



THE UNIVERSITY OF
SYDNEY

Australian and New Zealand Pectus Excavatum (PE) Consumer Advocacy Group

Meeting Summary (25 August 2026)

Organised by A/Prof Milena Simic, Discipline of Physiotherapy, Faculty of Medicine and Health

Present members

- 3 consumer representatives with lived experience of PE, including adults living with PE and parents/carers of children with PE.
- Research and consumer representatives involved in PE research, advocacy and education.

Purpose of the Meeting

The 3rd meeting focused on consumer experiences navigating healthcare systems, barriers to diagnosis and treatment, opportunities for advocacy with professional bodies, future research priorities, and strategies to increase awareness of PE across Australia and New Zealand. The group also discussed preparations for engagement with international PE experts and future advocacy initiatives.

Consumer Experiences Navigating Care

Participants shared experiences of seeking assessment and treatment for PE and highlighted recurring challenges in having symptoms recognised and appropriately investigated.

- Multiple consumers described being told that symptoms such as breathlessness, fatigue, chest discomfort and exercise intolerance were unrelated to PE despite significant functional limitations.
- Participants reported consulting numerous specialists, often receiving conflicting opinions regarding severity, prognosis, testing requirements and treatment options.
- Several consumers discussed the emotional and financial burden associated with repeated consultations, interstate travel and ongoing self-advocacy.
- The group observed that women and adults may face additional challenges in having symptoms taken seriously and recognised within current clinical pathways.

Assessment Pathways and Evidence Gaps

A major theme was the variability in investigations being offered and the lack of consistency in clinical assessment pathways.

- Participants described receiving normal results from routine investigations despite ongoing symptoms and functional impairment.
- The group discussed the potential value of more specialised investigations, including cardiopulmonary exercise testing (CPET), cardiac MRI and CT angiography, particularly where resting tests do not reflect exercise limitations.
- There was concern that many clinicians may not be aware of current evidence describing functional and cardiovascular impacts associated with PE.
- Participants highlighted the need for clearer guidance regarding which investigations are most informative and when they should be considered.

Treatment Pathways and Decision-Making

The group discussed both surgical and non-surgical management options and the challenges consumers face when making treatment decisions.

- Participants noted substantial variation in information provided about surgery, expected outcomes and prognosis.
- Consumers raised concerns regarding inconsistent recommendations between providers and difficulty identifying clinicians with specific expertise in PE management.
- Vacuum bell therapy was discussed not only as a treatment option but also as a potential strategy for improving chest wall flexibility before surgery, highlighting the need for clearer public information.
- The group agreed there is currently no easily accessible resource identifying clinicians experienced in PE assessment and treatment across Australia and New Zealand.

Advocacy Priorities

Discussion focused on how consumer experiences could be translated into meaningful advocacy activities.

- Members supported documenting lived experiences and collecting evidence demonstrating recurring issues in diagnosis, referral pathways and symptom validation.
- The group discussed engaging with professional organisations, including the Australian and New Zealand cardiothoracic surgical community, to highlight consumer concerns and inconsistencies in care.
- Participants considered broader public awareness initiatives, including media engagement and consumer storytelling, as potential mechanisms to increase understanding of PE and its impact.
- The importance of combining consumer experiences with scientific evidence was emphasised to strengthen advocacy efforts.

Research and Future Initiatives

The group identified several opportunities for research and evidence generation.

- Participants expressed strong support for establishing a registry or survey to better understand the experiences, symptoms, care pathways, treatments and outcomes of people with PE.
- Potential survey content discussed included healthcare utilisation, symptom profiles, treatment history, comorbidities and functional limitations.
- The group highlighted the importance of capturing co-existing conditions, including hypermobility, connective tissue disorders, autonomic dysfunction and respiratory conditions.
- Participants supported developing a consumer-informed opinion piece to raise awareness of healthcare challenges associated with PE. Interested consumers volunteered to contribute.

International Collaboration and Knowledge Translation

The group discussed upcoming opportunities to connect with international PE experts.

- An update was provided regarding participation in an international chest wall conference where PE research, allied health management and consumer engagement will be represented.
- Members welcomed opportunities to learn from international examples and improve translation of emerging evidence into Australian clinical practice.
- Participants requested updates on emerging topics including vacuum bell therapy, newer surgical approaches, rehabilitation, recurrence, hypermobility and long-term outcomes.

Key Decisions and Agreed Outcomes

- Continue collecting and documenting de-identified consumer experiences to support advocacy efforts.
- Prepare a summary of priority concerns regarding assessment pathways, symptom recognition and access to expertise.
- Begin exploring opportunities to engage formally with relevant cardiothoracic surgical organisations.
- Continue development of website resources and consumer information materials.
- Explore establishment of a PE registry and/or survey to generate Australian and New Zealand consumer-led evidence.
- Develop a consumer-informed opinion piece incorporating lived-experience perspectives.

- Continue monthly consumer advocacy group meetings.
- Establish informal communication channels to facilitate information sharing between meetings.

Next Meeting

The group agreed to continue meeting monthly. The next meeting was scheduled for Monday 28 September 2026, however due to A/Prof travel to the Chest Wall International Conference in late September, this will now be delayed to the following month: Monday 26th of October.

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