COMMUNIQUE

Driving the APFPR

The Australasian Pelvic Floor Procedures Registry 's (APFPR) success to date has been led by a team of highly-skilled clinicians who continue to make a significant contribution to the registry's Steering and Management Committees with their time, perspectives and expertise.

These clinical leads, including a device registry representative, monitor the strategic direction and development of the registry, and were nominated to provide craft group leadership through representation for Urological Society of Australia and New Zealand (USANZ),

UroGynaecological Society of Australia (UGSA), Colorectal Surgical Society of Australia and New Zealand (CSSANZ) and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).

Their work includes the development and finalisation of the stress urinary incontinence (SUI) minimum dataset (MDS) and SUI patient reported outcomes (PROMs) data, current ongoing support for both the Pain PROMS study and pelvic organ prolapse (POP) PROMs, with the POP mesh MDS to follow.

These individuals have been instrumental in identifying additional sites and contacting colleagues encouraging registry participation, while keeping surgeon colleges and societies abreast of registry progress.

This wealth of knowledge and experience has provided strong foundations for the Steering Committee which meets quarterly and also includes project investigators and stakeholder representatives from the Australian Government Department of Health; Therapeutic Goods Administration; Australian Commission on Safety and Quality in Health Care; and consumer representatives.

The APFPR Chair of the Steering Committee and Academic Lead Professor Susannah Ahern is supported by Research Fellow Dr Oliver Daly, who provides in-house clinical quidance and subject matter expertise for the project team.



Prof Helen O'Connell Urology



Dr Jenny King Urogynaecology



Dr Jessica Yin Urology



A/Prof Emmanuel Karantanis Obstetrics & Urogynaecology



Dr Elizabeth Gallagher Obstetrics & Gynaecology



Mr James Keck
Colorectal Surgery



Mr John Short Obstetrics & Gynaecology



Prof Stephen Graves Clinical registries



Dr Oliver Daly Urogynaecology

APFPR CONSUMER REPRESENTATION

Initial research from Monash University regarding consumer representation on steering committees for clinical quality registries has suggested it is important that consumer representation includes lived experience as well as advocacy experience, which is not always present in one representative. We have been delighted to welcome Pip Brennan, CEO of Health Consumer's Council (WA), to the APFPR Steering Committee to complement the work of our existing lived-experience consumer representative Dora Vasiliadis. Pip is a career advocate with a wealth of knowledge and along with Dora, they are guiding the APFPR on ensuring that the registry as it develops, remains patient centred as well as enhancing consumer involvement. This support and advice is critical to the realisation of the APFPR.





Dora Vasiliadis (left) and Pip Brennan Consumer representatives





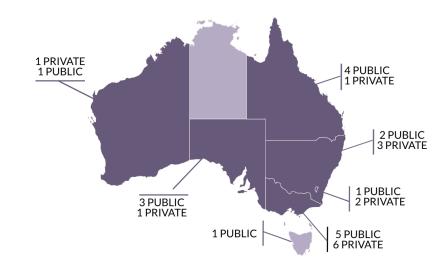
This bi-annual communique outlines the progress of the Australasian Pelvic Floor Procedure Registry (APFPR). The APFPR is a clinician-led national clinical quality registry, with the primary aim of monitoring the safety and outcomes of stress urinary incontinence (SUI) and pelvic organ prolapse (POP) procedures involving mesh and other implantables.

SITE RECRUITMENT

VIC: Monash Health*, Cabrini Health*, Bendigo Health*, Western Health*, St Vincent's Private Hospital*, Mercy Health*, St John of God Bendigo, Epworth, Waverley Private Hospital, Barwon Health, St John of God Geelong NSW: St George Public*, St George Private, Nepean Hospital, Westmead Private, Westmead Public

QLD: Gold Coast University Hospital, Robina Hospital, Varsity Lakes Day Hospital, Sunshine Coast University Hospital, Buderim Hospital ACT: Calvary John James*, Canberra Private, Canberra Public WA: Hollywood Private, King Edward Memorial Hospital SA: Royal Adelaide Hospital*, Queen Elizabeth Hospital*, Flinders Medical Centre, Calvary North Adelaide TAS: Royal Hobart Hospital

Sites with approval*/remainder in progress, including confirmed interest



TIMELINE JAN - AUG 2021



KEY REGISTRY ACTIVITIES

As of February 2021, the first site - Monash Health - was trained to register patients and collect data for the registry. More than 45 sites across Victoria, New South Wales, Australian Capital Territory, South Australia, Tasmania, Western Australia and Queensland are part of site selection in phase one.

Despite the initial disruption from COVID-19, which lengthened ethics/governance processes and made recruitment difficult, currently more than 30 sites have either been submitted to governance (or ethics), are in the process of being submitted or have confirmed interest in participating. Both ethics and site governance approvals need to be in place prior to contributing patient data to the registry. Currently there are now 32 patients registered with the APFPR.

With the establishment of the SUI mesh module, the POP mesh module is currently under development comprising a POP PROMs acceptability study and POP mesh minimum dataset determination. A pain PROMs study has also been undertaken by an honours student.

Communication and stakeholder engagement has been enhanced in the last six months with the public launch of the registry on Mesh Awareness Day (1 May), the onboarding of a second consumer representative, and a website refresh to be finalised in the coming weeks to incorporate a new logo and branding.

Two significant policy documents are being finalised to continue identifying pathways and processes for broader stakeholder and consumer engagement. A registry user group will also be established in the coming months to invite feedback on data processes.

SURGEON PARTICIPATION

The APFPR has been designed to support clinicians to meet any credentialing requirements of their institutions, based on the ACSQHC's transvaginal mesh credentialing guidance, and do this in a manner that reduces data collection burden. For more information visit: www.safetyandquality.gov.au

Currently the APFPR SUI mesh module is live and recruiting patients to the registry. The POP mesh module is due for release early in 2022. Demographic, clinical history and surgery details including outcomes and complications are collected. PROMs are administered by the APFPR at baseline, 6, 12, and 24 months post-surgery. Surgeons can access to their own patient data and accumulate CME/CPD points through their college or society.

PROCESS FOR ADDING PATIENTS TO THE REGISTRY

- Introduce eligible patients to the registry & provide patient flyer
- Register the patient by adding them to the APFPR database at least four weeks prior to surgery to allow for baseline PROM administration by the APFPR
- At time of surgery, add clinical history and surgical details
- At the post-operative visit, add surgical outcomes including complications

NEED ASSISTANCE OR INFORMATION?
Please contact the APFPR to confirm your hospital is participating and find out more about joining at apfpr@monash.edu