

18th June 2018

Australian Commission on Safety and Quality in Health Care (ACSQHC)
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OPEN Letter to ACSQHC

Re: Community Affairs References Committee

Number of women in Australia who have had transvaginal mesh implants and related matters. March 2018

This letter is a joint appeal from each state's Pelvic Mesh Support Groups and the current Health Consumer organisations in each State and Territory across Australia. On behalf of all mesh injured women of Australia, and those who may in the future access treatment for stress urinary incontinence or pelvic organ prolapse we write to you, the **Australia Commission for Safety and Quality in Healthcare** to comprehensively address the recommendations tabled in the above report. We need and value your support in addressing the urgent call for action to prioritise the management of this medical disaster that is crippling Australian women and their families.

Women from the Support Groups are struggling with lifelong complications, physical and mental ill health, pain, suffering, financial burden and significant loss of life as they knew it. They feel that there needs to be a dramatic cultural change in treatment, reflected from the top and ensured by ACSQHC.

There is a significant lack of trust in the medical treatment these women have received; they have been dismissed, ignored and gaslighted into believing their ailments were "all in our heads". As Senator Rachel Siewert, Chair of the Senate Inquiry, stated in her report release speech: ***They have suffered for so long without being heard. They have not been believed. In some cases, they've been belittled. They have been ignored. Well, for no longer shall they be ignored.***

Appropriate pathways for lifelong care are now required. A trauma based model is needed for treatment moving forward; together with empowerment for all women at every stage of their journey.

The results of the Senate Inquiry into transvaginal mesh in Australia, and its recommendations, give the ACSQHC a large amount of responsibility to assist with supporting mesh injured women. As a group, we want to make sure every single one of these recommendations are taken seriously, and interpreted with integrity. We expect a detailed action-oriented response as to how the ACSQHC will deal with its given responsibilities. The large group of mesh injured patients will make sure this happens and keep the ACSQHC focused on the task of doing so.

We understand that there are many items recommended for the **ACSQHC** to address, which broadly fall into the broad categories below.

1. Cultural Change

We expect to see a mission statement that drives cultural change in the treatment of mesh injured women and educates and informs health professionals, surgeons,

specialists & government service providers. We expect true co-design of all mesh clinics in public hospitals including multi-disciplinary team care, without the need for women to have to revisit the surgeons who have injured them. Women need to be treated with empathy, warmth and understanding using listening as one the main tool of assistance; and acknowledging physical, emotional and financial needs.

2. Consumer Input

We expect a commitment to TRUE co-design of all services and information materials with consumers. Token consumer consultations, while the real work happens without consumer voice, will not be accepted. Simplified messages released thus far about the rarity of complications are misleading, considering the level of overuse of transvaginal mesh devices. Consumer input is needed to increase relevance, precision and true informed consent.

3. Enforcement

We want to see stronger consequences for poor, unsafe and misleading practice. Mesh clinics have been marketed to mesh injured women before actual quality of care is established; leaving mesh injured women unnecessarily re-traumatised (experiencing further rejection and trauma). Surgeons continue to play down the risks of transvaginal mesh surgery and defend their actions by wrongly implying that complications are only found in extremely rare, unfortunate cases of women likely to have experienced poor health anyway. Such poor practice continues with impunity and we need better safety and quality systems to stop this occurring.

We implore the ACSQHC to act on behalf of mesh injured Australians, and put into practice all of the recommendations made by the Senate Inquiry.

It is imperative for every mesh injured person to be empowered to seek and obtain treatment that will allow them to live the best possible life moving forward with their injuries.

Signed,

Mesh injured support groups Australia wide

State and territory peak health consumer organisations

