# April 2024, ISSUE#8

# COMMUNIQUE

# **AUSTRALASIAN PELVIC FLOOR PROCEDURE REGISTRY**

## **PURPOSE**

The APFPR aims to identify and report on trends and complications associated with Pelvic Floor Procedures that treat 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, relating to thousands of surgical procedures.

# PROCEDURES CAPTURED

The APFPR currently captures outcome data relating to the procedures listed below. We also capture whether other procedures were performed at the same time (concomitant procedures) for risk adjustment purposes only. We do not capture outcomes for them. In January 2024, the APFPR expanded its scope and included two new SUI procedures, listed below.

#### **Stress Urinary Incontinence Procedures (SUI)**

- Mid urethral Sling (synthetic mesh)
- Urethral Bulking agent injections
- Bulking agent removal
- SUI mesh revision/explantation
- Autologous fascial sling (\*commenced this year)
- Burch colposuspension (\*commenced this year)

#### **Pelvic Organ Prolapse Procedures (POP)**

- Sacrocolpopexy with mesh
- Sacrohysteropexy with mesh
- Sacrospinous colpopexy with mesh
- Sacrospinous hysteropexy with mesh
- Transvaginal Apical support with mesh
- Transvaginal Anterior repair with meshTransvaginal Posterior repair with mesh
- POP mesh revision/explantation

# PATIENT RECRUITMENT

# 

# DEVELOPMENT PROJECTS

In 2023, in an effort to reduce the data collection burden, the APFPR initiated a **database review**. We have since completed the database review, and the improved database went live in **February 2024**. Changes include shorter data entry forms, streamlined data flow, two data entry timepoints (time of surgery and at post-operative follow up), the Inclusion of two additional SUI Native Tissue procedures, listed above. REDCap continues to be the APFPR's data platform. **We are grateful to clinicians who provided feedback**.

#### WHAT IS AN APPROVED HOSPITAL?

An 'approved hospital' refers to hospitals that have successfully applied for and been granted ethics approval and site-specific authorisation to participate in the registry. The APFPR received ethics approval from the Monash Health Human Research Ethics Committee and the Research Governance Office in each of the hospitals listed below. Once they receive approval, they are provided training and can commence entering patient data into the Registry. To date, **30 hospitals** have contributed data.

# む

# **Approved Hospitals**



#### Victoria

Bendigo Health\*
Cabrini Health\*
Epworth HealthCare Eastern
Epworth HealthCare Freemasons\*
Epworth HealthCare Geelong\*
Epworth HealthCare Richmond
Mercy Hospital for Women\*
Monash Health\*
St Vincent's Private Hospital Melbourne\*

St John of God Bendigo Hospital\*
St John of God Geelong Hospital\*
Western Health\*

Waverley Private Hospital\*
Frances Perry House

#### **Australian Capital Territory**

Calvary John James Hospital Canberra Private Hospital\* Canberra Public Hospital\*

#### Tasmania

Royal Hobart Hospital\*

#### **Western Australia**

Hollywood Private Hospital\* King Edward Memorial Hospital

#### **New South Wales**

Concord Hospital\*
John Hunter Hospital\*
Nepean Hospital\*
Royal Hospital for Women\*
St George Hospital\*
St George Private Hospital\*
Sutherland Hospital\*
Westmead Hospital\*
Westmead Private Hospital\*
Royal Prince Alfred Hospital
North Shore Private Hospital

#### **South Australia**

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

#### Queensland

Buderim Private Hospital\*
Gold Coast University Hospital
Robina Hospital
Sunshine Coast University Hospital\*
Varsity Lakes Day Hospital
Townsville University Hospital

# HOSPITAL ENGAGEMENT

Participation in registries is voluntary. The APFPR seeks expressions of interest from eligible hospitals and invites them to participate. We refer to this as 'recruiting'. The APFPR has recruited a total of **41 sites** (as at 23 April 2024), with a further 49 potentially eligible sites identified for the future. The list above names sites that have received ethics and governance approval. This means they are ready and set up to input data into the APFPR. The ones marked with this symbol\* already contribute data.

# Coming up

- Our 2024 Consumer Webinar will take place on **Thursday 16th May at 5PM** (AEST) via Zoom. Details can be found on the news section of the APFPR website.
- The APFPR team will attend the **32nd National Conference on Incontinence 2024 in Brisbane** with our consumer representatives. Pop by to see us at the APFPR stand!
- The APFPR **Consumer Reference Group** will meet again in **June 2024**, to discuss what useful resources about pelvic floor procedures could be made available to consumers.

## **CONSUMER UPDATE**

Our previous edition explained that APFPR **Consumer Reference Group, (established in 2022)** met in June 2023 to provide feedback on proposed APFPR Clinical Quality Indicators (CQIs) and Patient Reported Outcome Measures (PROMs).

#### What are PROMs?

Patient Reported Outcome Measures relate to surveys that ask patients how they feel after a specific type of treatment, such as undergoing a pelvic floor procedure. The surveys used need to have been previously tested by a representative sample, to determine their reliability and validity.

#### What are Clinical Quality Indicators?

Clinical Quality Indicators (CQIs) are measures of performance, that capture how well the care provided aligns to best practice. They can be process measures (whether a specific diagnostic test has been performed, such as a cystoscopy) or clinical outcome measures (whether the patients have experienced an improvement in their incontinence, or prolapse).

PROMS survey responses, combined with Clinical Quality Indicators (CQIs) and other clinical data provide a *comprehensive* perspective of the safety and quality of pelvic floor procedures.

Consumer feedback regarding the Clinical Quality Indicators has been positive; consumers acknowledged the CQIs are wide ranging and reflect measures that are important to them. They also reflected that, as the dataset grows, opportunities for additional indicators will emerge, which they will be consulted on. Feedback was provided on the PROMs survey in use at the time, the APFQ, which is a comprehensive tool that captures outcomes related to prolapse, bladder, bowel, sexual health and other domains. Consumers agreed the APFQ is a suitable, wide-ranging survey, but also indicated that it would be beneficial to include quality of life measures. The APFPR undertook research into several potential surveys that capture outcomes related to quality of life and proposed two new questionnaires to the Consumer Reference Group Co-Chairs. The new surveys were presented to and approved by the Steering Committee.

Current PROMs surveys being used by the APFPR include:

- The **Australian Pelvic Floor Questionnaire** (APFQ), (which is easily found online) which captures a broad range of measures relating to both Stress Urinary Incontinence and Pelvic Organ Prolapse.
- The Quality of Life EQ-5D-5L and
- The Patient Global Impression of Improvement.

Since January 2024, all three questionnaires are administered to women whose data is captured in the Registry. We anticipate that our next Annual Report will feature analysis on the data from all PROMs questionnaires. Lastly, additional feedback relayed that it is very important to the women who undergo pelvic floor procedures, that pain related to pelvic floor conditions is acknowledged, measured and captured. The APFPR notes that there is currently no questionnaire related to pelvic pain and will consider how to close this gap.

Don't forget to sign up for our **Consumer Webinar** on **Thursday 16th May 5:00-6:15PM**. Details are on the news section of our website, or copy this link: https://monash.zoom.us/webinar/register/WN\_RmO5licdRlaQAlL8nczvzg#/registration



# 2023 ANNUAL REPORT

In February we launched our **2023 Annual Report**. For the first time, the Annual Report presented analysis on the safety and efficacy of pelvic floor procedures, with analysis based on several data sets:

- Clinical data, reported by clinicians
- Clinical Quality Indicators, which is derived data, and
- PROMs Data, which is reported by patients themselves

The report also contains the first outcome data related to mesh explants, published with the caveat that patient numbers are low, and outcomes may not be representative of a bigger population. The annual report captures data for procedures on 436 women\*, of which 78% relate to SUI procedures. Key highlights from the annual report can be found on the <u>APFPR website</u>. The report was launched through a live, in person and online meeting which was very well attended, generating many questions. The recording of the annual report can be found on the <u>APFPR website</u>. \*As at 26th September 2023.

# **HOSPITAL REPORTS**

In December 2023, the APFPR provided its first set of 'hospital provider reports' to participating sites with >=5 recruited patients entered into the database (as at 28 November 2023). These reports included data relating to stress urinary incontinence (SUI) procedures, due to the lower volume of pelvic organ prolapse (POP) and SUI+POP procedures at the time. The reports included a comparative patient cohort and procedure data relating to the first procedure captured per patient. Hospitals with at least 20 recruited patients - who had undergone surgery and attended postoperative visits- were provided with preliminary post-operative data and unadjusted clinical quality indicator measure performance. The APFPR intends to provide these reports to hospitals at 6-monthly intervals, with the addition of POP and SUI+POP procedure information included, once sufficient case volume is achieved.

### **CONFERENCES**

In February 2024, the APFPR was privileged to benefit from a complimentary booth at **The Urological Society of Australia and New Zealand (USANZ) Annual Scientific Meeting** in Adelaide. The APFPR presented two papers at this prestigious conference:

- "The Australasian Pelvic Floor Procedure Registry: monitoring device safety in women", by Professor Susannah Ahern, APFPR Chair
- "Australasian Pelvic Floor Procedure Registry: the Database (v2)", presented by senior manager of surgical registries APFPR and ABDR, Natalie Heriot.

The APFPR would like to acknowledge USANZ for the opportunities provided to us.

The Continence Foundation of Australia will host the 32nd **National Conference on Incontinence (NCOI)** from 22-25 May 2024 in Brisbane. It is our privilege to benefit from a complimentary booth at this high quality multi-disciplinary event, as it enables us to connect to the broader community that operates in the pelvic floor domain: including clinicians from several specialisations, incontinence nurses, physiotherapists and consumers. We hope to see you there!



