

Inquiry into universal access to reproductive healthcare

Melbourne Hearing – 28 April 2023

Additional Response, Dr Samantha Mooney
Acting Clinical Director of the Julia Argyrou Endometriosis Centre at Epworth

I attach the following as additional evidence for the Inquiry. Unfortunately, I was not invited to give my brief discussion points at the start of the panel session.

As the Acting Clinical Director of the Julia Argyrou Endometriosis Centre at Epworth, I feel it crucial to highlight where Endometriosis and pelvic pain fit into the terms of reference for this enquiry.

With the establishment of the Julia Argyrou Endometriosis Centre at Epworth, Epworth HealthCare has been highly active in the endometriosis space, contributing early on to internationally significant research, advocacy and best practice patient care.

Endometriosis is a chronic condition that affects at least 1 in 9 Australian's assigned female at birth, making it one of the most common conditions managed in reproductive healthcare. Persistent pelvic pain, of which about half of sufferers also have endometriosis, affects about 1 in 5 Australians born female.

Due to numerous barriers – health literacy, societal paradigms, quality of wider medical education, finances, geography, and overburdened referral pathways – the average person waits 7-11years for a diagnosis of endometriosis. Often, due to the same barriers, the symptoms of disease go untreated during this time.

There are several critical steps that could be taken to achieve universal access to reproductive healthcare:

1. Firstly, an overhaul of PBS funding is needed for medications used to treat endometriosis and its associated symptoms – these include everyday contraceptives, most of which aren't PBS listed.

2. Secondly, Endometriosis more than trebles a person's risk of subfertility. Funding for medically indicated oocyte vitrification is largely limited to those with malignant conditions. There is an urgent need for funding for fertility preservation for patients with severe fertility-limiting non-cancerous medical conditions, such as endometriosis. At the moment, these patients have limited access to those technologies that have proven economic benefit. Funding for oocyte vitrification for patients with endometriosis will prevent future infertility for many patients with severe disease impacting ovarian reserve and oocyte quality. Increased federal funding for IVF access for patients with endometriosis is also urgently needed.
3. Next, Endometriosis is known to be associated with more than a dozen other chronic conditions. The longer a person suffers symptoms of endometriosis, the more likely additional disorders will arise. Early access to multidisciplinary and interdisciplinary care must be paramount, including general practitioners and nurse specialists. This care needs to be provided by appropriately trained and accredited practitioners following best practice guidelines. The federal government should prioritise research into the best model of multidisciplinary care for patients with Endometriosis, and fund these accordingly. Whilst a vital step, \$AUD700,000 over four years for each of twenty clinics is not adequate. Additional funding needs to be provided for widespread education in primary care, as well as funding for hospital services (regional and metropolitan) to provide coordinated multidisciplinary care, and to audit outcomes. All public hospitals providing care for patients with endometriosis should have a dedicated Gynaecology liaison nurse in the least (and Endometriosis Clinical Nurse practitioner in larger centres) to ensure adequate and early access to skilled care for all patients.
4. The federal government has a role in ensuring this training and accreditation. This is a challenging concept, but requires open and transparent discussions with RANZCOG and AGES, and ongoing planning to train and assess competency of all gynaecology specialists managing patients with persistent pain and endometriosis. There is currently no validation for what constitutes an "endometriosis surgeon". There is no mandatory ongoing competency assessment for endometriosis management (surgical or non-surgical), nor any requirement for involvement in audit of individual or unit outcomes in terms of *pain* nor *fertility*, the two main symptoms endometriosis patients present with.
5. The federal government should urgently assess funding frameworks for non-operative management of endometriosis and persistent pelvic pain. For patients with pelvic pain and endometriosis, gynaecologists are remunerated for surgical management, but there is inadequate remuneration for referral and coordination of multidisciplinary

care and medical pain management. This is vital – 20-30% of patients with endometriosis will not have symptom improvement with surgery, and then chance of symptom control declines with subsequent surgeries. Moreover, for those who do have benefits with surgery, approximately 50% will have recurrence of symptoms after twelve months.

6. More federal investment in endometriosis research is imperative. Endometriosis is twice as common than type 2 diabetes, yet receives nowhere near the amount of funding investment for research nor coordinated care. With the Australia-wide access issues to surgical management, particularly in regional areas, funding should focus on *predicting who* will benefit from surgery. At the moment, there is no focus on prognosis for pain symptoms for patients with endometriosis.
7. Adequacy of Imaging is paramount to guide care of patients with endometriosis. Ultrasound and MRI still cannot reliably predict presence of minimal/mild endometriosis, but there is progress in this sphere. Diagnosis and assessment of severe endometriosis, relies heavily on subspecialist ultrasound (COGU) and MRI. These studies are only as good as the person performing and interpreting the ultrasound, or reading the MRI. These modalities are primarily available in larger tertiary hospital settings, and access is limited in regional Australia. Federal funding for pelvic ultrasound rebates is inadequate. These studies take up to 40 minutes to perform, and assess at least three different organ systems. Rebates for these complex scans is less than a male pelvic ultrasound – an absurd discrepancy.
8. Federal funding for early and accurate education for young women is crucial. Resources should be available in the appropriate format for their audience. Quality and accessible education will promote early intervention, and may reduce the chronicity of the pain conditions experienced by patients with endometriosis.

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