June 2 0 2 3 , I S S U E # 6 COMMUNIQUE

AUSTRALASIAN PELVIC FLOOR PROCEDURE REGISTRY

PURPOSE

The APFPR aims to identify and report on trends and complications associated with Pelvic Floor Procedures, specifically Stress Urinary Incontinence and Pelvic Organ Prolapse, and to identify *best surgical practice* and *optimal patient health outcomes*. This knowledge will come from analysing high-quality data, over time, covering thousands of surgical procedures.

PATIENT RECRUITMENT



PROCEDURES CAPTURED

The following list shows the procedures that we capture outcomes for. We also capture whether other procedures were performed at the same time, for risk adjustment purposes only. We do not capture outcomes for them.

Stress Urinary Incontinence Procedures

- Mid urethral Sling (synthetic mesh)
- Peri-urethral Bulking agent
- Bulking agent removal
- SUI mesh revision/explantation
- Fascial sling (commencing in FY 2023/2024)

Pelvic Organ Prolapse Procedures

- Sacrocolpopexy with mesh
- Sacrohysteropexy with mesh
- Anterior repair with mesh
- Posterior repair with mesh
- POP mesh revision/explantation

DATA DICTIONARY

In March 2023, the APFPR published a Data Dictionary.

A Data Dictionary provides a description of all terms used in the database. The Data Dictionary is published on the website and can be found here: https://apfpr.org.au/the-apfpr-data-dictionary/

Consumer Engagement Update

The APFPR continues to focus on deepening consumer engagement.

Appointment of Lived Experience Consumer Representative

Jenny Leslie as the Steering Committee Consumer Representative with Lived Experience. Jenny's background includes careers in nursing and medical practice management before retiring from full time work to enjoy time with her grandchildren. More recently, she served as a consumer representative on the NSW Health Mesh Advisory Group from 2019 - 2022. "I am keen to ensure that there is an effective registry for urogynaecological mesh devices and mandatory reporting of adverse events, as well as ready availability of consumer-focused product information sheets for women who may require such procedures for pelvic organ prolapse", said Jenny. Jenny complements consumer representation on the Steering committee, working alongside Pip Brennan who has a background in systemic healthcare advocacy.

Establishment of Consumer Reference Group

Following an informative and successful meeting with a group of consumers with lived experience from all over Australia, held in December 2022, the Steering Committee agreed that this should be a permanent feature of the registry. The Consumer Reference Group will meet up to twice a year specifically to provide feedback on the registry's development activities, such as outcomes captured by the APFPR. The group met on 7th June and to discuss proposed Clinical Quality Indicators and Patient Reported Outcome Measures. More news in our next newsletter!

Appointment of Co-chairs for the Consumer Reference Group

In April 2023, the APFPR appointed two consumers with lived experience as Co-Chairs of the Consumer Reference Group. Ms **Kim Blieschke**, from South Australia, is a registered Paramedic working with the South Australian Ambulance Service for 34 years; she is also a Registered Nurse. "I have been a Consumer with lived experience in the Pelvic mesh arena for the last 8 years after having a mesh implant in 2006 for Pelvic Organ Prolapse, I have lived with multiple health issues as a direct result of this implant and it was finally fully removed in St Louis Missouri in 2016. I also run a social media support page for Mesh Injured with approximately 1800 members." Kim was involved in the codesign and setup of the Royal Adelaide Hospital Pelvic Mesh Clinic.

Ms **Michelle Kennedy** is a community engagement and communications professional who has lived experience of pelvic mesh injury. Michelle has used her experience to support women through their treatment journeys and is a consumer representative at the Queensland Pelvic Mesh Service (QPMS). Michelle was instrumental in the representation of consumers in the co-design of the QPMS since 2018 and was acknowledged with the award for Best Consumer Engagement at the Queensland Health Excellence Awards 2019.

The role of the Co-Chairs is to reach out to their networks to engage with lived experience consumers:

- to keep them informed of the work of the registry and also
- to identify potential members of the Consumer Reference Group.

SITE ENGAGEMENT

Participation in registries is voluntary. The APFPR seeks expressions of interest from eligible sites and invites them to participate. We refer to this as 'recruiting'. The APFPR has recruited a total of 36 sites (as at 15 June 2023), with a further 44 potentially eligible sites identified for the future. The list below shows sites that have had governance approval. This means they can now input data into the APFPR.

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Victoria

Mercy Hospital for Women
St John of God Geelong Hospital
St John of God Bendigo Hospital
Epworth HealthCare Richmond
Epworth HealthCare Freemasons
Epworth HealthCare Geelong
Epworth HealthCare Eastern
St Vincent's Private Hospital Melbourne
Monash Health

Cabrini Health Bendigo Health

Western Health

Waverley Private Hospital

Queensland

Gold Coast University Hospital Robina Hospital Varsity Lakes Day Hospital Sunshine Coast University Hospital Buderim Private Hospital

Tasmania

Royal Hobart Hospital

New South Wales

St George Hospital
St George Private Hospital
Westmead Hospital
Westmead Private Hospital
Nepean Hospital
Concord Hospital
Sutherland Hospital
Royal Hospital for Women
John Hunter Hospital

South Australia

Royal Adelaide Hospital The Queen Elizabeth Hospital Flinders Medical Centre Calvary North Adelaide Hospital

ACT

Canberra Public Hospital
Calvary John James Hospital
Canberra Private Hospital

Western Australia

Hollywood Private Hospital

SITE VISITS

Site visits involve an in person visit by a highly qualified APFPR team member to participating hospitals. We provide demonstrations to sites on how to enter details in the database, show the collection tools and answer any questions. So far, the following sites have benefited from a visit: St John of God Bendigo, Monash Health, Epworth Healthcare Richmond, Epworth Healthcare Freemasons, and Cabrini. We would like to thank these sites for their time and attention. We are currently developing our 2023/2024 **Site Visit Program**. Any approved sites who would like a visit may email us at apfpr@monash.edu to request one.

GOVERNANCE UPDATE

Associate Professor Emmanuel Karantanis stepped down from his role as one of the APFPR clinical advisors. He has been a great advocate for the APFPR, serving faithfully on the Committee since its establishment in 2019. We are most grateful for his support. He will be sorely missed by Committee members, APFPR operations team and APFPR Consumers alike. We look forward to keeping in touch in his role as contributing surgeon.

Following her appointment as Chief Executive Officer of the Australian Commission on Safety and Quality in Health Care, **Professor Anne Duggan** also stepped down from her role on the APFPR Steering Committee. We would like to thank her for her contribution.

Mr Jarrod Williams representative of Ministry of Health New Zealand, also stepped down. We would like to thank him for his contribution. He has been replaced by **Dr Hamish Gray**, Clinical Chief Advisor, Office of the Chief Clinical Officers. We warmly welcome Dr Gray to the Steering Committee and look forward to working with him.

Australasian Pelvic Floor Procedure Registry

COLLEGE & SOCIETIES NEWS

College and Society Meetings

Part of our engagement strategy with participating surgeons, is to keep in touch with relevant Medical Colleges and Societies to discuss potential developments within the registry. Following successful meetings with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the Royal Australasian College of Surgeons (RACS), and the Urological Society of Australia and New Zealand (USANZ), in February 2023 we met with:

The Colorectal Surgical Society of Australia and New Zealand

(CSSANZ) to explore opportunities for collaboration. The APFPR would like to thank Dr Elizabeth Murphy, President, Dr Rowan Collinson, immediate Past-President and Dr James Keck, colorectal surgeon and CSSANZ craft group representative on the APFPR Steering Committee - for their time and support of the registry.

In March 2023 we met with the **Urogynaecological Society of Australasia (UGSA)** to provide an update on our progress and to explore

opportunities for further collaboration. We would like to acknowledge Associate Professor March Carey (Chair), Dr Alexandra Mowat (Vice Chair) and Dr Fiona Bach (Non CU director) as well as the tireless efforts of Julia Collia de Polacek (Executive Officer) for their time and attention.

Conference attendances

In February 2023, we attended the **Urological Society of Australia and New Zealand (USANZ)** Annual Scientific Meeting in Melbourne. Professor
Helen O'Connell, APFPR Urology clinical lead and President of USANZ
presented 'APFPR open and ready for business'.

In May 2023, the APFPR had a presence at the **Royal College of Surgeons (RACS)** Annual Scientific Congress at the Adelaide Convention
Centre.

In our next edition

- Consumer Reference Group Meeting 7th June 2023
- NCOI Conference, Adelaide 14-15th June 2023
- Steering Committee Meeting 16th June 2023
- Annual Report mid 2023/2024
- Certificates of Recognition for sites two categories:
 - first criterion: APFPR greatest contributor (in absolute patient numbers) awarded for most individual patients registered up to 30 June 2023
 - second criterion: awarded to sites that reach at least 50 patients by 30 June 2023.
 - Award winners will be notified and announced on the APFPR website and in the APFPR Communique
 - Sites that contribute data will feature in the Annual Report
- Search for a **lived experience consumer from a First Nations** background. We are currently working with a number of health services to identify someone with the appropriate eligibility criteria
- Site reports will commence being published in the first half of 2023/2024

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