was, and I've already mentioned that, you know, the staff are very focused on continence products, and I think that probably relates to the fact that the main provider of education about incontinence in residential aged care

is, in fact, the manufacturers of continence products. So they provide enormous levels of support to the staff and will come in and run education and set up programs to help them to conduct an assessment and to order their products. So they, probably inadvertently, frame how staff understand effective continence management.

MR KNOWLES: And do you see that as a problem, Dr Ostaszkiewicz?

DR OSTASZKIEWICZ: I do because I think it promotes the use of incontinence products over preventative strategies, yes.

MR KNOWLES: Professor Murray, can I ask you, you, in your statement, have referred to the costs of incontinence. Are there studies that actually go to quantifying costs of incontinence in residential aged care facilities.

ASSOC PROF MURRAY: There's only, sort of, studies in terms of time, you know – so a resource cost and a product cost, and I think – which is all, you know, very limited and too few and far between. It doesn't mention any social cost. It doesn't mention any personal cost. And, indeed, cost can be a perverse driver. So in the new funding model, mobility is the chief driver and continence is not a factor at all which really tell – and the reason – the way they did this is they did time and motion studies and, indeed, my colleague has done some of these where, if you just put a pad on somebody, it's actually quite quick, and you can get the time down quite significantly to having a number of pad changes.

Whereas, mobilising people and getting them to the toilet or, even more importantly, taking that step back and saying, well, how do I help Michael manage his continence? What am I going to do about his diet because that will have a significant impact? How do I avoid, you know, huge dietary changes or constipation or constipation diarrhoea which will decrease his ability to defer and increase his likelihood of incontinence? Even before you start to think about mobilising to the toilet, which is in, sort of, a rather crude end stage effect, because, surely, it should be looking at reviewing the medications, re-enablement to try and maintain their independence as much as possible.

Because, quite frankly, if I can do something, if I can transfer on my own, if I can get to the bathroom on my own, if we can already have that chat around, you know, the dignity of risk and, yes, I might be at risk of falling, but just because I've got a risk of falling, I don't want to be confined to my bed and be forever incontinent because of that small theoretical risk. Because there's almost nobody, even patients with mild dementia – which, of course, and dementia is a huge variation in very minor cognitive impairment to very serious cognitive impairment – many people do have an ability to make an informed choice and to be an active participant in their care as, indeed, they should be. And, certainly, people at home should be – or, you know, that should be, very much, the focus of our care.

So, you know, that to me is – even before you get onto. So it's the re-enablement, it's the reduction, it's the medication reviews, it's the appropriate physiotherapy, it's

the appropriate occupational therapy to make sure you've got devices and aids and equipment, you know, with appropriate visual contrast, access, you know, doors that you can open. All of those sorts of things have significant impact, even before you start talking about individual mobility and assisted toileting. And I think they're all factors that if you only focus on mobility as your only cost driver and there's no cost for incontinency – indeed, there's costs savings because you don't have to mobilise people, and you just put them in pads, then I think you will get a perverse system in the long run which will not focus on people's dignity and choice and will just simply focus on minimising cost and risk as they – from a provider point of view.

MR KNOWLES: Can I move the focus, now, to workforce, and who, Dr Ostaszkiewicz, is, from your understanding, responsible for the provision of day-to-day continence care, typically?

DR OSTASZKIEWICZ: Well, the latest workforce report says that 70 per cent of the direct care work is provided by personal care workers, and the remaining portion is by registered and enrolled nurses. So personal care workers, largely, are the ones that are providing the direct continence care, yes, so - - -

MR KNOWLES: And what – can you tell the Royal Commission the significance in this particular area of continence care for information gathering and sharing by that workforce.

DR OSTASZKIEWICZ: So the education – I looked at the education programs for the personal care workforce that prepares them for work in aged care, and those courses don't contain any core units or competencies related that would equip them with knowledge and skills to actively prevent – implement any preventive strategies for incontinence. So they're not equipped to do anything other than to just manage the incontinence. Personal care workers are – so they need to report to a registered nurse or an enrolled nurse.

So the registered nurse is overall responsible for the quality of care in a residential aged care facility and so that registered nurse needs to delegate the care and that means that she needs to do an assessment to determine the appropriateness of delegation. So she needs to know the clinical problems for all of the residents and to match up the need in terms of whether the personal care workforce and the enrolled nurse workforce are able to address each resident's need. So there's a hierarchy.

MR KNOWLES: So how are those assessments that you've just referred to typically undertaken in a residential aged care setting?

DR OSTASZKIEWICZ: For continence?

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: Okay. So there are two different assessments. There's assessment for funding to complete the Aged Care Funding Instrument and, as I said,

they have to complete question 4 and 5 of the Aged Care Funding Instrument. One question is about levels of assistance to use the toilet, the other is about frequency of incontinence. And in order to obtain information about frequency of incontinence they have to do a three-day bladder chart and a seven-day bowel chart. So that's information that is used to inform the Aged Care Funding Instrument, but they also use it – can use and should use it for an assessment for clinical care.

So in order to provide targeted individualised continence care every resident should have a clinical assessment. That should be undertaken by a registered nurse who has the knowledge and skills to do that level of assessment. In terms of a continence assessment, some years ago my colleagues and I were concerned about the quality of continence assessments in residential aged care facilities across Australia. So we were funded through the national continence management strategy to do a project where we collated as many assessment resources as we could. We collected 74 from across Australia and then we rated them against the international standards for continence management in frail older people. So we looked at the criteria and we did this matching exercise. And we found that – and none of the tools contained all of the items that they needed to contain in order to conduct an evidence-based continence assessment.

So as you can imagine there's a whole range of factors that need to be considered. So then we went on and developed a set of resources, which have been available through the Department of Health on the Bladder and Bowel website up until a couple of years ago, and they're currently being updated. So there is a resource available that staff can use to help guide them through what they need to assess, but the beauty of this assessment tool is it wasn't just an assessment tool, it's also a management guide. So we took a lot of – sort of, the workforce and the sorts of – their health literacy, for instance. So the questions were targeted so that it would guide them into a management option.

MR KNOWLES: Are you able to say how widely those assessment tools were actually adopted in residential aged care facilities?

DR OSTASZKIEWICZ: We were funded for a dissemination strategy but not to do an evaluation of its use. But the National Continence Management Strategy was evaluated by an external agency, all of the projects were evaluated. And they looked at the number of downloads from the Bladder and Bowel website and there was something like 4000. This was some years ago now. My contact with people in the workforce suggests that the resources are not being used.

MR KNOWLES: Why was that?

DR OSTASZKIEWICZ: I think because, as the previous presenter mentioned, the residential aged care sector assessment approach is driven by the software commercial programs, and so our resources were copyrighted to Deakin and to the department. So in order for them to be used, they actually needed to be taken up and

integrated into the software programs, and that never occurred. So there was some good learning for us.

MR KNOWLES: Professor Murray, just returning to workforce, do you consider that there are adequate numbers of aged care staff to deal with continence care and incontinence management in residential aged care?

ASSOC PROF MURRAY: No.

MR KNOWLES: Yes. So do I take it from that, do you say that staffing levels should be increased to this end?

ASSOC PROF MURRAY: I think that there will be no doubt that we will all come to the conclusion that we are going to need to improve the level of staffing but more than just improve the level of staffing, we are going to have to improve the level of education and training and the level of oversight, the level of clinical governance. There will be a number of things required. Where the number settles is going to be a little difficult and it's going to be a little more subtle. There's almost never an easy answer to a complicated problem but in some areas, it will be a variation on a theme and some it will be a variation in the other direction because of the type of patient and the patient mix you are looking after. There is little doubt that in community-based care it's going to be significantly different from our care in residential care.

And even in residential care, there is little doubt that we are moving progressively towards more innovative models, more apartment-style models which give people greater choice, gives people the ability to be looked after together with a number of people. You could have an all-women apartment. You could have a Greek-speaking apartment. You could have no end of choices, young people, etcetera, could be all catered for in this sort of model which is yet a bit more expensive but offers significant benefits and improvements. And as those things happen then you will be able to tailor your staffing according to your target group and their needs. And I suspect we are going to find that there will be more clinical care staff needed, more nursing staff needed and more diversional therapy and more variety because staffing numbers alone or even staffing subsets didn't fix Oakden which had a much higher staffing level than even acute care.

So there is no doubt it will be the mix, and it will be the leadership which is always the things that are most critical in any good care environment.

MR KNOWLES: That leads to my next question, Professor Murray, which you've partially answered it in saying that, but what do you regard as hallmarks of good continence care in aged care?

ASSOC PROF MURRAY: Well, I think there's probably – the hallmarks of good aged care or good care within the community is really going to be a whole lot of things and I suppose it's one of my passions around governance, in a sense that gives you some oversight. It's going to be appropriately trained people with the

appropriate degree of expertise and resourcing to work with the consumers to get a developed plan that's done, you know, not to you but with you, to create that care model whether it be home-based or residential care-based, that will meet their needs. And I think that's going to be the sort of the critical care model. So you're going to have to have appropriately skilled people. You are going to have appropriately credentialed people, you are going to have appropriately supervised people. You are going to have to have some sort of – some standards.

You are going to have to have both accommodation of the eight new standards. You will probably have some KPIs that speak to those standards. You will probably have some sort of guidance around what good quality care, whether it be continence or wound or any other area around key geriatric syndromes and what that actually means to an individual and it's hopefully – or you would expect that these would be developed in conjunction with the individual who is the care recipient in whatever environment they happen to be, you know, in a sense meeting the expectation of both standard 1 and standard 8 around governance.

So I think if you've got all that, you've got the appropriately staffed people, the appropriately trained people, the appropriately supervised people, appropriate benchmarking and unlike benchmarking which is, you know, we tend to put data in and never get data out but it's clear and it's transparent and that we know people are being appropriately assessed, and we know if the staff have appropriate assessment skills which are around the KPIs we've suggested, this will, I believe, be much more likely to deliver high quality care and in turn it makes understanding funding and financing much, much clearer, in my mind, because you will understand what you are paying for.

MR KNOWLES: Yes. And on that, both you, Professor Murray. and you, Dr Ostaszkiewicz, have referred to the KPIs and I take it you are referring to the KPIs that are set out in item 121 on the last page of Dr Ostaszkiewicz's first statement. Is that what you are referring to Professor Murray?

ASSOC PROF MURRAY: Because she was also involved – Joan was involved in writing them, so she's the most sensible person to ask.

DR OSTASZKIEWICZ: I paid him.

ASSOC PROF MURRAY: She paid me.

MR KNOWLES: But in that regard, can I just ask you to explain how those KPIs were developed, what they would go to, and what they would be used for.

DR OSTASZKIEWICZ: So they address a major gap because we have a lot of KPIs that are medically focused but don't speak to the issue of care. And so my colleagues – international colleagues and I teamed up with an organisation that funded KPMG to do an international study where we developed key performance indicators for toileting and what we called containment strategies. So most people if

they're incontinent they still want to use the toilet and also manage with a containment strategy with an incontinence product. So they address a key gap. They provide organisations with a benchmark to aim for because at the moment they don't know what good care really looks like, and so it's left to the people who are providing education to them, to make judgments about what good care is.

So we used a Delphi approach to come up with this set of 14 key performance indicators. It involved a review of literature internationally, an expert panel and then reducing – reducing right down. So we divided them into clinical KPIs, KPIs that addressed quality of life and there's an economic KPI. So we considered three groups of people, people who were care-independent who could reach and use the toilet independently. People who were care-dependent who could express their need for assistance, and then a care-dependent group who could not. So you could imagine somebody with advanced – moderate to advanced dementia in an aged care facility; we needed KPIs that would support their care as well.

So we came up with 14 and, for instance, a clinical KPI is the proportion of staff who have the skills to perform a continence assessment and prescribe a toileting and containment strategy. At the moment we don't have thresholds. We can't say that, you know, if X per cent are in this category then that represents low care or high care. But over time, if organisations adopt these KPIs, then we will get enough data in order to differentiate and so it's a starting point.

MR KNOWLES: I see. You mentioned in an earlier question, Dr Ostaszkiewicz, socially engineered incontinence. Can I ask you about that concept in the context of incontinence pad rationing; are you aware of that occurring in residential aged care at all?

DR OSTASZKIEWICZ: Yes, absolutely. So again, we don't have any objective empirical data on how incontinence products are used in aged care. Based on some research I did in a subacute care facility it's likely that they're used indiscriminately, i.e., there's probably a lack of objective information that staff are using to make judgments about their use. So in the subacute care facility we did a survey and found that 41 per cent of patients were using products – an incontinence product but they actually hadn't had any episodes of incontinence, so they were being overused. But equally there were patients who had incontinence but no product.

So I suspect the same is happening in an aged care facility where we have ageist attitudes predominate, as they do in society more broadly, and we all know lots of examples of people admitted to hospital who are automatically put on a continence product with the assumption of just in case or, you know, they're elderly. So there are a whole range of factors that coalesce to create a situation of incontinence rather than continence in institutional care settings, whether it be hospital or residential aged care facilities and that is what I call socially engineered incontinence.

The International Consultation on Incontinence yourselves the term "disability incontinence" but I think that puts the blame on the person whereas, in fact, I think

we are creating a situation of incontinence in many situations. Did you want to add to that?

ASSOC PROF MURRAY: Look, I think there's – people have become very fearful of people falling and, you know, there has been some of my colleagues who have very – very eloquently pointed out the risk of falls in residential care and the sometimes adverse consequences with falls and serious fractures and even death. But even those same individuals have also pointed out, like many of us, around this concept of dignity of risk and that there is inherent risk. Life is full of risk, and it's something we understand and take up every time we get into the car where you might say needs must. And it's the same for an older person. You know, there is plenty of evidence internationally that older people can make value judgments around risk/benefit.

They understand the things that are important to them and they understand the things that aren't. But nevertheless, as part of this sort of, person-centred domain of discussion around their plan, should always be, you know, the concept of how much will be transfers, mobility, toileting, the risk of falls, et cetera, and that's sometimes a problem for residential care. They get very concerned about anyone falling, and then, therefore, they tend to want to confine people to non-spill chairs or to devices that contain them because they're concerned about an adverse events. Now, on occasion, that's absolutely appropriate. They – some individuals are at very high risk, people, particularly, with neurodegenerative diseases, like advanced Parkinson's disease especially associated with cognitive impairment where their ability to make an informed choice is limited or may be limited.

So it is a subtle and complex – or can be subtle and complex scenario which does require some negotiation, but I've almost inevitably found that when you talk to the care recipient, where possible, and their family and let people know and talk about their choices, people are really, not only very appreciative of the fact that you've actually gone to that trouble to discuss it, but almost, inevitably, more often than not, you can come up with a reasonable balance where people will be able to say, "Mum would rather have more independence even if she didn't live as long," and I think we all understand that we'd much rather quality, sometimes, than just quantity if that's not of high value.

DR OSTASZKIEWICZ: If I could just illustrate this problem - - -

MR KNOWLES: Yes.

DR OSTASZKIEWICZ: - - - at practice level. When I did observations for my PhD study in two aged care facilities, in one of those facilities, none of those residents got assistance to the toilet at night. In the other facility, a very limited number did. The rationale was the fear that people would fall, but also the staffing levels. So if you think about, you know, people over 65, most people over 65 need to use the toilet at least once a night. So it's, again, a situation where there may well be a lot of incontinence that's socially engineered.

MR KNOWLES: Dr Ostaszkiewicz, I asked Professor Murray earlier about what goes to good continence care and how it could be better delivered. For your part, what do you see as needing to change in that regard?

DR OSTASZKIEWICZ: I'd like to see education about continence as a core component of the education programs that prepare all of the health care workforce, nurses, doctors, and personal care workers in the community and who work in residential aged care. I think caring for people, people with their personal care needs is fundamental care and – but it's not just about practical care. It's how to communicate with them in ways that protect the person's dignity and not make them feel further humiliated. So I have a lot of examples of communication strategies that support people's sense of integrity, but, equally, others that shame them, possibly inadvertently. So I think we need some education about communication strategies that make care recipients feel safe and protected and hold together their dignity. So that's building on what Michael said.

We also need education, and if we provide that level of education, I think we could minimise a whole lot of the distress that residents – some residents experience when we try to help them with incontinence or when we try to take them to the toilet. So I mentioned before that some people react in a really distressed manner to our attempts to assist them to the toilet, and that could be related to the way they interpret the care that we're providing, or they could have something like an early trauma, that it's triggering some bad memories. So if we, as staff members, react badly to that, if we don't know how to manage that situation, it can escalate into a situation of conflict in care or, in other words, abuse and both parties can be damaged in that situation. So we need education there. It needs to be built into the dementia education programs, in particular.

And I agree entirely with Michael that we need to really have this discussion about respecting people's rights to take risks to reach and use the toilet. So we have a lot of examples of patients in hospital who attempt to get out of bed to go to the toilet and who fall over and, you know, we've tried to restrain them, but that just makes the situation much worse. So I think education about people's basic rights for what I call physiological autonomy, the right to use your bowel and bladder. Clearly, I think we need more toileting assistance, and we need to recognise that that needs to be resourced, and much better assessment than what we have at the moment, and not an assessment for funding, but an assessment to provide person-centred care.

And you're right. You know, we can't go wrong if we go by the resident's expressed preferences or if they can't themselves express their own preferences, then they will have a family member that can do that for them. I have examples from research of family members who were so dedicated to their parents' dignity that they would go and sit with and stay with their mother or father in order to provide them with the level of assistance they felt their mother or father needed to go to the toilet because they recognised that staff weren't able to do that. So, again, I think service providers have an opportunity to involve family members much more in care.

MR KNOWLES: Professor Murray, is there anything else that you'd like to say to the Royal Commission at this juncture yourself?

DR OSTASZKIEWICZ: I'd just like to thank the Commission for this wonderful work that you're doing and for giving us this amazing opportunity. I mean, I – you can see we're both passionate about this, and we've been working to try and improve the quality of care for many years, so it's great to have this happening.

ASSOC PROF MURRAY: Yes. Yes, I thought I'd put my continence off until residential care or away ..... in the future, but it came a little quicker than I anticipated, to be honest, but it has given me the respect – or the newfound respect for negotiating goals of care with individuals, and of both harm minimisation, but also the value of assessment. And not only assessment as a one-off event, but as an ongoing thing in one's life, that you're assessing people all the time.

Many people come to hospitals who are constipated with poor care, with lots of health related problems sometimes caused or exacerbated in residential care, and it becomes apparent that more negotiated discussions with the resident and the family, there are just so many opportunities for us to improve care. And continence is one of those, really, where medicine hits the psyche which its social – it's a – it is a really profound opportunity to get right or to get profoundly wrong, and I think we've got an opportunity to get continence right, hopefully, for current residents, but, if for nobody else, but for us in the future. So – thank you.

COMMISSIONER TRACEY: Just to tease out the practical ways in which continence care of people in aged care residence can be improved, one of you cited the example of a resident of – who has faecal incontinence and retreats to his or her room and doesn't want to participate, for obvious reasons, in community life. In a practical way, how would you go about improving the lot of that person?

DR OSTASZKIEWICZ: I will start. Look, because incontinence is accepted as a condition of old age, it's likely the person themselves believes there's nothing that can be done about it. But I would ensure that they have access to an assessment in the first instance, and that assessment should be somebody who's skilled and knowledgeable about continence because it's highly likely that there's something that's reversible. So there are studies showing that 80 per cent people living in aged care have a reversible cause for their incontinence, and laxatives is the most common risk factor for faecal incontinence in aged care, the misuse of laxatives. So it's – so that would be a starting point with this person and, you know, we've all had a lot of success stories with people whose continence we have resolved or improved simply by identifying the underlying cause.

ASSOC PROF MURRAY: Yes. I think assessing continence and using external expertise when you don't have that expertise internally. You know, we have a problem in the current funding model getting continence nurses to visit residential care and getting residential care people to continence services is problematic. We've got a problem within the community. I put to the Victorian Government that

everybody who receives a care package who is also being funded for continence related problems should have an assessment. It should be almost a mandatory thing because, at the end of the day – well, for all the reasons we've said around quality of life. So I think the – assessment should be mandatory and a plan should be put in place, inasmuch as the consumer will be accepting of it.

COMMISSIONER TRACEY: Well, thank you both. You've both travelled a long way to share your expertise with us. We're very grateful for that, and please be assured that we're going to take on board the suggestions you've made for improving the lot of elderly people who are suffering from incontinence, and it's somewhat reassuring to know that, whilst not in all cases, in many, something positive can be done. Thank you very much.

DR OSTASZKIEWICZ: Thank you.

ASSOC PROF MURRAY: Thank you.

<THE WITNESSES WITHDREW [2.56 pm]

MR KNOWLES: Commissioners, the next witness is Ms Catherine Sharp. I understand she is just being located at the moment. She may have just stepped outside of the room.

COMMISSIONER TRACEY: That's all right. We'll await her return.

MR KNOWLES: Yes, I call Ms Catherine Sharp.

<CATHERINE ANNE SHARP, SWORN [2.58 pm]

<EXAMINATION-IN-CHIEF BY MR KNOWLES

MR KNOWLES: Ms Sharp, can you tell your full name to the Royal Commission for the transcript.

MS SHARP: My name is Catherine Anne Sharp.

MR KNOWLES: And you've prepared a statement dated the 3rd of July 2019.

MS SHARP: I have.

MR KNOWLES: Yes. Do you have a copy of your statement with you there?

MS SHARP: In my handbag. Do I need to get that or just use this one?

MR KNOWLES: Perhaps if it can be brought to you.

MS SHARP: Sorry. I think I'm holding things up.

COMMISSIONER TRACEY: Not at all. You take your time and get comfortable. The witness box is not a place that people regularly inhabit.

MR KNOWLES: Now, Ms Sharp, do you now have your witness statement there?

MS SHARP: I have.

MR KNOWLES: Yes, and that's your statement dated 3 July 2019?

MS SHARP: Yes.

MR KNOWLES: Yes. And it's numbered WIT.0240.0001.0001. Have you read your statement lately?

MS SHARP: I have.

MR KNOWLES: Yes. And do you wish to make any changes to your statement?

MS SHARP: No.

MR KNOWLES: And are the contents of your statement true and correct to the best of your knowledge and belief?

MS SHARP: They are.

MR KNOWLES: Yes. I seek to tender the statement of Ms Catherine Sharp.

COMMISSIONER TRACEY: Yes. Just remind me of the date?

MR KNOWLES: Exhibit 6-27 was the corrigendum - - -

COMMISSIONER TRACEY: No, no.

MR KNOWLES: The date, pardon me. 3 July - - -

COMMISSIONER TRACEY: It's not on the screen.

MR KNOWLES: No, it's at the signature page. Pardon me. It's 3 July 2019.

HIS HONOUR: Thank you. The witness statement of Catherine Anne Sharp dated 3 July 2019 will be exhibit 6-28.

EXHIBIT #6-28 WITNESS STATEMENT OF CATHERINE ANNE SHARP DATED 03/07/2019 (WIT.0240.0001.0001) AND ITS IDENTIFIED ANNEXURES

MR KNOWLES: Now, Ms Sharp, you presently work as a wounds consultant.

MS SHARP: I do.

MR KNOWLES: Yes. And can you describe to the Royal Commission what your work in that role entails.

MS SHARP: My role as a wound care consultant is to see residents in aged care facilities at the request of staff, GPs or the director of nursing or a registered nurse anywhere in Sydney. So I've probably been in 200, maybe even 300 residential aged care facilities. Mainly to see residents with lower leg ulcers, skin tears and pressure ulcers. Pressure ulcers would probably predominate.

MR KNOWLES: And can you tell the Royal Commission what your qualifications are?

MS SHARP: Well, I'm a registered nurse. I trained in the UK in the 1960s. I am a sick children's nurse, registered nurse. I've done several other things which are all listed from certificates in intensive care to a Master of Clinical Nursing many years ago. A Master of Public Health Research on pressure ulcers, a Master of Health Law from the University of Sydney, and I am completing my PhD on pressure ulcers in aged care facilities and that will be submitted in the next month or so.

MR KNOWLES: And what is the topic of that PhD?

MS SHARP: It's on clinical practice, patient safety and legal implications of pressure ulcer care in elders.

MR KNOWLES: Thank you. And in terms of your experience in the aged care system, can you provide some details of what that has been in the past, in terms of your working role since 1997, I think you say in paragraph 4 of your statement.

MS SHARP: Yes. Yes, in 1995 to 2000 I was working at Royal Prince Alfred Hospital in Sydney as an infection control wound care consultant, and I had a call from the GP asking me if I could go and see a resident in a facility who had a pressure ulcer. I had never been asked to go outside the hospital system to do anything like that and I did in my own time. And I remember the woman, I remember her name. I remember her daughter. I remember her pressure ulcer, and it was huge. And it was horrendous and it was a full thickness sacral buttock pressure ulcer. The daughter was a nurse and she was very upset that this had happened.

I had quite a bit of knowledge at the time about alternating pressure air mattresses because I had sat on state and national committees going out to see the mattresses and find out how they worked. So I was able to order one for her. I've got to say I think she died; it didn't ever heal up but for the most part my experience is that pressure ulcers in aged and frail aged do not heal. They die with pressure ulcers. And in my PhD research, a third of our residents died in aged care facilities with one or more pressure ulcers. And from that time on, I was also a member of the Wound Care Association of New South Wales and we were writing guidelines for pressure ulcer prevention but from that time, I just seemed to get more and more and more requests to go to aged care facilities and that's what I do now. That is my clinical role now, although it's not full-time or anything, it's really on an ad hoc basis.

A few years ago, I was funded through the St George division of general practice in their allied health program. I think they had funding from the Commonwealth, and I was the wound care person, asked to go. So I was funded for a period of, I think, four or five years but only really intermittently and in that time I saw residents in possibly 40, 50, 60 facilities in the St George region of Sydney.

MR KNOWLES: So from that, I take it you have considerable experience and expertise in the area of assessment and treatment of pressure injuries or pressure ulcers, as you term them.

MS SHARP: I think I do but certainly not in prevention, really. I've got some experience in prevention but for the most part, by the time I'm asked to see a resident with a pressure ulcer, it's so far gone that it will never heal up. But there's certain things we can do to minimise the pain and the – they're excruciatingly painful. If I can suggest that – to imagine how a pressure ulcer develops as we are all sitting here, if we focus on the bones in our buttocks and sit and do not move for two hours or three hours or four hours or eight hours, we will have excruciating pain and that's ischaemic pain caused by lack of blood supply to the area, and what happens deep in the tissues there's death of tissue and then we end up with a big bag of pus under the skin. That skin may or may not break open.

Sometimes I've been asked to debride. So I put a scalpel in to the sacrum and out comes a gallon of pus, and then we have to start wound management which, for our care staff, is extremely difficult. It's very time-consuming. We have to clean out the pus and that's – that's so painful, so hard.

MR KNOWLES: Ms Sharp, you mentioned earlier that you often get called in when people are so far gone.

MS SHARP: Yes.

MR KNOWLES: Why do you think that is, and obviously I take it from that you would much rather be called in at an earlier time whereby you might be able to manage the wound successfully.

MS SHARP: Well, it would be much easier to prevent but sometimes I've had calls from really upset aged care staff that say, "Look, this morning there's a big hole that wasn't there yesterday" and when I go in they will describe the skin yesterday was intact, even though it's blue, blotchy black, bruised, but there was nothing leaking out of it yesterday. And that's because the pressure ulcers can begin deep at the bony interface or at the skin level or anywhere in between the middle model. So there's death of tissue and a big bag of pus and then it will open up. And I've actually put a scalpel into one lady's sacrum and the pus just spurted out all over me. It's under such high pressure.

But then when you clean it out, often you can see bone. By that stage there's often osteomyelitis if it's going to be diagnosed. And they simply do not heal up; there's nothing you can do to heal them up. We need surgical intervention then. I like to ask the GPs to refer these people to a surgeon.

MR KNOWLES: So what would you recommend then, to staff in aged care facilities dealing with people who are at risk of developing pressure ulcers and who might show early signs of a pressure ulcer, do you have recommendations for how staff might better approach that?

MS SHARP: Well, even before they get an early sign of a pressure ulcer, that can just be a red mark but because we know pressure damage, tissue death can start within half an hour of unrelieved pressure, so the unrelieved pressure we feel now sitting on a chair. Decades ago a wonderful researcher called Mary Bliss who was a gerontologist in the UK, she actually showed that pressure damage, tissue death, pressure ulcers can start in 30 minutes, and yet all our care staff are taught to reposition two-hourly. Two-hourly is too long.

So even right at the very beginning, as soon as somebody cannot reposition themselves, cannot move to relieve pressure, we have to relieve it for them. And the two-hourly repositioning regime will not work. It is not soon enough. We need to have them on alternating pressure air mattresses that relieve pressure every few minutes throughout the 24 hours. And the other downside of repositioning every two hours means that you are waking people up. You are constantly disturbing them and that's – sleep deprivation in our aged is really unacceptable. If they're on a mattress, we can let them sleep for hours and hours and hours and then reposition when they're awake, reposition, sit them up, give them a drink, roll them over, change a pad, if necessary. Sit and have a chat with them.

But the other thing that happens when care staff are repositioning every two hours, often the residents, whether they have dementia or not, they become really aggressive and they hit and scream and we've had lots of care staff injured while they're trying to reposition.

MR KNOWLES: You mention alternating pressure air mattresses. Can you just explain to the Royal Commission how they work, what they do to deal with the potential for pressure injuries in the elderly.

MS SHARP: Yes, have you got the photograph of the alternating mattress that can go on the screen or not.

MR KNOWLES: Not in the - - -

MS SHARP: Okay. Don't worry. These mattresses have tubes of air that go across the bed from top to bottom. Every few minutes, say every 10 minutes, the cell deflates and then inflates; the other one deflates. So that 24 hours a day residents are getting complete pressure relief and it's like – it's like us; we move in bed all the time. The ones I am particularly fond of allow safety measures, so they have long tubes of air at each side of the mattress. So that if the resident rolls to the edge of the mattress, it will not collapse because there's lots and lots of literature that shows that if suboptimal mattresses are used, you know, perhaps big bags of air that have nothing to support the resident at the side, they have actually rolled off the bed and on to the floor, and I saw one a couple of weeks ago doing just that because the edge of the mattress collapses.

There's plenty of stories in the literature about residents who have been found dead. They've actually asphyxiated between the edge of the mattress that has collapsed and the bed rails or they have slipped out between the bed rails and choked. So rolling off a mattress that doesn't provide support is – it's unacceptable. And these are el cheapo mattresses but the cost of providing a really good air mattress, alternating pressure air mattress is about $1.40 a day to rent, that's all.

Whereas to put on a sacral dressing on a sacral pressure ulcer can be five, six, seven, $12 for one dressing. And that dressing is – well, you hope it will stay on for a few days. But often it doesn't because residents, if they have a little bit of dementia – even a little bit of dementia, they will feel this foreign body in their pants and then they will go and pull it off and you will find them on the floor or in a bin. So they have to be reapplied. And it's very, very costly.

MR KNOWLES: Ms Sharp, can I just ask you by way of conclusion, do you think that there is substandard care in the area of pressure wound prevention in aged care and, if so, why, and how would you propose that there be improvements?

MS SHARP: Well, I think there is substandard care but that's not because of the care staff or the registered nurses in the facilities. It's the people who provide or pay for equipment. Now, if providers don't want to rent mattresses, good mattresses, they just simply don't. And they insist that the staff keep repositioning every two hours. But as we know, repositioning is simply not enough. And if you were to reposition, to prevent pressure ulcers, you would doing it several hundred times in the 24-hour period.

MR KNOWLES: And so how would you like to see wound care in aged care improved, Ms Sharp?

MS SHARP: We do need many more staff. And there are people whore writing about ratios, you know, how many registered nurses we need, how many ENs, how many AINs. And it depends on the facility but, certainly, we need numbers. So, for example, if I go in to a facility to see a resident, let's talk just about sacral ulcers, and I want to debride the dead tissue off that ulcer so we can perhaps get some healing going, I need two care staff. I need – especially if there's some dementia. I need one to hold the resident on his or her side. We do need a nurse to give pain relief prior to me starting the wound dressing, but often there's not a registered nurse free to do that. And not all facilities allow care staff to give analgesia, and often the analgesia is simply not enough.

So to then start doing the wound dressing, I want a care worker on that side of the bed, to look at the resident's face, to tell me if they're in pain or not while I'm working away with the scalpel. And then we have to have two to help to stick on another wound dressing, to gather up all the waste. And waste disposal is also another expense in aged care. Disposing of dirty dressings and gloves and gowns. And these two care staff – if they're helping me, then there's nobody else in the facility for those who are calling for a bedpan or who have fallen over in another part of the ward. It's all – it's too difficult. There's not enough care staff anywhere.

MR KNOWLES: Is there anything else that you would like to say to the Royal Commission, Ms Sharp, now?

MS SHARP: I do want to say a huge hello and thank you inform the hundreds of aged care staff I've worked with over the last 20-odd years. Without them, care would be much less than it is now. And there's so many facilities where we're running on, you know, one member of staff looking after 60, 70 residents. Some facilities on night duty have nobody. They lock the doors of the units with demented residents in and there's nobody in there looking after them. So - - -

MR KNOWLES: I do not have any further questions for Ms Sharp.

COMMISSIONER TRACEY: Ms Sharp, we have heard evidence in other proceedings about a number of different types of bed, to accommodate the needs of people who are susceptible to pressure sores. None of them have referred to your $1.40 a day model. In your experience, how common is this seemingly wonderful mattress?

MS SHARP: I've been fortunate to work with many directors of care who have taken my advice and put this particular mattress in to their facilities – to some of the beds, not necessarily all of them, but we have – I and other wound care consultants have together monitored and written reports for the facilities to show that they end up with no pressure ulcers. Unfortunately, that work is not published, but I certainly have the reports. And people – I think there's a perception that, "Pressure ulcers in the elderly are inevitable, so we're not going to" – "we won't bother about them too much". Heel pressure ulcers are a huge problem, because, often, that resident will end up having to have an above-knee amputation; they never walk again, they can't

get shoes on. The $1.40 a day – the particular mattress that I've shown previously is estimated to have a life of five years. So it's $1.40 a day to rent for five years. To me, it's a no-brainer.

COMMISSIONER TRACEY: I wonder if you would be so kind as to provide the Commission staff with a copy of that unpublished report? I think it would make very good reading.

MS SHARP: If I'm allowed to. I would - - -

COMMISSIONER TRACEY: Well - - -

MS SHARP: I would have to ask the facility.

COMMISSIONER TRACEY: Well, of course. I don't want you to breach any confidences - - -

MS SHARP: I know. That's - - -

COMMISSIONER TRACEY: - - - or anything of that kind, but it just seems something that could be of great benefit to a great many people.

MS SHARP: I absolutely agree. And there's many places that have – they've taken on board this particular mattress and no reports have been written. So I think - - -

COMMISSIONER TRACEY: Thank you.

MS SHARP: I didn't think it would take this many years to make changes, but it has.

COMMISSIONER TRACEY: Yes. Very well. Nothing arising?

MR KNOWLES: No. Thank you, Commissioner.

COMMISSIONER TRACEY: Ms Sharp, thank you very much for your evidence. It has been an eye-opener, certainly to me, about one aspect that we've heard so much about – have caused deterioration and great harm to elderly people. And if it can be avoided and remedied, then we ought to be doing something about it and doing it soon.

MS SHARP: It's very easy.

COMMISSIONER TRACEY: Thank you.

MS SHARP: It is. Thank you. Thank you for having me.

<THE WITNESS WITHDREW [3.21 pm]

MR KNOWLES: Commissioners - - -

COMMISSIONER TRACEY: Do you want to take a break now or are you ready to go straight on?

MR KNOWLES: We're in the Commissioners' hands. But Mr Rozen is here to take the next witness.

COMMISSIONER TRACEY: Yes. Well, we'll do that?

MR KNOWLES: Thank you.

MR ROZEN: Commissioners, the next witness is Sally Hopkins. I call her. Whilst she is coming to the witness box, I wish to express her gratitude to the Commissioners and the staff for interposing her this afternoon. We have just changed the batting order a little bit to accommodate Ms Hopkins' travel plans this afternoon, which were otherwise in peril.

COMMISSIONER TRACEY: Not caused any inconvenience at all.

MR ROZEN: Thank you. Please take a seat, Ms Hopkins.

<SALLY JEANNE HOPKINS, AFFIRMED [3.22 pm]

<EXAMINATION-IN-CHIEF BY MR ROZEN

COMMISSIONER TRACEY: Yes. Mr Rozen.

MR ROZEN: Thank you, Commissioners. Ms Hopkins, is your full name Sally Jeanne Hopkins?

MS S.J. HOPKINS: It is. Yes.

MR ROZEN: And Jeanne is spelt J-e-a-n-n-e?

MS HOPKINS: Correct.

MR ROZEN: And for the purposes of the Royal Commission, have you made a witness statement, dated 24 June 2019?

MS HOPKINS: I have.

MR ROZEN: The code for that is WIT.0200.0001.0001. That should be appearing to the screen, or at least the first page of it, in front of you now, Ms Hopkins. Have you had a chance to read through it before coming along to give evidence today?

MS HOPKINS: Yes.

MR ROZEN: Is there anything in it that you would like to change?

MS HOPKINS: No.

MR ROZEN: All right. Its contents are true and correct?

MS HOPKINS: Correct.

MR ROZEN: I'll tender the statement of Sally Jeanne Hopkins, 24 June 2019, Commissioners.

COMMISSIONER TRACEY: Yes. The witness statement of Sally Jeanne Hopkins, dated 24 June 2019, will be exhibit 6-29.

EXHIBIT #6-29 WITNESS STATEMENT OF SALLY JEANNE HOPKINS DATED 24/06/2019 (WIT.0200.0001.0001)

MR ROZEN: Thank you, sir. Ms Hopkins, you are the executive director of Eden in Oz & NZ Limited?

MS HOPKINS: That's correct.

MR ROZEN: That's Oz, spelt O-z, and the letters N-Z, Limited. You've held that role since 2009?

MS HOPKINS: Yes.

MR ROZEN: I will ask you a little bit more about Eden in Oz in a moment, but by way of qualifications, you have a Masters in Administration Hospitality?

MS HOPKINS: Yes.

MR ROZEN: And you have a career prior to 2009 in the service industry, is it fair to say?

MS HOPKINS: Yes.

MR ROZEN: And so far as your experience in the aged care sector, you have the 10 years in your current role, plus previous role as a provider of hospitality services to the aged care sector?

MS HOPKINS: Yes. That's correct.

MR ROZEN: All right. At Eden, you hold a number of roles. You are an Eden Alternative Educator?

MS HOPKINS: Yes.

MR ROZEN: You're a consultant?

MS HOPKINS: Yes.

MR ROZEN: And you are also a community visitor to homes and organisations implementing the Eden Alternative Philosophy?

MS HOPKINS: That's correct.

MR ROZEN: That's in Australia, New Zealand and in Singapore. And you are also the vice chair of Eden Alternative International?

MS HOPKINS: Yes.

MR ROZEN: All right. Now, Eden in Oz and New Zealand, unlike many organisations that we have had witnesses from, it's not actually a provider of aged care services?

MS HOPKINS: No. We're not a provider.

MR ROZEN: How would you describe the organisation and its purpose?

MS HOPKINS: The entity – we are an education provider of culture change services.

MR ROZEN: Yes.

MS HOPKINS: And really looking at changing the culture of care in aged care and community care.

MR ROZEN: And can you tell us a little bit about the background to Eden in Oz? It started in the United States; is that right?

MS HOPKINS: The Eden Alternative commenced in the USA, and Eden in Oz & New Zealand, we hold the licence for Australia and New Zealand and now South-East Asia. And, really, we are linked to another – we are actually a global

organisation. We're linked to another 16 regions around the world. So our remit is really to change the culture of care.

MR ROZEN: Okay. And perhaps to better understand the background to it – we are very grateful you set out in paragraph 12 of your statement, if that could be brought up on the screen, please, on page 2 – you tell us that a Dr Thomas was the founder of the Eden Alternative?

MS HOPKINS: Yes.

MR ROZEN: And without a biography of Dr Thomas, can you tell us a little about him.

MS HOPKINS: Dr Bill Thomas is an innovator. He's a world-renowned innovator in – in care, really. He's a medical doctor.

MR ROZEN: Yes.

MS HOPKINS: And he commenced an internship – or started working in a nursing home in the 90s. And in the States they have a medical director status standard, in terms of how you get the clinical care from a medical perspective - - -

MR ROZEN: Yes.

MS HOPKINS: - - - within nursing homes. And when he went to work in a nursing home, what he found – while he could provide really good clinical care and write out prescriptions left, right and centre, he still had people dying. And it was – one day, a lady actually said to him, even though he was providing great clinical care in giving her a prescription for a rash on her arm, she actually told him she was really lonely.

MR ROZEN: Yes.

MS HOPKINS: And when he went back to his Harvard medical book, he couldn't find a prescription for loneliness. And that really started him on this path of changing the way we see nursing home care particularly, and that's where he started. And then – and merging that into community care.

MR ROZEN: Yes.

MS HOPKINS: So he identified loneliness, helplessness and boredom exist in - - -

MR ROZEN: Loneliness, helplessness - - -

MS HOPKINS: Helplessness and boredom.

MR ROZEN: - - - and boredom. Yes.

MS HOPKINS: Yes. So we can have good clinical care, but we still have people who are suffering from those three – we call them three plagues – of loneliness, helplessness and boredom.

MR ROZEN: Yes. And I think you're making the point, if I understand it, in paragraph 12, that they're the antithesis of good quality of life?

MS HOPKINS: They are.

MR ROZEN: Yes.

MS HOPKINS: Yes.

MR ROZEN: And is it fair to say that, at its heart, the Eden Alternative is about promoting quality of life in aged care settings?

MS HOPKINS: Yes.

MR ROZEN: Now, can I just ask you a little bit about how that works in practice? So do you accredit an approved provider of aged care services in some way? Is that how the model works, in practice?

MS HOPKINS: How does it work? Goodness. Yes. There's a – two-part. There's the education process of educating the organisation, particularly the staff and the leadership within a home or an organisation. And the residents or the clients as well, because this is a whole-of-organisation approach, so there's that part.

MR ROZEN: Yes.

MS HOPKINS: And then the organisation looks at their policies and procedures and the way they do stuff now, the way they actually operate, and looking at, "How do we shift from an institutional model response to one that's actually around the person?"

MR ROZEN: Yes.

MS HOPKINS: So it's much more person-directed.

MR ROZEN: Okay. So we had a hearing in Perth a couple of weeks ago, where the focus was person-centred care.

MS HOPKINS: Yes.

MR ROZEN: And you will probably be familiar with that. This is a model of aged care provision that seeks to be person-centred.

MS HOPKINS: It is.

MR ROZEN: Yes.

MS HOPKINS: And we use the phrase "person-directed" - - -

MR ROZEN: Yes.

MS HOPKINS: - - - to be quite clear about who is the person that is directing the care.

MR ROZEN: Right.

MS HOPKINS: And in this case it would be the resident - - -

MR ROZEN: Yes.

MS HOPKINS: - - - or in community care it would be the client or the person in their home. So we sort of go the extra step in shifting, again, people's perceptions of the care that's required and who is actually being involved in making those decisions.

MR ROZEN: It's a bit of a cliché, I know, but it sounds like what you're seeking to implement is a paradigm shift in the way people deliver aged care services.

MS HOPKINS: Absolutely.

MR ROZEN: All right. Now, say I'm a provider of aged care services. I'm an approved provider and I think that it might be good for my business or it might just be a better way of providing aged care services as an end in itself, I want to be accredited as providing the Eden Alternative style or form of aged care. How do I start that process? I give you a call, I suppose, do I?

MS HOPKINS: That is a good start.

MR ROZEN: Or I look on the website and then what happens? Do you come out, have a look at my premises or what's the process?

MS HOPKINS: We usually have a conversation about what's the vision for the organisation. In the ideal world the query – or the inquiry has come from the CEO because we do talk about whole of organisation change. So we don't necessarily go to the home straightaway or the organisation. We do a bit of research on the side. It's really looking at what their objectives are, and why they are looking at something like the Eden Alternative because culture change is hard work. So once we have, in a sense, validated the genuineness of the inquiry because some people think if we just put in plants, animals and children that that's culture change, and that's not culture change. We actually need to look at the way we provide services within the home. So we then come and train the staff.

MR ROZEN: Yes.

MS HOPKINS: They take – the organisation then takes the opportunity to look at what they're doing and start to implement the Eden Alternative around the framework of 10 principles. It really is quite organic, and we look at principles 2 and 10 as a starting point. Principle 2 is about creating home. Principle 10 is about leadership.

MR ROZEN: Perhaps if we can go to page 16 of your statement, please, .0016. And we can see the first four of those principles at the bottom of page and then – because I know we have the technology to do this, the remaining – there we are, they're all there. You, I think, mentioned a moment ago, 2 and 10 is being the initial focus. Is that right?

MS HOPKINS: That's right.

MR ROZEN: So 2 is:

> *Creating a human habitat which requires close and continuing contact with plants, animals and people of all abilities.*

MS HOPKINS: Correct.

MR ROZEN: 10 is:

> *Wise leadership is the driver of genuine human caring and change.*

And you mentioned a moment ago the importance of CEO interest and input. It probably goes without saying but why is it important for the successful implementation of the model for the CEO to be driving it?

MS HOPKINS: In in the institutional model what we see is a top down bureaucratic approach to decision-making. And this is "I tell you. I'm the CEO". In the institutional model I tell you how it's going to be and that's exactly what happens in spite of any potential resistance. We want to turn that on its head and we want the leaders to show – it's the walking the talk to say, "We want to be different and I need to lead that team in a manner that's different to the way we have always done it". So they need to be a part of the solution, and not only the leader but also growing leaders underneath them.

So instead of people pushing up and trying to lead from the bottom, which is really hard work and basically doesn't achieve anything, that they lead by example whether it's good, bad or indifferent. But they say, "We want this" and that sends a really strong message to the team. It's not just them.

MR ROZEN: Right.

MS HOPKINS: A lot of the times we see models where the frontline staff are trained but that's where it ends. You know, you are shown an opportunity but not anything else as far as how would – do you support – does the CEO actually support what we are doing.

MR ROZEN: Yes. And I steered you towards the CEO, but of course most approved providers would have a board of directors sitting above the CEO - - -

MS HOPKINS: Yes.

MR ROZEN: - - - to whom - - -

MS HOPKINS: So the board also needs to be a part of that.

MR ROZEN: Yes. And how do you ascertain that? Would you meet with the board? What's the - - -

MS HOPKINS: We do meet with the board. When the people are implementing the Eden Alternative, we really look at what is their strategic plan, how do they – what's their vision, and in their vision really stating that this is where we see our organisation going. The Eden Alternative forms a platform for us to expand and building on the good stuff we are already doing. A lot of organisations are doing really good stuff, but this is the next level that requires commitment and the board – having a board committed to that, and if it's in their strategic plan, really again sends a strong message this is who we are and where we are going.

MR ROZEN: Is that what you are looking at before you would give the tick to an approved provider?

MS HOPKINS: Absolutely, yes.

MR ROZEN: And you've described the need for – for provision of the training and the completion of the training. Is that it or is there some further form of assessment that you do to see that the principles that have been the subject of the training are actually implemented?

MS HOPKINS: We – when an organisation starts to implement the Eden Alternative we – they apply for recognition on our registry and it's fairly rigorous, and we actually do site visits and we call it validation. So it's completely separate to anything that the agency may do. This is what we do. So we visit - - -

MR ROZEN: When you say the agency there you mean - - -

MS HOPKINS: So the Aged Care Quality Agency.

MR ROZEN: The government regulator.

MS HOPKINS: Yes, the government regulator. That's - - -

MR ROZEN: This is independent of them.

MS HOPKINS: It's independent from them.

MR ROZEN: Yes.

MS HOPKINS: And we visit – it's to see how well that organisation or home has gone in changing the way they were to the way they want to be because it's a process that is longer than a day and it takes time.

MR ROZEN: Okay. And in a practical tangible sense what are you looking for to make that assessment? Is it literally watching the way staff interact with residents or do you look at policies and paperwork? How do you make that assessment?

MS HOPKINS: Around principle 10 we look at the policies and procedures and the changes that they start to look at in terms of the how, part of the operational manual for want of a better phrase. And then in principle 2, because we are looking at creating home, and what does that mean and then looking at how organisations have started to include residents – particularly if we're thinking about residential aged care – how they are including them in the decision-making that directly impacts them. And one of the critical questions for me is, "Have you ever asked your residents what does home mean to you" because for everybody in this courtroom, for example, home means different things and it's the same for our older people living in residential care.

MR ROZEN: And having been through those steps and either satisfied yourself or not, I suppose, I imagine it's not a formality to get the tick, you have to be positively satisfied that the organisation has embraced the principles. Is that right?

MS HOPKINS: There's – there's a criteria that they need to meet. When we make recommendations that goes to our own board, in Australia – we have a small volunteer board – as recommendations to accept them on to the registry and/or to accept them for recognition in additional principles over time because we start with 2 and 10 and then you've got these other eight to work your way through.

MR ROZEN: I see.

MS HOPKINS: So it's not a case of it just stops there. It's really this is the starting point and then when we go to visit for additional recognition in those other principles we then look at how much deeper are you going with your culture change or is it just superficial, and then we guide them and that's where our consulting service comes into it. We guide them around ways they can start to shift again because it's hard work and people are locked into an institutional response constantly, unfortunately.

MR ROZEN: Yes. I do need to ask you this: the funding for the organisation, does that come from the consultancy work that you do?

MS HOPKINS: It comes from our training. We are self-funded. We don't get any government funding. So we live and die on the services that we provide, whether it's education, registry, merchandise. We have a conference in October. I slipped that one in. They're the main things, yes.

MR ROZEN: Right. Okay. And I see from your statement that there has been a recent expansion into Singapore. That was two years ago.

MS HOPKINS: That's correct.

MR ROZEN: And the service that's been provided in Singapore is broadly similar to what you're doing in Australia?

MS HOPKINS: Very similar to what we do here, and it's about starting the conversation as much as anything, and we are working with two different groups, a community care group and a residential care group. So that's our first foray and the same issues in Asia as Australia or New Zealand in terms of how do we support people as they age.

MR ROZEN: I neglected to ask you this earlier, but it's not just residential care that this is relevant to in Australia. Do you also provide accreditation for home care providers?

MS HOPKINS: We do, yes.

MR ROZEN: Right.

MS HOPKINS: Yes, so people – sorry, organisations who support those living with dementia and also organisations in community care who also support people with a disability.

MR ROZEN: Right. So I think Alzheimer's Western Australia is one such organisation.

MS HOPKINS: They are.

MR ROZEN: In Mary Chester House is a facility that we heard about in the Perth hearings. They are accredited.

MS HOPKINS: They are.

MR ROZEN: Right. So how many organisations in Australia – how many approved providers of aged care services would I see if I looked up your website list?

MS HOPKINS: You would see approximately 30.

MR ROZEN: Right.

MS HOPKINS: Eden registry members, and we know there are homes who are implementing the Eden Alternative but haven't as yet put their hand up and said we want to be on your registry. And that's one of those takes time issues as much as anything else, and then we obviously have registry members in New Zealand as well.

MR ROZEN: All right. Now, if I could ask you little bit about what an Eden Alternative home looks like, what one would expect to see. Before I do that, I just wonder if there might perhaps be an error maybe in principle 3. I wonder if the word "boredom" there in 3 should be loneliness.

MS HOPKINS: That's actually back to front. It should be loneliness. Yes. Absolutely.

MR ROZEN: Loneliness there. Okay. So we can make that – so you want to make that change, I take it?

MS HOPKINS: I think so, yes, that would be good.

MR ROZEN: We can't have an error in the 10 commandments.

MS HOPKINS: 10 principles, no commandments, thank you. We aren't a religion, although it might seem so at times.

MR ROZEN: All right. I withdraw that. I just want to ask you some questions about some specific areas in your statement about the model. I wonder if we could start, please, on page 3. At the top of the page there you were asked a question in the request from the Commission itself about who you consider are the people responsible for the care of residents in a residential aged care facility. And you make a point there about the importance of language and the meaning of care. The point as I understand it is you are saying, well, it depends what you mean by care. If you are using it in a narrow clinical sense then it's this range of people, but if you are using it in a more holistic sense which I think you would be more comfortable with, then we can see the range of people in paragraph 19 would be much broader. Am I understanding correctly the point that's being made there?

MS HOPKINS: That's correct, because the definition of care provided by the Commission is really the clinical approach as much as anything and the daily living activities. It's not really looking at helping someone to grow which is our definition.

MR ROZEN: Just to clarify, you don't say that clinical care and attendance to daily needs are irrelevant to quality of life.

MS HOPKINS: No.

MR ROZEN: No. I assume they're necessary but they're not sufficient. They're not the whole picture. Is that – am I understanding that correctly?

MS HOPKINS: That's correct. I mean, the current – for a lot of organisations, the clinical drivers tend to dominate what is happening in the operational space. We ask that that is balanced more with a person-directed approach that really engages the person receiving the care more in the decision-making.

MR ROZEN: At paragraph 24 you make a point that we heard a lot in the Perth hearings and that is about the need for continuity of staffing to promote relationships and to promote quality of life of residents. Why do you think the frequent use of agency staff, for example, can undermine the ability to provide proper person-directed care, to use your phrase?

MS HOPKINS: The biggest issue with agency staff is really (a) knowing the home, and how they operate; (b) knowing the staff, the other staff members that may be there, and also then the residents that they're supporting. And if you are new into an agency space and it's your first time in a home, you – it's like starting a new job. You – you're totally lost about what to do, how to do it, where to go, all that sort of stuff. So it doesn't enhance success, really, for the agency staff member and the rest of the team. And quite often I have people say to me we would rather run short than to have an agency staff member because they might not even have the skills required. It's more have you got a pulse and are you breathing, and to fill a hole and to say is this really the right person for that role. Now, that's not saying that agency staff are not – not required but if we are always relying on agency staff to fill a vacuum, then we are setting everybody up to fail.

MR ROZEN: Does continuity of staff and long-term presence of staff in an aged care provider does it tell you something about the organisation from your experience?

MS HOPKINS: Absolutely. It tells you about stability. It tells you that the staff feel valued, that they are making a difference, and I think that's significant. I think most of us go to work, those of us that are working, even if you not, you want to try and make a difference in whatever capacity that is and the value of what I do, the work that I do, because it's not always as nice as it could be.

MR ROZEN: Can I ask you about paragraph 31 which appears to page 4, if we could please have that highlighted on the screen. It's the first sentence there which caught my eye:

There's a minimal focus upon a clinical approach to care.

Is that – perhaps if you can explain that. What's intended by you there? What do you mean a minimal focus upon a clinical approach?

MS HOPKINS: When we're talking about a person-directed model of care, we're really looking at the total reciprocity of relationship. And so, quite often, in the clinical approach to care, if someone is in distress, for example, in the institutional model, we tend to drug them first, and we might ask a question later. So there's an overuse of medication.

MR ROZEN: Yes.

MS HOPKINS: Most of the time, it's totally unnecessary because we actually haven't looked at the unmet needs of the individual. So it's really – from a clinical perspective, if the clinicians have done the things they need to do in looking at pain and infection and all that sort of stuff, that's an absolute that needs to be checked. If that's done, then it's looking at what else is happening for that person.

MR ROZEN: Yes.

MS HOPKINS: So we're looking at not having a total clinical approach to living.

MR ROZEN: I understand. Is there, at play there – and we've heard this from other witnesses – a potential conflict between good clinical care and quality of life, or is that a false non-existent dilemma in your view? Can you have both?

MS HOPKINS: You can't not have both. I don't think you should be trading one for the other. It is – if you've got – if anybody is – in this room has pain and you treat yourself with Panadol, you'll eliminate the pain, you'll feel a whole lot better which can then enable you to be the best of yourself at that time, and the same would be required and should be happening in residential aged care.

MR ROZEN: Yes. Now, you make a point on page 7, if that could be brought up in a – and this is a list of important features of quality of life, and I can't – really don't have time to go through all of them, but I was particularly interested in 43.2.9. So this is in the context of organisational transformation, that is, what you would seek to see in an organisation transforming to the model - - -

MS HOPKINS: Yes.

MR ROZEN: - - - that you're advocating. You talk about the importance of language and that language that is used being less institutional and more about the person or home, and you give a number of examples that I think we can all relate to here at the Royal Commission. The one I've highlight is not using the word "facility", but, rather, using the word "home". Why is language important in this context, Ms Hopkins?

MS HOPKINS: The language that we currently use in residential aged care is quite institutional. It's come out of the hospital – yes, the hospital model. So when we think about, "This is my home where I'm now moving to," in residential aged care, it creates – it sets up a different expectation than, "I am moving into a facility." The

only thing – if I was to move into residential aged care tomorrow, the only thing that's changed for me today is my address.

MR ROZEN: Yes.

MS HOPKINS: Everything about me, my health, my background, my likes and dislikes and my friends come with me through that door. So we want to have that sort of continuity of transition that's less about the clinical and more about the person. So our language holds us back. It's – a lot of our language is ageist. It's disabling, we are seeing people described as a disease first and then the person, for example, the dementia patient. There is nothing in there that says who is the person and it's the – in fact, it's the only group of people that are described by their disease status first. We don't describe people living with cancer as X, cancer person or whatever. We usually say such and such has.

MR ROZEN: Yes.

MS HOPKINS: So it's quite debilitating and disabling. So we're really starting to get people to think differently around what comes out of their mouths first, and that's a significant shift, and the more you practice it and not just practice in the saying, but in the doing, the better the outcome, and it's ongoing. Seriously ongoing in terms of that challenge.

MR ROZEN: Yes. Well, the habits are well entrenched, aren't they?

MS HOPKINS: They are.

MR ROZEN: Residential aged care facility rolls off the tongue.

MS HOPKINS: Yes.

MR ROZEN: In a practical sense, when you're seeking – or when the model is being implemented in an approved provider, are you descending to that level of detail? Are you looking at their policies to see the language that is being used, and are you expecting them to embrace language that is more - - -

MS HOPKINS: Absolutely.

MR ROZEN: - - - in conformance with the ideas?

MS HOPKINS: Yes, because if you don't make even that fundamental change, then it's just paying lip service to something that's not real.

MR ROZEN: So picking up on something you said a moment ago about the only thing that should change is the person's address, moving from, essentially, one home to another home, we've heard a lot of evidence, including in Perth and elsewhere,

about what people give up when they move into residential aged care facilities. I think we might have even asked you the question - - -

MS HOPKINS: Mmm.

MR ROZEN: - - - about what people give up. I take it you would say as little as possible, in an ideal world; is that - - -

MS HOPKINS: In the ideal world, yes, they would give up as little as possible, but the reality is most homes they move into, they give up quite a lot.

MR ROZEN: Yes. Is part of the aim of an Eden alternative home for them to give up perhaps less than they might otherwise be - - -

MS HOPKINS: Give up very little, really.

MR ROZEN: Yes.

MS HOPKINS: It's really about enabling people to continue to live to the capacity that they're able.

MR ROZEN: Yes.

MS HOPKINS: And/or to set new goals that enable them to improve their health which we do see.

MR ROZEN: All right. Just excuse me for a moment. Just one last matter I want to ask you about in your statement, and then I will take you to another topic. It's on page 16 of the statement, and we extended the invitation for you to include any other information that you considered relevant in your statement, and at paragraph 93, you talk about CEO and board commitment and accountability, and I've already asked you about those things, but I wanted to ask you about what you perceive to be the alignment between the new aged care standards which, of course, have been in operation for a week, and the Eden principles. Can you explain to me why you consider there is a comfortable alignment between the two?

MS HOPKINS: If I look at the new standards, which are now eight, rather than 44, and we can match the requirements of each of the standards against any of the principles that are provided – so if we look at the governance space, that particular standard, that's around principle 10. If we look at the first standard which was really looking at choice and autonomy and really being involved with the person and what they want, that's really around all of the Eden alternative, really, but really looking at principles 3, 4, 5 and 6. So the opportunity to give and receive care and to be doing things that are meaningful for me as the resident, not meaningful for you, and really reducing that focus of a clinical response to what I might – may or may not – may or may not need or want.

MR ROZEN: It occurs to me that the role that you're playing in relation to those, at least those 30 providers that find their names on your web list – on your website, is a – it's not quite a regulatory role, but it has some aspects of that about it, operating as a type of private regulator, at least to the extent of giving consumers some information about – how they might inform choices about where they want their relatives to go in residential aged care. Is that something that's sort of part of the thinking of your board, or is that – have I got that completely wrong?

MS HOPKINS: No, that's correct in the sense that you when you're shifting your culture of care from institutional to one that's much more around an Eden model or any other, it's the – I call it show and tell, but it's really saying, generally, with confidence that if I was to go to a home that's on our registry, they would be meeting certain criteria, and it's an organic process. It's not a tick and flick process. We actually do look at what is happening organically within the organisation. So when they're on a – when they're a registry member, they've passed that first space - - -

MR ROZEN: Yes.

MS HOPKINS: - - - and it's an ongoing process and there's revalidation required all along the way, depending on what's happening.

MR ROZEN: And I suppose that leads into the next question which is what, if any, relationship do you have with the Aged Care Quality and Safety Commission?

MS HOPKINS: Nothing directly.

MR ROZEN: Okay.

MS HOPKINS: Obviously, we know of them and, through our clients, we know the focus that they have, and for the last 15 years, any of our Eden homes have been compliant with the standards,

MR ROZEN: Yes.

MS HOPKINS: - - - and we don't expect that to change in the new space. In fact, they would be enhanced because a lot of the requirements are already in place - - -

MR ROZEN: Right.

MS HOPKINS: - - - for a lot of the homes. Not all, but a lot of them.

MR ROZEN: Is compliance with regulatory requirements one of the features of a provider that you look at in that accreditation process that we spoke of?

MS HOPKINS: Absolutely, yes.

MR ROZEN: That brings me to the last topic I want to ask you about. The Commission, next week, sits in Cairns, as I think you're aware, and one of the case studies or case study that we'll examining in Cairns happens to be a provider that is an Eden alternative accredited provider, MiCare in relation to the Avondrust home that they operate in Victoria, and what I would like to read to you, if I could, is a statement made by a witness who will be called next week, who I think you know, Petronella Neeleman. She happens to hold the titles of Eden Associate and Eden Mentor. Can I just ask you what those terms mean? What is conveyed by those terms, and what is her relationship with the organisation that you're the CEO of?

MS HOPKINS: So MiCare, which was formerly DutchCare, were one of the first organisations that was involved in bringing Eden alternative to Australia. So they've had a long-term history of association. Petra as an Eden Associate has completed a three-day Eden Associate course. Was one of the first participants of the training provided by Dr Bill Thomas, in actual fact, which was before my time.

MR ROZEN: Yes.

MS HOPKINS: She was the founding chair of Eden in Oz, and then stepped off the board in 2009 before I started with the organisation. Her homes have been involved with Eden as a consequence, and have been on the registry for the last eight or nine years.

MR ROZEN: Right. And how many homes does MiCare operate?

MS HOPKINS: They have three that are on the registry and a fourth that is in the process, really, and that's in Queensland which we don't have anything to do with, at this stage.

MR ROZEN: Now, of course, the evidence hasn't been heard about this case study, but what I propose to do is just read to you three paragraphs of Ms Neeleman's statement, and perhaps if – just excuse me a moment. We're just bringing up the statement on the screen. We're just getting the code. I'll start to read it for you while that's being done. So the context here is that the case study will be examining the care that was provided to Mrs Bertha Alberts. I think you've had an opportunity to read the statements that have been filed with the Commission concerning the case. And Ms Neeleman is the CEO of MiCare as you've indicated, which was the provider that was operating the home where Mrs Alberts was living – the late Mrs Alberts.
And under the heading:

> *Apology to the Family of Mrs Bertha Alberts and Commitment to Improvement* –

I will just get the statement. It's WIT.0260.0002.0001, and it's the fifth page of the statement. So Ms Neeleman says:

Apology to the Family of Mrs Bertha Alberts and Commitment to Improvement.

And under that heading, she says:

> *I want to express my heartfelt sorrow that we were not able to adequately meet the needs of Mrs Bertha Alberts and apologise on behalf of the staff, managers and the board of MiCare and of myself that we failed to deliver the care that Mrs Alberts required.*

She goes on, as you can see, in paragraph 5 to indicate that:

> *The most important thing for MiCare is to deliver the high standard of care that our residents and families deserve.*

And then at paragraph 6:

> *Unfortunately, at Avondrust in 2018, we did not consistently deliver on this aspiration. We've addressed the issues and have made changes to the staffing mix and improved the services we provide and the education levels.*

And we understand Ms Neeleman will give that evidence next week. On that assumption that that's in fact the case, has there been any process of – or reassessing MiCare as an accredited Eden alternative facility?

MS HOPKINS: Firstly, I need to make a comment. I actually don't know about this particular scenario, other than what you've provided.

MR ROZEN: Yes, I understand.

MS HOPKINS: So I can't really comment on the content.

MR ROZEN: Yes.

MS HOPKINS: But from an Eden perspective, from our perspective, at this point in time, the home in question is not seen as to be a fully accredited home with Eden Oz and New Zealand.

MR ROZEN: Right.

MS HOPKINS: And we would be going – looking to go back to revisit this home probably before the end of this year. They are in this space and that needs to be assessed appropriately, but they are not considered to be fully registered with us at this point in time.

MR ROZEN: Okay. And what was the trigger for that? They were removed from the list, were they?

MS HOPKINS: They're off – they're there, but they're actually not on our website. They're not identified as that mainly because of the sanctions that were brought to bear late last year.

MR ROZEN: Yes.

MS HOPKINS: And, you know, part of our review is, you know, when homes or organisations apply for membership to our registry list, there needs to be no non-compliances, and when you are sanctioned, that's a significant non-compliance.

MR ROZEN: Yes, I see.

MS HOPKINS: And that's a trigger for us.

MR ROZEN: And for them to get back to that full registered status, what would they need to demonstrate to you?

MS HOPKINS: They'd need to demonstrate (a) that they've actually passed the requirements from an aged care agency perspective, and then we would be looking at what they've done to really realign themselves around the 10 principles as well.

MR ROZEN: Right.

MS HOPKINS: But particularly around principle 7 which is medicine as the servant and not the master.

MR ROZEN: Okay. One of the areas that will be the subject of exploration next week when this evidence is led in this case study concerns staffing levels, particularly nursing staffing levels, and the evidence we anticipate will be that subsequent to the events that are the subject of the case study, there was a considerable increase, particularly in nursing staffing levels.

MS HOPKINS: Mmm.

MR ROZEN: Is that a matter that you are at all concerned with in part – as the accrediting body in relation to the Eden alternative?

MS HOPKINS: Staffing levels are really up to the individual organisations more than anything else, and so we don't dictate what the minimum or the maximum would be because, really, that is a decision by the organisation more than anything.

MR ROZEN: Right. I'll just ask you a general question if I could about clinical errors in care being made by approved providers, without focusing on any specific provider.

MS HOPKINS: Mmm.

MR ROZEN: How would you expect a provider to respond where there has been a clinical error? What would be a response that was consistent with the principles, the 10 principles that you've identified?

MS HOPKINS: If we're looking at wise leadership and what that might mean, from an Eden perspective, we talk about accountability and transparency, and so it's really taking ownership that it's not other people's fault, if I can use that word.

MR ROZEN: Yes.

MS HOPKINS: It's actually, you know what, we're all in this and, ultimately, it stops the CEO and/or the board. So accountability at the top needs to be seen and expressed accordingly.

MR ROZEN: Thank you. Commissioners, they're the questions that I have for Ms Hopkins.

COMMISSIONER TRACEY: Yes, thank you. Ms Hopkins, does your organisation get consulted from time to time by providers who are contemplating establishing greenfield sites or adding to the accommodation on existing sites?

MS HOPKINS: Not directly unless they're looking at something like small house styles such as the greenhouse model.

COMMISSIONER TRACEY: That's where I was going.

MS HOPKINS: Mmm.

COMMISSIONER TRACEY: I was interested to know what your recommendation would be to such an organisation as to the best type of accommodation, drawing a distinction between what looks like large hospital type corridors and multi-level buildings, which don't seem to be quite compatible with your principles.

MS HOPKINS: No. In the ideal world, we would have smaller living spaces of – depending on the organisation. In the States, when Bill Thomas created the greenhouse model, he worked on, sort of, a group housing space of six to eight people. In Australia and also New Zealand, we know that for organisations to break even, under the current funding space, it's about 16 residents, but of two groups of eight. So it's really looking at creating smaller households. So in existing buildings where they are the multi-storey 120 resident establishments, it's looking at how do you break that down to smaller households, rather than one big home, and within each household, the residents or the people who live there create that environment of home, whatever that might mean for them. But smaller would be better than the five-star resort style.

COMMISSIONER TRACEY: Thank you very much for your evidence. We're exploring the best ways for caring for the elderly in this country and your formula

seems to be working. So we will certainly have it in mind when we come to make our recommendations.

MS HOPKINS: Thank you.

COMMISSIONER TRACEY: Are we taking a break now.

MR ROZEN: We are entirely in your hands.

COMMISSIONER TRACEY: Yes. All right. We'll take a 10-minute break.

MR ROZEN: Commission pleases.

<THE WITNESS WITHDREW

ADJOURNED [4.06 pm]

RESUMED [4.23 pm]

COMMISSIONER TRACEY: Yes. Mr Knowles.

MR KNOWLES: Thank you, Commissioners. We have Adjunct Clinical Associate Professor Geoff Sussman and Ms Hayley Ryan in the witness box.

<HAYLEY MAREE RYAN, SWORN [4.24 pm]

<GEOFFREY MENDES SUSSMAN, SWORN [4.24 pm]

<EXAMINATION-IN-CHIEF BY MR KNOWLES

MR KNOWLES: Professor Sussman, could you tell the Royal Commission, for the transcript, your full name?

ASSOC PROF G.M. SUSSMAN: Geoffrey Mendes Sussman.

MR KNOWLES: And, Ms Ryan, could you also tell the Royal Commission, for the transcript, your full name?

MS H.M. RYAN: Hayley Maree Ryan.

MR KNOWLES: Yes. Now, you have, together, prepared a joint statement on behalf of Wounds Australia; is that correct?

ASSOC PROF SUSSMAN: Correct.

MS RYAN: Correct.

MR KNOWLES: And can I ask you, first, Professor Sussman, whether – save for, obviously, the matters that – sorry. Pardon me. You've both read it in recent times, I should ask.

ASSOC PROF SUSSMAN: Yes.

MS RYAN: Yes.

MR KNOWLES: And can I ask you both, together, is there anything that you would like to change in the joint statement?

MS RYAN: Please. Two quick amendments on the – paragraph 16. We have put "upper limbs". It should just be referring to "limbs", because it does affect – skin tears affect both upper and lower. And - - -

MR KNOWLES: I'm sorry. That is in which line of paragraph 16?

MS RYAN: First line.

MR KNOWLES: Thank you. That's the first change.

MS RYAN: First change.

MR KNOWLES: And the second?

MS RYAN: And the second change on paragraph 45(g), where it refers to paraffin gauze dressings. It should also state after that that this is in the management of rogue maggots.

MR KNOWLES: Thank you. Now, subject to those corrections and insofar as the information is specific to each of you – and I will ask you this in a moment – Professor Sussman, are the contents of the statement true and correct, to the best of your knowledge and belief?

ASSOC PROF SUSSMAN: Yes. They are.

MR KNOWLES: And, Ms Ryan, are the contents of the statement true and correct, to the best of your knowledge and belief?

MS RYAN: Yes. They are.

MR KNOWLES: I seek to tender the statement.

COMMISSIONER TRACEY: Could we have it called up?

MR KNOWLES: I'm sorry?

COMMISSIONER TRACEY: Could we have the reference to it and have - - -

MR KNOWLES: Pardon me.

COMMISSIONER TRACEY: - - - it called up?

MR KNOWLES: Pardon me. It is WIT.0257.0001.0001. And it's the statement of Ms Ryan and Professor Sussman, dated 25 June 2019.

COMMISSIONER TRACEY: Yes. The joint statement of Professor Sussman and Ms Ryan, dated 25 June 2019, will be exhibit 6-30.

EXHIBIT #6-30 JOINT STATEMENT OF GEOFFREY MENDES SUSSMAN AND HAYLEY MAREE RYAN ON BEHALF OF WOUNDS AUSTRALIA DATED 25/06/2019 (WIT.0257.0001.0001)

MR KNOWLES: Professor Sussman, can you tell the Royal Commission your present employment positions?

ASSOC PROF SUSSMAN: Certainly. I am currently a clinical wound consultant at the Austin Hospital. That's one of the major multidisciplinary wound clinics in the country. I am an associate professor in the faculty of Medicine, Nursing and Health Sciences at Monash University and the professor of wound care in the Monash Institute of Clinical Education. I also spent some five years in the summer school at Saint Anne's College at Oxford University, teaching on wounds, and also some five years at Auckland University, in the faculty of Medicine, Nursing and Health Sciences, teaching wounds there as well.

I'm an executive member of the International Wound Infection Institute. I'm the current chairman of Wounds Australia and I'm the president of the Asia Pacific Association for Diabetic Limb Problems. I've been in the field for probably close to 40 years, have over 100 publications and currently writing my 29th and 30th book chapters in medical textbooks. So I have a very extensive experience – worked both as a clinician, a researcher and an educator.

MR KNOWLES: Thank you, Professor Sussman. And, Ms Ryan, could you tell the Royal Commission your own present position and what it entails?

MS RYAN: Yes. I've been in the aged care and acute sector for almost 17 years as a registered nurse. I'm currently the director of my own company, Wound Rescue. We provide all levels of education, quality reviews and referral system, including telehealth, across Australia and New Zealand. I also work for a large not-for-profit organisation and I'm also a board director of Wounds Australia.

MR KNOWLES: In respect of Wounds Australia, Professor Sussman, could you tell us what that body actually is?

ASSOC PROF SUSSMAN: Certainly. Wounds Australia was formed in 2016, from what was originally a federation of state bodies. And it was felt that to move forward we had to convert into an ASIC registered company. And so we, if you like, demutualised from what we originally, as a group of state bodies, into a formally registered company as Wounds Australia, with a board. And we are now working very strongly to improve the state of wound management all around the country. We also have very strong relationships with Europe and South-East Asia and areas within our region as well. The original body was formed in 1993, as a result of a meeting, where we formed a committee to see about a feasibility of forming a body in Australia. And it was formally formed in 1994 at a meeting in Melbourne and I was on that formation committee and was the inaugural vice president of the body and became its second president. And as I say, that all went on from there.

MR KNOWLES: And who, typically, are the members of Wounds Australia?

ASSOC PROF SUSSMAN: Our constituents will be a lot of nurses, but certainly doctors, geriatricians, surgeons, pharmacists, podiatrists, dietitians, occupational therapists. We have a very broad church of health professionals because in the wound area, so many people are actually involved and that's why the clinic that I'm senior consultant in is totally multidisciplinary because no wound is so minor focused that you can just deal with one particular profession. You have to look at – and it's something I've taught for years – treat the whole patient, not the hole in the patient because you have to look at the broad picture.

MR KNOWLES: Now, I'm going to be asking you questions about wound management. Perhaps my question is directed to one or other of you; if the other person does wish to answer part of the question or wishes to say something in addition to it, please do so. Ms Ryan, can you describe what the main kinds of wounds are that you come across in your work in the aged care system.

MS RYAN: Yes. Yes, so this also in the literature as well. We know that within an aged care environment it's generally pressure injuries, skin tears, ulcers being arterial ulcers, diabetic and venous ulcers. And I would also add in, as for our skin integrity, dry skin is quite a complicating effect.

MR KNOWLES: And just taking it back to basics, what are pressure injuries?

MS RYAN: Sure. Pressure injuries are directly from pressure and shear and friction as well. It can be impacted by age and also medical comorbidities. There are different stages of pressure injuries and the National Pressure Ulcer Advisory Panel put that classification together and it's well known, so stages 1, 2, 3 and 4 are suspected deep tissue injury and also unstageable pressure injuries. There is also some intrinsic and extrinsic factors that can contribute such as immobility, cognitive impairment, sensory concerns – I'm sure you've heard of all of these – poor nutrition, hydration, certain medications and chronic illness but I would also say moisture as well, and the prevalence in the older person is quite high.

MR KNOWLES: Can you explain how those causative factors might increase the risk of a pressure injury developing that you've just referred to, perhaps going through some of them and elaborating on the way in which they contribute potentially to pressure injuries.

MS RYAN: Sure. Well, I would actually talk more to a residential aged care home where we're seeing that, yes, people are staying at home a lot longer now and so when they are entering aged care they are at that higher level of care that's needed. With that there comes the immobility, the cognitive impairments, the medical comorbidities so they are already at that level where it's quite heightened for that risk of pressure injuries developing.

ASSOC PROF SUSSMAN: If I can add, part of the issue is as we age the physiology of our skin changes quite dramatically. We lose about 80 per cent of the thickness of the dermis. The epidermis separates very easily. That's why you get skin tears all of the time. Your circulation changes you, lose 40 per cent of your circulation and it becomes very fragile. The collagen starts to break down so the normal structure which gives you tensile strength in tissue disappears. So therefore tissue breaks down a lot more easily and whether it's direct pressure or whether it's friction – and, again, you can get that just from sliding in the bed or a chair, and that's also shearing where the skin will stick to the surface but the bones move and that's what causes the break.

And as was mentioned before, pressure injuries come from below up, not from the surface down although you will get some direct surface effect but the majority is where you've cut off the circulation from the arteries over a bone and then it becomes hypoxic, it loses oxygen therefore the tissue dies, and then you will get this build-up often with haematoma and the problem with haematoma is it's a focus for infection.

MR KNOWLES: Can I ask you, Ms Ryan, just on that topic in relation to pressure injuries and how they often develop below the surface and the full extent of them is not necessarily known; how does that cause difficulties in residential aged care settings for people who are caring for older people?

MS RYAN: Well, it means that they have to increase their workload because the only way to actually get rid of that pressure injury is to offload the pressure and if

they don't maintain that on a consistent approach 24 hours a day until it's resolved completely and even after that, it will deteriorate. So it will – it will increase their workload.

MR KNOWLES: And in terms of detecting that there is some evidence of a pressure injury on the surface of the skin, what would you say should occur as a result of that being detected?

MS RYAN: Well, it comes before that. It's about preventative measures, and it's well evidenced in the literature that if you put more time, effort and money into preventative measures such as implementing those pressure devices that we heard of earlier or repositioning more frequently or looking at the person and deciding are they at risk and doing those risk assessments. That far outweighs actually managing the wound, or even that redness which would be a stage 1 pressure injury, from the get-go and that's more important.

ASSOC PROF SUSSMAN: There is certainly clear evidence that if you know that a patient is at risk and there are risk scores which I provided copies of the three main ones, if you identify a patient at risk, you can institute treatments that will in fact prevent – and there was a very good study done at the Royal Melbourne Hospital in their intensive care by Professor Santamaria, where they showed by putting a simple device on heels and sacrum of intensively ill patients they actually prevented pressure injuries. So you can intervene early if you know that the person is at risk and with quite simple and relatively inexpensive treatments prevent the problem. I mean, the cost of managing a pressure injury – and there's a very good case that was published where it's just one stage 2 pressure injury costs $67,000 to heal. One. So the cost is huge.

So if you can do some simple things when you can identify the patient at risk, you can prevent them. And one thing that Hayley mentioned, and there's very good evidence now, is nutrition. It is very clear that malnourished patients are far more likely to get pressure injuries and if someone has a pressure injury, if you boost the protein intake in their diet and we use this – certainly, amino acids like L-arginine, you can actually speed up the rate of healing of pressure injuries. So there are techniques; you can using negative pressure therapy which helps to speed up the healing of pressure injuries. So very good techniques today that we can in fact help people.

MR KNOWLES: Yes. How quickly can pressure injuries develop?

ASSOC PROF SUSSMAN: Hours.

MS RYAN: Yes, I was going to say the same.

ASSOC PROF SUSSMAN: I have a case study that I teach my students of a woman who went to theatre for a coronary artery bypass graft which turned out to be a 12 hour operation and she came back with a pressure injury in the sacrum because she

was on a cold steel operating table and that was sufficient time to cause the pressure injury.

MS RYAN: And you have to remember the older person has different anatomical problems with their skin, Geoff has already said, so they will develop even quicker.

MR KNOWLES: And one of those preventive measures I think you mentioned earlier was preserving skin integrity through the application of moisturising creams.

ASSOC PROF SUSSMAN: It is very clear that you can prevent skin tears by using good quality emollients. The problem is that the standard emollient being used out there in residential care is the cheapest which is an aqueous cream. Now, aqueous cream was developed, not as a moisturiser, as a substitute. But unfortunately it's now used extensively as a moisturiser and the problem is the evidence has shown us that aqueous creams cause increased transepidermal water loss and dry the skin. And in fact, some of them are cytotoxic, they actually kill skin cells. So a simple quality moisturiser – and there's a beautiful study which I've given you from Professor Keryln Carville in Western Australia where she showed in a randomised control trial that twice a day application of a quality moisturiser compared to just a standard one that's being used, reduced the skin tears in 23 nursing homes and some 1400 patients by 50 per cent.

Now, I also received from her last night the cost saving and in that study they showed the cost saving by doing this twice a day, moisturising, was something like half a million dollars. So the huge monetary benefits to the organisation, to the government, by a simple program are quality moisturising can make such a difference.

MS RYAN: And what the study also showed was using a pH neutral emollient is best and applied twice a day, which isn't too unreasonable.

MR KNOWLES: So that goes to the next form of wound that is commonly seen, that is skin tears. What are the ways in which they might arise, Ms Ryan?

MS RYAN: Yes, generally from trauma. It's exactly what Geoff had said. With the changes to the anatomy of the skin, what we commonly see in a residential aged care home it is often from a fall, or manual handling or certain medications as well such as anti-coagulants which also thin the blood. And because they've got paper tissue thin skin, it breaks very easy. It's not uncommon for me to actually see a resident who has literally just brushed across their bedsheets and sustained a skin tear.

ASSOC PROF SUSSMAN: Anatomically, the epidermis is joined to the dermis by what are called rete pegs which are little structures that hold the two layers of skin together. As we age they disappear. So therefore the top layer of skin is so vulnerable to the slightest trauma, they will just separate.

MR KNOWLES: And, finally, in terms of the last type of wound that you described, Ms Ryan, that was leg ulcers; can you just indicate what they are and what factors contribute to their development.

MS RYAN: Sure. It's generally caused by venous hypertension but also arterial disease. In the elderly they have other diagnoses that can contribute, such as – if you think about oedema – swelling of the lower legs where somebody over the age of 65 may have heart failure and they develop this oedema. Now, if they have that in combination with an ulcer, for example, it can actually hinder that ulcer from healing until you get that oedema under control. The other problem is in a residential aged care home, in practice it's about classifying and diagnosing the correct type of ulcer because that can really hinder how you treat the ulcer. For example, if it is a venous ulcer we know that the best treatment and what will halve the life of that wound – this is what the literature tells us – is to use compression bandaging; that's the appropriate treatment. But unfortunately we rarely see compression bandaging within that residential aged care environment, and that's partly because of knowledge.

ASSOC PROF SUSSMAN: Yes, I think Hayley said a very important factor, one of the biggest problems we see out there is misdiagnosis. I saw it in a nursing home only last week where this elderly lady with a painful wound was misdiagnosed as having vasculitis and they treated her with a topical steroid and it just got worse. Now, when I saw the patient, I immediately said there is no indication of vasculitis. They have none of the classic things that you would need to have for it to be a vasculitis. So about 80 per cent of the wounds are clearly just venous, arterial or a mixture, because you get a mixture, but 20 per cent can be caused by auto-immune diseases, it can be caused by the blood itself, polycythaemias, cancer.

I mean, unfortunately, skin cancers are very, very prevalent and what starts off as a minor thing can then break down and become a serious wound and this is one of the problems with non-healing wounds. A normal venous ulcer can convert into a squamous cell carcinoma if it's left unhealed. So if a wound remains unhealed for years, then it will then become what is called a Marjolin's ulcer which is a squamous cell carcinoma growing in what was formerly just a simple venous ulcer. If treated correctly it would have been healed in a relatively short period but unfortunately these things are left and left and then they become .....

MS RYAN: The problem in practice, if I may just quickly add, is if they develop a cancer then the outcome is, well, am I going to get it treated. So the resident may say, well, I'm not going to treat it so there's no need to do further investigation. So we don't really understand the full diagnosis in order to treat.

MR KNOWLES: You've already mentioned some of the ways in which wounds of these kinds might be best prevented or managed in older people but can you tell the Royal Commission some others, Professor Sussman, some other means by which wounds of this kind are best managed or prevented.

ASSOC PROF SUSSMAN: It's very clear that you need to regularly assess patients and look for even small indications that there may be an issue or by doing a really good quality history of the patient if you know that there are comorbidities that can impact on, say, oxygenation of tissue, they have congestive airways disease, they have asthma, they have other diseases which will impact on the ability to let oxygen transport. If they have been smokers – and the problem with smokers, people tend to think about lung cancer or things like that but smoking will have a very significant effect on arterial blood supply. It will occlude the arterial blood supply so you need to be very cognisant of things like that so if you know that so if you know that someone has arterial disease you need to look at what sort of strategies you can implement to improve their circulation. And certainly with the venous ulcer, the big problem is older people won't wear compression; it's just too tight.

But, in fact, there are some strategies and a lovely randomised control done by Professor Carolina Weller showed if you get three layers of just simple tubular bandage which normally, by itself, would be useless, but when you put three layers, one on top of the other, it's additive. So you can get the 24 millimetres of compression for at least basic compression by putting a long one, a medium one and a short one on top of each other. And they're very inexpensive, and the person can put them on themselves and take them off themselves.

And they will wear them, and the beauty of the study that Carolina did was it showed that this method was more successful than the most expensive and complex compression garments. Why? People left them on. So there are simple things that you can do. Certainly, skin care. Certainly, one of the big problems with older people is they lose the sense of taste. So, therefore, I love food and you eat food because of the beautiful taste, but if you – everything tastes the same, it affects your willingness to eat. So we've got to encourage that they get a bit creative. For instance, I encouraged the residential aged care facilities I deal with to give their patients watermelon. You'll say why watermelon? Because watermelon is one of the best sources of amino acid L-arginine, and that helps protein deposition, helps immune system, helps vasodilatation.

MS RYAN: .....

ASSOC PROF SUSSMAN: So some simple little things like that you can do to improve their nutrition and keep them as healthy as you can. Exercise, getting them out of bed, getting them – I mean, I teach even my old patients on Zimmer frames to do exercise. Simple little standing on the Zimmer frame, doing ankle raises, little dorsiflex of the ankle. You'd be amazed that if you do 30 in a row, you'll get 60 to 80 millimetres of compression and get blood flowing.

MS RYAN: It's all about a holistic review of the person, and I'd even say in practice too, it's about the assessment, and one of the assessments we know is a good mnemonic is using the HEIDI assessment process which stands for history, examination, investigation, diagnosis and implementation, and what that does is it looks at the person from the whole person and not just the wound, and I think that's

where we often go wrong is just looking at the wound and how do we treat just the wound.

ASSOC PROF SUSSMAN: And the problem that then happens is when the wound doesn't get better, they blame the product. So they take that off and put a different product on, and when it doesn't get better, they say that was a terrible product, we'll put something different on, instead of saying it's not the product. It's you. You haven't, in fact, identified the actual cause of the wound. You don't treat the wound. You treat the cause, and then you can get some success because you're treating why the wound is there, and that's so critical.

MR KNOWLES: How does environment and equipment – what role do they play in prevention and management of wounds in the aged care facility environment?

ASSOC PROF SUSSMAN: Why don't you go first.

MS RYAN: Look, I'm happy to say what I often see in all the aged care homes I go to is that there's just not enough equipment. Quite often, they're taking alternating mattresses off people to give to somebody else because they need it, but then that other person is compromised. I believe that they mean well and they try their hardest, but it's getting those resources. Environments are quite tricky, and I would never suggest that a whole home be taken down and re-established, but it's more about walking around that facility and thinking of the perspective of the aged person who may have some vision impairment, for example. I mean, I've often walked down corridors that are quite glary. Now, for an aged care person, that's going to present a risk where they could possibly fall, which would then cause a wound, and the list goes on. So it's looking at the practical things that you can change within the home to make it more suitable.

ASSOC PROF SUSSMAN: But things like humidity, temperature, and just a simple thing of cleaning a wound, you should never put something cold on the wound. You should warm it up to body temperature because if you put something cold on a wound, it will cause vasoconstriction and slow the blood flow. So, therefore, you need to do simple things like that to minimise the potential risk, but I agree with Hayley. A lot of them don't have the equipment that they need or even a basic testing device. So if you are uncertain of someone's circulation, you could use a simple little machine called a Doppler, and you could very quickly listen and look at the circulation. But I don't think I've been to a residential aged facility that would have one.

MS RYAN: No.

ASSOC PROF SUSSMAN: And yet for roughly inexpensive amount of money, you could have one of these simple devices that you could look at potentially at risk patients and very quickly determine there is a risk. If you know that's a problem, refer them on and get some specialist help, but you do need to have some basic things like that, that you can clearly identify potential risks.

MS RYAN: There's one other quick element as well is that the person that is coming into the home, it's knowing that person before they arrive. So if they're going to come into the home forever from a hospital, it's having that clear communication with the hospital and the home as to what their needs are, so that those resources can be established before they actually come into the home.

COMMISSIONER BRIGGS: Can I ask why don't you think homes have these kind of arrangements?

MS RYAN: I would have to say it's heavily budget driven. So there's budget issues. There's possibly a lack of knowledge of when should I implement? Quite often, I will go and see a patient in a home, and they've got a stage 3 pressure injury, for example, and the first thing I say is, well, where's the alternating mattress? They didn't think of that. So there's a knowledge gap and there's also a resource gap with budgets.

COMMISSIONER BRIGGS: And ..... information - - -

ASSOC PROF SUSSMAN: I think there's enormous pressure from the owners of facilities to try and control costs. So they tend to say that's $2 and that's $10. Will the $2 do what the $10 does? Oh, probably. Well, we'll go for the $2 one. But what they don't do is, instead of looking at the cost of, say, a product, they should look at the cost of managing the patient. I've given an example in the submission where we did a study comparing gauze and saline. That's the cheapest possible thing you can put on a wound. Costs cents. That was being four times a day. We compared that with a similar group of patients getting an $8 dressing twice a week, and at the week, the gauze and saline group cost $240, the expensive dressing one was $20. So, again, look at the cost of total management, not the cost of product A as against product B.

MS RYAN: If I can just answer the Commissioner one more time, it's also about the person because it's not uncommon for me also to hear from the resident who says, "I just don't want to sleep on that mattress it's uncomfortable, and I prefer my own." So there's an element of that as well, and on the flip side, I've also been involved with family members who just say, "No, this is what mum's going to have because we prefer that." So it's knowledge gap for them as well, so making sure we educate those clientele.

MR KNOWLES: Can you say, Professor Sussman, what guidelines exist in Australia for wound prevention and management?

ASSOC PROF SUSSMAN: Yes. Wounds Australia is proud to be the producer of a number of these documents. We have standards for wound management that Wounds Australia has produced. Wounds Australia has been a world leader in developing guidelines. For instance, the current venous ulcer guidelines which were published in 2012, we are about to redo the second version of those. The international pressure ulcer guidelines, which are now Pan Pacific, were done in

Australia and are accepted right throughout the region, and we will release the new version of those in November this year.

So Wounds Australia sees this as very important to help people understand by providing evidence based guidelines that they can then follow, and we provide them in several forms. You have the full form, then you have a shortened version and some simple flow charts, even, so that people can recognise by just looking at the flow charts and the photos, that's – oh, that's the sort of pressure injury that our particular resident has. So we think it is very important as a leading organisation to actually provide guidelines that are evidence based and quality that people can download free of charge from the website and get them.

The International Wound Infection Institute, of which I'm a board member, produce guidelines on wound infection, and that's – to me, one of the big problems we face out there is the gross overuse of antibiotic in chronic wounds. There are very few chronic wounds that need to have antibiotics, ands, yet, the standard thing is you do a swab, every swab of wound will grow bacteria, therefore, you give them antibiotics. And we did a study where we looked at that comparison, and we found that 70 per cent of the patients referred to us had had one, two, three, four course of antibiotics, and, yet, when we tested them and evaluated them, less than five per cent actually needed antibiotics. They're grossly overused and it's one of the reasons we have a problem worldwide with multi-resistant bacteria because of excessive and overuse in wounds of antibiotics.

MR KNOWLES: Just following up on that question about the guidelines that are in Australia and promulgated by Wounds Australia, Ms Ryan, do you see them used widely in residential aged care facilities? And if not, why not?

MS RYAN: Unfortunately, generally, they're not used. I think why not because there's limited knowledge of their existence and limited knowledge of where to actually access them from, and I'd also say that there are some homes that actually do it quite well, and I know this because when I'm looking at their policies and procedures, I can see them well referenced or I can see the flowcharts hanging in the clinical areas. But, on average, generally not.

MR KNOWLES: Yes. Can I turn to a different topic now. What do you say, Ms Ryan, are the consequences of substandard wound prevention care and management both for the individual and more broadly?

MS RYAN: Okay. So substandard care would provide delayed wound healing, wounds that deteriorated. In the extreme circumstances, possibly amputation, even death, and for the person, increase in pain, possibly increase in symptoms, such as exudate fluid, odour. If they present with odour, then the person may become isolated to their room because they don't want to come out. So there's a social aspect as well. For the home, there's a cost to the home which will be increased, but also to the economy as well. More importantly, it's about quality of life. What is

that doing to the person who now may suffer from depression or increased pain, or, like I said, the effects of socialisation?

And as we said earlier, it starts with the correct diagnoses. It's about knowledge. It's about having the capability to apply that knowledge and, more importantly, making it sustainable. Using appropriate dressings, we know, is an absolute must, and it's something we are pushing for at Wounds Australia. And it's about appropriate skin products, and not using things like antiseptics and topical antibiotics, and I have to say the biggest thing is it's about early intervention of referrals to external providers, whether that be a GP or a specialist in wound management. And I give the example of my company are often called out when it's too late, when the wound is quite advanced, or on the flip side, while there's an audit that is about to occur within the home, so they suddenly want us to review every single person. That, to me, isn't about quality care. It's more about let's put out that fire before it, you know, gets any worse.

MR KNOWLES: It sounds reactive - - -

ASSOC PROF SUSSMAN: If I could - - -

MR KNOWLES: - - - rather than proactive.

MS RYAN: Reactive, rather than proactive.

ASSOC PROF SUSSMAN: Yes. If I could extent this - - -

MR KNOWLES: Yes, indeed. Please.

ASSOC PROF SUSSMAN: - - - inappropriate wound management by a simple example. We've heard earlier that diabetes is a major issue in aged care, and diabetics will have three types of neuropathies. That's a change in tissue. They will have a sensory neuropathy, have a lack of feeling. If you can't feel, then you can damage yourself, be unaware, and what starts off as a minor little skin break will very rapidly deteriorate into a wound, and the problem with the diabetic, they have a five-time risk of infection compared to the non-diabetic. So infection gets in, the infection very rapidly gets into the bone.

You have osteomyelitis, and the main treatment of that is amputation, and the reality of this is you start with one two, then it's three toes, then it's half a foot, then it's a foot, then it's a below knee amputation. And the reality of that is anyone who has a major amputation for diabetes, within two years, will have the upper limb amputated and be dead within eight years. And the worrying thing within Australia is the level of amputations for diabetes has gone up by 30 per cent in the last 10 years. So someone loses a limb in Australia every three hours as a result of an amputation for diabetes. So it is an enormous problem.

MS RYAN: And if you consider you're an aged person as well, they may not fit the requirement for surgery. It may be too risky.

ASSOC PROF SUSSMAN: Yes.

MS RYAN: So then will they then, in fact, have to die with a possible wound that's not going to heal that can be quite painful?

ASSOC PROF SUSSMAN: Yes. I had an instance of a residential facility – I was asked to look at a patient with a leg ulcer, and this frail tiny lady in terrible pain, when they undid the bandage, certainly, she had a small leg ulcer, but her foot was black. She had gangrene. They weren't worried about the gangrene, just an ulcer. I said this is dreadful.

MR KNOWLES: You've mentioned proper selection of wound care products such as dressings and what should be applied topically is critical.

ASSOC PROF SUSSMAN: Absolutely.

MR KNOWLES: You've made it very clear.

MS RYAN: Mmm.

MR KNOWLES: Is the selection of those types of products, in your experience, Ms Ryan, restricted in some facilities, and if so, why is that so?

MS RYAN: Yes, it can be restricted in some facilities. It – there's a couple of reasons. One, it could be a recommendation from the hospital. As Geoff suggested before, the use of moistened gauze, I often see, coming from a hospital onto a discharge paper and, therefore, the aged care home feels that they have to follow that, and that's problematic. It's generally restricted because of their stock levels that they have on hand. Unfortunately, that's very budget driven as well. The other thing that I often see is that the aged care home for cost optimisation, they'll often focus on one supplier.

Unfortunately, they will often focus on one supplier. Unfortunately, suppliers cannot provide all of the products needed to treat all the wounds that we see, and so when they have that restriction, quite often, you'll go – I always take my own kit because I know that, often, I won't have the products there to actually use for what the wound needs, and that's based off the characteristics of the wound. We also need that we're avoiding, for this aged group, those adhesive dressings. Those dressings that are going to stick to the wound and potentially pull off the skin, should they be removed inappropriately.

MR KNOWLES: We heard earlier in relation to the evidence given by the panel of experts about incontinence that, sometimes, suppliers of incontinence products provide training to aged care staff. Is there an analogous scenario that exists, in your

experience, Ms Ryan, in this context of dressings and other products in the wounds context?

MS RYAN: I would have to say that there's a large reliance on suppliers to provide training. I would suggest that that's probably because they are free of charge. The problem with that is you can then have a home that becomes quite adamant that they're the products and the only product that they need to use. You know, the company has done their job. They are sales people, but it doesn't help for actually treating the wounds that we need to.

MR KNOWLES: Professor Sussman, from your understanding of – you're very involved in the training of people in terms of wounds. What training, more broadly, for staff is available and what should be available?

ASSOC PROF SUSSMAN: I will start at what should be available. One of the greatest problems we face is that very few tertiary institutions that train health professionals who will be involved with wounds get any training at all, or if they get training, it is so minimal, it doesn't matter. Within a four-year nursing degree, and Hayley could clarify this, they might get one or two lectures. Most medical schools provide none with the exception of Monash University. We teach – I teach in third year, fourth year and fifth year. They get lectures. They get hands-on tutorials, and in fifth year, they get an exam in wound care with – if they don't pass, they won't graduate.

Now, this is rare in Australia, and this is one of the big problems we face that there is so little training at the tertiary level in wound care that the level of ignorance out there is breathtaking, and you wonder why treatments are done so badly if people don't understand even the basics. How can you get adequate management? And we need to do a lot more. There are wonderful courses available, certainly, Monash University and I helped establish it – has – is the only university in the southern hemisphere has postgraduate qualifications. You can do a graduate certificate, a graduate diploma or a Masters in wound care at Monash, and we have students from all over the world doing our course because there are not many.

But there are some very good courses. You can do a simple short two-day course that's available. There are many, many providers that are not company, that will provide some good basic education for residential aged care, and I think we've got to almost make it mandatory that residential aged care have to have a minimum standard of training in the wound area for their staff, be it registered nurses, be it state-enrolled nurses, be it personal assistants, that they all need to have basic knowledge so they don't actually make things worse by doing it wrongly or not diagnosing it correctly. So there is availability out there,

I think there's got to be a lot more, and I think one of the recommendations that should come out of the Commission is that the Committee of Deans have got to look at this as a core element of training for doctors, for nurses, for pharmacists, for podiatrists, for all of these groups of professionals who are working with wounds to

have, at least, built into their curriculum, a basic training in wound care to understand the biology, the pathophysiology and the basic management. That's something I think should be absolute as a minimum standard, and then, of course, you then offer the higher trainings and qualifications. One of the things that Wounds Australia is about to launch in October this year is we have developed credentially, so that for someone to be called a wound specialists, they have to be credentialed and go through a very rigorous assessment of their skill and knowledge and training for them to be actually called a wound care specialist, and we are about to release that in October this year. Now, that to me is very important that we have people out there who not only claim to be wound specialists but actually have the right training and can be validated by being credentialed as being appropriate wound specialists. And the more we can do that the better the overall standard of practice will happen.

MS RYAN: Can I quickly add, too, that nurses are screaming out for this. It's not uncommon for me to hear a nurse say, "I'm so glad you are here because I really just don't know what to do". They want to give the best treatment. They really care and they're very compassionate. They just need the resources and the knowledge to do it.

MR KNOWLES: And that touches upon another aspect of your evidence; that is the multidisciplinary nature of the approach that you say needs to be occur. Can you elaborate on that in this context, please?

ASSOC PROF SUSSMAN: Certainly. The big issue with any patient is it's not just the wound. They often have dementia. They often have nutritional problems. They often have comorbidities. There are so many facets and that's why, as I say, in my own clinic we have a total multidisciplinary group of specialists who will see the same patient on the same admission and we then look at the whole picture. And it's only by looking at the whole picture often we will then say, look, there's a psychological issue, we should get our psychologist involved. Virtually 90 per cent see our dietitian because there are nutritional issues.

So many have feet problem, they'll see our podiatrist and be dealt with. Because no wound patient has just one simple problem because there are so many underlying intrinsic or extrinsic factors. The medication they're on, the things they're using in their diet, they're smoking, there are so many things that can impact on the ability to heal and so by having a broader church of people looking at the patient, it means that you can very quickly assess the problem and get to the nub of what you need to do to intervene. So it is very much multidisciplinary.

MR KNOWLES: And that multidisciplinary approach, to the extent that it should be and is employed, would presumably make demands of people in terms of their communication and documentation.

ASSOC PROF SUSSMAN: Absolutely critical. I go into some places and their histories are so bleak, there's barely three words, patients wound is good. Or treated, redressed the wound today. No other information whatsoever. So it's critical and

this proper communication, if you have a concern, speak to someone. Don't just keep it bottled up inside. You have to have good lines of communication within the organisation and I'm sure Hayley can enlarge on that.

MS RYAN: Yes, I would add by saying that access is a problem for residential aged care because quite often they can't actually leave the home. So it's having the knowledge for that home knowing there are external services that can come in and provide, and there's not enough of them, I will say. So we've got to work on that particularly from a Wounds Australia point of view. But giving that access to come to the home and give all that requirement and that extra advanced technique in wound management is needed.

MR KNOWLES: How do you, in your practice, Ms Ryan, engage in that access where the relevant aged care facility is in a remote or regional area?

MS RYAN: Yes, good question. Remote and regional areas are extremely difficult. We are seeing them definitely at the advanced wound stage where you are thinking am I going to be able to save this limb. I'm finding telehealth very beneficial and whilst the technology isn't great – and that's an area the government should consider looking into – it's one way around it to provide immediate assistance to that area, and I'm finding it very beneficial for the person.

ASSOC PROF SUSSMAN: There are leading areas in most capital cities that could set up a telehealth advisory service where if you have a remote area, they could Skype in or have some system like that where you could actually see the patient, get the full history and then without bringing them to a major city, start the treatment from being able to see them, being able to get some idea from the clinician all of the other aspects of the patient's history, and you could then have a much more streamlined system and in the long run it would save a lot of money by having to fly people down to major centres to get treatment, if we could set up a system of having some major advisory centres that could work with regional areas.

MS RYAN: My company does that quite regularly. We do it via telehealth but one of the issues is access to the products as well, resources. We will quite often ship them over to them but there is a distribution issue as well to the regional and remote areas so we have to factor in how do they get these supplies if we are recommending them. That's another factor.

MR KNOWLES: Can I just ask each of you whether or not you think that aged care recipients are receiving substandard wound care on your observations and if so, why you think that is so?

ASSOC PROF SUSSMAN: I'll let you go first.

MS RYAN: This is quite complex. I would say that it's not that the nursing home or the individual wants to provide substandard care. I would believe that it's the lack of knowledge, number one. It's the availability of resources to provide that

treatment. It's the budget restraints that the home has. You know, I've heard nurses – I've seen nurses in tears that say to me I'm just so upset today because I just didn't have time to give the optimal care that I needed to. That's heartbreaking because I know that they want to give the best but they just haven't had the time.

Is the answer more staff; well, I think that's come very clearly through all of the hearings that you've heard that more staff but the question I would have is where do you get them from, and are they trained and do they have that knowledge because that's another gap is that, unfortunately, the aged care industry isn't just – it's not considered a specialty. And that would be a recommendation that I would have is let's start looking at aged care as a speciality, start teaching that as an extra specialty, core subjects at that university level so that we can make it attractive for people to want to come to. It is not uncommon for me to hear, that "I'm coming up to retirement, I will go into aged care and start working". And then they realise how difficult it is, and retirement comes quicker.

ASSOC PROF SUSSMAN: If I can answer a question.

MR KNOWLES: Yes.

ASSOC PROF SUSSMAN: I have seen such a variation from some wonderful, excellent residential aged facilities that have the top best quality care, high-level trained nurses and I've seen others at the very opposite. In fact, the study, which I've given you a copy of, which we did as a randomised control trial in nursing homes where we clearly showed a dramatic difference, and one of the interesting things in the control group, we found that there was quite some variation in the information they provided and that's why we, in the study we had two control groups. We had the intervention control group where our assessors went in every week and looked exactly at what they were doing and annotated it.

Then we had a second control group that only went in on the first and last days of the study. That avoids what's called the Hawthorne effect. Because the problem is if someone is looking at what you are do you say "Oh my god, I'm being looked at. I better be a bit more careful." And sometimes you get a false positive. And it was very clear that there's a vast difference. And as I say, there's some wonderful residential aged facilities that I've seen, and there's some dreadful ones as well. So there's no consistency; it's either very good, moderate or pretty bad.

MS RYAN: One of the things that actually plays on that is because it is such a highly regulated industry the focus is what other assessment do I need to complete in order to show that I'm doing this. Now, documentation is extremely important but when you have five documents for the one assessment it doesn't make sense and what you often will see is the nurse sitting down and spending more time on administrative tasks than actually doing the work.

ASSOC PROF SUSSMAN: If I just read you the conclusion of the study it says:

Standardised treatment provided by multidisciplinary wound care teams save costs and improve chronic wound healing in nursing homes. The main source of the savings was the cost of the nursing time and applying traditional dressings and the cost of their disposal.

MR KNOWLES: Professor Sussman, do you see there being any particular challenges in the Northern Territory or regional and remote settings here in the Northern Territory?

ASSOC PROF SUSSMAN: Yes, I do. One of the things that worries me particularly, and wearing my diabetics hat, the level of diabetics within the Indigenous and Torres Strait Islander community is exceptionally high when you compare it to the non-Indigenous community in Australia. When you look at figures like in 2014/15 30 per cent of Aboriginal and Torres Strait Islander children aged 4 to 14 reported to have eye or eye problems. So that is the nephropathy – the retinopathy from diabetes. The number of Aboriginal and Torres Strait Islander women that have gestational diabetes is 10 times that of the non-Aboriginal and Torres Strait Islander community.

The number of deaths as a result of diabetes within the Indigenous community; the death rates in diabetes increased further in major cities from 51 in 100,000 to almost 92 in 100,000 in remote areas and the deaths for people with diabetes and coronary heart disease and stroke differed greatly from major cities of 309 per 100,000 to 521 in regional and remote areas. So there's a real major issue with things like diabetes within the Indigenous community and because of the remoteness and the difficulty in getting treatments and the difficulty with the diabetes is they end up with kidney failure, they end up with loss of feeling, they end up with loss of circulation.

And I well recall doing a ward round in Alice Springs and in a morning I would have seen probably 25 to 30 relatively young Indigenous and Torres Strait Islander men with one or bilateral amputations, and it is a shocking reflection on us as a community that this still exists in Australia, and I would like to see a heck of a lot more in this particular area than we have done in the past.

MS RYAN: And, unfortunately, there's no statistics – there's not much in the way of statistics for wounds in those remote and rural areas, and it's simply because it hasn't been researched. And that's something we would definitely be interested in pursuing with the government, hopefully.

ASSOC PROF SUSSMAN: That has always been one of Wounds Australia's major concerns is that so many people compete for research funding from NHMRC and ARC and it's very hard to get funding to do wounds because it's not cancer, it's not diabetes, it's not more important things. It's only a wound. Well, in Australia on any given day, we have over 400,000 people with non-healed chronic wounds which is costing us over $3 billion annually, and that's the reality.

MR KNOWLES: Can I ask each of you for your final reflections on how wound care, prevention and management can be improved in aged care.

MS RYAN: I would start by saying make aged care a specialty. That needs to occur. Certainly looking at research aligning with Wounds Australia so that we can certainly support that. Education, as we have spoken about throughout universities for all levels, so doctors, nurses, allied health teams. The access to regional and remote areas by telehealth so looking at adequate equipment to do that. Standard protocols of products and how we can streamline the types of products that should be considered within an aged care environment, and we do need to consider funding of some of the wound products under the PBS.

ASSOC PROF SUSSMAN: Yes, if I can, to just add to that. To me, the number one thing is education. We have to have better trained people out there. I would love to see Wounds Australia work with the government to develop a standard simple protocol for managing wounds in aged care and in the study that's what we did and it worked extremely well. To develop a simple product list that is appropriate for residential aged care, to ensure that there is adequate provision of the sort of things we need in the way of moisturisers and simple preventative devices so that we don't even get to the situation of having wounds, that we prevent them by instituting relatively inexpensive practices so that we have decent nourishment. We have simple skin treatment.

We have simple devices where if we know someone is at risk we put them on to or in a particular product which will then prevent the thing happening and it's this awareness of risk and decent assessment. So we have to develop that. And it involves getting the right people involved because it is multidisciplinary. You know, having a pharmacist go into a nursing home to do drug reviews is wonderful. But having a trained wounds person also going in to do reviews on wound management should be funded by the government. So just as someone can go in and look at their drug use, someone should be able to go in and look at their wound management as a service, not just like Hayley's service is to go in and provide specific treatment but to go in and just assess the processes and assess what is being done to ensure that there is a basic level of knowledge and practice that will help to (a) prevent and then rapidly treat so that you don't get to the situation of the stage 4 massive pressure injuries. I've seen them the size of a water melon. That bad. And it shouldn't happen.

MR KNOWLES: Thank you, Professor Sussman. Thank you, Ms Ryan. I have no further questions, Commissioners.

COMMISSIONER TRACEY: We thank you both very much for travelling so far to come and explain the intricacies of wound management to us. We've, as you can imagine, along the way seen some dreadful wounds pictorially and left us wondering how it could possibly happen in this modern age. You have explained that there are ways of stopping that happening, and we will certainly be giving full account to your evidence about how best to stop this happening. It has got to stop. Thank you.

ASSOC PROF SUSSMAN: We thank the Commission for the opportunity to be able to enlighten and enhance the exposure of wounds because we think it gets put under the table. We call it the elephant in the room. So we do thank you so much for giving us the opportunity.

MS RYAN: And we are clearly passionate.

<THE WITNESSES WITHDREW [5.21 pm]

COMMISSIONER TRACEY: Subject to advice from behind you, is 9.30 or 10 appropriate tomorrow?

MR KNOWLES: 10 is the advice that I believe that I've been given, yes.

COMMISSIONER TRACEY: Very good. The Commission will adjourn until 10 o'clock tomorrow morning.

MATTER ADJOURNED at 5.22 pm UNTIL FRIDAY, 12 JULY 2019

Index of Witness Events

Index of Exhibits and MFIs

EXHIBIT #6-23 SECOND WITNESS STATEMENT OF JOHANNA IRENE MARY WESTBROOK DATED 11/07/2019 (WIT.0196.0002.0001) AND ITS IDENTIFIED ANNEXURES	P-3233
EXHIBIT #6-24 AMENDED WITNESS STATEMENT OF MICHAEL JOHN MURRAY DATED 01/07/2019 (WIT.0273.0001.0001)	P-3271
EXHIBIT #6-25 FIRST WITNESS STATEMENT OF JOAN OSTASZKIEWICZ DATED 05/06/2019 (WIT.0222.0001.0001)	P-3272
EXHIBIT #6-26 SECOND WITNESS STATEMENT OF JOAN OSTASZKIEWICZ DATED 25/06/2019 (WIT.0222.0002.0001)	P-3273
EXHIBIT #6-27 CORRIGENDUM PREPARED BY JOAN OSTASZKIEWICZ DATED 11/07/2019 (WIT.0222.0003.0001)	P-3273
EXHIBIT #6-28 WITNESS STATEMENT OF CATHERINE ANNE SHARP DATED 03/07/2019 (WIT.0240.0001.0001) AND ITS IDENTIFIED ANNEXURES	P-3299
EXHIBIT #6-29 WITNESS STATEMENT OF SALLY JEANNE HOPKINS DATED 24/06/2019 (WIT.0200.0001.0001)	P-3306
EXHIBIT #6-30 JOINT STATEMENT OF GEOFFREY MENDES SUSSMAN AND HAYLEY MAREE RYAN ON BEHALF OF WOUNDS AUSTRALIA DATED 25/06/2019 (WIT.0257.0001.0001)	P-3327