LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON SOCIAL POLICY

(Reference: Inquiry into endometriosis and other pelvic pain conditions)

Members:

MR T EMERSON (Chair)
MS C BARRY (Deputy Chair)
MISS L NUTTALL
MS C TOUGH

PROOF TRANSCRIPT OF EVIDENCE

CANBERRA

THURSDAY, 14 MAY 2026

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Secretary to the committee:
Ms K Langham (Ph: 620 75498)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

WITNESSES

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Amended 20 May 2013

The committee met at 9.03 am

FISHER, MRS KATE, Manager, Australian Endometriosis Coalition
McGOWAN, MISS JESSICA, Peer Support Group Lead, QENDO Canberra
TAYLOR, MS JESSICA, Chief Executive Officer, QENDO

THE CHAIR: Good morning, and welcome to the public hearings of the Standing Committee on Social Policy for its inquiry into endometriosis and other pelvic pain conditions. The committee will today hear from QENDO, Endometriosis Coalition, Dr Warner, Sexual Health and Family Planning ACT, Living with Disabilities ACT, Women's Health Matters, the Australian Medical Association (ACT), Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Endometriosis Australia, and the Minister for Health.

The committee wishes to acknowledge the traditional custodians of the lands we are meeting on, the Ngunnawal people. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of the city and this region. We would also like to acknowledge and welcome any other Aboriginal and Torres Strait Islander people who may be attending today's event.

This hearing is a legal proceeding of the Assembly and has the same standing as proceedings of the Assembly itself. Therefore, today's evidence attracts parliamentary privilege. The giving of false or misleading evidence is a serious matter and may be regarded as contempt of the Assembly.

The hearing is being recorded and transcribed by Hansard and will be published. The proceedings are also being broadcast and webstreamed live. When taking a question on notice, it will be useful if witnesses use the words, "I will take that question on notice," which will help the committee and witnesses to confirm questions taken on notice from the transcript.

We welcome representatives of QENDO Canberra and the Endometriosis Coalition. Thanks for being here, and thanks for your submission. Please note that, as witnesses, you are protected by parliamentary privilege and bound by its obligations. You must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly.

Before we go to questions, would anyone like to make a brief opening statement, perhaps focusing on any matters that are not covered in your submissions?

Ms Taylor: I will begin. Thank you so much to you all for your time, and also the attention on this matter. It is long overdue. Endometriosis is not a new condition, but it is a newly spoken about condition.

My name is Jess, and we also have another Jess here; apologies for that confusion. QENDO is a national organisation. The "Q" in QENDO stands for "quality of life" of the people living with endometriosis and pelvic pain. Our role is that of a care navigation support system. We call it the ecosystem because we know that people living with these conditions will present very early on, but it is lifelong, so we need to support them throughout that whole lifelong approach.

We support not only endometriosis but adenomyosis, PMOS—it is a new change from PCOS—pelvic pain, and those lifelong chronic conditions. We do this through care navigation with our nursing support, telehealth care clinics through an MDT support program, mental programs, and we collaborate with governments—state, territory based and federally.

With our branches across Australia, we have a local one here in the ACT which has been here for quite some time, championing the voices of the local ACT members, and that formed the basis of this inquiry. Nationally, we support 99,000 people a year.

There is a significant, urgent need for care that is in collaboration with tertiary primary care, but we know that these individuals have such a fast-medicine approach to those services, and it is when they come into community that we see their real quality of life improved.

Miss McGowan: I have been a part of this group since its formation 14 years ago. From the very beginning, we have seen the gaps. There are a number of issues within the ACT that were identified 14 years ago. Many of those still remain today, unfortunately. Over the last six years, our membership has grown by 320 per cent. While awareness is increasing—and that is wonderful—the availability and accessibility of services have not kept pace.

Almost 27,000 people in the ACT reportedly have endo, based on ABS data. Many join our group at an incredibly vulnerable time. They are searching for a diagnosis; others have recently been diagnosed. They are left feeling overwhelmed, isolated and unsure where to turn next. Our role is to guide, support and educate them, while helping them to advocate for themselves within a system that too often feels fragmented, difficult to navigate and, at times, actively working against them.

As the nation’s capital, the ACT should be leading the way in the treatment and care of people living with endometriosis and other pelvic pain conditions. We have a unique opportunity to set a national benchmark for accessible, coordinated and trauma-informed care, and we are hopeful that this inquiry can mark the beginning of meaningful and lasting reform.

Ms Taylor: Awareness for awareness’s sake is done. We know this term now, but we need action, so that is what we have been calling for, and what the members are calling for. You have the workforce here in the ACT. You have some of the best models of care that other states and territories are now following. They are just not resourced; they are not funded appropriately, or at all.

We are not making up new ideas; we are supporting the solutions that started here, but have fallen away because of lack of attention, no funding, and where we cannot keep that workforce. If we do not have a well workforce, we will not have well women.

THE CHAIR: Mrs Fisher, do you want to add anything?

Mrs Fisher: Sure. I am representing the Australian Endometriosis Coalition. Just in case anyone does not know who that is or what we do, we are Australia’s peak body for endometriosis and pelvic pain. We have over 150 member organisations from all states and territories across Australia, so we have that true national representation. Our members make up, and we represent, clinicians, researchers, policymakers, carers—which is a new big one that we are really representing—and patient communities.

In 2005, we delivered the largest consultation ever undertaken on endometriosis and pelvic pain nationally. We had individual consultations and reports from every state and territory in Australia. The ACT roundtable was held in March 2025 at the QENDO Canberra Pelvic Pain Expo, and the outcomes from that inform our submission and this report, so it really has come from the voices of people within the ACT.

I would note briefly—and I am happy to take more questions on this—the difference between the national priorities that came out in the national report from those roundtables and the ACT one. The top national priorities were multidisciplinary care, cost of living with endometriosis, and education. For the ACT, the cost of living with endometriosis was also the top priority, multidisciplinary care, and funding came through as a really strong priority, primarily in terms of educating and upskilling health professionals in this area. I think there is a desire; there just is not the funding to make it happen, and appropriate education for those health professionals. I am happy to take further questions on that, if that would be useful.

THE CHAIR: Thank you. That is a great lead-in to a question I wanted to ask, about barriers to diagnosis, and perhaps a need—I think this is identified in QENDO's submission—to better train ultrasound technicians on ultrasounds to diagnose endometriosis. What is preventing this training from happening, and what kind of government intervention or support would help to make this feasible?

Ms Taylor: We saw the change in November, the new Medicare item number coming in, to cover the ultrasounds. This is not a general pelvic ultrasound; this is a specialised pelvic health ultrasound. I will say a couple of things. There is a requirement to have new technology, so five years ago, when we used to say endometriosis cannot be detected on ultrasound, we did not have the right training, skills or technology.

This is not just your general ultrasound procedure from an ultrasound space down the road. With respect to the barriers, equipment needs to be bought. It needs to be trained within the hospital, within the tertiary space, and that requires time off the floor for those sonographers to go and do that training, as well as scholarships to enable that, and that ongoing support and care.

As well as that, there is the education and the understanding that it can be detected. It will be ruled in, but it cannot be ruled out—endometriosis, if seen on an ultrasound, done and performed by a qualified, appropriate sonographer with the right technology and the right reporter. You would not have someone who is trained in breast cancer review and assess a cardiac ultrasound, so they need to be done.

They are there nationally, but in Canberra we do not have those skills readily available. There are a couple of them, but we have seen people travel to Sydney, New South Wales, to get that care.

Miss McGowan: We only have two of these machines in the ACT, and it is either a very long wait to get into one of them or very expensive for the other. That is why a lot of people go interstate.

Mrs Fisher: I very much echo that, from the coalition. I think this comes under the great call from the people of the ACT that they want to be able to access more timely, cheaper and advanced care here, so that they do not have to travel interstate. The beauty of making sure that we have appropriate imaging and sonography is that they are able to plan surgeries, and quite often avoid surgeries.

That will save the ACT government money. It will save the individual potential extra trauma. An example could be that, if there is bowel involvement, knowing beforehand that you need to have a colorectal surgeon on hand and making sure you have that set up, rather than going in for your initial surgery, being told, "This is too complicated," coming back out and going through that again.

That is additional cost to the ACT government, but it is also additional impact on the person who is having that surgery. Making sure that is available is good for the individual, but it is also good for the government.

Ms Taylor: Through ultrasound, we can now diagnose if there is endometriosis seen, in collaboration with a good clinical background, and that will help this diagnostic laparoscopy approach. As Kate said, when we do go for surgery, it is planned with the appropriate skilled gynaecologist, and it is planned in the space of what other team we need.

That will then help to reduce, as Kate said, getting in there, opening up a patient on the table and seeing the impact on other organs. Endometriosis is not just confined to the pelvis; it can be found in every organ of the body, as of 2022—that research. This is not just a pelvic health issue; it is a systemic, whole-body issue, but we are still treating this as a gynaecological issue.

The scanning starts to map out that body, map out what we are seeing that we cannot see with our eye because it is invisible inside. It gives us that better planning, so it is a better use of time of theatre, which is so precious, time of our surgeons, again, and the waitlist.

MS BARRY: Thank you very much for attending today. In your opening statement, you mentioned that we have the best model of care. Can you expand on that and why that is not translating to better care for patients?

Ms Taylor: The Canberra Endometriosis Centre was established as a nurse model. It was established as a nurse-led model in collaboration with a multidisciplinary team—pelvic health physio, and those other members. That was established by Melissa Parker, and it had been running for several years. It was very difficult to have funding at the hospital, and for it to be continued. Often, those physios or nurses were funded under other areas within the hospital, like maternity, and were utilising their additional time to build those needs.

What was great with that is that there was patient education, so they brought the patients in, in a group setting. They had broad conversations. When we are looking at these conditions, it cannot just be the lesions in the body, it cannot just be the medical space; we need to consider this as a biopsychosocial approach, “biopsychosocial” meaning that, yes, we have medical, but then we have community, we have peers—similar to mental health.

They are modelled, so they brought the people in. They had group settings, discussions, they have met other people; that reduced the isolation that comes along with this condition. They provided education, which gives them tools on how to manage outside the tertiary and primary healthcare settings. They connected them with others, so people started to build their own networks, like the QENDO Canberra network.

They then sought a nurse, so it was led by nursing. They are excellent at collaborating and communicating with those other disciplines—with a pelvic health physio, to assess the bowel, the bladder, how people are holding their pelvis, or their sexual function. Again, it is not only about the lesions in the body; it is about all the other pathophysiology that this condition comes with, as well as psychology. Then, if surgery is needed, they have that pathway.

That is a lot of pre-hab and rehab, as well as surgical. That was established by Melissa Parker and her team here many years ago. The Gold Coast Endometriosis Centre was established, based on that model, so that is one example. That is now in practice. The QENDO care model, with a multidisciplinary telehealth clinic, and lessons from the Canberra model were established—

MS BARRY: Sorry, which one?

Ms Taylor: The QENDO care model. It is a multidisciplinary nurse-led model. There is the Epworth centre, down in Victoria. The Epworth Julia Argyrou Endometriosis Centre learnt from the Canberra model, again. It is still very much a leading model of care that is now being adopted elsewhere but not funded here.

Miss McGowan: It has never been fully funded. Their entire list of what they needed, and the goals, were never fully funded. People will go in there, and there are only two of the five available to them. It has never had the full funding.

Ms Taylor: The outcome is that we have had a loss of the workforce, who needed to go and find other roles, so we have lost that expertise. They are there, and we can pull them back in, but they have a mortgage to pay.

MS BARRY: I know that, a couple of years ago, the Commonwealth gave special funding to SHFPACT. How are you seeing the impact of that funding?

Miss McGowan: SHFPACT do a great job, but it is not fully bulk-billed. There is a charge, and that is just not possible for a lot of people. It is different to the Endometriosis Centre. They offer different things. While that is helpful, again, it is not like the Endo Centre, which has everything there. But the benefit of that is that it is in the community, which is a very prioritised thing that our members do want.

They do not want to have to go to the hospital and be triggered or re-traumatised every time they need to see a nurse. If they go to SHFPACT, it is more comfortable for them, but it is different.

Ms Taylor: It is a concern with referral pathways, though, because if we do have an escalation of someone in that community centre, the pathway to a tertiary space or more specialised care, they just get put into that system, and they need to go through a lot of the steps. I note that we have 27,000 people in the ACT who are affected by this condition, and that number is very conservative and does not cover pelvic pain, adenomyosis or PMOS. With one clinic that is very under-resourced and underutilised in the community, and a clinic or centre in the tertiary that is not funded, you can see that there is really no service here that will meet the need at all for this community.

MS TOUGH: I want to pick up on the referral pathways and the general delays in diagnosis. There is a very long delay in diagnosis. Some say seven or 10 years; some people wait for 14 years. We have had a submission where someone waited 27 years. It is a long time of knowing something is wrong, seeking treatment, but not getting the right pathway. What are some of the factors that are contributing to that here in the ACT, and are they different to the national factors?

Miss McGowan: Generally, people are not educated enough—the medical professionals. I think that is the main thing.

Ms Taylor: We have a barrier with GP understanding of the condition, and it is a very out-of-date view that it is based only on the lesions in the body. The fact is that we have had additional clinical guidelines updated, where we can have that scanning and clinical assessment.

The first barrier is a lack of understanding from GPs, and a lack of access to that specialised ultrasound technology, which we spoke about earlier. You are speaking with RANZCOG later; it will be great to have their perspective there. Then we get to the space where we need to be referred in. If we have mapped out the procedure, let us say in a perfect world we can get into a pelvic health physio. We can start to get some mobility on quality of life back for these people. That is not actually the case. We cannot even get to that point, but if we go ahead in that pathway, they are referred into the tertiary centre, if they do go and have a laparoscopy.

We do not have the appropriate gynaecology specialists here, or people who have a special interest in Canberra to service this population, so they are going interstate. They are needing to travel interstate to get that care. That is additional cost, time off work, pressure on the family. When they return from that diagnosis, they are returning to an area where they do not have the care to continue that ongoing support.

That all adds up over time. We also know that there is medical misogyny out there. We know that people go in, expressing their inability to be able to get back to work and take the kids to school, and they are met with, "Just go on the pill," or "This is just a bad period." There is definitely still that stigma out there.

We know of people who presented to emergency with rupturing ovarian cysts, being told, "Just a bad stomach ache, go home," and it is repeated up to three times before someone is taken seriously, and you would have read that in submissions. It should be noted that this is not an uncommon experience. This is what people are experiencing every single day and, over time, that reduces your confidence in the healthcare system.

That is where stigma comes into play, with people saying, “Why would I bother going to the healthcare system? I’m not going to get the help I need.” There is a trust element there as well.

Mrs Fisher: I will add to that. There are inconsistent pathways as well. With the Sexual Health and Family Planning ACT model, as opposed to the in-hospital model that we were talking about before, if it was appropriately resourced within the hospital setting, someone could present to ED and be referred to that service for the education while they are waiting for the surgery.

Different healthcare professionals in different settings are using different pathways. What is important to be aware of is the change in a patient, their symptoms, how acute it is, and even what their primary reason is for seeking treatment. It might not just be pain; it might be nausea. It might be that they want to improve their sexual function. It can change between when they first present and when they are able to access treatment.

We have had shared very strongly from people from the ACT that there is a lack of culturally safe care available in the ACT, and that was right across Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people, and particularly the LGBTQIA+. Once you have eroded that trust with those people—and it does not just have to be with endometriosis care; it is across the whole healthcare setting—it is very difficult for them to feel safe in accessing that care. That needs to be front of mind, if changes are being made.

Ms Taylor: Collaboration with the local ACT health service is really key. They are the ones that are front facing; they are also frustrated and unsure about how to support these individuals. Establishing emergency guidelines is a step, and saying, “If we’re going to work out the journey and mapping of the very different presentations, what referrals on do we have back to community, so that we can pick them up and support them to reduce that need to re-present,” because we know it can happen. We have the data to show community biopsychosocial services can help the health system, the health service, and the individual to continue to improve their quality of life, but it needs to happen in a holistic way and in collaboration.

MS TOUGH: I will go back to presenting at emergency and people being dismissed and sent home, and with repeat presentations. When people present at emergency, depending on which doctor is on, and they are getting a different response as to what to do, has there been any improvement over the years, or any difference in people presenting and being told, “Okay, it’s pelvic pain; have you seen a gynaecologist? I’ll write you the referral,” or is it still just the hit and miss of who you are getting when you show up?

Miss McGowan: It is very hit and miss, unfortunately. We do have people that present and occasionally come across a wardsman, a random staff member, that is knowledgeable and knows what needs to be done. Although they have their own pathways, their own guidelines, and they understand it comes down to the individual, overall, it is still very much hit and miss, and people are still being treated pretty poorly when they present.

Ms Taylor: A great example of a potential model is a gynae reg emergency. This has been trialled in another hospital in Australia where they are available from 6 am to 11 pm at night. That is what they were funded for. If someone does present, someone that identifies as a woman or was assigned female at birth, presenting with things like query appendicitis, bowel, bladder pain, query ruptured ovary, they bypass emergency—within the system, but they are referred directly to that gynae reg and are known to the gynae outpatient department, or service.

That helps to reduce the unnecessary interventions, the unnecessary scans that people will often experience and have. If the gynaecology department is known to a patient, they can access their information and be managed by a registrar; it can be really interesting and quite helpful.

THE CHAIR: Where did you say that was being done?

Ms Taylor: At the Gold Coast hospital.

MS TOUGH: We might look into that.

Mrs Fisher: When these services are set up, even emergency department staff will often think about endometriosis and pelvic pain conditions as impacting women within their child-bearing years. It is not recognising endometriosis and pelvic pain conditions as something that impacts people across an entire life span.

We will often see a perimenopausal woman at the point where she really needs that additional care; she might not have needed emergency services previously to help manage her pain, her haemorrhaging or whatever it is, and when she is going at that age, or teenagers, it is often that drug-seeking behaviour that is being assumed, so it is about educating our staff to make sure that it is recognised as a lifelong condition.

Ms Taylor: That is where nurses come in, too, because they look at that lifelong approach. I need to reiterate again that there is the workforce out there, the growing expertise, the growing mentors of new and upcoming nurses. There is incredible passion. They are trained to look at the whole person. Even in the workplace, QENDO has run a workplace program since 2018. It was the first-ever endo-pelvic pain-perimenopause work program in Australia. We connect those people who are haemorrhaging in the bathroom in the workplace, or the manager who is really concerned about one of their staff, with a nurse, to talk them through, keep them working, keep them living their life. A nurse can hold space for that.

It does not necessarily have to be that medical intervention; it could be from a nursing perspective, and it could also be a matter of being aware of the pathways, the guidelines and the referring opportunities.

MISS NUTTALL: I am curious about the coverage of endometriosis and pelvic pain conditions in the ACT's education system, and where you think we might be able to do better on that front.

Miss McGowan: The last I heard, there was not a whole lot of mention of pain, period pain, chronic pelvic pain, or anything in the public schooling; I do not know about private. When they do their sex ed, as far as I am aware, there is just a slight mention. "It's not normal," and they move on. They do not go into detail, I do not think, in having that in every public school. In all schools, it would be wonderful; in public schools in particular, it would be incredibly helpful, and there are programs available to do that.

Ms Taylor: It is educating people about what is normal, what is not normal, and what to do about it. I note that the school nurses are a really key point. They know the girls that come through again and again, and they are giving them a heat pack, because they are also not sure. There is a real opportunity to provide some school education, provide that understanding of pain, pelvic pain, whether it is endo or not, in a way that is not inflammatory, but just basic education about the human body and cycles. It is about giving the school nurses some tools. Again, there is education and training out there for them; they just cannot access it.

Mrs Fisher: We recently had a nurse contact the coalition asking for guidance, from a private school in the ACT, about this exact issue. They were not able to access what they needed through the ACT health resources. It was not only about supporting these people when they are coming through to access a school nurse; it was also about having resources for them to be able to get an extension on their assignment or be able to stay engaged in school and education.

It is also about educating boys. This is not just a girls' issue. We need to make sure that everybody is educated, because endometriosis and pelvic pain are impacting everybody. If we can make sure we do that from an early age, I think it will change the quality of life and outcomes for these people on a long-term basis.

Ms Taylor: May I share a story of a recent year 12 student who needed additional support in her year 12 exams. They had quite significant endometriosis and had surgery at the time of the exams. Under the education system, they were not given, provided with or approved time for endometriosis, to get up and get a heat pack reheated, or have another five or 10 minutes because there was a flare, in quite a lengthy exam situation.

They went to their GP and told them they were just having anxiety, and they were then granted all those additional supports. But because they had said endometriosis, that was not covered in those additional supports. It was not recognised. That is a key thing. We have our year 12 students trying to get through that last year of their exams and needing to utilise a different diagnosis to get the support they need. That will impact their university opportunities, their workplace and their schooling. There is still significant stigma.

MISS NUTTALL: When it comes to attendance, there are not specific attendance or absence provisions for pain due to endometriosis and things like that; that is not a—

Ms Taylor: No. An excellent study was done recently by the Pelvic Pain Foundation of Australia, and we can take that on notice and provide those specific details to you. From a very hazy memory, almost one in two people who do have a period were missing school. It was incredibly high, and they have delivered their education to hundreds of thousands of students now, so it is a very good dataset. They were surprised at the high number of individuals who were taking time, at least one month out of every few, because of their pelvic and period pain. That is our next generation of society, who are really struggling.

MISS NUTTALL: I know a couple of other submissions have mentioned the Period Pain and Endometriosis Program, PPEP, which runs for years 9 and 10, and I think it is available in some primary schools in the ACT. Have you heard anything about the program? Can you speak to whether it might be useful?

Ms Taylor: We have been big supporters of the PPEP program for several years. We have worked really hard with them to get the pilot funding to bring it into different states and territories. It is delivered by health professionals; that is the first thing. They go into schools, and they can talk, from a qualified perspective, about, "This is what's normal; this is what's not normal, and here are all the tools and things you can do about it."

They go in. They talk about menstrual cups. They talk about period underwear. They show them. They show them what a Mirena looks like. They have pelvic models with boys and girls, and those who identify as other genders, so it is incredibly inclusive. It is also backed by pain neuroscience. They are not just talking about the lesions in the body; they are talking about the whole body, the pain cycles. They are educating these young people incredibly well. It is the benchmark of that type of care in Australia, and it is funded federally. That organisation, under the Pelvic Pain Foundation, works with the states and territories to co-fund that for private and public schools.

That program is capped at a state's appetite to then co-fund that. Where a state has not come to the table with that funding, it is only delivered in private schools in that state, so we are then furthering that inequity between public and private. It would be a recommendation—and I hope they have put a submission in—to really look at that opportunity. It is a well-resourced, incredibly well evidence-based program that is then delivered by those health professionals.

They can upskill the nurses. They have access to pain specialists and gynaecologists, if there are additional concerns. We know that those students come up to those health professionals because they are actually outside their school environment, and have some in-depth conversations about, "This is what's going on for me," so that educator can then provide the referring options and connect them with the right people.

THE CHAIR: QENDO, in your submission, mentioned the cost, and we have already spoken about this—$8,000 to $15,000 per year. There must be a massive disparity based on socio-economic status and access to diagnoses, treatment. Do we have data on that? It is hard, especially with access to diagnoses. You can talk to the issue generally, but if there is any data that you are aware of, that would be interesting, too.

Ms Taylor: Ernst & Young did a review in 2011. We do have the national productivity loss. We have endometriosis contributing to an estimated national productivity loss of $7.4 billion to $9.4 billion annually. We know that there will be some data coming out in the next few months that show that annual productivity loss to be around $20 billion, so it is increasing.

In terms of the individual costs, they are very much down to, again, the out-of-pocket expenses. There is the unaffordability to take time off work, to afford medication or try new medication. I like the term, "We are currently throwing spaghetti at the wall and seeing what sticks." And that adds to the cost. You need to see a pelvic health physio. You need some medication, if that works for you. But if that one does not work, we have to try all these others. That is with a GP who is trying their best, I know, but they are not well educated in this space. They really struggle.

Mrs Fisher: That figure is just for endometriosis; it does not encompass all the other pelvic pain conditions. So that is a very conservative estimate. As I said before, it is important to look at those economic costs, not just in terms of being able to access treatment in the short term, but across a person's lifespan. That can look like not being gainfully employed, maybe because you could not access education when you were younger. The big impact that we are seeing now is homelessness, because people do not have appropriate superannuation.

These older people have not had things addressed properly when they were younger, and it is a chronic health condition, but if it is not well managed initially and in its acute phase, it becomes a chronic health condition that impacts across a whole life span in a much more significant way.

Ms Taylor: We are also seeing people take their super out to get the treatment, or travel interstate. It is not uncommon for people to apply for up to $10,000 to $12,000 to support them, because of the inability to afford private health, and being unable to access that locally. That is then impacting their later state.

Endometriosis can be a progressive disease, so every time that person is having a bleed or having some sort of cycle, that is increasing that inflammation to the body. With endometriosis, if we think about it as an umbrella term, we have this overarching umbrella where you have adenomyosis as well. There is pelvic pain. There are other comorbidities. Over time, without the right care, the pain increases, the cycle increases and those lesions will grow. Every time there is a bleed, there is a mini-inflammatory event in the body, and that impacts; this is where we are coming into over 72 other comorbidities. It is so significant.

I would like you to consider endometriosis being similar to cancer, in terms of that umbrella. We have really good cancer services. I am not saying in any way that endo is like cancer, but it is, in the sense that it is an umbrella, and we have different types of cancers. Endometriosis is thought to be very similar to that. There are different presentations. There are different types of the disease; therefore, it is not just one size fits all. As with cancer, it is not one size fits all.

We are encouraging targeted care which needs to be considered potentially on the model of how they built cancer services. You have nurses. You have the specialist centres. You have the rehab, the treatment. That is the model—that whole-body model. We know what radiation does to people. We know what chemo does to people. Think about that in the way of endometriosis treatment, in that it is not just a lesion, it is not just a treatment; it is that whole body and that whole life impact.

Miss McGowan: For those that do not have private health, or do not have super that they can access, they are stuck, waiting in the public system. They are stuck with any gynaecologist. They do not get to choose. A lot of times they will be operated on by a general gynaecologist that is not trained to effectively treat that person. Sometimes people are left with long-term damage or fertility issues because of that initial surgery. That then impacts everything else for the rest of their lives. There is this added burden right from the start.

Ms Taylor: If you have a skin cancer, you go to a skin cancer doctor. They are usually trained and have expertise in that space. For endometriosis and pelvic pain, you do not just go to a general gynaecologist. They need to have done the additional training.

MS BARRY: There is lots of conversation about a multidisciplinary approach. How do we bring that all together? I do not like strategies for the sake of strategy; do we have an endometriosis strategy in the ACT?

Mrs Fisher: No, you do not.

MS BARRY: Do you think one is required?

Mrs Fisher: We need one, yes. I encourage you—it is attached to this submission, but we can provide it again—to look at the ACT report from the national endometriosis and pelvic pain roundtables from last year. There is an overarching national findings report and an ACT report that sits underneath it. There is a full set of recommendations for both policy and funding in there that comprehensively addresses that question.

Ms Taylor: And speaks through what that multidisciplinary team would be.

Mrs Fisher: In short, appropriately funding the Canberra Endometriosis Centre that is within the Canberra Hospital that, at the moment, only part-time funds one physio and one nurse.

Miss McGowan: Their wait times to get in are two to three years and a year or two for surgeries. It is long.

Mrs Fisher: It is brilliant but not appropriately funded.

Ms Taylor: There is a model of care that will be published in the coming weeks that we can also send to you. That is evidence based, with 400 patients that have gone through a similar service, that you can then base your model on.

MS BARRY: Thank you very much.

THE CHAIR: Thank you very much for your attendance today and for all your work in this area. We really appreciate it. I think we had one question taken on notice. Please provide your answer to the committee secretary within five business days of receiving the uncorrected proof *Hansard*.

WARNER, DR RACHELLE, Personal capacity

THE CHAIR: We welcome Dr Rachelle Warner.

Dr Warner: I am a proud Wiradjuri woman and Canberra resident of 20 years. I am appearing in a personal capacity, as a reproductive medicine specialist, researcher and clinician. I would like to declare my association with the Robinson Research Institute, where I am an adjunct fellow, specifically in the chronic reproductive conditions research group, but this is an unpaid position.

THE CHAIR: Thank you. Please note that, as a witness, you are protected by parliamentary privilege and are also bound by its obligations. You must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Before we go to questions, would you like to make a brief opening statement covering any matters that are not in your submission?

Dr Warner: I will, if that is okay. Chair, Deputy Chair and members, thank you for the opportunity. The national capital should set the benchmark for what best practice looks like, and right now it does not. The evidence shows that endometriosis and chronic pelvic pain are not just clinical issues; they are also system design issues. Delays, fragmented care and inequitable access are not accidental; they are produced by how the system currently operates.

I want to briefly note two recent developments that underscore exactly why this inquiry is very timely and that Australia is actually already leading the way. This week, *The Lancet* published the global consensus of renaming PCOS to PMOS: polyendocrine metabolic ovarian syndrome. I have a copy of that paper if you would like to table it. Led by Monash University, the name change reflects what the evidence has long shown: the old name was inaccurate and contributed to diagnostic delay, fragmented care and stigma. A condition affecting one in eight people with urachus just had its core framing corrected.

The policy frameworks, including this inquiry, need to keep pace with that change. A blood test for endometriosis, PromarkerEndo, developed with the Royal Women's Hospital in Melbourne, is currently in the commercial launch process. For the first time, we have a non-invasive pathway to earlier diagnosis, but, if it launches without Medicare listing, it just becomes a private test for those who can pay, while public patients wait years for a laparoscopy. That is a new layer of inequity.

The ACT has a unique opportunity. In a small, centralised system, reform can be implemented consistently, but, when the system fails, those failures are also amplified. Getting this right requires four things: an integrated care model, mandatory disaggregated data, co-designed inclusive pathways, and independent accountability. The question before this committee is not whether Canberra can afford to get this right; it is whether Canberra can afford not to. I have also brought with me my latest paper that was published recently on endometriosis and interception, if you would like to consider tabling it. I welcome your questions.

THE CHAIR: That would be great. Thank you. I will pass straight to the deputy chair.

MS BARRY: Thank you for your submission. It was really useful to read. I have a few questions around the multidisciplinary care model. One of the concerns that have been raised in several submissions is lack of diagnosis, and then, when patients present at emergency, there is a lack of care and support, particularly in that space. I want to get your views on what we can do in the early stages when people present, to not just ensure that women have a good experience but also ensure the condition is taken seriously, with a proper referral pathway to other services.

Dr Warner: Regarding the early stages, the most fundamental thing is that we believe them. It is pretty well-researched and documented that for women in particular, and those who belong in marginalised or intersexual identities—Indigenous people of colour, LGBTIQ people, people with disability, larger bodied women; I have been through the system as a larger bodied woman, and I can tell you that, every time I go there, I say, "Just tell me I'm fat and I should lose some weight"—the system has to believe their pain. There was also a longstanding thing of it just being period pain—"Don't worry about it. You'll be fine. Here, have some Panadol" or "Have a drink of water. You'll feel fine." I can see Ms Tough nodding along. She has been through this process.

The first part is education of clinicians, the people who first see them when they present at emergency, or the GPs who see them at the initial time. Believe their pain. Even if you did the earlier diagnostics—X-rays, CTs and exploratory laparoscopy—it does not mean you did not miss something. As a clinician, one of the first things I learnt was that the patient knows their body and they will tell you what is wrong. So if they tell you, "I know what your tests are telling me, but they're wrong. Please keep looking," you have to keep looking. The first part is: believe the patient.

The second part is the associated trauma, and this fits for a lot of chronic conditions—having to tell your story 20 billion times and going through the process of having to be believed 20 billion times. Perhaps we can create what is effectively a front door that people come through and they are believed, and they get early access to diagnostics, be it the new blood tests that are coming through or the use of ultrasound that is emerging quite well now, but they also get access to everything they need through that front door. That might be a gynaecological specialist who can do the laparoscopic surgery, if that is where it goes. That might be the pelvic pain physiotherapy that accompanies a lot of these therapeutics. That might be psychology and social work to help them work through both the trauma and the navigation of the system to access standard care.

One of my recommendations was about effectively a nurse navigator or a coordinator who can guide them through that journey. So many people who go through the system have to advocate so strongly for themselves, have to navigate the system, have to do all the research and have to look for what is next. If we are able to give them one person who can help them navigate through that system—and I do not speak from lived experience, but I do speak from people having told me how traumatic the system is—give them that kind of support, back-up and help to navigate an extremely complex system, it would put us as frontrunners.

We already have components of that in the Canberra Endometriosis Centre and Sexual Health and Family Planning, but what is missing is that connective tissue that I was talking about: the nurse navigator and integrated protocols that bring it all together.

That can be achieved without building new infrastructure. That is a couple of nurses' wages—moving them out of other places. That is looking for specifically trained nurses in pelvic pain care who could help that navigator role.

MS BARRY: Thank you very much. You talked about mandatory disaggregated data. Can you please expand on that a bit?

Dr Warner: Yes. I have a complex relationship with data. I both love it and hate it.

MS BARRY: Me too. It is useful sometimes.

Dr Warner: I think anyone who has done any kind of research goes that way. I talk about disaggregated data. A lot of the research, particularly on marginalised groups, does not exist. We just say, "One in five people in Canberra suffer from these conditions." What that hides is the underlying discrimination in some cases, medical bias, and the additional intersectional difficulties that lay on top of that. For you, if I may, a darker skinned woman who—well, straight up, because you are black, you are probably going to face a bigger challenge to be believed.

MS BARRY: That is correct.

Dr Warner: You are a woman, so you are probably going to face a bigger challenge to be believed. You may or may not have a disability—I do not know—so you may face a bigger challenge to be believed. They are not a one plus one plus one situation. It becomes exponentially worse when you start putting that on top of people. The disaggregated data is when you are surveying—"It is not one in five people; it is this"—and I do not know the figure, so I am making stuff up at the moment. Let's say, one in 10 are Indigenous people of colour, and the extra biases they face in getting a diagnosis mean that their diagnosis time takes longer. It is generally around six to 12 years. For somebody with one of those marginalised identities, it becomes 14 to 15 years, because they spend so much longer fighting the system to be believed, because of the other identities. That disaggregated data is hopefully what is going to start making things visible. You have to take what is currently invisible—those extra challenges—and make it visible, and then make the pathway easier. It could be that we have a separate, co-designed First Nations pathway—First Nations people seeing First Nations practitioners.

First Nations people, as I am, also have intergenerational distrust of the system. The Stolen Generation is still very real. There are still 30,000 of them walking around at the moment. Most of them are heading towards aged care, but there is the trauma that goes with that. If they said something was wrong, they were locked up, they were punished. If they sought care, they were treated as less than human. My great-grandmother's birth certificate is a cattle register. That is how recent it is. I do not announce what this country has done to my people. So you have a people with a complete mistrust of the system. They are not going to a doctor and seeking help, because they are terrified of what will happen if they do, or, if they do seek help, they are not believed.

We need that disaggregated data showing we have Indigenous people or we have LGBTIQ people or we have transgender men who still have periods and have endometriosis because of their choices of treatment. You can imagine a man going to a gynaecologist and saying, “I think I’ve got endometriosis.” They are probably going to be locked out of the office, and I have heard of that happening, which is appalling for some of my fellow clinicians. Anyway, that is a very longwinded way of saying, if we make the invisible visible, by having the actual data of how many of these marginalised groups are there, we can make sure that we provide the right care for the right people at the right time.

MS BARRY: We have heard conversations about culturally appropriate care. What you mentioned would help inform that culturally appropriate care.

Dr Warner: Culturally appropriate care is very specific. My current job, when I am not researching, is cultural safety in aged care. The best people who can tell you about that are the people who are living that experience. So, again, that data is what can tell you: “I need this for it to be a culturally safe place for me to seek care or for me to seek treatment.” We have some facilities. We have Winnunga. There are some Aboriginal or Torres Strait Islander practitioners in Canberra, but I think a co-designed place where the Indigenous population tells you what they need is setting it up better for success for all sides.

MS TOUGH: Thank you for starting your submission with women being believed. I think I speak for a lot of the committee when I say that reading that is so reaffirming, so thank you. I want to talk about the delays in diagnosis and retelling the story over and over. You see a GP and you are sent to a gastroenterologist or you are sent to a gynaecologist or you are sent for an ultrasound or you are sent to a dietician—name any specialist—but how do we then overcome going to a person and not getting a diagnosis? How do we keep going on the journey to diagnosis rather than just going back to square one?

Dr Warner: Hopefully that fits in that multidiscipline model, when I was talking about one front door. You are believed, you get the examinations that you need, and you are in a place where they are going to keep digging, if that is what is required, but you also have access to a nurse navigator who would guide you to where you need to go next. If they say, “We think a blood test is suitable for you,” there might be pathology on site that can do it. You get those results within about 72 hours at the moment. “Okay, we’ve got that result back, but, in the meantime, do some pelvic physio. That might help decrease your pain.” You have a GP there who can prescribe medication if that is what is needed. You have somebody there who can explain all options to you. You are involved in the decision-making of how your pain is treated. Basically, all those services are in that one front door, so you are not retelling the story; you are a dedicated case that is managed as a person, not a number, and you are not referred to a specialist that takes 12 months to see. You have that all in one facility.

MS TOUGH: That sounds wonderful. How do we make sure that specialists who are not gynaecologist specialists—because it is hard enough making sure gynaecologists are trained—how do we make sure that other specialties that someone who possibly has endo is being referred to can say, “I can probably help you with something, but have you considered endo?” How do we help that navigation?

Dr Warner: A lot of it is about early clinician training and raising awareness. I am sure you have been watching social media. The name change from PCOS to PMOS has brought them all out of the cupboard. I saw some last night saying, “Why don’t we just leave the acronym but change the name?” “We’ve changed it. We’re moving forward.” If I am allowed to be blunt: particularly in the time that I came through, there were some pale, male and stale clinicians, and they are probably ultimately not going to change the way that they operate, because they have done it for the last 50 years and they are not going to change now. That is sad and unfortunate, but there are always going to be those people, and I think we are better concentrating on the new ones coming through.

I think the younger generation, basically because they are living it and they are far more likely to stand up and advocate for themselves, are also becoming good advocates for patients. Within the ACT, we have the benefit of a very concentrated workforce. Getting that additional training, particularly for the specialists that we would refer to, would cost money, but I think it would be well worth the investment. Let’s make some additional training for GPs. Let’s make sure GPs know where to refer to. “If you are referred to a gastro, have you made sure that all of those specialists are also made aware of—” That is an education campaign. That is something the government could push for. That is something we can talk to the professional colleges about—making sure that they are actually including it in their residency and fellowship training, to say, “If you’re looking for something, this is an option.”

I think the advent of the blood test is going to be amazing, as long as it is Medicare listed. If it is just for those who can pay for it, that is not great. Being able to say, “I don’t know, but I’m going to send you for a blood test,” which we know is about 90 per cent accurate, is going to be life-changing. If they say, “I’m going to ask for full bloods, but I’m chucking an endo blood test in there,” all of a sudden you have an early diagnosis and can start to refer into the centre.

MS TOUGH: Wonderful. You mentioned the name change from PCOS to PMOS. On my social media, that is all it has been about for the last 24 hours, including on my own page. I put a post up and it is now being shared to people I do not know. It is such an exciting—

Dr Warner: It needs your face. Sorry—keep going.

MS TOUGH: It is a very exciting development. So far, I have seen one person online make the case for changing the name of endo. Do you think that, potentially in the future, this is somewhere we could go, to recognise it is bigger than just a pelvic disease?

Dr Warner: We could, but it is a pretty extensive process. If you look at the PCOS renaming, it is after 14 years of global collaboration. It included 22,000 survey respondents. It is a massive gathering, internationally, over such a long period of time. While the outcomes and the benefits of that are going to be phenomenal, if they are leveraged the right way, do we have 15 years to wait for endo to be renamed? Absolutely, that is something we could work to, knowing that the benefits are there, but I think for now, in a similar way to how they started concentrating on PCOS, the research that may come to “Maybe we should change the name” will actually help to progress treatment anyway. Yes—cool—in 15 years, but that does not help those who are coming through the system now.

MS TOUGH: Thank you.

MISS NUTTALL: On page 12, you talk about the importance of culturally safeguarded practices. Could you talk a bit more about that? And what does best practice look like?

Dr Warner: Culturally-safe care is incredibly personal to each First Nations person. I can speak as me; I cannot speak as every First Nations person. But, for those that I have worked with, it is an opportunity to see a First Nations practitioner. It is an opportunity to understand the impact of being in hospital for a First Nations person. It is not so much the case within the ACT, but, if people from remote communities come to Canberra for treatment, it may be the first time they have been in an institutional environment again, which flicks them back to institutionalisation—the days of the missionaries. They could well be the only person of colour in their ward, which automatically isolates them. Their educational level may not be the same as the people there, so they are less likely to talk to people. So having a First Nations clinician or having a First Nations liaison officer, or someone who can actually guide them through the process, would be incredibly helpful.

I guess it goes back to: believe them. There is a very misguided belief among some people that black people are more stoic and that we can handle pain better. That is garbage. It may be that some First Nations people present that facade because they are too scared of showing any kind of weakness, because they know what happens when you share weakness. Then you are targeted. It is kind of hard: you cannot give them exactly the same treatment, because they need to be treated as an individual, but you should not be saying, “That’s a black person and that’s a white person. The black person doesn’t feel the pain as much. They’re not as urgent”, or whatever underlying systemic racism bias exists. The most practical thing is having First Nations clinicians or a First Nations liaison person who can explain to them everything that is happening and explain it to them in a way that they understand.

I cannot say I have ever asked a First Nations person about endometriosis surgery, but I can relate to an aged-care First Nations elder. They wanted to amputate his leg because he had septic ulcers, and he declined. They said, “But you will probably die if we don’t amputate your leg.” What they failed to understand was that First Nations people need to return to the Dreaming, and we need to return to the Dreaming whole. By removing his leg, he would not return to the Dreaming whole; therefore, the ancestors would not allow him to return. There was so much cultural impact on him that the practitioners did not understand. Their approach was very clinical, black and white—“You’re going to lose your leg or you’re going to die, buddy.” To him, not being able to return to the Dreaming and his ancestors whole was actually worse than dying. A First Nations woman may say, “You’re taking part of me.” They may have the same kind of belief. But, as I said, I cannot speak for them, but I imagine that may be a possibility.

A First Nations person could talk them through the process. For example, for that gentleman, we managed to keep his leg, basically. Rather than it going to biohazard waste, we put structures in place so that he could keep his leg. It was held at the funeral home, and then, when he eventually passed, it went with him, so he kind of went whole. I would hope that some kind of First Nations liaison person would be able to either negotiate a similar kind of thing or explain to them the importance and why and how.

Cultural ceremonies might be appropriate. Allow them in the system. I have visited aged-care residences where they have absolutely beautiful cultural ceremonies about death and dying. It may be similar: part of their anatomy is dying; could a cultural ceremony be allowed in the public hospital or whatever it is?

MISS NUTTALL: Thank you very much. I am also interested in cultural safety when it comes to trans, gender-diverse and LGBTIQA+ people. Obviously, a lot of services are in women and children's hospitals and places like that. What sorts of practices can services put in place to make sure that things are safe for LGBTIQA+ folk?

Dr Warner: I am very unqualified to answer that. I would say: ask the person. It ultimately comes back to what is safe for that person. For example, I can only imagine that putting a transgender man in a maternity ward, which is where we tend to put people with endometriosis, would be appalling and unsafe. There has to be an alternative to that. If they are a man and they are living as a man, and there is no other reason why they cannot be put in a ward for men, why not? Nobody else needs to know what care they are receiving. Nobody else needs to know which specialist is visiting them. We should be doing everything we can, given that they have probably had a 15-year journey by this point and have struggled to be believed because of their positionality in the world. We should be doing everything we can to make them as comfortable as we can, with what, I assume, is a horrifying journey—to not want to own the body and then have something like this, such a traditionally female condition, and to live with it as a man. I cannot imagine what that would be like, so I cannot make a recommendation, but my suggestion would be to ask the person. They will tell you what they need and they will tell you what is going to make their care safe.

MISS NUTTALL: Thank you. It has not come up in any submissions that I have read so far, but, having chatted with asexual folk, when it comes to things associated with reproductive health, they are often left out of the question. Have you ever chatted to any asexual folk about their experiences with getting help for endometriosis and other pelvic pain?

Dr Warner: It would be rare. There may have been one or two in the time of my research. From memory, they have told a similar story—that they are already facing challenges in that people think they are a bit odd in a way, because they are asexual. The first question any woman is asked when they go to emergency is: "Are you pregnant?" For somebody like that, that would be an appalling question. It goes to my argument again that we have to have disaggregated data and ask: who is actually out there, why are they so invisible, how can we make them visible, and how can we make the diagnosis and treatment pathways far better? The short answer is no, I have not really chatted to many about their experience, but I think it would be much along the lines of anybody with one of those marginalised identities, where it is so much harder to be heard and then get what you need to feel safe, and even more so if you are scared to speak up because you know you will be targeted in some way.

MISS NUTTALL: Thank you.

THE CHAIR: We have heard about endometriosis diagnosis and treatment being very costly. Are you aware of any data? Of course, this is commonly the case with health care: it is massively stratified or variable, based on socioeconomic status. Are you aware of any data on this, specific to endometriosis or pelvic pain conditions more broadly?

Dr Warner: Are you after data on the cost of endometriosis treatment?

THE CHAIR: The cost and then who—I mean, it is hard to track who is not getting treatment, but is it the case that people who are getting diagnoses and treatment generally tend to be in middle-income and above groups?

Dr Warner: Yes. The Women's Health Matters ACT survey data would have given you quite a bit. The difficulty with the current data is that it collects data on people who are already diagnosed, and the people who are already diagnosed tend to be the ones who can afford it, particularly in the ACT. The ACT has both the benefit and the disadvantage of being very small, very concentrated, but there are only a couple of specialists who deal with endometriosis. If you have a bad experience with one, you may or may not try again. We are limited in pathways and we are limited in other options, whereas in New South Wales, if you go to Sydney, if you go to one specialist and you do not like them, there are 20 other options. In the ACT, there are two or three and they might have a 12- or 24-month waiting period.

I would suggest that the current data reflects the better economic status, because people can afford to get a diagnosis, they can afford to keep going to specialists, and they can afford to go interstate to get a diagnosis; whereas the ones who actually need the most help, which is those who cannot afford it—those who are Indigenous people of colour, those who are disabled, those who are LGBTIQ—do not have those options and therefore do not pursue the diagnosis; they just live with the pain. I can certainly take it on notice and will come back to you if I can find any.

THE CHAIR: That would be great. Thank you. I imagine people in those categories are often also unaware of the existence of this potential diagnosis, so I am wondering if you have views. You spoke earlier about education. How do we help address that entire pathway, not just for clinicians but also for the general population?

Dr Warner: Social media is a very powerful tool, if you look at the last 48 hours. I would guarantee that, if you talked about it on the street, most people would know what PCOS or PMOS is. Even if they do not actually understand what it is, they will know that it exists. I think there is a lot to be said about leveraging those tools. You have a younger generation of advocates who know how to use social media way better than I do. I am also on the board of Australian Science Communicators. Our job is to communicate science. So you have a whole bunch of people who know really well how to communicate science.

I think it needs to be addressed at every level. My personal experience has been that lived experience stories make it real. You can put endometriosis over here. I have had pain since I was 11. It took 15 years to be diagnosed. During that time, I had six exploratory surgeries. I was referred to so many specialists. I was isolated. I missed so much school. I have missed so much work. Putting a real-human picture on what it is tells a better story to people than: "There's a concept over here of what endometriosis and pelvic pain is." I think it is about leveraging the science communication community and leveraging the research that is out there. To be honest, using this PMOS renaming as almost a springboard for other pelvic pain conditions is probably a good tactic.

THE CHAIR: We have about 30 seconds. Is there anything you want to add?

Dr Warner: I could keep talking all day. This is my specialist area.

THE CHAIR: Thank you very much. On behalf of the committee, thank you for your attendance today. There are a couple of documents that we will table.

Dr Warner: It is more about research, but, if you are into it, go for it. My paper will explain the intersectionality part of it—if you have intersection identities, how much harder it is to be diagnosed for endometriosis, or any kind of pelvic pain condition. That might go further than my very blunt explanation earlier. The other document is the research that went into the PMOS renaming. And could I just say: thank you so much. It is such a cross-party, willing committee, and the time is right. It was a real privilege to speak to you today.

THE CHAIR: Thank you.

The committee suspended from 10.20 am to 12.03 pm

FROMMER, DR TARA, Senior Medical Officer and Clinical Lead, Sexual Health and Family Planning ACT
HALL, MS TRACEY, Chief Executive Officer, Sexual Health and Family Planning ACT

THE CHAIR: We welcome representatives from Sexual Health and Family Planning ACT. For the Hansard record, could you please state your name and the capacity in which you appear.

Dr Fommer: My name is Dr Tara Frommer. I am a GP and I work at SHFPACT as a senior medical officer and clinical lead for our pelvic pain clinic.

Ms Hall: Hi, I am Tracey Hall. I am the CEO of Sexual Health and Family Planning ACT.

THE CHAIR: Thank you. Thanks for being here today. Please note that as witnesses you are protected by parliamentary privilege and bound by its obligations. You must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Before we go to questions, would either or both of you like to make a brief opening statement.

Ms Hall: Yes, I will. As I said, my name is Tracey Hall. I am the CEO of Sexual Health and Family Planning ACT. We are more commonly known by our acronym SHFPACT. We are the lead provider of sexual and reproductive health services here in Canberra. We provide clinical services, a clinical training school and non-clinical services. We do a whole lot of education in schools and the community. There is one of us in every state, so we come together as Sexual and Reproductive Health Australia, and the acronym for that is SRHA.

In 2023, we were one of the successful providers in the first tranche of the endo and pelvic pain clinics across Australia. The funding for that program is particularly limited, and it has been indexed since its commencement, but the benefit of our model is that we were able to leverage our expertise and our existing programs and infrastructure to essentially bolt the pelvic pain clinic on to what we do in SHFPACT.

I think what has also been of note is Tara and the team have had a lot of collaboration with the first 22 clinics. They share a lot of ideas and service development initiatives.

The other point of note is that we have been able to leverage our learnings through the clinic in the other services that SHFPACT provide; education in schools and so forth.

That was really all I was going to say as an opening statement. Thanks for having us here. We thought the best use of the time might be for you guys to ask questions and delve a bit deeper.

MS TOUGH: Thank you both so much for your submission and for coming in. I want to start with the pelvic pain clinic; what the local demand is of the clinic, and what that level of demand is showing you about what services are needed.

Dr Frommer: I have been working in this space, not necessarily in the clinic, but in this space for a while and I was very well aware that there would be a significant demand. Our initial opening was a fairly soft opening, and it is probably only in the last 12 months that we have been looking at trying to get our name out there louder—because, probably, a really common feedback we are getting from patients is, "I wish I knew you guys were here earlier."

We remain really fortunate in the fact that we still have been able to keep our wait times down. At the moment our model has patients seeing our dedicated pelvic pain nurses initially, and at the moment I think we are down to about two weeks depending on who is on leave and various other things like that. And, usually, most patients can get in to see the doctor three weeks after that.

But there continues to be a steady demand, and we expect that to continue to increase as we try to make ourselves a little bit more known—but we are also mindful that we want to keep those wait times down so people can get in.

MS TOUGH: And what kind of services are available in the broader clinic?

Dr Frommer: The way we have set up our clinic is to work with the fact that we know that, probably, up to 25 per cent of women experience pelvic pain, so this is a really really common condition. So, really, what we were looking to be was a referral service that did not subtract away from a patient's own relationship with their GP.

But we also know from the research that is out there is that GPs really do not feel confident in this space, and our hope has been that by sitting adjacent and supporting primary care, we can actually help upskill GPs.

So, at the moment the way our service works is we, like I said, have dedicated pelvic pain nurses as well as primary care GPs who have a special interest in pelvic pain. But you might have seen in our submission we also run and were involved in setting up the ACT Pelvic Pain Network which is a multidisciplinary network aiming to get clinicians from all areas of working in pelvic pain together to collaborate. That has been really useful for our clinic because it allows us to be able to do what we call "warm referrals" in a trauma-informed space, making sure that we know the people that we are sending people out to and that they are appropriate for the patients.

That is something I think often gets missed in pelvic pain. People feel like they are often sent off, and feel really dismissed rather than supported in health. So, whilst we would love to have more money and have more people inhouse, we have been able to make the best of that by having that network to rely on.

MS TOUGH: What kind of referral services are you able to send people out to? What does the broader care network look like?

Dr Frommer: I think you guys are probably aware—and you guys have been here for half a day and read lots of submissions—endometriosis and chronic pelvic pain are chronic conditions and like most other chronic conditions they often, depending on the individual and how their condition affects them, can need multiple providers to actually establish good quality care. And that looks very different for individuals, but common places that we would be considering referring for would be pelvic health physiotherapists, dieticians, surgeons, exercise physiologists, and gynaecologists obviously play a significant role. So, it is quite a diverse range of people that become involved in a patient's care, and we know that from all the research in this space, that is what we should be aiming for.

It is probably what we have been missing for a while. It is definitely something that has been tried to be established in Canberra before, but it has not really existed. Does that answer your question?

MS TOUGH: It does, yes, thank you.

MISS NUTTALL: Thank you. Following on from that and, obviously, appreciating that you try and keep costs low for your patients: when you start to refer out to different specialists, do you see that there is a bit of a drop-off where someone says, "I have appreciated your services here, but I cannot afford fortnightly pelvic floor physio," or things like that?

Dr Frommer: It is absolutely something that is super important, and it varies in our patient group. I wish I could say that it is only the people who cannot afford services that have been missing out on good quality pelvic pain management, but historically in Canberra that has not been the case.

We do have, definitely, a good amount of people that are able to engage with care but we do also utilise the public system and so there will be a number of patients that we refer to the public pelvic health clinic—the public health physiotherapy clinic—but with the acknowledgement that there can be wait times, and there is a bit of a limitation on how much that service can accept.

So, we usually work with patients and actually just be really honest about what they can and want to actually engage with, because—you are completely right—there is no point in me sending someone to a pelvic health physio that they cannot afford. And sometimes they do not want to engage with them for other reasons.

What we have been able to do is establish a really good set of resources so that, for my patients who cannot or do not want to, they can still get a lot out of different aspects of pelvic pain management.

Ms Hall: There is something else I would add in that speaks to the issue of, possibly, funding or finances being a barrier. What has been great with the endo pelvic pain funding, although it is limited, is that it is quite flexible. So, as a trial, Tara and the team made a really strong relationship with a pelvic pain physiotherapist, and we were able to use a small portion of the funds to buy sessions in bulk, which meant Tara and the team could work with particular clients and refer them to these sessions which were essentially at no cost to the participant.

What was impressive and notable is that there were 10 positions, if you like, in this class, and it was full. There were no vacancies. Tara and the team worked with these patients, told them about the sessions, and often—I mean, in all aspects of public health—there is drop-off, no-shows, et cetera, but there were none. I think that is worth noting.

MISS NUTTALL: That is amazing, actually. When it comes to things like bulk billed appointments, appreciating that you have got GPs that you work with who are not necessarily bulk billing, what happens with that? Is it a structural barrier or is it really about funding and, actually, if you had the funds, you would be able to make sure that those appointments are bulk billed?

Dr Frommer: Are you talking about our clinic, or patients seeing their own GPs?

MISS NUTTALL: I believe it is your clinic that has—.

Ms Hall: So, obviously, when patients see a doctor it is part of the MBF system so we do need to include a gap fee for some clients, but as part of SHFPACT's whole service offering we have a concession policy. So, Tara and the guys apply that when they can and we bulk bill for the medical appointment when we can, but for nursing appointment and everything else is at no cost to the client.

THE CHAIR: Something you raise in your submission is the specialised DAS ultrasound. That is not publicly available on the ACFP, currently? Do you have an understanding for why that is? Has not just been invested in, or has it not been prioritised? What is the barrier there?

Dr Frommer: It is probably worth starting with that I do not currently work in the public system, and so anything that I say is all hearsay. But I think it is probably a combination of the fact that it requires a skillset, and it requires it to be developed, and at this point it does not appear that it has been prioritised.

You can get generalised pelvic ultrasounds within the public system, but they have a relatively low rate of picking up deep infiltrating endometriosis, and would not be what I would usually accept as the standard, particularly for patients that are planning surgery and we really actually need to have good quality information about what is there.

THE CHAIR: In terms of privately provided specialised ultrasounds, we heard earlier, I think, that there are two locations that are doing this in the ACT?

Dr Frommer: Yes. So, there are two. Historically there have been two. I would acknowledge that some of the general radiology providers have recently tried to pick up this line of work, which is an interesting new step because historically these scans have been done by gynaecologists, or gynaecology-led practices. Historically, even within the private sector, patients have been waiting sometimes up to four months from when they call to get a scan, which is obviously quite a long time.

THE CHAIR: I am wondering where your referrals come from. What do you hear from patients about where they have come into contact with the service?

Dr Frommer: Probably the majority of our patients self-refer. We do get a good number of referrals from GPs. Sometimes they are through hospitals and ED departments who are aware of our service but, I think, still, the majority are coming from self-referrals.

THE CHAIR: This was a follow-up on public referrals from public emergency departments, because we have heard from people who were sent to emergency, perhaps get some pain management, and then are sent home. Are there any issues there, with that referral pathway in the ACT, do you think?

Dr Frommer: It is probably not an official referral pathway because, as you are probably all aware, theoretically we have a publicly funded endometriosis clinic that fits within the public system but has unfortunately struggled with staffing and intake issues. I have done a bit of education, and our nurses also have done a bit of education with the emergency departments so that they are aware of our service. As a result, sometimes we do get people who come in and have said they have seen a doctor or a nurse and they suggested that they come to us with the knowledge that they can also be referred publicly. But those wait times are quite extensive at the moment.

THE CHAIR: Yes, longer than two weeks.

Dr Frommer: Somewhat longer, yes.

MS BARRY: I have got a few follow-up questions. Do you have information on what the physiotherapy wait list time is?

Dr Frommer: The public one?

MS BARRY: Yes, the public one.

Dr Frommer: The public one, last time I referred through—and it varies because obviously they have got a triage process—it was actually not that long. I have definitely had patients get in within three months, which is pretty good for a public thing to be honest.

MS BARRY: I was waiting to hear “two days”.

Dr Frommer: No, no. It can be quite a good service but I have had patients tell me previously that—and this seems to vary depending on, I guess, how they are triaged and what their issue is—sometimes it seems that there is a limited number of sessions that they are willing to offer. And we understand that chronic pelvic pain is just that; it is a chronic condition that often requires ongoing care.

That sometimes can be managed really well in the public system with what they have, but I have definitely spoken with some of the pelvic health physios that work within that system and discussed how they are still limited in what they can do in terms of funding and how much availability they have.

MS BARRY: Thank you. You have talked about the referral pathways, and sometimes it being an informal referral from the public system. Is there a standard protocol for women who present with endometriosis? Are you aware of any?

Dr Frommer: In terms of the public system?

MS BARRY: I would ask the minister, but I just wanted to know from your experience, having spoken to people at ED, is there a standard protocol?

Dr Frommer: It is a really good question. I think there have been lots of attempts to try and standardise how patients are cared for in the emergency department. There is an informal protocol on how to manage these patients.

Like I said, there is officially a funded endometriosis clinic that sits within the hospital. There is also an acute gynaecology service that sits within the hospital. Unfortunately, the endometriosis service has not had a gynaecologist on its books for the last—I am trying to work it out—18 months.

Even before then, patients were still waiting three or four years. And it was a big thing before I started this clinic that I was often seeing people who had been two or three years waiting on that list and their condition continued to deteriorate when actually there were very accessible, potentially life-changing options for their management but they were not being offered.

I think this is sometimes the bit that we miss, that when you put people on wait times like that, things get worse. By the time somebody has had three or four years of worsening pain, that is an extra three or four years of stuff that I have to unwind.

It is really quite heartbreaking because, actually, if they have been directed appropriately or even if we just upskilled their GPs to understand what their options were so they could properly educate them, it did not need to happen.

So, I think that is why I felt quite strongly about our clinic being accessible—because this really should not be happening for women. Women should not be waiting until they are in their mid-twenties and they have got horrible pain before they actually get access to treatment.

The rates of this problem are quite high, and if we continue to focus on not upskilling our GPs, it is probably always going to be a problem—regardless of whether we finally get a gynaecologist that sits on a clinic—which is why we felt quite strongly about trying to get out there and educate GPs and actually empower them. Because all the education I received as a GP was that if you think a patient has pelvic pain and endometriosis, you should just refer them into a public clinic. So that, historically, is what GPs have been doing. They have been doing what they have been told to do. And patients have been really suffering for it.

MS BARRY: Thank you. This is probably, having the clients you see and having to do this every time, heartbreaking, even for someone who is used to it. On the specialists, we have heard in this committee that some of the public doctors are closing their books and I just wanted to find out from you if you have heard why.

Dr Frommer: Some of the public doctors?

MS BARRY: Yes, so the public specialists are closing their books, so they are not taking public patients anymore. They are going private.

Dr Frommer: Lots of the specialists go privately and leave the system. So, previously, at the endometriosis clinic, the specialist that was heading that up, who left 18 months ago, left the public system.

MS BARRY: Do you know why?

Dr Frommer: It is probably out of my level of knowledge to comment on that really well, because the complexity of inter-hospital politics is a little bit out of my expertise.

MS BARRY: All right. So not because it is the speciality or the lack of support, or whatever it is. It is a different—.

Dr Frommer: Yes. It is my understanding, but like I said, I do not know that I am probably very well qualified to comment on that with authority.

MS BARRY: Thank you. One more question if that is okay. On the education piece: we have heard evidence in this committee, from lived experience, that if they were educated in primary school, for example, or in high school then they would probably be aware of the symptoms, manage it better and know how to advocate for themselves. I just wanted to know what education covers. You have mentioned you educate people in the emergency department. I wanted to understand if there were any other education pathways or programs that you run for the younger people.

Dr Frommer: So, education for us has two arms. The arm that I am more responsible for is making sure that our clinicians that are working in pelvic pain are well-educated. That includes making sure that we have had educational sessions for GPs so that they understand or are empowered that when they see that 13 or 14-year-old, they are not dismissing them and telling them that this is just their lot in life, but they are actually educating them and providing the service that they need. As well as through the ACT Pelvic Pain Network, then, making sure that everyone understands who is in the space and how do we refer and how we utilise what we do have in the ACT.

What I am going to defer to Tracey for is our other arm, which is our school education system, which you can talk more about.

Ms Hall: Yes. So, SHFPACT is the lead provider, if you like, of—the acronym is CRSE—Comprehensive Relationships and Sexuality in Education. We are funded to do that from HCSD through our sexual and reproductive health grant. That grant funds two things, or three things, but the two largest being the clinical training school and the working schools. To go to your point, we do receive some funding. We provide education and support services starting at grade 3. So, grade 3 to grade 6 in primary schools, a little bit in high schools and then again in colleges.

We work with providers in all of the other jurisdictions. We share information.

We are in approximately a third of primary schools, and our CRSE program covers all aspects of puberty. So, yes, we do touch on periods, menstruation, what is a period, what is normal period pain, as well as everything else to do with puberty and age-appropriate sex education, if you like. At high schools, again, we cater the topics—and again for colleges.

One of the points that is notable is pretty much all other jurisdictions are scaling up their CRSE programs, perhaps because of endometriosis but also because of a number of other social issues that are happening that children, young people, families, schools want more information on.

So, as I said, we are in a third of primary schools. We charge a co-contribution for students and parents and families as well. I think it is important to note that there were other submissions that mentioned the work we do in schools as well.

The point that I need to be honest with is that funding is uncertain. At this point we are only funded until the end of June. We will be finding out next week how long that grant will be extended for. It will be either six or 12 months at this point, and the funding envelope may decrease. If it does decrease, it is either the clinical training school or our work in schools that we will need to decrease, obviously, to fit within the funding envelope. I was not going to make a point of that. I was not going to lead with that. But for the committee to be sitting hearing that SHFPACT does all of these things, we want to continue to be able to, and we are advocating to be able to do that, but I cannot sit here and say that is confirmed, going forward.

MS BARRY: How much is the funding?

Ms Hall: The whole funding envelope is 770 but that covers the clinical training school, where we are the only clinical training school in Canberra so we do all of the training for doctors, nurses. It also covers all of our work in primary schools. It also covers that we provide an unintended pregnancy counselling service. So, all of that within the 770 which we have been advocating for some period of time to have extended, but also maintained at the current level.

THE CHAIR: Just quickly on the primary schools: the third of primary schools is in the public system?

Ms Hall: All primary schools. We are in government and non-government.

THE CHAIR: So, a third of the total of primary schools in the ACT?

Ms Hall: Yes.

THE CHAIR: And how does the co-contribution work and how is the program delivered? I guess I am thinking specifically about government schools.

Ms Hall: Yes, so the syllabus itself is catered to the age. So, we have a grade 3-4 syllabus and a 5-6 syllabus. Across both syllabuses there are two workshops. The first workshop is physical changes of puberty; the second is emotional and relational aspects of puberty. So, the first covers sexual reproduction and all elements of physical changes and includes menstruation, period products. We pull them out, we have got a little box that the staff take. They work with the whole class and the teacher and make it an interactive workshop.

The second one, obviously depending on the age appropriateness, starts with consent, healthy relationships, the building blocks, if you like. That is the second workshop.

The charge is, if it is just one workshop—I hope I am getting my figures correct here—something like $25 per student, and if it is both, $45, I think. Can I just make that a ballpark? Do not hold me to that one.

THE CHAIR: "Something like" is fine.

Ms Hall: But it means that across all jurisdictions there often is a conversation of who should be funding this work. In most jurisdictions it is a health funded service. In others, sometimes education chip in as well. So essentially our model here is largely health funded with a co-contribution from schools and families in one way or another.

MS BARRY: Is that the state funding, so state education or state health?

Ms Hall: Yes, territory.

MS BARRY: Yes. ACT.

Ms Hall: Yes, so HCSD is our main funder with a co-contribution fee coming from—Look, different schools do it differently. Sometimes it is the P&C, sometimes the school passes it on to the family, sometimes the school chips in, it is whatever works for that school and that community. But we absolutely rely on the core funding from HCSD.

THE CHAIR: I am thinking specifically about government schools. I imagine there would be less of an inclination to ask parents to cover the costs and instead maybe the principal would say, "This is something we are going to fund for the class." How have the third been selected?

Ms Hall: We would love to be in every school.

THE CHAIR: So, it is kind of that some schools have said, "Yes, we really want to prioritise this", others have not?

Ms Hall: It is whoever gets in first. In the current model, we basically answer the phone and work with the school to book it in. Once we are at capacity, we are at capacity. We would love to be in every primary school. We absolutely think—we are really quite passionate—that every young person in Canberra should have the opportunity to have expert advice, working alongside teachers and schools and families and the community. It is unfortunate that only a third have that opportunity at the moment. It is more unfortunate that, depending on the dialogue over the next week, it could be less than that.

THE CHAIR: Thank you.

MS TOUGH: I want to pick up on the waiting times and how, when someone is waiting, they are often not getting treatment. In your submission you talk about the risk of focusing on the diagnosis as the important part of someone's journey, rather than the whole journey and the managing of pelvic pain, regardless of what is causing it. What are the risks involved in letting someone sit and wait for a diagnosis and not doing anything about it in the meantime?

Dr Frommer: That is a really good question. Probably the best way I can describe it is by what I see from these patients that have been waiting. What we know, around chronic pelvic pain particularly, is that the longer that you are exposed to it, the more likely it is to worsen. Even if your endometriosis remains stable, your pain is highly likely to worsen. What I see in these patients is often untreated; they have increasing issues with pain sensitisation, which is not a matter of these women being over-sensitive, let me be clear. I am very careful about the use of "sensitive" in a women's health space, because women, for a very long time, have been told by the medical system that they are being over-sensitive. Instead, this is a really normal nerve response that happens when we get exposed to long-term pain.

When that happens, we are getting women who are getting more frequent pain, more severe pain, with greater impacts on their life. My patients are very tough; let me be clear. Women are very tough. We have also completely normalised pelvic pain within our society. Women expect that they should just keep going. By the time that they have waited for years on that waitlist—because it often takes them a long time in the first place to recognise that this is a problem, then they are waiting years on that wait list—often, it has been at least a decade, by the time they are actually getting reasonable care. It is often impacting their work life, it is starting to impact their relationships, it is starting to impact their self-esteem, their sexual wellbeing, and potentially it is impacting their fertility. It is quite a wide-range impact. I think we do not necessarily recognise how significant that impact is.

As I said before, there are lots of things that we can do, and diagnosis is still an important part of that puzzle. Historically, the way we have been taught is that you need to diagnose before you even start managing. All the research we have and all the knowledge we have now shows that I do not need that diagnosis to start managing these people and put them on a completely different path. Does that answer your question?

MS TOUGH: It does. What about a system that, when someone presents with pain, looks at treating the pain first, managing the pain, in whatever way that takes, while waiting for the surgeon, so that by the time someone gets to a surgeon, they might have a really great management system, and maybe the surgeon says, "You don't need surgery now. You can keep waiting because everything is under control"? Or the surgeon might say, "Okay, yes, you've tried these five things." Would that be a better model?

Dr Frommer: That is the model that is mostly being proposed, as we move forward and understand pelvic pain better and better. A lot of women do not need early surgery. Definitely, there are some who will not respond to medical management, and they absolutely should have access to the surgery they need. But we also know that repeat surgeries have lots of negative impact around potentially worsening pain and definitely worsening long-term fertility outcomes. These women should be offered, and can be offered, medical treatments prior to that.

You are right; by the time they potentially get to the surgeon, when they get to that point, potentially they are really well managed, and they can come back to surgery if they need it for pain or for fertility management. Unfortunately, both because of the lack of education amongst society and how we look at pelvic pain in society, and the fact that the first point of call for these patients is their GPs, and they are not confident in managing it, they are stuck on these waiting lists.

MS TOUGH: How do we make sure that we do not end up back where we were, where, while waiting for a surgeon, you are just given five different contraceptive pills to try, without putting in that support and the focus on treatment? If we are told, "Yes, we're treating you, because we've tried you on these things," how do we make sure that that pathway is real treatment and not just dismissive, and saying, "Here, take this pill; here, try this"?

Dr Frommer: That is really important; with a lot of my patients, that is how they feel that they have been managed. The way I have been encouraging GPs, when I talk to them, to approach this is to acknowledge, in the first instance, that when someone presents to you with significant period pain or pelvic pain, we know that they have a 50 per cent chance of having endometriosis. That is often the first thing I am saying to patients, because they need to know that. Whether they decide that they want to chase down getting an ultrasound or seeing a surgeon in that very first instance, it needs to be their choice. They need to be well informed about that. That is not a model that GPs have felt confident in, until now. They have felt like, if they say those words out loud, they need to be sending them to a gynaecologist in a specialty clinic.

You probably saw it a lot in our submission; we were talking a lot about education, at both a societal and a GP level. That is what really has to change. Once we can educate these patients—and their GPs will still need to be the first point of call—they can know, "Okay, we're not just throwing things at you, we're actually talking through one of the many management options, one of which is hormonal therapy."

Patients need to make a decision about what they want to do. Often, a lot of my patients, when they turn up to the clinic, will say, "What I want is surgery," and once we have talked it through—and I would never say no to referring anybody for an ultrasound or surgery—a lot of the patients, by the end, say, "I actually really don't want surgery." Most of us do not want people to cut into us, if they do not have to. They are just so relieved to know that there are other options, because what they really want is for their pain to be better.

MS BARRY: To go away.

Dr Frommer: Yes.

MISS NUTTALL: I have a question about cultural safety, because it has come up in a few different submissions. Specifically, they were talking about trans and gender-diverse folk, First Nations people, people from culturally and linguistically diverse backgrounds, people with a disability, and a lot of people that are young people, people on low incomes, and people with larger bodies as well. As a community provider, how do you make sure that your services are culturally safe but approachable for these different cohorts?

Dr Frommer: It is a real, significant consideration. In the time that I have worked with SHFPACT, we have made it a really big priority, when meeting those potentially at-risk populations. They are the populations that we are more likely to either discount or bulk-bill. We make extra-long appointment times, to make sure that our service can meet their needs.

We have more capacity to engage with interpreters and other support structures to be able to support them, as well as being an environment that—from the feedback I get from patients—feels inclusive and supportive. Patients often come to us saying, “I don’t feel comfortable talking about this with my GP, but actually I know you guys are a safe place to talk about this.”

Ms Hall: All of our services, not only clinical but non-clinical as well, are client centred and trauma-informed. We do run regular training. We have Meridian in, for LGBTQI training. We work alongside Winnunga and other Aboriginal providers. Almost historically, from the very beginning, the underpinning, foundational principles of SHFPACT have been to be inclusive and culturally aware.

MISS NUTTALL: I very much appreciate that, because it is one of the challenges. Is there an advantage in being embedded in community rather than necessarily in the private space or the public hospital system, which people associate their trauma with?

Dr Frommer: Yes. That is a really good point. As you are probably aware from a number of the submissions, a lot of patients, by the time they get significantly into their journey, have significant medical trauma that often has occurred within the public system. We can be a safe place that exists somewhere between the two, and that can be really helpful. It also means that we can guide them, for when they do need to interact with any of those spaces, as to how they might do that in a trauma-informed, safe way.

Ms Hall: One of the other elements of our service that we are really proud of is complete integration across all of our service streams and wraparound supports. Quite often, we will have so many scenarios where a person might become aware of SHFPACT through our disability service stream. They might be accessing education or counselling in a disability stream.

Through that, the staff will hear about pelvic pain—I will use that example—and there can then be a warm referral into the clinic and walking with the client into the pelvic pain service. Likewise, Tara and her team might first come across somebody—I will use that same example—through the pelvic pain clinic who does have a disability and did not know about our disability patient and counselling services.

I think that goes to not only not being embedded in a hospital and being in a primary-care community-established organisation, but the wraparound service that comes from that, and support for the client or the patient, wherever they start, the whole way through their journey.

MISS NUTTALL: Your submission points out that there are about 20,000 Canberrans living with type 2 diabetes and around 50,000 women and people assigned female at birth in Canberra who have been affected by chronic pelvic pain. I do not want to pit those two conditions against each other. Both deserve a good response from our medical system. I am curious as to how you would compare the scale of available public and community supports between those two.

Dr Frommer: That is a fabulous question, and it is the reason that we included it in the submission. We have all heard of the extensive services, and the GP training that goes in to managing type 2 diabetes. Type 2 diabetes is often the focus of most of the structure of how we manage chronic conditions, whereas often GPs are not aware of even thinking about chronic pelvic pain and endometriosis as chronic conditions, and how we might coordinate their care.

I would like to say it is better, but it is not as good as it should be. Those numbers really speak to the fact that this needs to be a coordinated response. There are a lot of women who are being very tough, but their lives are being significantly affected by this. Historically, it has got a tiny drop in the ocean worth of funding to be able to do that.

THE CHAIR: We are out of time. On behalf of the committee, I thank you for your attendance today. I do not believe we had any questions taken on notice. The committee will now suspend the proceedings.

Hearing suspended from 12.46 to 1.47 pm

ANDREW, DR MERRI, Research and Policy Manager, Womens Health Matters
MALIK, DR TAYYABA, Research Officer, Womens Health Matters
NEWMAN, MX PIPPA, Senior Policy Officer, Women with Disabilities ACT
REED, MX KAT, Chief Executive Officer, Women with Disabilities ACT

THE CHAIR: Welcome back to the public hearings for the inquiry into endometriosis and other pelvic pain conditions. We welcome representatives from Women with Disabilities ACT and Womens Health Matters. Please note that, as witnesses, you are protected by parliamentary privilege and bound by its obligations. As such, you must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Would any of you like to make a brief opening statement before we go to questions?

Mx Reed: We have a quick opening statement.

THE CHAIR: Go for it.

Mx Reed: Firstly, thank you very much for the opportunity to speak with the committee today. We want to use our opening statement to affirm the importance of this inquiry and to advocate that information gathered through this inquiry process is shared widely to genuinely improve access to care for people with endometriosis and chronic pelvic pain.

We have noticed that this issue has been carved out in policy spaces, often with the assumption that it is being addressed elsewhere. For example, WWDACT, Women with Disabilities ACT, and Womens Health Matters have been funded under the Disability Health Strategy to scope sexual health information and services for women and gender diverse people with disabilities. Accessing services to treat and manage endometriosis and pelvic pain is not explicitly in the scope of this project and thus is not addressed under the Disability Health Strategy. So, in our scoping report, we will not be able to comprehensively report on the experiences of people with disabilities who have endo or pelvic pain.

People who have shared their stories either directly in this inquiry or through surveys like that conducted by Womens Health Matters and WWDACT are relying on this inquiry process to be the catalyst for seriously considering how the territory is providing care for endometriosis and chronic pelvic pain. We need this to be visibly addressed in future policy work, such as the upcoming ACT Womens Plan and a future women’s health strategy.

THE CHAIR: Thank you. We will now go to questions. Miss Nuttall, we will start with you.

MISS NUTTALL: Thank you all for appearing today. We appreciate it. Some submitters that we have heard from have called for an emphasis on pain management rather than diagnosis being the be-all and end-all. Obviously diagnosis can take ages. Do you largely agree with the principle of that statement? Do you think our approach is alright right now?

Dr Andrew: I am happy to start on that. That is actually one of the more complex issues that we came across while writing our submission. I think it is fair to say that there is a consensus, backed by evidence, now that affirms that diagnosis should not be the only goal of the systems that are in place to deal with endo and pelvic pain and that management can be a way to alleviate disruption to people's lives and wellbeing separate from diagnosis. However, in the system as it currently is, which is resource constrained and where people have often had to have a diagnosis in order to get effective help with their pain, it is understandable why there has been such an emphasis on diagnosis.

MISS NUTTALL: On access to both pain management and to a diagnosis in our current system, how do you think we can do those things well? Is it about workforce planning? Is it about public and government subsidised community-based care? Is it about cultural safety? What do you think are the sorts of first interventions that we need to make to improve availability of support services?

Dr Andrew: Our submission was developed on the basis of research more broadly and stakeholder engagement, but primarily on the basis of our survey research, which collected several hundred qualitative open-ended responses from people with experiences of endometriosis and pelvic pain. We have developed a recommendation to create an integrative pelvic health system which basically, in answer to your question, looks at the whole system rather than picking off individual parts for prioritisation and development. The parts of that system would be a focus on educating early; a focus on assessing in the community; building and connecting a hub-and-spoke network with specialist capacity at its heart, located in Canberra Hospital; and a way to treat complex cases in a multidisciplinary way. Those things are detailed in our submission in a lot more detail. But, in answer to your question, there is no one single part of the system that can be changed to fix the whole thing.

MISS NUTTALL: On that—and I think I recall something about it in your submissions—do you see a particular role for care coordination within that, and where do you think that role should sit?

Dr Andrew: We consulted with Sexual Health and Family Planning as part of our development of our submission, and we are aware of the work that they are doing currently. We think that expanding their service to incorporate care coordination would be the logical way to go ,because they are already developing the provider network that can support that and they have the experience of already starting to provide some of that navigation support.

MISS NUTTALL: Absolutely. Across the board, some of the evidence we have heard goes to the fact that community-based services are often the ones that people trust more—that there is more of a sense of cultural safety if you are a person with a disability that faces excess medical stigma and things like that. Is that what you are finding as well—that the community-based support makes a difference in that?

Mx Newman: I think also just having access to care coordination is something that people really struggle with, particularly if they are interacting with the healthcare system in a number of ways and are likely to have had a large number of experiences with health care and potentially experiencing medical trauma at all stages of trying to seek health care. Having diagnostic overshadowing is an issue that arose through people that we spoke to in preparing our submission to this inquiry, where people having a disability of another kind means that their chronic pelvic pain is not taken seriously and they are not referred to the people that they need to be. I think having a centralised forward-point of care coordination and expanding access to this in the ACT would have allowed lots of people to actually be able to know what is out there and where the next steps are to receiving care. A lot of people—not just people with disabilities—have reflected that they tend to be knocked back the first time, the second time or the fifth time of trying to be taken seriously for their condition.

Dr Andrew: Just to add to that, I think a key part of that is having the time in that initial consultation to unpack all the aspects of someone's experience, rather than someone needing to go into a very short consultation with a GP, for example, and having to already have packaged that all up as a case for them getting further assistance. Having the time for that to be explored in a way that is sensitive and responsive can prevent that turn-away experience.

MISS NUTTALL: Thank you.

THE CHAIR: Your submission spoke about both Sexual Health and Family Planning and the Canberra Endometriosis Centre within the public system. How do you see the two operating in tandem? How are they complimentary? Obviously, you are welcome to put in Women with Disabilities as well. What is the best way of managing that in a small jurisdiction?

Dr Andrew: There is definitely a place for both in this vision of an integrated public health system that we have. I think the hospital-based service probably has immediate connections through to more acute care surgical pathways in a way that might not be as straightforward for community-based care but, ultimately, we would want the community-based care to be connected with that centre as well.

THE CHAIR: Obviously, in an ideal world, we would not have people having to go interstate for treatment. It has come up through the day that that is what is happening currently. Some people seem not to have been aware of the Patient Travel Assistance Scheme and others have said it has been limited. Can you say anything more about potential reforms to that scheme that might be necessary while we establish a more comprehensive offering here in the ACT?

Dr Andrew: I think you are right that some people were not aware. Also, there are certain thresholds for how much can be paid out and then there are issues with documenting and justifying the need for that. So I do not think it is a very easy process to go through for people to access it. But, for people who have been able to, it has sometimes made a huge difference. We heard from someone in our survey, who was able to advocate through that for a really quite high level of assistance, that it made a huge difference to the care that they were able to receive in Sydney. So it is very uneven in terms of people's experience, I think.

Mx Newman: We heard similar from the people that we spoke to. I think it is important to note that people's other disabilities sometimes make travel very difficult or impossible, particularly when trying to access accommodation that has accessibility requirements that people might need. From what we heard, when they were able to access the scheme, the reimbursement did not cover what was required in order to have accessible accommodation. We have heard a couple of instances of people knowing that it existed and advocating for their needs to be met. But there are vastly more experiences of people not knowing about it at all.

THE CHAIR: So it needs to be better promoted and expanded. Governments are often very good at making you aware of the things when they are taking things from you but not so good when they are offering things to you and wanting you to apply for them.

Dr Andrew: Yes, I think sometimes there is a reluctance to promote things really broadly, because there is an awareness within the system that, if it were taken up to the full extent of eligibility, the system would not be able to cope with that.

MS BARRY: Thank you for your attendance and for your submissions. Picking up on your initial comments around a scoping report, you mentioned that it would have been really useful to have some of these issues ventilated in that report. What was the breakdown there? Why was that not picked up as a system joined-up approach to issues facing women with disability? What broke down?

Mx Newman: This project, which is the Sexual Health Scoping Project, is funded by the ACT Health and Community Services Directorate under the Disability Health Strategy. As part of the strategy I think there was an awareness that there were other programs and policy pieces in train, such as the Women's Plan or a projected women's health strategy, that would happen further down the line, and there was I guess an inclination to not duplicate work early that is likely to be funded later on. We wanted to highlight in our opening submission the importance of making sure that, because those things have been assumed to happen later, this important work from the inquiry does not become lost.

Mx Reed: Our experience with working with this project under the Disability Health Strategy, particularly when we are talking about disability and women's health, is that there is such an interconnectedness with disability and different conditions. I think the machinery of government and the way funding works and the way particular topics and particular projects are funded means that sometimes we have found it very difficult to carve out space, in the example for this one, in the report, to capture the full picture of the experiences that we are hearing from people, because there is such a limited scope from, I suppose, the government side in terms of what it is meant to address. But the reality of people with lived experience is that so many of these things are interconnected and they all contribute to the overall experience. I think it has partially also been quite hard, particularly with women's conditions, like women's health conditions, because conditions are so interconnected.

MS BARRY: In an ideal world, what would a joined-up approach look like? The reason I am asking this question is that, if there is work that is currently being done, it is really important that they are all joined up. In an ideal world, how do we design or capture the things that are important to people living with disability so there is a holistic approach to care?

Mx Newman: We have used our project as an example of something we have come across a number of times when looking at actions under various strategies where, for genuine funding constraint reasons, the strategies are trying to limit the scope of their actions. If there were an awareness of policy pieces that were upcoming and using the projects that were currently in existence and the consultation mechanisms that do exist and being open to collecting information to inform the next stages of policy, even if it is not able to be acted on right away under the current strategy or the current funding environment, I think that could have worked really well for this particular example and, more broadly, for things like a disability strategy, we would then want to be interacting with other strategies like the Domestic, Family and Sexual Violence Strategy, which is also upcoming, and have different directorates talking to each other about what actions could overlap and where funding could be shared or pushed a little bit earlier, so that we are not going out to people multiple times to get the same kinds of information.

MS BARRY: Thank you very much. There has been a conversation in this committee around disaggregated data and the importance of that in ensuring that we are designing care that fits a broad spectrum of people—people living with disability, LGBTQI, people from the CALD community—and I just wondered whether you were doing any work on that.

Dr Andrew: Yes; quite a lot.

MS BARRY: Yes? What was the data showing.

Dr Andrew: Thank you for asking about data,

MS BARRY: I am a data person. I love data.

Dr Andrew: Womens Health Matters has a long history of working on data collection in relation to women’s health. Our key mechanism at the moment is a survey of women’s health and wellbeing that we conduct every two and a half or so years. We are now, under a new agreement, sharing that data directly with Women with Disabilities ACT to make sure that that is a community resource, not only something that we are using in a proprietary way. This inquiry has been an early instance of where we have been able to do some of that work together. We did analyse across a number of variables whether people’s backgrounds and characteristics in various dimensions had an impact or seemed to be related to how much people were experiencing pelvic pain conditions. Would you like me to give an overview?

MS BARRY: I would love you to; thank you.

Dr Andrew: We initially looked at migration, visa, country of birth and language background as a set of variables. For those variables, we generally found that there was very little difference in prevalence when comparing on the basis of country of birth, migrant background, preferred language or main language spoken at home. In relation to visa status, we had a finding that temporary visa holders reported lower rates of persistent pelvic pain, but it is not exactly clear why that would be. Given issues around education and access to services, it is probably not related to the genuine prevalence in those communities; it is probably more related to ability to get health services in order to explore conditions.

In relation to financial stress, we found significant differences depending on financial stress, noting that these impacts can go both ways. We cannot infer causation from these findings, especially in this area, because having persistent pelvic pain can limit someone's ability to earn income but having a low income can also impact ability to get health services and other protective factors. So it can work both ways, but it was quite stark. We found that, among people who had experienced at least one form of financial stress in the last year, 26 per cent had experienced persistent pelvic pain compared with only 11 per cent of those who said that they had not experienced any financial stress, which is more than twice the proportion; and that people with persistent pelvic pain were twice as likely to have gone without medical care or medication because of not having enough money, compared with people who did not have persistent pelvic pain. So there is a strong relationship, even though we cannot say exactly what is causing what. In relation to age, as probably would be predicted, people who are aged 25 to 34 and 35 to 44, in those age groups, were more likely to have experiences of pelvic pain.

We did look at gender. In our survey, we ask whether people are non-binary, trans, agender or genderqueer. Although the survey has a scope of women and people who are firm identifying or align themselves with those groups, we also ask in more detail about gender. We did not have enough respondents to be able to make strong findings about any patterns there. But, drawing on input from other organisations, including WWDACT, there are definite challenges faced by trans and gender diverse people in seeking support with pelvic pain. That is something that definitely needs to be addressed, particularly where services are described as "women's health services".

We looked at sexuality in relation to pelvic pain. People who told us that they were queer had higher reported rates of pelvic pain compared with people who told us that they were straight, gay or lesbian. So that is something, perhaps, to unpack. But it is also reflected in our other research about access to primary health care where people who told us they were queer had lower or poorer access to health care. We asked about neurodivergence, and people who told us they were neurodivergent reported much higher rates of pelvic pain. Thirty-six per cent of people who were neurodivergent in our survey reported pelvic pain compared with only 12 per cent of those who told us they were not neurodivergent, which is pretty striking.

We have already touched on this, but people with disabilities experience pelvic pain at more than twice the rate of people without disabilities—again noting that there are some complexities there where the pelvic pain could be an aspect of disability or could be a different disability separate from that. We also looked at mental health and found there was a strong relationship in the statistics with people who reported high levels of psychological distress. Thirty-one per cent of people who reported high levels of psychological distress also reported having pelvic pain compared with only 13 per cent who reported lower levels of psychological distress. There were similar patterns with people having reported ever having mental health conditions or having mental health conditions in recent years as well.

Finally, experiences of violence also appear to be related to higher rates of pelvic pain, particularly with people who had experienced sexual violence specifically. For people who had experienced sexual violence, 26 per cent reported persistent pelvic pain compared with 13 per cent who did not report sexual violence, which is consistent, in general, with other research that has found that people who had experienced any kind of violence tended to have more chronic pain in general and that pelvic pain, specifically, was linked with experiences of sexual violence during childhood or adolescence.

Those are the main dimensions of how the demographic data relates to pelvic pain. Those relationships are very similar when we looked at endometriosis, adenomyosis and PCOS separately. So I will not go through all of that, but there were very similar patterns to pelvic pain in our data.

THE CHAIR: Would you consider tabling that data for us to be able to access?

Dr Andrew: Yes, of course; very happy to.

THE CHAIR: That would be great; thank you. It is incredible data.

Dr Andrew: Thank you very much. I hope you do not mind that I took several minutes to go through it all.

THE CHAIR: No; it was really helpful. I am just thinking also if the endometriosis links have that specific data, in case we need it for our recommendations and findings.

Dr Andrew: Sure; no problem.

THE CHAIR: Thank you.

MS TOUGH: Thank you all for your submissions. I want to pick up on that data and the intersectionality discussion and then the financial barriers of accessing care. We have heard a lot this morning and in submissions that there is already a financial barrier to accessing care. We have had one person describe it as a two-tier system, where, if you can afford to pay you will get help quicker and, if you cannot, you will be waiting longer and potentially not getting much help in the meantime. When you add on the intersectionality of having a disability or another factor that is already making it harder to access health care or is making it more expensive, how are people navigating this and what are the barriers?

Mx Newman: We heard that people are really struggling to navigate this. This was the overwhelming theme. We spoke to 22 people as we prepared this submission and the survey, and nearly all of them said that cost was a really significant barrier to accessing diagnosis or care.

MS BARRY: Sorry, did you say cost?

Mx Newman: Cost, yes. In terms of how people are navigating it and how it is relating to their other conditions, we already mentioned people are less likely to be able to afford to go interstate and also less able to access private providers to receive care. We have a case study in our submission of one person that we spoke to who was spending thousands of dollars per year on management. One of the key things that came out was that lots of the recommended sort of pain management approaches, such as particular forms of contraception and certain pills, are not on the PBS. So it can cost hundreds of dollars for people, but it can be really essential in maintaining their day-to-day ability to live their lives and not be in significant pain.

We see this a lot in all of our work where people with disabilities are already less likely to have full-time employment and, on average, have less disposable income and so are more likely to struggle to access health care across the board. It is particularly an issue for this area in endo and pelvic pain, where people are likely to have to continue to advocate for themselves and potentially approach multiple people to be taken seriously, and the cost of that can be prohibitive. Even just going to finding another GP if your first GP did not give you the care that you needed, with the lack of bulk-billing clinics in the ACT, that can be the first barrier for people.

Mx Reed: I would just add that we heard that, when it comes to the approach of managing pelvic pain, a lot of that comes down to the help and support of allied health professionals, which are, again, a huge step up in cost compared to the public services. Even the chronic conditions management that some of our members accessed only gives you access to about six sessions before you need to have that renewed. We heard a few times that the rebate that they would actually get would mean that they are still spending upwards of several hundred dollars on each individual session with an allied health professional. Also, unfortunately, because we are talking about women’s health and there is a lot of integrations, some of our members said that, at any given time, they were accessing three to four different allied health professionals to deal with the same condition. So the cost really adds up very quickly.

Dr Andrew: One thing that I just wanted to add is that, often in the context of people’s lives, their own health is just one aspect of health that they are managing. Women with disabilities are more likely to be carers than people without disabilities. In general, being responsible for the wellbeing of others in your household often means that the priorities of other people’s health need to be taken into account. So it is not as if anyone is only full-time just focusing on finding affordable care for themselves; it is also often for others as well.

MS TOUGH: Thank you. I want to move from the financial side to navigating multiple health professionals. If you are seeing a health professional or multiple health professionals for pelvic pain and then you are seeing other health professionals for other health conditions you have, how do we make sure those professionals are talking to each other, are aware and trained enough to say if, for example, you go to one doctor, not about pelvic pain, but you explain your symptoms, “Have you considered you might have endo or you might have something else? Are you getting help for that?” and then not just dismissing anything you do have that you are there to see them for as “That is just because of endo; I cannot help you”? How do we make sure that all our professionals are talking to each other and giving holistic care as part of broader care?

Dr Andrew: I think we have some recommendations about training coordination.

Dr Malik: Yes; under care coordination and accountability, we recommend establishing a required reporting framework for pelvic health presentations across ACT. It means that every time someone with pelvic pain visits any ACT health service, like ED or GP or any specialist, their data should be recorded and reported. Currently, it is fragmented or not recorded at all. That is why we also see that the official estimate of the prevalence is lower than what our survey data shows.

We recommend that all the data should be collected in one report and then maybe the government or officials can share that report after a year or two years to track down what is actually working. This data should be accessible to those organisations working with women on improved health, wellbeing and education. If the report is also accessible to the community, this will show the community what system is actually working and what is actually improving or not. It is also important because, from the perspective of organisations and advocates who are working for women's health and wellbeing, it will make it easier for them to track down what is actually working and make government accountable for future advocacy stuff.

MS TOUGH: Wonderful. How can individual make sure that their doctors and their health professionals are talking to each other? Right now it falls to the individual to have to retell their story to every single health professional they see. Some health professionals might go, "Why are you coming to see me; that is so and so's problem," when they have a pelvic pain condition but they are coming to this specialist for something different. How do we empower individuals to be able to do that but also ensure that there is that education across different health professionals?

Dr Andrew: There are probably other people who can speak to this in more detail who are working in medical professions, but we do recommend developing skills and knowledge right through from medical training to continued professional development. I know this is not exactly what you are asking about in terms of system integration.

MS TOUGH: This all helps.

Dr Andrew: If each successive generation of doctors and professionals coming through their training comes into the system with a higher level of understanding, networks of expertise and interest, like the one being convened by Sexual Health and Family Planning ACT, get strengthened and that understanding diffuses through the whole system. Then, even if there is not an information sharing mechanism, at least there will be less dismissal and less referring on to someone else to deal with an issue and more awareness that there might be a pelvic pain or endometriosis issue.

MS TOUGH: Yes, thank you.

Mx Newman: It is important to consider how this works in tandem with education on other things. We had quite a number of people report that, when they went to a doctor about a pelvic pain condition, their other conditions or disabilities were not necessarily understood or remembered and some recommendations made by those medical professionals did not take disability into account and put people in genuine danger. I think it speaks to the need for various kinds of training and information for medical professionals about pelvic pain and also about disability and intersections of different conditions. Merri mentioned the high prevalence of people with endometriosis or chronic pelvic pain who are neurodivergent. I think that is a particular intersection that could be considered in the education and upskilling of medical providers.

Mx Reed: In responding to your question about how we can ensure that individuals are more empowered, I think health services themselves could do more to be a bit more explicit with patients around what rights they have, particularly around things like if they are not feeling heard and where they go from there. There should definitely be some community education around self-advocacy within the health system. I know there are a number of organisations in the ACT already doing some great work on that. Some investment in that and some greater visibility of that could really support individuals to be able to navigate that.

MS TOUGH: Thank you.

MISS NUTTALL: I want to go back to the high co-occurrence with neurodivergent people. I do not know if I am just an ADHD and projecting, but do you have any idea what mechanism sits under that—from your conversations with your members and responses to your survey? Are there things like the executive function makes it difficult to organise appointments; you encounter a closed door and it takes longer and, at that point in time, your pelvic pain has gotten worse or is more severe? Is it something like that? Do you have any idea why?

Dr Andrew: I do not have that knowledge; sorry.

Mx Reed: From what we have heard from some people, absolutely some of it is the executive function. If people are managing four different allied health professionals as well as their GP, that is already a lot of appointments. We know that, particularly for people with ADHD and autism, that kind of executive function and just managing those appointments can become a part-time job. One person that we spoke to mentioned going to see a professional or a specialist for something, thinking that your needs would be taken care of and you would be guided through that consultation, and that sometimes that is not actually the case—that the consultation might go a very different way. I think for neurodivergent people, being able to navigate that socially and that self-advocacy component can be quite a huge burden and can be something that means that they need to book a second appointment to go through the same information or to pursue a different path, because that was not offered to them in the appointment.

Mx Newman: There is a lack of research in this area, but the links have been identified with clusters of conditions such as neurodivergence, connective tissue disorders and endometriosis and how that intersects with gender identity and queerness. It is not necessarily clear what the causation of these things are, but I think there is definitely improvements that can be made in the health system that remove some of the barriers to accessing health care for those people. I think it would be interesting to consider, particularly as the territory considers a neurodiversity strategy, how that intersects with accessing health care and particular clusters of conditions that are experienced at higher rates by neurodivergent people.

Dr Andrew: Yes; I think that is a general point that we could make across a lot of different data findings where we find that certain people with certain experiences are more likely to have pelvic pain conditions and, even where we do not understand what the mechanism underlying that relationship is, just that fact of representation can be taken into account when system reforms and services are being designed, because then we can presume that a certain large proportion of people needing a service are going to be neurodivergent and so design it in that way.

MISS NUTTALL: In the Womens Health Matters submission you talk about PMOS and the barriers to treatment, because AFAB folks have their health concerns taken more seriously when they are trying to conceive and things like that. Do you have much information on or do you hear much from your members about how that emphasis on reproductive health impacts asexual people and people on the a-spectrum trying to seek support?

Dr Andrew: We have not, I do not think, had any of our responses in our survey directly address that experience from the perspective of someone who is asexual. We know, as a more general kind of finding, that navigating health systems that are focused on so-called women's health as someone who is queer or LGBTIQA+ is alienating and not very welcoming. I do think often it is centred around this presumption of childbearing or not childbearing, like in either direction, sometimes as well.

THE CHAIR: We are out of time, unless anyone has a "I wanted to say this, but did not get my chance to" contribution.

MISS NUTTALL: Excellent data sources; thank you.

Dr Andrew: Thank you, yes. Regarding the data sources, I wanted to mention that, in our data, we explicitly ask about whether someone has been diagnosed with or treated for endometriosis, adenomyosis or PMOS. I should be saying PMOS now instead of PCOS. We explicitly said "diagnosed with or treated for", because of the diagnostic delay that you would have heard so much about where some people are just not able to get a diagnosis. I just wanted to mention that, because in some other submissions, I noticed that our data was used in the context of "diagnosed with". So I just wanted to clarify that but also explain that there is a reason behind that—that it is really because some people have not been able to get a diagnosis, and we do not want them to be excluded from the data.

THE CHAIR: Thanks for that clarification. That is really helpful. Thank you all for your submissions, your contributions and your time to be here today. We very much appreciate it. I do not think we had any questions taken on notice, but we are going to steal that data from you and make use of it—so thank you.

Short suspension

AUST, DR KERRIE, President, ACT Branch, Australian Medical Association
MENDE, DR MARTINA, Associate Board Director, Royal Australian and New Zealand College of Obstetricians and Gynaecologists

THE CHAIR: We welcome representatives from the ACT Branch of the Australian Medical Association and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

Dr Mende: Thank you for having me today. I am not a specialist obstetrician and gynaecologist; I am a GP obstetrician. The reason I am presenting here is that I work within the ACT. I work for Sexual Health and Family Planning ACT, in the commonwealth funded pelvic pain service, and I am also a member of the RANZCOG endometriosis living evidence guideline group and chair of the subcommittee, the fertility group, which we are about to start working on next week.

THE CHAIR: A very appropriate witness for the inquiry, by the sounds of it.

Dr Aust: She is amazing. I have been a long-term fan. I am also a Canberra GP, with a special interest in pelvic pain. I might highlight for members of the committee that all three of the women sitting in front of you have lived experience of pelvic pain and navigating the health system; in my case, also through my daughter. We can talk from both sides. I would also like to introduce Ms Sarah Colyer, who is the ACT journalist for the AMA, and she was instrumental in helping to do the research and putting together our pelvic pain submission.

THE CHAIR: Thank you very much. Please note that, as witnesses, you are protected by parliamentary privilege and are also bound by its obligations. As such, you must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Before we go to questions, would anyone like to make a brief opening statement?

Dr Aust: I think both of our submissions stand on their own, so we are happy to launch in.

MS BARRY: Thank you very much for attending today. We have heard lots of conversations around delay in diagnosis and, significantly, women presenting at emergency departments and not being believed. From your experience, where is the disconnect?

Dr Aust: I will start with my GP hat on. As we discussed in our submission, there is a huge range of causes of pelvic pain. I am really pleased that there has been such a huge amount of awareness of endometriosis, which is starting to flow through to things like research. When we have research, it is much easier to develop guidelines and have evidence based treatments, and also investigations. Some conditions are very easy to diagnose. I had a gentleman with pancreatitis. He turned up with very typical epigastric pain. On palpation, it was very clear what was happening, and blood tests and a CT scan confirmed that. Within about 48 hours, we knew exactly what we were dealing with.

Pelvic pain is much more complex than this. We think about everything: “Is this secondary to common things such as sexually transmitted infections? Is this endometriosis? Is this dysmenorrhoea from heavy menstrual bleeding, fibroids or pelvic congestion syndrome?” The list can be quite significant, including non-gynaecological conditions, such as irritable bowel syndrome. Sometimes these things take time to work up. You start with common and important differentials. I might need to rule out something like an ectopic pregnancy, and then we start to work through them. But you cannot order a laparoscopy, deep pelvic ultrasound and colonoscopy to exclude irritable bowel, endo, a fibroid or something like that all in one go. We have to have a staged approach to diagnosis. That said, I absolutely accept the fact that we get the feedback that it takes up to five years to diagnose. It is unacceptable, and it is a space where both RANZCOG, the RACGP and the AMA have been working, to make sure that those pathways become more straightforward.

The second part to the diagnosis, if we are thinking about endometriosis, is that there are some treatments that you can start with, when there is what we would call a reasonable suspicion. We may not have tissue diagnosis or a visual diagnosis. It is quite reasonable to start women on some of the specialised contraceptive pills, which in the last 12 to 18 months—correct me if I am wrong—have been put on to the PBS. They are incredibly effective for medical management. In the case where somebody has an excellent response to an oral contraceptive pill or a Mirena or Kyleena, a working diagnosis of endo may not need a tissue diagnosis at that stage.

Obviously, wait times in the public system for a tissue diagnosis via laparoscopy are very long. The current triage category for suspected endometriosis is category 3, and that is not unreasonable when we look at how the health system resources are managed. Cat 1 includes catastrophic bleed, suspected ectopic pregnancy or cancer. Cat 2 might be other conditions which are causing heavy menstrual bleeding to the point where somebody is experiencing things like anaemia. Again, it is not unreasonable to have that triaged at a higher level, but waiting 18 months to three years for a laparoscopy when somebody is experiencing pain—and the initial treatments are not working and we need to step up to those that need a tissue diagnosis in order to prescribe under the of PBS—is where some of the challenges might start coming into play.

Some factors might confound this. Especially for those who have experienced sexual assault and complex trauma, that can create a big interplay in how their pelvic pain starts to present. We know that long-term opioid use significantly changes people’s pain pathways and can cause chronic pain to get worse. That can be a factor that comes into play in diagnosis. I have probably spoken enough now, so I will let Martina answer the question as well.

MS BARRY: I trust you to give me all the information. I ask one question and the information is—

Dr Mende: Kerrie said everything that I was going to say, but I will add to it. Don’t give us the floor, because we have lots to say!

Dr Aust: You didn’t want to see anyone else today, did you!

MS BARRY: Why don’t we give you an hour!

Dr Aust: We talked about this last time.

Dr Mende: I completely agree with what Kerrie has said. You mentioned women presenting to the emergency department, and I just want to say that, when I refer to "women", I also acknowledge that not everyone was assigned female at birth. For the purposes of the inquiry, when I say "women" I need to be inclusive, because people identify in many different ways. When someone with a chronic condition presents to an emergency department, there is a scope issue. An emergency department has a particular scope. It can order certain investigations and it can manage acute presentations. An emergency department is not equipped to deal with a chronic condition and it is not the place for chronic conditions to be managed.

When somebody presents to the emergency department with a flare of pelvic pain, be that a first presentation or after multiple presentations, a number of systemic steps have to happen to ensure that the person gets follow-on care. The emergency department can patch up that pain or that presentation for a period of time. There is a process where the person will be assessed and it will be decided whether they are unwell enough or have an acute problem, where they need to be admitted to hospital for immediate management. But, with a chronic condition like pelvic pain, if we can get the pain under control and make the person comfortable enough to discharge home, often home is better than having a prolonged hospital admission.

During the hospital admission, we cannot do all of the investigations that Kerrie spoke about, because they are not available in hospital or the waiting time is too long. Once somebody has presented to the emergency department and has had sufficient analgesia or pain relief to manage their pain and is well enough to go home or has had an admission with limited investigations, they will be referred to their GP for care. What we then need to see is that the discharge summary makes it back to the GP. The GP can access the Digital Health Record. There have been significant issues for primary care to access those records, and also for specialists—gynaecologists and obstetricians—to access that database. Or it needs to be uploaded to My Health Record, and, again, some issues can occur there.

Once the patient is discharged, we rely on the patient to present to a primary health care provider or, if they have been referred to a specialist, the specialist. We also rely on that information being shared. There is a systemic issue where information is very poorly shared across health services and it can often be very hard to get results. Often tests are replicated. It is also a major leak for Medicare, because we are replicating tests that have already been done, but we simply do not have access. Once that happens, a reverse referral process needs to happen. One of the biggest limitations, once we have exhausted resources within the community, is that we do not have a multidisciplinary team that looks after pelvic pain within ACT Health or Canberra Health Services. We have Sexual Health and Family Planning ACT, which provides the commonwealth funded pelvic pain service, which relies on both public and private pathways, but we do not have a dedicated public service within the ACT.

We lack the pain specialists and the gynaecological surgery specialisation. Sorry—I have not phrased that very well. We are currently lacking the recruitment process and succession planning. We previously had a service. It is non-functional at the moment. We also have insufficient funding for the physios, psychologists and all the allied health that needs to be part of that multidisciplinary team.

There is a large disconnect in the systems. There are a lot of really keen clinicians in Canberra who are very frustrated by this fragmented care, because they want to provide the best care to women presenting with pelvic pain, which, as Kerrie mentioned, can be really complex and may require multiple providers—not just medical professionals but also allied health, nursing staff, midwifery teams, psychologists et cetera—a wide range. At the moment, the care is fragmented and there is no place to refer them specifically for pelvic pain.

THE CHAIR: There is no gynaecologist within the Canberra Endometriosis Centre. What are the other gaps there? We heard earlier that it is a good model of care, but you have just said it is also underfunded, so how could that be turned into the kind of integrated care that you were talking about?

Dr Mende: Essentially, what we would like to see in a true multidisciplinary team, particularly around chronic conditions and pelvic pain, is a lead, as you need in any team. That might be a pain specialist who has a special interest in, particularly, pelvic pain; it might be a gynaecologist who has a special interest in pelvic pain and endometriosis. You will notice in our submission that we talk about AGES, which is the Australasian Gynaecological Endoscopic Surgery Society. They have specialised skills and do advanced laparoscopic surgery. I note that not all patients need this, but there are some patients that do need this. You need a team leader who is really interested.

You need some nursing staff who have some really specialised services. At the moment we have the wonderful Melissa Parker, who has held up the service for many years in Canberra and has excellent expertise, but we only have one. You actually need robust nursing support within that space. Then we need to look at what allied health services also support pelvic pain. Within a pelvic pain team, you would ideally want to see some pelvic health physios. At the moment, we have one pelvic health physio, who is being funded out of the existing mesh money, after money was allocated for the mesh complications. There is a community—

MS BARRY: Sorry—what is mesh?

Dr Mende: Mesh was for pelvic organ prolapse. A surgical procedure involved putting mesh, which is kind of like netting, inside the vagina to hold up the organ prolapse, but unfortunately it was associated with quite significant complications. A lot of those patients had to come back and have their surgery revised and have quite significant pelvic floor physio, surgery and revision. It is another cause of pelvic pain, so it also fits inside this inquiry.

Also, we would like to see dieticians to help with irritable bowel and bowel symptoms. Sometimes we also need gastroenterologists and endocrinologists associated with the medical team, and also psychologists, exercise physiologists, sex therapists, and multiple other complementary therapy that can be included in a multidisciplinary team. It involves a large investment. It also involves succession planning, because it cannot be reliant on one person, which has been a problem in Canberra, where we have one person holding up a service. If they are sick, go on leave or something happens, we find that the services fall down.

A multidisciplinary team also needs to involve primary health care—the connection between making sure that patients have access to a regular, reliable primary healthcare provider or GP, as a care coordinator who then works with the multidisciplinary team to coordinate the care and get the best outcome for the patient.

THE CHAIR: I go back to the scenario of someone going to the emergency department with pelvic pain, which we have heard about throughout the day, and perhaps getting some pain management treatment—not just being sent home. Under this scenario, you would have a multidisciplinary team. Would that person refer directly to that team as well, as part of the presentation?

Dr Mende: You could potentially have a referral process.

THE CHAIR: Is that the ideal scenario or is there a better—-

Dr Mende: You still want to involve the primary healthcare provider. One of the things that we find that really impacts on all chronic conditions, not just pain conditions, is that fewer patients have regular GPs. We really need to support patients to have regular GPs, who could then link in with multidisciplinary teams.

Dr Aust: The Primary Care Pilot evaluation has been drafted but not finalised. I think it would be worth looking at the outcomes from that. It is not specific to pelvic pain, but it looks at how we improve the support for GPs to provide wraparound care. To follow up from that, as a GP, when I receive a discharge summary when somebody has presented to ED, they are recalled for a review. The benefit of them coming back to the GP is that we have often done a range of investigations and we can provide those with a referral to the pelvic pain clinic, so that they understand what has already been done and what medications have already been tried; they are not starting by reinventing the wheel and doing the things that we have already done. But that does not happen by magic. There is no funding for us to do that, just based on: “The person has been to ED, so I’ll write a referral.” Quality referrals take time, and therefore the patient has to come in and see us. It is also to talk to them about what their wishes are: do they want to go through a public system, do they want to be seen in Canberra, and would they like to link to private services? Everybody has their own preferences.

MS BARRY: Dr Kerrie, you mentioned that you would not request a laparoscopy until you have ruled out some of the other conditions. Why is that? Is it because it is too expensive?

Dr Aust: Can I give that one to my team?

MS BARRY: Yes.

Dr Mende: I can answer that. Laparoscopy is keyhole surgery, and for many years it was considered the gold standard of diagnosis for endometriosis. However, the new guidelines that we developed have shown—and there is a good evidence base—that we can now use more non-invasive diagnostic methods. There is evidence that surgery for certain population groups has some benefit, but surgery needs to be planned, well thought out, and there are always risks and benefits to invasive versus non-invasive procedures. For surgery, one of the barriers currently in the Canberra Health Service is that there are not enough surgical lists and the surgical wait times are long. To get a histological diagnosis of endometriosis, you need to perform keyhole surgery; however, to manage endometriosis, you do not need that histological diagnosis. That is really important.

The new evidence shows that, if we have good-quality, specialised women's health ultrasounds—deep infiltrating endometriosis ultrasounds, with the terrible acronym of DIE—we can diagnose a lot of women without having invasive surgery. We also know that there is increased utility of MRI. MRI still lacks a Medicare rebate for the diagnosis of endometriosis and there are limited specialists who can report on endometriosis ultrasounds. It is an area that needs to be upskilled, but it is a non-invasive way to diagnose endometriosis.

Surgery should be reserved for people who have had medical management in a multidisciplinary team and are either still suffering from fertility issues or have failed the medical management. I should not say "failed", but the medical management has not sufficiently controlled symptoms with a multidisciplinary team. What we are aiming for is one or maybe two highly planned, good-quality surgeries, because at the moment we are seeing a lot of women having multiple surgeries and the benefit is not in the evidence. Surgery can be quite expensive and very invasive and can involve side effects and risks. We need to be really cognisant that surgery is an important part of endometriosis management, but also that not all pelvic pain is endometriosis. Quite often we will do surgery and not see any endometriosis at all.

The other really complex issue around endometriosis is that you can do surgery on someone who ticks all the boxes in terms of their history and even their ultrasound and you find absolutely nothing. You can take biopsies, but taking a biopsy, if you cannot see it, can be like finding a needle in a haystack. You can still find that the biopsies are negative. In some cases, you can do surgery for something else and it is really obvious that there is endometriosis, but the person has never had symptoms of endometriosis in their life. So it is a really complex condition to diagnose. Also, as Kerrie mentioned before, it does not happen overnight. It is a complex chronic condition. You could do surgery at one stage and find nothing, and then five years later, if they are not managed between, you could find that the surgery looks very different.

I think surgery is a key component. The group of specialists very interested in pelvic pain within the ACT is very concerned about the wait times that we have for surgery, and particularly gynaecological surgery in the ACT. I think we mentioned that category 3 takes about 365 days. But what has come to the forefront is that we need access to publicly funded ultrasound diagnosis, and, as I said, we really need to have that multidisciplinary team, because most of the time we will go through a whole process before we even need to move to that surgery space. It is a quite difficult space at the moment because there is a lot of external pressure, such as on social media, from particular groups around the importance of surgery, but the evidence is actually showing that it is not the first line for diagnosis now. I think that is really important. It needs to be accessible for women who really need it, but we also need to have all of the other diagnostic modalities in place so that we can have a less invasive way to diagnose endometriosis in the ACT.

MS BARRY: That is really useful. Thank you. Regarding presentation at emergency, what we have heard is that it is the first port of call for people who do not realise that they have endometriosis, rather than a GP, because some GPs are not bulk-billing and the cheaper way is to go to emergency.

Dr Aust: I am sorry—did you just say that the Medicare rebate does not cover the cost of providing care?

MS BARRY: Pretty much! I have heard from friends who are gynaecologists that a standard protocol of care would be really useful. What are your views on that?

Dr Aust: Let's talk about fragmentation of care. The first time I take pelvic pain history from a patient is usually around the time that she gets her first period. If I am really lucky, I will sometimes have a chat to young women beforehand and say, "You're going to start getting your period soon. We're seeing the early signs of sex characteristic development. These are the sorts of things that I want you to red-flag. If you get really bad pain, come and see me and we will have a chat about it." When we see women going to a range of services, including pharmacies to get their prescription for the pill, we do not have the opportunity to provide education. The first step is having a relationship with a GP that hopefully develops in childhood, when we are doing their immunisations and when we are giving them their annual flu shot. The time when you do a flu shot is a great opportunity to say, "Hey, how's everything going? Do we need to catch up? Are there any issues?" Often they will make the face and you know that you have to book them in. Let's not fragment care; let's put GPs back at the heart of health care.

The second thing is helping to break down the normalisation of severe pelvic pain, which is sometimes intergenerational. To share my personal story, I did not know I was in labour for eight hours, because it was not as bad as my period pain. It was only when I said, "Wow! This is happening every three minutes. Oh, gosh. I'm probably in labour." I was so relaxed that the midwife looked at me and said, "There's no way. We're going to send you home," and then they said, "Actually, this is all very exciting." We normalise pelvic pain for women, and often women will say, "I don't have much of a pain threshold," but I can promise you that they do.

Where we have established pathways—and we use the Living Evidence Guideline—it is about understanding the bleeding pattern, understanding the pain pattern, and how to get in front of it with things like non-steroidal anti-inflammatories for a few days before a period actually starts. Do we pop women on to an appropriate oral contraception for their age and future fertility plans? Are they better off getting a long-acting contraception such as a Mirena or Kyleena? I put them in my rooms and have long discussions. Sometimes these consults will go for 45 minutes while we talk to them about what their contraception needs are.

It is amazing when they come back to me after the insertion. I ask, "Was the pain as bad as you were told it was going to be? And are you happy that you had an IUD put in?" Universally, my patients say, "I cannot believe how little it hurt compared to what I was told." **I** will give them a green whistle, which is a bit of Penthrox, and they do not use it. They hold it in their hand, but they do not use it. **I** have had two in the last two years where I have not been able to get them in and I have sent them to a gynaecologist for insertion under anaesthetic. That was as part of the consent process. But they are not as painful for many women as social media often states. That is mainly because women who find the insertion a tiny bit uncomfortable but not too bad do not tend to blog about it; they do not tend to get onto social media. I have had four, and all of them have been done in rooms. You feel a bit uncomfortable, but it is not too bad. Tackling the social media misconception is a really important part of starting to improve the way that pelvic pain is managed, because it gives us an opportunity to do our jobs.

Sorry—I went really off topic. I got on my bandwagon. To come back to the question, the emergency department is not the right place for these women.

MS BARRY: That is what I got from that.

Dr Aust: They need to come back to us so that we can put in place the multidisciplinary team.

MS TOUGH: You covered a few of my questions.

Dr Aust: Sorry!

MS TOUGH: No—it is very helpful. I have a few more. Part of it is about multidisciplinary teams and multidisciplinary care and, I guess, training for GPs as well, so that when a woman presents with pelvic pain, whether she is 12, 27 or 40, she has a relationship with a GP and the GP has the training to say, "The first step is this. Go and see this doctor. If that does not work, come back." It is about ensuring the GPs have the knowledge and training to not say, "Well, you've gone to these three specialists and got nowhere. Too bad; so sad"—

Dr Aust: "Good luck."

MS TOUGH: And "Good luck." Then the patient feels dismissed and either finds another GP or just gives up. There might need to be a colonoscopy and there might need to be other things—the GP keeping up that care—

Dr Aust: Absolutely. I have listened to some of the feedback that patients have given throughout these hearings. We absolutely need to hear, acknowledge and address some of the really significant concerns that women have about being heard. Anyone working in any form of chronic pain space understands how often patients do not feel heard and how often we wish that we had a magic wand and a magic pill which could take everything away.

I can leave this with you. RACGP provided me with a copy of their women's health curriculum summary, which, if it is permitted, I will leave with you. Our education around pelvic pain, menstruation and gynaecological procedures has two parts within medical school. One is opportunistic within our general practice placements, and the other is a dedicated gynaecological term as part of our women's health term, which at the ANU is in year 4. This very much comes down to level of interest and opportunity. One of the things that I would highlight from observing the experience of my male medical students is that they are often asked to leave the room before the patient is even asked whether they are willing to have them stay. This is something that we need to continue to remind our supervisors—and this happens in general practice as well as within the hospital: the only way that we get men more confident with pelvic pain is by providing them with the opportunity to take histories from women, examine women and be involved in their management. With the exception of one or two, every female patient of mine has said, "Absolutely. I'm happy to have a male medical student," and, as a result, the men who leave our general practice placements are much more confident with their pelvic exams.

Part of this is about teaching. We teach kids how to consent, so we talk to them about the minimum standard that they should ask for when someone says that they want to do a genital examination. We teach them safe words and putting their hands up and saying "Stop" if they are feeling uncomfortable, and, if they want a chaperone, we teach them how to ask for it and how to advocate for themselves. This is part of "How do you address it so that patients feel safer?" and "How do you address it so that doctors feel safer?" We still have challenges where women are not believed about sexual assault and sexual harassment, and I think this colours people's concerns. By addressing this at a societal level, we also start to improve their experiences with GPs.

Providing more opportunity for training is a big part of this. I waited for my Mirena insertion training. It was about 2½ years before I managed to get a spot. The lack of opportunity comes down to how well we fund organisations like SHFPACT to make sure that people have an opportunity. You do not want to "see one, do one, teach one" with Mirena insertion. You want people to do 10 to 12 before they start doing it on their own, because, while it is a very straightforward procedure, women's anatomy does not behave like textbooks. Training is very beneficial, and I would like to thank SHFPACT for providing me with such exceptional training. Funding training for GPs is a really great way to do it.

The part that is outside of your remit as a territory government is adequate funding for MBS rebates, so that it is worthwhile. I would like to acknowledge that the MBS rebate for Mirena insertion has been significantly increased. Now, for many of us, it comes very close to covering the cost of putting one in. Unfortunately, the cost of our consumables keeps going up, but it has resulted in a significantly smaller gap fee for women. That is a space where I think we have seen some improvement.

Dr Mende: Could I add to that? Recently, RANZCOG, in association with the living guidelines, have developed free online modules which any GP can access. We have different levels of modules for GPs and for specialist O&Gs. RANZCOG is currently developing some additional modules within GP obstetric training around pelvic pain, as well as an advanced pelvic pain pathway for specialist O&Gs. There is certainly a lot of investment from RANZCOG into pelvic pain and developing these educational pathways.

A barrier for both private specialist O&Gs and GPs that work within the community is that when we do education, we have to pay for it. We do not get leave; we do not get study leave. It is in our own time and it is often after hours. We are a predominantly female workforce; we have family caring duties. There is actually very little capacity left at the end of the day for GPs and O&G specialists to do a lot of this training. Again, it comes down a little bit to Medicare rebate, because within the Medicare system there is no capacity to be paid for your paperwork, your education activities et cetera. We have to meet CPD requirements. But when you have had a full week, jam-packed, and then you have to spend your time, after hours and in evenings, attending meetings, education sessions et cetera, it can become quite a burden to stay up-to-date with every single thing that is changing within the healthcare environment.

Dr Aust: I would also like to acknowledge the pelvic pain special interest group. I have forgotten what they are called.

Dr Mende: Network.

Dr Aust: Network. So much of that group's expertise comes from volunteers who take our questions and our calls. As part of our trying to reduce the burden on the public system, a lot of non-GP specialists working in private will take the call and give you some advice over the phone, and they are never remunerated for that. It is very rarely acknowledged, but it takes a significant amount of time. I called three specialists this morning, before I saw my first patient, about three different matters, one of which was pelvic pain. I am always grateful to those people who answer our calls, but it is not an unlimited resource.

MS TOUGH: I have a question about specialist gynaecologists and how many gynaecologists go on to become endoscopic gynaecologists. How many physicians are there in the college and how many people are taking up that extra training?

Dr Mende: When you get your FRANZCOG, which is your fellowship of obstetrics and gynaecology, you are qualified as a laparoscopic surgeon. There is additional training through AGES, the Australasian Gynaecological Endoscopy and Surgery Society. They provide more in-depth laparoscopic training for particularly complex cases such as endometriosis. I would have to take on notice the actual numbers. The numbers are not restricted by the colleges. The numbers are restricted by the number of training positions which are funded by state governments, so that is really important.

The numbers are also restricted by the exposure that a trainee can have. If you are in Canberra, say, and we have, for example, 10 registrars, and we say we want to improve that, we can say, "Okay, we can take on five more registrars, but unless five more registrar positions are funded, we can't take on more trainees." The next aspect is that, once we have done that, we then need the surgical lists and the case loads so that those people are sufficiently trained at the end of their training.

Often there is a lot of talk of just increasing training positions, but that is magical thinking, because those training positions need to be funded, they need to be supported, they need to have the case load to result in a person who is competent and safe to practise at the end of their training, and they also need to have the trainers or the supervisors—again, that is often non-remunerated work within the system—to be able to supervise the trainees through this process. As a trainer myself, it is a huge time commitment which is not often built into your work day, and that is in both public and private. That is an outside commitment that essentially you are volunteering to do.

With solving training positions, there is a lot of work being done at the commonwealth level. There is the Medical Workforce Strategy, which is happening at the moment, with a large committee, and the Hon Mark Butler is leading that committee. RANZCOG is doing a lot of work about how we increase access for training positions, how we increase the output of trained people, and looking at the GP obstetrics space and increasing GP skills in the area as well.

MS TOUGH: I heard from someone in the last week who had an experience of going to a specialist just to get a script repeat. There was not even a face-to-face consult; it was just, "I need a new script for my endo treatment medication," and he charged her $250 to write the script, without seeing her and, because there was no consultation, there was no MBS on that. I am wondering whether that is something common that you have heard—people being charged?

Dr Aust: I am wondering why she did not see her GP.

MS TOUGH: I do not know.

Dr Mende: And there should be an MBS item.

MS TOUGH: Yes. She went back to her gyno specialist for her endo—

Dr Mende: So she saw him?

MS TOUGH: Not in person. She called up and said, "I need a script." They wrote a script, and it was $250 for the piece of paper.

Dr Aust: I cannot answer that question. One, I do not know who it was, and two—

MS TOUGH: No, but I am wondering whether you hear that that is a common thing or if it is—

Dr Aust: No. A lot of businesses will run various practices. We talk about "just a script". That will—

MS TOUGH: I know it sounds like "just a script", but the way she spoke, there was not even a consult.

Dr Aust: Yes. There is a medically legal responsibility to review a patient file, which can take time. Most of us do charge for scripts outside consults because our time is not free. However, I would suggest that that be taken up with the person directly. Again, this is where having a relationship with a GP who can coordinate care is actually a really—

MS TOUGH: And you could come back to a GP for the script.

Dr Aust: Yes, it is a really important part. Often, non-GP specialists will start people on a particular line of treatment. Whether or not we can continue to prescribe depends on the PBS rules. Again, many of the endometriosis treatments are available on the PBS, but some might need a tissue diagnosis, such as Ryeqo, and that will come down to what documentation the GP has in order to continue that.

MISS NUTTALL: Cultural safety has been a big thing that has come up. You can think about a trans guy not wanting to go into a women's and maternity hospital, and things like that, and wanting to see themselves in the diagnosis options. For First Nations people, sometimes there is the associated medical trauma of hospitals and things like that. How do you work to build cultural safety among your practitioners, and what is the best practice that you are aiming for?

Dr Aust: That is a really wonderful question. Martina led with talking about the fact that not everyone who has a uterus or experiences endometriosis identifies as a woman. This is, again, where the benefit of holistic care with a regular GP and the long consult really comes into it, because pelvic pain is something that many of my trans men do experience, and sometimes there can be some challenges associated with hormonal treatment and fear around feminisation. It is about coming down to what our goals of care are, often getting specialist sexual health physicians, endocrinologists and gynaecologists involved in their care. You can provide additional information around where the sensitivities are for the patient. I do find that Canberra Hospital teams have been incredibly kind to my trans patients around what their experiences are. Sometimes it is a simple case of picking up the phone.

My trans patients are fantastic at giving constructive feedback to me and giving us the opportunity to have those colleague-to-colleague discussions. We are all learning in this space, and I know that this is an area where everyone is trying to do a little bit better. We also find similar challenges for women from different cultural backgrounds. We talked briefly before about those who have experienced sexual trauma. If we provide that information in referrals, I do find that people overwhelmingly go out of their way to create safe spaces. It is about being able to communicate that.

Dr Mende: RANZCOG and RACGP both have cultural safety training embedded within our curriculums. We also examine on it, and it is examined within our communication skills. However, we can teach that within the context of our curriculum and colleges, but we cannot influence what individual health services do in that space.

MS BARRY: You mentioned that training positions need to be funded by state governments. Do you know how many training positions we are funding in the ACT?

Dr Mende: I would need to double-check. Can I take that on notice?

MS BARRY: That is fine.

Dr Mende: I can get back to you on exactly how many training positions we have, and I can tell you what levels those training positions are.

MS BARRY: Thank you.

THE CHAIR: Trend data might be interesting—whether that has changed over recent years.

Dr Mende: Yes.

Dr Aust: Can I add one thing? This is on behalf of one of my patients. I would like to caveat this by saying that I recognise there is a controversial evidence base for it. Two or three of my patients have said they wished that the public botox clinic for pelvic pain could be reinstated. We recognise that botox is not necessarily suitable for all patients, but for some it can result in such a significant pain reduction that they are able to start doing their pelvic floor exercises. We acknowledge some of the factors that led to it being removed, but we would say that, in some spaces, individualised medicine is worth exploring.

Dr Mende: That is the sort of space where you would see a real benefit from a multidisciplinary team, because the journey regarding the decisions that were made there may have been quite different, if a multidisciplinary team had been involved.

THE CHAIR: Okay, thank you. Dr Aust, how long do you have left in your role?

Dr Aust: I finish up on 28 May, so this is part of my farewell.

THE CHAIR: This might be the last hearing that you attend in this role, so thanks for your service.

Dr Aust: I was elected to council, so I hope that I will continue to have some opportunities to be grilled by such a wonderful group of people.

THE CHAIR: We will rope you into a hearing.

Dr Aust: I will be taking a three-month sabbatical. I am taking three months leave without pay—as a GP, no patient, no pay—to address getting my groove back. Thank you so much, once again, for the sensitivity of the questions that were asked today. It is not a small thing to come and get grilled by your local members, and I have appreciated the professionalism of this committee. Thank you for highlighting the fact that women's pelvic pain is a challenge for many people in this community, because I do think that, with some really good investment, we can have some great outcomes.

THE CHAIR: Thank you, and thanks for your contributions, your candour, your submissions and your time this afternoon. On behalf of the committee, I thank you for your attendance today.

Dr Aust: What is the process for formally submitting an additional paper?

THE CHAIR: You can hand it to one of the secretariat staff and it will be tabled. Dr Mende, you took some questions on notice, so you have some homework.

Dr Mende: Yes.

THE CHAIR: You will get a copy of the uncorrected proof transcript. Five business days after you get the transcript is when we would like to get your response, if that is okay.

Dr Mende: Yes.

THE CHAIR: Thank you so much.

BOWRING, MS VICTORIA, General Manager, Endometriosis Australia

THE CHAIR: We welcome the witness from Endometriosis Australia. Could you please state the capacity in which you appear?

Ms Bowring: I am representing Endometriosis Australia, as the general manager of the organisation, and I have 38 years of lived experience myself, and my eldest daughter has recently started her journey.

THE CHAIR: Please note that, as a witness, you are protected by parliamentary privilege and bound by its obligations. As such, you must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly.

Before we go to questions, would you like to make a brief opening statement?

Ms Bowring: No, thank you.

THE CHAIR: Miss Nuttall?

MISS NUTTALL: Let us begin where we left off last time, with the ideas of cultural safety, if that is okay.

Ms Bowring: Yes, absolutely.

MISS NUTTALL: Obviously, it has been a theme throughout this inquiry, with trans and gender-diverse people, First Nations people, people from a culturally and linguistically diverse background, people with a disability, and young people and people in larger bodies, all facing barriers and, at times, stigma. What have you heard from your members regarding cultural safety? Where is it being done well and what are the elements of that?

Ms Bowring: We have heard a lot about being able to have information that is disseminated in a way that is either culturally appropriate or culturally sensitive to the different cohorts with which we work. We are currently in the process of designing and disseminating fact sheets that are translated into various languages for the priority populations.

There is a great deal of difference that we have noticed in the way in which information needs to be presented, spoken about and shared with various groups in order to make sure that it is understood and that it is received in a way that is empowering them to act on that information. In some areas it is done well; in some areas it is not. It is very much a case, also, of how, geographically, they have access to the information. One of the things that we mentioned in our submission, particularly around the centre for endometriosis in Canberra, is that often, if it is located centrally, as is the centre here, those population groups that live further afield in that area may not feel comfortable coming in to the centre of the city to access areas or may not be able to. Often those priority population groups that we work with are geographically determined.

A lot of it is down to the sensitivity and the way in which information is presented, as well as access to various services, geographically, for those groups.

MISS NUTTALL: I am thinking particularly about people in larger bodies; there is a consistent experience of having your concerns dismissed because of your weight or because of your presentation.

Ms Bowring: Yes.

MISS NUTTALL: Do you have particular information for women with larger bodies?

Ms Bowring: Not statistically. Qualitative feedback is that there are high levels of dismissal around women in larger bodies, largely due to the fact that there is often stigma around their increased weight. There is reference made to potential other issues causing the problem, around requiring weight loss, and lack of health generally, that is attributed to their pelvic pain rather than a focus on the fact that they are experiencing pelvic pain and with that being the primary topic to address, rather than what is seen in front of clinicians and caregivers.

MISS NUTTALL: For young people, often young people do not have high earning capacity, or they are studying and having to work part time, and things like that. Have you heard much from young people that there is a particular barrier to access there?

Ms Bowring: It is hard to define based on age whether or not the cost is the initial factor there. There are multiple reasons around younger people being either dismissed or not accessing care. Some of it does come from parental information—parents and primary carers not understanding the condition or being able to advocate for them when addressing the concerns of the younger people.

Cost is a factor, particularly in that young adult phase, where they are at university, and they are working to support themselves whilst they are also studying. They have a fairly high cost of living that they are solely responsible for. Often, as you have heard in previous testimony, the tests and diagnostic measures can be costly; therefore, they are consciously having to make that choice about whether or not they can afford it.

MISS NUTTALL: Is there also an element with young people of the fact that a lot of the initial diagnostic measures are quite invasive, like the transvaginal ultrasound and the laparoscopy? Does that ever factor into both young people's willingness to approach diagnosis and, from a medical professional's perspective, their willingness to suggest that they undertake these procedures?

Ms Bowring: There is not so much a lack of willingness to suggest, particularly, the transvaginal ultrasound, from a practitioner's or a GP's perspective. A lot of our younger community express that there are kindness and gentleness that come from their GP, particularly, around explaining what that process would look like for them and what that would mean. Also, when they are at the radiographer's, they are well trained and well versed in being able to put them at ease as to what is going to happen.

There is very much more of an embarrassment level, particularly, if they are quite young, and we are seeing more and more reasonably young girls experiencing pelvic pain. For them, any kind of investigation that involves the pelvic region, a vaginal investigation, can be quite daunting. In the absence of a parent advocating for them, going along with them and being able to talk them through that process, it can be something that can be a barrier to them seeking help.

MISS NUTTALL: We heard earlier in the day about a blood test that might be used to diagnose or at least indicate endometriosis with reasonable accuracy. Do you think that kind of thing would lead to more diagnoses among young people, if that was an option?

Ms Bowring: I think anything that provides an ease of diagnosis would be welcome, definitely.

THE CHAIR: Going back to the location of the Canberra Endometriosis Centre, I noted in your submission you mentioned its co-location with maternity services, and that it might present a barrier to accessing care. Is this a common mistake, if you want to call it that? Is it a common habit? Do you see this across the country?

Ms Bowring: I am a bit hesitant to refer to it as a mistake because everyone is human, when they design these centres, and they are great to have, and they are required. There seems to be a natural gravitation towards connecting anything that is classified as reproductive health around fertility clinics, family planning and maternity services, because they are naturally grouped together. There is an insensitivity that is inherently built into that sort of model. For many women who suffer from endometriosis, fertility and potential infertility is an enormous consideration.

Going through that diagnostic process, and even treatment and care, to have to front up to a centre where it is quite obvious that you are part of a community where there are other people that are having families, and they are not experiencing the same challenges that you are, can add to the anxiety, stress, pressure and mental health issues that go with that. There are times when we have had people report to us that that actually stops them going there.

THE CHAIR: You have also mentioned the benefit, which we touched on earlier, perhaps of a community-based location. Is there somewhere that you have in mind in the ACT? Are there any risks involved in moving it away from a hospital setting, in terms of integration with what else is going on in the hospital?

Ms Bowring: As far as where in the ACT, we do not have any recommendations or suggestions at this point. With moving it away from a hospital setting, as long as there is good communication—and I was listening earlier about integrated care and the lack of communication that can happen between care providers—and access to hospital services, if and when required, these centres can work outside hospital settings. They can also work within hospital settings, but potentially in different areas of the building, where they are not having to physically sit with a woman who is going for her six-month pregnancy check-up, and that kind of thing.

THE CHAIR: Or who has a six-month-old with her.

Ms Bowring: Absolutely, yes.

THE CHAIR: Finally, on this line, is there somewhere we can point to in Australia where we can see that they are doing this really well, resourcing it appropriately, and we should be copying them?

Ms Bowring: No one specific location. With the pelvic pain clinics that are being rolled out nationally, it is early stages yet to see the efficacy and the evaluation of that project. They seem to be working quite well, in having that care model owned by a GP clinic. Ideally, it would be wonderful if every GP clinic had at least one specialised, trained staff member, whether that be a nurse or one of the GPs themselves. At the moment, there is no one centre or one area where you would say it is a model that absolutely solves all the problems associated with addressing endometriosis.

MS BARRY: I have a few questions around some of the experiences of your members in dealing with the public health system. I am interested to understand what is working, where the breakdown is and how we can better support a better care model.

Ms Bowring: It is a combination. There is never one aspect to that public health system. Wait times is a big one. Access, whether it be due to wait times, cost or location, is an issue. There is definitely room for improvement around that. Where it works really well is that there is often nursing staff in the public health system that have undergone specific endometriosis nursing training. We run a program through the Australian College of Nurses around endometriosis training for nursing staff. Where hospital and public health providers have those trained nurses, it works really well, because they are able to have an understanding of what the patient is going through in the absence of specialists who are trained in that area.

It is mainly dismissal. It is never a nice thing to consider, but the public health system itself is so stretched with so many different conditions, priorities and needs of the community that endometriosis and pelvic pain is something that is largely dismissed. Not being believed seems to be the greatest concern of our community—"I was given Nurofen and Panadol and told to go home and just continue to take it every four hours until the pain subsides." It is that level of not taking it as seriously as it needs to be in the first instance and often repeated instances.

MS BARRY: Thank you very much. We have heard evidence that there is an ad hoc or siloed approach to care. One of the suggestions by one of the group was a strategy. Do you think that would be useful and would you support that?

Ms Bowring: Absolutely. Anytime that there is an overarching sort of protocol, strategy and approach to care of certain conditions always adds benefit. There was a pilot throughout 2025 around an endometriosis management plan where there are online guides and tools available to GPs to be able to develop a plan that is specific to the patient that has presented with the pelvic pain and endometriosis concerns and they are able to set their goals for their treatment, manage additional allied health services that they will require and sort of check in with the patient. The patient feels heard and seen and feels a level of comfort and confidence in the fact that they have a plan and that that plan is actually being supported by a medical professional as well. That type of strategy goes a long way to creating a better environment for those suffering.

MS BARRY: There have been lots of conversations about GP training and GPs being trained enough to understand and to refer on. My question is: why is that training just for GPs and not ED doctors as well? There's mixed evidence about ED. We had evidence that the ED doctors are not best placed to manage this. Would it help or benefit ED doctors to have the same training, so you are reducing that not being believed and the interactions every time?

Ms Bowring: Absolutely, yes. We talk a lot about GP training, and that is largely due to the GP often being the first port of call for a patient experiencing discomfort to go and also because allied health professionals are often a part of the treatment plan and GPs will be able to refer or suggest et cetera. Any professional in the medical field that interacts with somebody who presents with pelvic pain would benefit from the training—and maybe at different levels, too. It may be that there is a level of training, understanding and awareness that is slightly different for ED staff than a full module or training program et cetera for GPs. But it would absolutely benefit—even just a base level understanding of what endometriosis is and how it impacts a person's life, so that there is less of that desire to dismiss or not believe or jump to something else.

MS BARRY: Thank you.

MS TOUGH: I also want to pick up on the training thread. With the partnership between Endometriosis Australia and the College of Nursing with the scholarships for nurses across Australia, what is the take-up of that like for nurses?

Ms Bowring: It has been quite high. We have had the program now running for two years. It is coming towards the end of its second year now. We had a goal of 100 nurses endometriosis trained at the end of a three-year period. We are now sitting at 60 nurses fully trained. It is yet to be evaluated. It was a first pilot study for us to see how this worked and how successful it was. The full and formal evaluation is not yet complete. The University of Tasmania are conducting that for us and will be available next year. However, the qualitative feedback that we have had back from nurses so far is that it has been invaluable to their communities, particularly in regional and remote areas. For small primary health networks or local regional hospitals that do not have the specialists on board that are trained, having these individual nursing staff has made a huge difference to the community.

MS TOUGH: How are the nurses spread across the country right now? You said that some are in smaller health networks. Are there some in hospital? What is the kind of spread?

Ms Bowring: I do not have the exact data on that, but I can take it on notice and get back to you.

MS TOUGH: Thank you. It would just be helpful to know how many are working in hospitals.

Ms Bowring: Absolutely.

MS TOUGH: Building on the education and that fragmented care—where someone presents to an ED or presents to a GP, and they end up at a GP and the GP sends them to this specialist or that specialist and keeps them going—how do we keep the patient engaged and the GP supportive while helping them navigate different parts of the system to rule things in and out and get treatment as they go along without feeling dismissed by multiple specialists? How do we keep that whole system helping someone find treatment and a diagnosis?

Ms Bowring: That is a very difficult thing to do and is very independent to the individual who is seeking the treatment. We do see that, where that cohesion is maintained and where patients tend to continue on their journey, that is when there is open discussion and conversation around what their options may be from the beginning—so transparency from whomever is their initial point of contact around what could be potentially a long process. It is not that you are being dismissed or not believed or "We just do not know where to send you"; it is a complex issue. It can present in very many different ways, and there are other conditions that need to be ruled out in order for us to categorically be able to address endometriosis.

Most times when I speak to members of our community, they just want transparency and the time taken to actually have the conversation with them. As long as those conversations happen—"We may send you to a physiotherapist. It does not work for everybody but it may work for you. If not, come back and we will find something else." It is about having that consistency with one or two people within their health provision who are a go-to throughout that process who also understand that it is not just one treatment that is going to be required; it is multiple.

MS TOUGH: So having that transparency and that point of contact will reduce people feeling like, "I did not get diagnosed for 10 years; no-one cared."

Ms Bowring: Yes.

MS TOUGH: But, actually, "Maybe it was 10 years to diagnosis but, in that time, I have explored different treatments and different options and different things."

Ms Bowring: Absolutely, yes.

MS TOUGH: Thank you.

MISS NUTTALL: I am curious about education. A lot of people have brought up PPEP. I cannot remember what it stands for, but people have been fans. What is your perspective on it and on our current education offerings in public schools? Are there things that we are doing well? What do we need to do better?

Ms Bowring: The program that you are referring to is an initiative of the Pelvic Pain Foundation. It is the Periods, Pain and Endometriosis Program, and it is run in primary school education. It is not available to all schools; it is very dependent on whether a school can afford to run it. Here in the ACT at the moment it is largely run in the Catholic school system and not so much in the public school system, where you have got 45,000 students enrolled.

I do not have quantitative data around how effective it is or whether or not there are initial outcomes that can be attributed directly to the program. But what we do see and know is that it opens a conversation at a stage in life where it makes it okay to talk about it. It educates not just young girls but also young boys, which is an important part, an important aspect. Where it works well in the format in which it is delivered and the fact that it is a school-based education program is that often families will not talk about this at home. That can be for various reasons—whether it be cultural reasons; or if you have divorced parents where it is not a single family unit. These conversations are being held in a controlled environment where they are able to ask questions and receive information that they may not get at home.

It also takes the mystery and the stigma out of it. For young girls and those assigned female at birth, when you first get your periods, it is quite daunting and, if you do not have information available to you, you immediately tell yourself, because no-one else around you is telling you different, that everything that happens throughout that process is normal—and not everything that happens throughout that process is normal. So it goes a long way to preventing the normalisation of pelvic pain and discomfort, which means that young people will seek help and treatment much earlier.

Whether it be a disease or chronic condition or situation, these awareness programs and education programs are great for information dissemination but they are also really great at changing behaviour. When you get the behavioural change from a program—which, in this instance, would be seeking help, speaking up and going to mum or dad or whoever is your primary care in your home and saying, “Something is not normal and I know it is not normal because I was told at school that that is not normal”—it starts a behaviour change and, with that, then comes better access to treatment, maybe different access to treatment and reduces the suffering. We have members of our community that have gone 35 and 40 years without being diagnosed and then told, “No, that was never normal. Had you come and seen somebody when you were 12 or 13, we potentially could have minimised your suffering.” That is what these kinds of programs are really great at doing: minimising the suffering that we know historically has occurred.

MISS NUTTALL: Is there also sometimes a “penny drop moment” for the parent if the kid comes home and says, “I was learning about this in school and they are saying all of these things, and I am not experiencing it,” and the parents are sitting there going “Ah”?

Ms Bowring: There is. There is a fair bit of taboo around talking about menstruation, pelvic pain and women’s issues as such, but it gives permission for mum to go. It gives permission for mum to say, “Actually, I had exactly the same thing and so did my mum. Your grandmother suffered from it too.” The ripple effect of that is not only the lightbulb moment for everybody; it is also the sharing of intergenerational information that can then be given to the medical professional to help define a pathway of treatment for them, particularly if it is an hereditary issue.

MISS NUTTALL: Thank you.

THE CHAIR: Is there anything that we have missed? Is there anything that we really need to know?

Ms Bowring: No, not at all. As the previous group said, thank you so much. It has been a long-awaited inquiry for many people. As somebody who has been on this journey for 38 years, it is wonderful to see so many people so keen to make a difference and really make a change going forward.

THE CHAIR: Thanks for saying that. I think Ms Tough can take a lot of credit.

MS TOUGH: Well, you agreed to do this with me—so thank you.

Ms Bowring: I did not want to single anyone out.

THE CHAIR: No; you made sure you looked into everyone’s eyes, but she is leading the way. On behalf of the committee, I thank you for your attendance today. I think you did take something on notice. If you could, please, provide your answers to the committee secretary within five business days of receiving the uncorrected proof *Hansard*, that would be fantastic.

Ms Bowring: Definitely. Thank you so much.

Short suspension

STEPHEN-SMITH, MS RACHEL, Minister for Health, Minister for Mental Health, Minister for Finance and Minister for the Public Service

BEAR, MS JACQUI, Executive Branch Manager, Health Policy and Strategy, Health and Community Services Directorate

GLADING, DR JODI, Chief Medical Officer, Health and Community Services Directorate

VAN DIEMEN, DR JANE, Clinical Director, Division of Women, Youth and Children, Canberra Health Services

WAKEFIELD, MS KATHERINE, Executive Director, Women, Youth and Children, Canberra Health Services

THE CHAIR: We welcome Ms Rachel Stephen-Smith MLA, Minister for Health and Minister for Mental Health, and officials. Please note that, as witnesses, you are protected by parliamentary privilege and bound by its obligations. You must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Would you like to make a brief opening statement before we go to questions?

Ms Stephen-Smith: I believe not.

THE CHAIR: Let’s go to questions.

Ms Stephen-Smith: Not that I have read my brief. Maybe I should have!

THE CHAIR: That works for us. That is fine. We have an hour with you. Thank you for taking the time. When SHFPACT appeared earlier, they said the Canberra Endometriosis Centre has not had a gynaecologist for the past 18 months. I first want to confirm that is true.

Ms Wakefield: The Canberra Endometriosis Centre is part of the gynaecology outpatient service at Canberra Hospital. We have a number of gynaecologists working across the breadth of the department, and we have gynaecologists that see women with endometriosis and pelvic pain.

Dr Van Diemen: We absolutely have gynaecologists. We have three gynaecologists that are routinely rostered on to see patients who have been triaged to the Canberra Endometriosis Centre work queue, which comes in via the gynae outpatients pathway. They have been employed with us for a significant number of years.

THE CHAIR: Where would that evidence have come from? What would she have been referring to? Did a specialist leave 18 months ago or—

Dr Van Diemen: Yes. A specialist left Canberra Health Services. I think it was more than 18 months ago—

Ms Wakefield: In 2024.

Dr Van Diemen: That was an advanced laparoscopic surgeon with specialty in endometriosis and complex laparoscopic surgery. They left, but we have other clinicians.

THE CHAIR: Was there any kind of gap left in specific services as a consequence of that departure that you have been unable to fill since then?

Ms Wakefield: We recognised that our model was probably single-person centred at a period of time, and so, when that person left, we had to recognise how we would deliver a service. The head of department made sure that we were able to still see those referrals, those women, when they came through. And we have spent a lot of time and effort since 2024 on re-establishing the service that we would like to deliver. That is an ongoing process. Yes; there was a period of time when it was not what we would like it to be and we had to rebuild.

THE CHAIR: Is advanced laparoscopic surgery available currently?

Dr Van Diemen: Yes.

THE CHAIR: Is that the gap that existed for a period of time?

Dr Van Diemen: No—we have had them in—

THE CHAIR: You said the service was not quite where you wanted it to be. I am trying to understand. You have shifted the service somehow because of the departure of a specialist. In what way has some part of the service dropped away?

Dr Van Diemen: No. What has probably happened is that a surgeon with a special interest and a special set of skills was running the clinic and had carriage of the clinic. When they left, it took time to work out: “What is the clinic going to be? What is it going to look like? And who is going to step into that role?” I do not know whether there was a specific gap in service. The clinicians that are part of the clinic or see patients in the clinic have been employed for more than 18 months. They were still on staff, even when that specialist laparoscopic surgeon left.

Ms Wakefield: It has been something we have been targeting in our recruitment. When we put our ads up for more staff specialists, we say that we are looking for those skills as well.

THE CHAIR: Is there any active recruitment for the Endo Centre going on at the moment? Are you attempting to fill any positions?

Dr Van Diemen: From a medical perspective, we will have recruitment soon into our obs and gynae department, not specifically into the Canberra Endometriosis Centre. We are recruiting into our obs and gynae department for general gynae. We are certainly recruiting and looking for specialists who have advanced laparoscopic skills. We are waiting for a surgeon to come from the UK. He has some administrative delays. We recruited him 18 months ago and we are waiting. He certainly has advanced laparoscopic skills. When we are looking at recruitment, we are looking for staff that can work across the full gamut of obstetrics and gynaecology at a level 6 centre.

Ms Stephen-Smith: I note in relation to Dr Van Diemen’s evidence just then that we were in a meeting this morning where we were talking about this very lengthy delay in bringing in someone who has been recruited from the UK. I have asked for some further information in order to write to the commonwealth about it, because, as you might be aware, there has been a lot of work at the level of health ministers in relation to improving the pathways for recruiting international medical graduates and specialists, and particularly specialists in areas of shortage across Australia, such as this. It is very frustrating to see that it is still taking more than 18 months to get a specialist from a country where that specialty would be absolutely comparable to Australia.

THE CHAIR: Regarding the advanced laparoscopic skillset, is someone already in the system who can deliver that right now? Is it one of those three or all three?

Dr Van Diemen: Two out of the three, and one at North Canberra.

THE CHAIR: Will the centre return to the kind of model that I think you described, where you have an individual who more leads the centre, or is that something that you have moved away from?

Dr Van Diemen: What we have within our medical specialists is clinical leads. We have clinical leads in gynaecology and obstetrics. Then people have portfolios, and that is more about special interest. We have not necessarily had the luxury of being able to appoint one specific person to lead the Canberra Endometriosis Centre. That is a work in progress.

THE CHAIR: That might happen with this UK recruit?

Dr Van Diemen: Yes. It does not have to be a surgeon. For somebody to lead the Endometriosis Centre, they could be a medical specialist—either a gynaecologist or a medical pain specialist. That is what is replicated in similar models.

Ms Wakefield: We want to make sure that we have a reliable system so that, when someone is on leave, we still have a service that meets the needs of our consumers and can continue. We mitigate some of those risks with a single-point model.

THE CHAIR: Finally on this point, what were the circumstances around the departure of that particular specialist? Was this during the time of the VMO salary stuff?

Ms Wakefield: My understanding is they had been reducing their FTE over a period of time, and then it was their personal decision. That is my understanding.

Dr Van Diemen: One of the difficulties that we have in this specialty is the lure of private work. It is before my time, but all I am aware of is that there was a reduction in FTE or a reduction in the fraction in the public sector and a move into private work.

THE CHAIR: An earlier witness mentioned inter-hospital politics. I do not know if that is a direct quote, but it was something to that effect. Are you aware of that issue?

Ms Stephen-Smith: Sorry—could you repeat that?

THE CHAIR: They mentioned inter-hospital politics or something like that. Do I have that right? I think I am directly quoting. Do you think that may have been part of the reason?

Ms Stephen-Smith: It is no secret that there have been some cultural issues over some years in obstetrics and gynaecology, so that involves some intra-hospital politics. The team has done a great job in pulling together and is now on a really positive trajectory, but it is certainly a matter of public record that there were some cultural issues in obstetrics and gynaecology a couple of years ago.

THE CHAIR: To your point about being lured to the private system, is the gynaecology skillset generally well represented in the private system in the ACT? Do we have a high proportion of specialists in this field in the private system?

Dr Van Diemen: I do not know. That is the honest answer. What I can tell you from our specialists who work at Canberra Hospital is that the majority have a fraction in the hospital and a fraction that is private, and that is replicated in other jurisdictions. Certainly, when you have people who have a special interest in fertility—and fertility is not in the public system—that is private. Sometimes there is a nicer work-life balance in being outside of a public hospital. It is not uncommon for obstetrics and gynaecology to have fractions that sit across both the public and private systems.

MS TOUGH: I want to start by talking about school nurses and the role they play in education in schools, but also as a point of contact for adolescents navigating when they have pelvic pain, either before they have started their periods or when they have started their periods—a trusted person to go to and help them when they ask, “Where to from here?” I want to know how prevalent nurses are in schools and whether they have an education role. What is their role around pelvic health?

Ms Wakefield: Canberra Health Services has a service called School Youth Health Nurse. The nurses are in public high schools in the ACT, and their role is around health promotion and early intervention. It provides young people the opportunity to access a health professional in a school setting. Those School Youth Health Nurses have a program that they have developed on menstrual health. It is a health promotion package. It includes information about endometriosis and painful periods. They also use the Period ImPact and Pain Assessment tool. They meet with students, one-on-one if necessary, and go through that tool, and they help them to access other health services. It may be primary health care, for example, if the tool comes back with a signal that they might need more help.

MS TOUGH: Do they have a role in referring straight to the Canberra Endometriosis Centre or do they go back to a GP, primary health, and then to the centre?

Ms Wakefield: Access to the Canberra Endometriosis Centre tends to be by referral by a GP.

MS TOUGH: They provide that information to the student on how to get that help?

Ms Wakefield: Yes—how to take the tool with them to their GP appointment to help them talk about some of the ratings that they got on that tool.

MS TOUGH: That is in all public high schools?

Ms Wakefield: We are in the process of broadening the School Youth Health Nurse program across more high schools, and that is part of some funding we got from the government to expand the School Youth Health Nurse program.

MS TOUGH: How many schools have them at the moment?

Ms Wakefield: It is a moving feast, so we do not have a specific number. They are working with principals all the time around where the areas of need are and how many days are needed—upping or downing based on the student profile at that time.

Ms Stephen-Smith: We will take your question on notice. I took a question on notice last week during the sitting around a similar issue, but we will take the question on notice in relation to whether there are any schools that do not have a School Youth Health Nurse at all at the moment and how many days the School Youth Health Nurses are available.

MS TOUGH: Thank you. Different groups have given us different evidence on what is in schools and it is—

Ms Stephen-Smith: As Ms Wakefield said, that is probably because it is a bit of a moving feast.

MS TOUGH: Do those school nurses link up with some of the other services? I think SHFPACT offers service in some schools. Some schools have different external providers coming in to do courses around sexual health, periods et cetera. Do you know if the school nurses have a relationship with those external providers or are they doing different things?

Ms Wakefield: I am not specifically sure. SHFPACT might have done some health promotion activities together, but I would have to take that specific question on notice.

MS TOUGH: Thank you. Going back to Canberra Health Services, the hospital and the experience of patients in the hospital, one thing we heard in earlier evidence was about a patient turning up at the Endometriosis Centre, being seen by a gynaecologist but then being told, “There’s absolutely no chance you have endometriosis. There is no point being here,” only to then be diagnosed after seeing someone else. It compounds being dismissed. What kind of training and education is in Canberra Health Services, particularly in obs and gynae, to make sure there is not that kind of dismissal—even if the doctor did not mean to be dismissive, to make sure they do not come across as dismissive?

Dr Van Diemen: That is incredibly disappointing to hear. There is ongoing education. There is ongoing education specific to chronic pelvic pain, ongoing education specific to endometriosis, and ongoing education on how we communicate with our patients—how we are able to involve them in decision-making or make the patients feel heard. That education and communication is there and will be there, and we will continue to do better.

MS TOUGH: Thank you. I think Gold Coast hospital is trialling a model where—I think it is during the daytime—the gyno registrar at the hospital is on call for ED. So, if someone turns up at ED with pelvic pain, instead of waiting to see which registrar gets to them in ED, they are put on the gyno registrar's list and the gyno registrar comes in to try to reduce the number of unnecessary tests, procedures and scans that might not actually be useful to treatment. Is that something that has been trialled—or having a nurse with additional training available in ED, because it is not necessarily the right place to go but it is a place that people go when they are looking for help?

Dr Van Diemen: We would certainly need to look at the data and we would need to look at the demand. We certainly have registrars that cover the emergency department. What we would prefer to see is that there is another avenue that is not the emergency department. Certainly, the emergency department is for acute deterioration or acute need as opposed to addressing any subacute or chronic issues.

THE CHAIR: Your submission notes that 1,800 people presented to the emergency department for endometriosis in 2023-24. I have seen that the Australian Institute of Health and Welfare tracks pelvic pain presentations more broadly, but we have not been able to find the ACT-specific data on pelvic pain presentations. Is that something that you are tracking? It might have been published in a question on notice.

Ms Stephen-Smith: I know that the committee has made a range of data requests, and I apologise that I have not written back to you in response to that request. I have a brief in my folder today. We are happy to take questions on notice in relation to data that might be additional to the data request, but you have already made a number of requests in relation to that. I might hand over to Ms Wakefield for any information that we have at hand.

Ms Wakefield: Nothing in addition to what the minister has already said. Could you repeat the specific data you were after? It was pelvic pain—

THE CHAIR: Yes—presentations to the emergency departments for pelvic pain.

Ms Wakefield: Whether we specifically monitor that?

THE CHAIR: Whether that is tracked. I thought you might have it at hand, but I know we put in a lot of data requests.

Ms Wakefield: No. I am sorry; we do not.

THE CHAIR: It connects up with what we have heard from witnesses. It is not a counterpoint to what you are saying, but obviously people show up not knowing that they have a condition. There is Barrett's diagnosis. We heard from a witness who had repeated presentations at the emergency department with pelvic pain but never got a diagnosis. Tracking that would be helpful from that perspective. I am wondering if that is being tracked and if that is being used in any way to inform referral pathways out of the emergency department.

Dr Van Diemen: I cannot speak to the tracking. What I can speak to is the development of a clinical pathway within the emergency department to manage people who have come in with chronic pelvic pain or acute exacerbation of chronic pain and/or endometriosis flare-ups. That is certainly a pathway that has been developed. Lots of education happened and is ongoing for the emergency department, medical and nursing teams, as well as looking at what the appropriate tests might be for that cohort of patients and what appropriate treatments might be. We want the emergency department to be used for acute exacerbations. The most common would be a flare-up of pain. Diagnosis is not always possible or appropriate in the emergency department, so knowing where to refer the patient or being able to provide good enough documentation to the GP to allow the GP to refer the patient to diagnostic ultrasounds or other investigations would be most appropriate.

THE CHAIR: I might come back to that.

MISS NUTTALL: A common theme that has come up through the inquiry has been about the scale of response. Another submitter earlier today pointed out that there are 20,000 people living with type 2 diabetes in the ACT, and possibly somewhere around 50,000 people who experience pelvic pain in the ACT every year. How do you find your current public response to endometriosis? Does it adequately capture the scale of the number of people experiencing the condition in the ACT?

Ms Bear: In terms of the response, a broad response would be to say that there are a lot of challenges across the health system in supporting people with chronic disease. This is a really important one that we are focusing on today.

With one hat on, if you ask me about the adequacy of a response, I am always thinking about it from the perspective of the range of things that we are responsible for in the directorate, in terms of funding availability, other pressures on the system, and workforce. The commonwealth are also an important player in the health system, in terms of funding responses in this space, particularly in the primary care area, and particularly in terms of the role they have had in leading work on a national action plan for endometriosis. Part of that has funded the pelvic pain clinic here in the ACT, as well as over 30 across the country, and it has encouraged a lot of effort in terms of clinical education and all those other things that I know have been discussed here earlier today.

From one perspective, I would say that there is always more that we can do, in a lot of spaces. This is probably one of those areas where I have been particularly interested, when I have been able to today, to listen in to the evidence that people have given. I have also read through the submissions you have received. It has been about looking through a lens at the health system from the perspective of people experiencing this chronic condition, as you have heard today, which is something that they travel with through a long period of their lives.

In terms of going back to the responses, we have a range of services in the ACT, in the non-government sector, in the primary care space through GPs and at Canberra Health Services that are all working together as a system to try and address a chronic health condition which, as has been evidenced today in some of the material you have heard, is complex to diagnose for many people and leads to quite backwards and forwards pathways through the health system. It is a complex journey to take.

We have a range of things in place. We are always interested to understand how we can improve. I think that is true for many things in the health system, in terms of improving people's experience of their care. Some of the issues have already been highlighted, about the need to factor in, in the ACT, the small size of our jurisdiction, the workforce challenges we have, the dependencies when we lose one person, and what that means, when we only have three people operating in really specialist positions. They are all factors that make for a very complex set of levers, where there is no one lever to pull to fix things.

There are things in place, and we are very keen to hear, and are listening to, the ideas that come from this committee about what else could happen.

MISS NUTTALL: When you talk about workforce challenges, one of the things we heard at the start of the day was that we do have a lot of capable workforce here in the ACT, but we are seeing a loss to the private system, which makes it challenging for a lot of people we have heard from who have not been able to afford to go private, so they have been on long waiting lists in the public health system. What do you see as the biggest workforce constraints? Is it about the people willing to do the training? Is it about whether that training is funded or whether they are funded to take time out of their current, very demanding job to do the training? What are the big hold-ups? Is it the case that, if we funded more training and more positions, there would be ample people to fill them?

Ms Stephen-Smith: There are probably two elements to that example, one of which is around the additional scope of general practice which can be expanded to some significant degree in this space. I will ask Dr Glading to talk about that. The other is in relation to obstetrics and gynaecology specialty, in which, as we talked about earlier, there is a national shortage of specialists. I will ask Jodi to talk first about general practice and where that fits in.

Dr Glading: There is certainly scope to increase in general practice, and I think that has been a focus that the directorate has recognised. What we really want to do is capture people early and get diagnosis early, so that we can avoid some of the stuff that is putting people into the hospital system, which is not the best place for them to be treated. We know that if we can intervene early and diagnose early, the primary care space can help to take care of some things that might otherwise end up in hospital. Hospital is not the best place to end up in.

With some of the training that we are currently doing, we are very lucky in the ACT that we have a single primary health network, so we are working very closely with the primary health network. We have already run this year four different programs for general practitioners to be upskilled in this area. It might be a face-to-face on IUD insertion for people with pelvic pain, specifically looking at women who have had previous experiences or who are worried about their pain increasing. We have run with the PHN some education and training for general practitioners that has been online; we have had a sex therapist involved who has talked about intimacy, partner intimacy, what pelvic pain experience is like for women and how that interacts with their sexual health and their sexual life.

There is a range of different types of things that we offer. As part of the government's commitment to the General Practice Wellbeing and Professional Development Fund, there is additional work that we are doing in that space. That relies on a GP putting their hand up to say that they have an interest in that area. It does rely on a GP identifying that this is an area in which they believe they could use some additional skills, so that they are working in that space.

We have also had some work with SHFPACT and with the hospital to make sure that our general practitioners get access to some of the clinic work. Where there is some of the technical skill development that needs to happen from the general practice workforce, they get that skill set and they can be supervised by people within the hospital system that already have that training. They can then take that back into general practice.

Dr Van Diemen: From a hospital perspective, if we are talking about endometriosis and pelvic pain, it is not just the medical specialist. From a medical specialist perspective, there is difficulty recruiting gynaecologists across the country, in all areas. That is why they have been put on the expedited specialist pathway through AHPRA. That is why we are having to look overseas, because the workforce in Australia is not enough to meet the demand.

When we are looking at the rest of the workforce that is needed, certainly for the Canberra Endometriosis Clinic, it is the multidisciplinary allied health and nursing workforce. That is a workforce that would need specialist training or further training, and time to be able to get training in that area. Absolutely, any increase in money and funding in that area would be fabulous.

Ms Wakefield: We are supporting nurses in the gynaecology clinic to do study, a course, in endometriosis and pelvic pain. That supports their course fees.

MISS NUTTALL: There was one mentioned by RANZCOG, a funded course for nurses who want to specialise in pelvic pain. They said that it is state and territory funded. With their barrier right now, they know more people would do it, but they do not have the funding. Does that line up with your experience of demand for that particular program?

Ms Stephen-Smith: We met with RANZCOG this morning and talked about that and some further work to look at what they are offering compared to what we are currently offering to nurses.

Dr Van Diemen: I cannot speak to the nursing component. Kath, I do not know whether you can speak to the nursing—

Ms Wakefield: Is there a RANZCOG course? Our other course is not from RANZCOG.

Ms Stephen-Smith: I think the work that needs to be done is to look at what it is that RANZCOG is offering, and how that fits in—Jodi was in the meeting as well—with the broader suite of training and education that is already on offer in the ACT. Some things will work better for some people than others.

Dr Glading: We also did a piece of work on our peak critical systems governance committee, looking at what are the different allied health professions that are offering help in pelvic pain, endometriosis or PCOS. There are over 20 different private practices, with a whole range of different interventions within the ACT that are offering services. We did a bit of a stock-take to understand who is already trained and who might be underutilised in this space. As part of the next step of that work, now that we have done that stock-take, we are working with Women's Health Matters and the PHN to make sure that primary care clinicians understand who those practitioners are, so that they can get into early referral pathways.

Some of those practitioners do have an out-of-pocket, and some of those allied health practitioners have very little or no out-of-pocket. It will depend on what the issue is and what the patient is seeking to get out of that interaction. We have started to do that piece of work because we realise that there are qualified people who already have specialist interest in this area but are not necessarily being utilised to the level that they could, or women are finding out about them much later or through their social pathway, rather than through their clinical pathway. We are doing some work to try to increase the knowledge so that people get to the right person with the right qualification or special interest.

THE CHAIR: What do the wait times in the Canberra Endo Centre look like?

Ms Wakefield: The clinic?

THE CHAIR: Yes.

Ms Wakefield: While we are looking for that, I can tell you that the school youth health nurses are in 12 high schools.

Ms Stephen-Smith: Do you want to ask another question, and we can come back to that once we have found it?

THE CHAIR: Yes. While you are searching for that, I want to ask about specialised public ultrasounds. We have heard about this throughout today. They are very valuable in diagnosis; it sounds like there are maybe only two locations that are able to do this in the ACT. Is this something that the government is looking at providing publicly?

Ms Stephen-Smith: Again, this was a topic of conversation in our meeting with RANZCOG this morning. One of the challenges—and I will get Dr Van Diemen to talk about this, as she did so eloquently in that meeting as well—is a shortage of really skilled sonographers right across the board, and radiologists to read—

Dr Van Diemen: Gynaecologists with specialist qualifications.

Ms Stephen-Smith: Gynaecologists with specialist qualifications to read the ultrasound. So it is about both taking the ultrasound and reading the ultrasound, and interpreting that. That is a skill set that we require in our maternal fetal medicine unit. That is an ongoing challenge. Our team do an incredible job. Jane might talk about what that looks like. Again, it is a national issue; it is not just an issue here.

Dr Van Diemen: Yes. I am sorry; I missed the question. Wasit specific to DIE scans?

THE CHAIR: Yes, the DIE scans.

Dr Van Diemen: We do not offer it in the Canberra Health system, primarily because the skill set for the sonographers to do the scan is incredibly complex, and there are additional skills that they need. We cannot perform them. The other part of it is reporting on them, and we do not have the expertise to report on them at the moment. Certainly, with the people who would have the qualifications—there are some specialty qualifications within gynaecology—their skills are being utilised within the maternal fetal medicine service.

We do not have the capability to either increase the training for the sonographers or provide staff that have the appropriate qualifications to be able to read the scans. In Canberra, there is a private option available to people. In New South Wales, there is a public option available to people at one of the tertiary referral centres. I might be wrong, but I think it is the Royal Women's. We do not as yet have an established pathway to refer patients there, and it is replicated in other jurisdictions, where they might have a subspecialty centre that does DIEs in the public system, and the waitlists are incredibly long for those, so they are not able to accept referrals outside the area.

THE CHAIR: Do you have the technology to do it? That was the other barrier that was mentioned earlier. Is additional equipment required to perform those specific tests?

Dr Van Diemen: Not that I am aware of. I will check and get back to you.

Ms Stephen-Smith: We will take that on notice.

THE CHAIR: Okay; thank you. I understand it is not being done now. Is this something that is a priority for the government, to be able to bring more staff in and train them up to do that, to do those scans? We have heard all day about the benefit of an early diagnosis and how much that can save—obviously, a lot of suffering, but also time and money down the track.

Ms Stephen-Smith: One of the things that we will look for, coming out of this inquiry, is where the committee concludes that we really need to focus our effort. Obviously, there is a lot we could do. In every space across the health system, there is more that we can do. We do not have the resources to do everything, everywhere, all at once. That will be something that we assess, and we will look forward to the committee's view about where we should be focusing our resources in this space.

Dr Glading: There is work happening nationally. I was at a meeting yesterday, and the college of obstetrics was there as well. Part of what we are talking about is that you need to have enough trainers to train the clinicians who might have an interest and who want to. Yesterday's meeting talked about how we create capabilities so that our trainers can train those who are coming, not just as their replacement but to increase. We were looking at that across multiple disciplines, but gynaecology was one of the key areas that we were looking at.

Nationally, there is some focus on how we do that, so that when the timing is right for ACT to hire someone with that skill, there are people with that skill. While it might not be something we are doing specifically locally, we are still tapped into pushing that agenda at that national level and working with the colleges.

Dr Van Diemen: RANZCOG also are doing a piece of work on establishing what qualifications and guidelines are required, and skills to be able to do the scans and be able to read the scans. We will wait for that piece to come out.

THE CHAIR: Ms Wakefield, you look like you may have finished searching.

Ms Wakefield: Yes. I do have a figure, but it is internal operating data. In the gynae outpatient clinic, we have a single-pool wait queue; our doctors triage that and we are able to triage those onto a separate work queue. Rather than having general outpatient data, I think it is that data that you are looking for. If we take that on notice, we can give you that based on category.

THE CHAIR: That would be great. Any detail that you are able to provide would be fantastic.

Ms Wakefield: I think we can even show some improvement over time.

Ms Stephen-Smith: Yes; recognising that, whenever we provide the outpatient data, at the moment it is operational data, so it is subject to change.

THE CHAIR: Okay, thank you.

MS TOUGH: I want to talk about out-of-pocket costs of care when people go to the private system, because the wait times in the public system are quite complex and the public system is not equipped for people's situation. I will not talk about ultrasound, because the chair has already gone down that path, but we have heard a bit about IPTAS today from some people who have accessed it. For some people it did not quite cover what they needed, because of their disability. The accommodation they needed interstate had to be disability-accessible and the money did not quite cover that level of accommodation. And there were people who had not heard of it and had never used it. What is the threshold for using it, and how widely known is it? Someone's GP may say, "If I send you to Canberra Health Services, you're going to be waiting a long time. I think you could really benefit from getting someone now. I don't want to send you to one of the private gynaecologists in Canberra," or the person may have seen a few of them here and did not have a good experience. Would it count if they were being sent to, say, Sydney or does there need to be a higher threshold? And are GPs aware that it is there, in order to help their patients access it?

Ms Stephen-Smith: I am looking at the eligibility for IPTAS now. It is generally for people who are referred for medical care interstate by an ACT or Queanbeyan medical professional but live in the ACT. You have to be a permanent resident of the ACT and be referred to the closest service to the ACT that provides the medical care. Some people are unlikely to be eligible if they choose to go interstate for a service that is available in the ACT. We know that people choose to go interstate for a range of reasons, some of which you have touched on. You are not eligible, for example, if you are travelling to seek a second opinion, having received care, or are travelling to receive care from a health professional of your choice when it is available in the ACT, and that might be where it is available in the ACT either publicly or privately. I recognise that creates challenges for some people, particularly because of the very significant out-of-pocket costs from going privately in the ACT.

We are also aware that some work is underway to look at IPTAS at the moment. It is quite cumbersome to apply for IPTAS. The process is not very streamlined at the moment. It is very much about filling in a PDF form, submitting it, waiting to be reimbursed, and all of that stuff. We have certainly heard a lot about that from parents with kids receiving care interstate. And it is not a full reimbursement scheme. That is also clear up-front. A set amount of funding is available for people who access IPTAS. It is not intended to be a full amount, and I think it is the same across every state and territory where they provide patient travel assistance schemes. They often do not cover the full cost, but many people can get a reduction in the cost of accommodation in the other jurisdiction when they have to travel—or even not within another jurisdiction; lots of patients living in New South Wales get the New South Wales scheme to travel to Sydney. It is not a perfect scheme and it is certainly something that we are currently looking at improving.

MS TOUGH: Is there much knowledge of it among primary health providers, and even in the hospital, to make sure that, if patients are going to be eligible, they are aware? It is not going to cover everything, but there might be something there to help.

Dr Glading: There is information in the clinical pathways called HealthPathways, which general practices have access to. It shows the model of care within the ACT and whether there is no option, but that relies on the GP using it. If the GP is trying to use their own professional networks and does not go onto HealthPathways, they may be unaware that there is an option for a patient to access something that is not currently provided within the ACT system.

MS TOUGH: Fair enough. On out-of-pocket costs, a lot of that obviously sits federally with the MBS and the PBS, to make sure that out-of-pocket reimbursement is higher than it currently is and more bulk-billing is available. This morning we heard about a blood test that is in development for diagnosing endometriosis, with about 90 per cent accuracy, so, if it comes up negative, obviously you would not be able to rule it out, but you can definitely rule it in. I think that somewhere in Victoria is developing it and it is kind of in the final stages. One concern is making sure that it is MBS funded so we do not have a two-tier system, where people with money can get a blood test and a diagnosis and people without will be stuck waiting. Is that something that Canberra Health Services and ACT Pathology, separate to the MBS, are able to take on or does it all go through the same system?

Ms Stephen-Smith: Primarily—and I think I am right about this; Kath will correct me if I am wrong—when people do a test through ACT Pathology, outside of the hospital, it is MBS billed. It would be reliant on what the MBS is able to support. But, having said that, there are things that we can deliver internally in the hospital that might not be supported by MBS. It is certainly one of those areas where, once it comes onto the market and is available, there would probably be an assessment of whether we just wait until it comes onto the MBS or it becomes available for people. If it is a more cost-effective way of undertaking diagnosis, my view is that that is the kind of thing that we want to invest in, but it is a question of capability, cost and timelines, in terms of approvals, and those are commonwealth issues. It is for a great development in an area that has been under-represented, in terms of effort around both research and treatment for a long period of time, as is the reason for setting up this inquiry.

MS TOUGH: On the out-of-pocket costs again, one of them is allied health. A lot of services through Canberra Health Services offer allied health services. What is the pathway to some of those health services? And what allied health services can someone access in the public system if they were referred?

Ms Wakefield: I know that for our gynae outpatient department and the Canberra Endometriosis Centre, some of the pathways come out of our clinics, specifically. As far as other referrals to those services go, we would have to check on that.

Dr Glading: I have the list of the 20 different allied health practices or practitioners and what they provide, as well as their subspecialty. I am happy to provide that.

MS TOUGH: That would be perfect.

Dr Glading: You could see the breadth and the depth of things that are being offered. There is limited information around the exact amount of out-of-pocket costs that would potentially be the burden, because we did not go down to how much it actually costs out of pocket. We were mainly wanting to figure out who is offering what and where, but we have an indication that some said, “We would do this bulk-billed—nil out-of-pocket cost.”

MS TOUGH: Wonderful. Thank you. Knowing physios, dieticians—who, where and what people can access—

Ms Stephen-Smith: Yes. As you are probably aware, Canberra Health Services has pelvic health physiotherapy as part of the community care program. My understanding is that there has been growing awareness of that and it is now quite well subscribed. There may now be a waiting list for that. It is also one of the things we are having a really good look at—what our community care program looks like compared with what is available in the private sector and what the eligibility criteria are for that. We need to balance that, with the public system being available for the people who need it most and, where people can afford to access allied health in the private system, that might be the most appropriate option for them. But no decisions have been made in relation to any of that at this point in time. We will continue to have a pelvic health physiotherapy service as part of our community care.

MS TOUGH: Thank you.

Dr Glading: Going back to education in the general practice space, one of the other things that we are doing as part of the educational piece is reminding general practitioners that they can do a chronic care plan that will allow access to things, because we heard regularly, even before the information came up for this inquiry, that people were not aware that it was a pathway. That reverts back to the doctors not thinking about putting someone onto a care plan that would open those pathways.

MS TOUGH: Thank you.

THE CHAIR: Could I quickly jump back to the list of 20 allied health professionals. In their submission, one of the earlier witnesses essentially called for an ACT government website where that sort of information would be provided. Is that under consideration?

Dr Glading: It is most definitely part of the consideration. It is just about making sure that there is upkeep of the data. Then you can put information there. But, if the general practitioners do not go to it and use it, it is about how we then build it into education so that people know that it is there and it is regularly updated. And it needs to fit into a place that general practices would go to get information, versus them having to come to our website and then going to the PHN website. It is about figuring out where it sits so it is easiest for them to access.

THE CHAIR: I think the recommendation was that it would be for the general public as well so people will know who they can go to, not just for GPs. We can potentially mention that in our report as well.

Ms Stephen-Smith: The other element of it is that we are currently a participant in and funder of healthdirect, which is an online national service which has a service finder that includes some allied health professions, though not all. But that is transitioning to the national 1800MEDICARE, so one of the conversations we are having is: what does that look like? We do not want to put up an ACT government website that replicates what is going to be available on 1800MEDICARE, but we also need to ensure that we are providing input to whatever is on 1800MEDICARE to ensure that it is comprehensive, with built-in information that we know is available.

MISS NUTTALL: I am interested in the part of your submission that talks about the fact that, for trans and gender-diverse folk assigned female at birth, chronic pelvic pain is significantly more frequent than for cis women, according to a 2024 paper. You can appreciate the fact that services often do not feel safe for them or are located in female-specific areas. It becomes a challenge. I am interested in whether you have any idea why it might be more frequent. Has that ever come up?

Ms Bear: The short answer is no. It is an under-researched area. You could have conversations and get an anecdotal indication, but, from the material I have been reading through, it is an area where more work needs to be done. I am happy to be proved wrong by other people who made submissions. It is a really interesting question and a really important part of addressing people's individual needs as they engage with health services.

MISS NUTTALL: Absolutely. When we talked to Women with Disabilities ACT earlier today, they talked about clusters of conditions, like POTS, neurodiversity, being trans or gender-diverse, and things like that. That is a theory that has been knocking around today. It is something we need more research on. When it comes to supporting trans and gender-diverse people and other cohorts for whom services might not be culturally safe, like First Nations people and people with disability, what sorts of measures do you take to make sure that your services are culturally safe and that people know how to make sure that it is a safe place for their patients?

Ms Wakefield: Our staff do additional training. This is not new and it is something that is part of our practice every day. Certainly, regarding our group education, if people do not want to go to that, there is another option for them to go straight to individual appointments or to a treatment team that is not in group education, if they would prefer that. It is part of general practice and how we provide person-centred care as much as possible. If people tell us, then we try to tailor that as much as possible.

MISS NUTTALL: Specifically, what does that look like? Does it look like gender-affirming language? Does it look like making sure that endometriosis and pelvic pain services are not located in maternity wards, and things like that?

Ms Wakefield: Our gynaecology department is separate to antenatal maternity and maternal-foetal medicine, but it is gynaecology and that is where our team is based to deliver some of that care. They try to make it as welcoming as possible, and I am aware that we do some outreach services where possible, so that might be some way in which we can provide person-centred care.

MISS NUTTALL: Do you do particular work to interface with community based services, where there might be an additional level of comfort? People might not necessarily want to seek help from a hospital in the first instance; they may be more likely to get help from a community based service—perhaps like SHFPACT—in the first instance. Do you then work on making sure that there are referral pathways through community based services if people need support from the hospital or from CHS?

Ms Wakefield: It might be based on the referral information that we receive and the detail in that, and then we can look at how we can provide the tailored care based on the referral information. The consumer may also call us ahead of the care or we may offer an appointment to see if there are any adjustments that they would like us to make.

MISS NUTTALL: Thank you.

Dr Glading: Kath, you might want to talk about this. One of our public clinicians also works through Winnunga to make sure that it is culturally safe for our Aboriginal and Torres Strait Islander patients, as part of his work. It is delivered in a space that they are comfortable with, rather than having them come to the hospital to seek that service.

MISS NUTTALL: Is that someone who is practising as part of the CC?

Ms Wakefield: It is one of our gynaecologists.

THE CHAIR: Ms Tough might like to ask about pelvic Botox.

MS TOUGH: Yes. It has come up a lot today. The petition recently closed and the government is considering a response, but, on behalf of the submissions and quite a few people who came in today, I want to know where things might be up to with pelvic Botox. One person told us they travelled interstate recently and they were $6,000 out of pocket. They had previously been getting it publicly here and now it costs $6,000 to get it. They were wishing that it would come back.

Dr Van Diemen: What we know about pelvic Botox is that it is not a treatment for endometriosis; it is for chronic pelvic pain. There is limited research. It is not a cure and it is a relatively short-lived treatment, as Botox is for all of its various uses. It would be appropriate for use in a very small number of patients. Pelvic Botox is not something that is offered at Canberra Hospital or North Canberra Hospital at the moment. When we are looking at using medications, a threshold needs to be reached to make sure that we are using it for the right reasons and there is enough evidence to suggest that the benefits outweigh the risks, and we need to go through a really strong and strict governance process to be able to use a medication like Botox within the public health system. We have not reached that threshold.

Ms Stephen-Smith: What we have indicated—as I think you are aware, and it would be in the response to the petition as well—is that, if someone wants to bring forward a proposal for a research trial, that would be considered through a research pathway, but the last I heard is that no-one had done that.

Dr Van Diemen: We would look at where it is being used publicly in New South Wales; we would look to our neighbours. As far as we are aware, a trial in Western Sydney is looking at the use for chronic pelvic pain in a specialist or a subspecialist urogynaecological centre. We are not a subspecialist urogynaecological centre. Trials are appropriate in the subspecialty centres. Moving outside those centres would need some consideration.

MS TOUGH: If it is being offered publicly in New South Wales, is that something IPTAS would be able to help someone with, because that is the closest place it is being used?

Ms Stephen-Smith: It probably depends on—

MS TOUGH: It depends on the circumstance.

Ms Stephen-Smith: It probably depends on eligibility for the trial as well. It would not be unusual for an ACT patient to access a clinical trial that is occurring interstate, but that would depend on how the clinical trial was set up and whether they are taking patients from other areas or they have a particular patient cohort.

MS TOUGH: Thank you.

THE CHAIR: This has come up multiple times today. We have heard about the Pelvic Pain Foundation’s Periods, Pain and Endometriosis Program. It sounds like that is being provided to primary school students in the non-government sector. Earlier, SHFPACT said they are providing their relationships and sexuality education workshops in a third of primary schools in the ACT but were concerned about uncertainty of their funding. Is this something you are keen to see delivered in all primary schools—perhaps all government primary schools? I know we are now onto education, but they are funded through HCSD, so I am curious about the government’s position on that.

Ms Stephen-Smith: We have been talking to SHFPACT about their funding situation for the education that they are delivering in schools. That has been a conversation with both HCSD and with Education. We are working through that with them. It sort of bleeds into a wider discussion about what is available in which schools and why some things are in one school and not in another. Sometimes there is a very good reason for that, and other times it is a question of: “Why isn’t this a universal program across all schools?” That is probably a bigger conversation that is not only related to this particular subject matter.

THE CHAIR: Sure. We will wrap it up there. On behalf of the committee, thank you for your attendance today. For questions taken on notice, please provide your answers to the committee secretary within five business days of receiving the uncorrected proof *Hansard*. On behalf of the committee, I thank all witnesses who have assisted us through their experience and knowledge. We also thank broadcasting staff, Hansard staff and the secretariat for their support. If a member wishes to ask questions on notice, please upload them to the parliamentary portal as soon as possible and no later than five business days from today.

The committee adjourned at 5.04 pm