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

Meeting Summary (27 July 2026)

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

Present members

- 6 Consumer representatives with lived experience of PE, including adults with PE and parents/carers of children with PE, living in Australia and New Zealand
- A researcher and consumer representative, parent of a child with PE, NSW, Australia.

Purpose of the Meeting

The 2nd meeting of the consumer advocacy group continued the work of identifying community priorities, building public-facing resources, shaping research and advocacy activities, and exploring stakeholder partnerships for pectus excavatum in Australia and New Zealand. The meeting focused on initial website content, information needs for patients and clinicians, system barriers to care, opportunities for consumer involvement in upcoming consumer-led grant applications, and potential alignment with musculoskeletal and connective tissue organisations.

Website and Public-Facing Resources

The group supported beginning with a simple public website that clearly explains the existence and purpose of the consumer advisory group, provides a pathway to sign up for updates/newsletters, and shares accessible, evidence-informed information about PE. A proposed early resource was a one-page summary or leaflet that people could take to clinicians to support conversations about symptoms, screening, and appropriate assessment.

- **Suggested messaging:** Participants strongly supported language that challenges the perception that PE is “just cosmetic”.
- **Core website content:** Plain-language explanation of PE, typical symptoms and impacts, assessment options, and possible overlap with connective tissue disorders, while being careful that not all PE presentations are necessarily related to connective tissue conditions.
- **Connective tissue alignment:** The group discussed the affiliation between connective tissue disorders and PE, noting that there are many aligned issues and similarities across these communities, including diagnostic complexity, multisystem considerations, variable recognition by health professionals and the need for evidence-informed consumer resources.
- **Clinician-facing resource:** A short leaflet or appointment resource to help health professionals recognise potential physical and functional impacts, including when symptoms may not be captured by basic tests.
- **Review process:** The group discussed seeking multidisciplinary clinical review, including paediatric cardiology and other relevant expertise, before public release of health information.
- **Monitoring reach:** Website use and downloads could be tracked to understand demand and guide future advocacy priorities.

Stakeholder Engagement and Partnerships

A/Prof Simic updated the group that discussions had been held with Musculoskeletal Health Australia, described as Australia’s largest musculoskeletal health organisation, whose purpose is to support consumers to make evidence-based, informed decisions about their healthcare. Collaboration, partnership or other support is currently being explored, with Musculoskeletal Health Australia generally interested in supporting people affected by PE.

The group also discussed the affiliation between connective tissue disorders and PE. While not all PE presentations are necessarily linked to connective tissue disorders, participants noted substantial alignment and

similarities, including overlapping support needs, diagnostic uncertainty, multisystem considerations and the importance of connecting consumers with accurate information and relevant organisations.

Key Issues and Experiences

Participants described recurring experiences of symptoms being minimised, normalised, or attributed to anxiety or cosmetic concerns rather than investigated as potentially related to PE. Discussions highlighted the burden of repeated self-advocacy, difficulty accessing appropriate testing, and uncertainty about the likely benefits and risks of treatment, particularly for adults and females.

- Breathing restriction, fatigue and functional limitations were repeatedly discussed as important lived-experience concerns.
- Participants noted that normal spirometry or resting cardiac tests may not reflect how people feel during exertion, raising interest in cardiopulmonary exercise testing (CPET) and other more functional assessments.
- The group discussed the need for better information across the lifespan, including childhood/adolescence, adulthood, pregnancy/post-pregnancy experiences, and ageing-related changes.
- Participants raised concerns that females and adults may be under-recognised in current evidence, services and clinical pathways.

Treatment and System Challenges

The meeting identified ongoing barriers across the care pathway, including limited awareness among health professionals, variable access to PE-experienced clinicians, inconsistent access to specialised testing (e.g. CPET), and uncertainty about surgical and conservative treatment decision-making. Participants also discussed the difficulty of weighing surgery when clinicians cannot confidently predict symptom improvement.

- **Assessment pathways:** Participants discussed challenges obtaining, interpreting, or repeating CPET and other investigations that may be relevant to function and treatment decisions.
- **Surgery decision-making:** The group raised the need for clear, balanced information about Nuss and modified Ravitch procedures, including expected benefits, risks, side effects and recovery considerations.
- **Overseas treatment:** Risks and follow-up considerations for surgery overseas were discussed as an area requiring careful clarification before being included in public resources.
- **Interstate variation:** Participants noted possible differences in access to testing and clinician responsiveness between jurisdictions, suggesting a future advocacy and mapping priority.
- **Conservative management:** Vacuum bell therapy and physiotherapy remained priority topics, including the need to understand who may benefit, when to intervene, and whether adults may still have options.

Research Insights and Emerging Questions

A/Prof Simic updated the group on consumer-led grant applications focused on a clinical trial of vacuum bell therapy with physiotherapy. The group discussed how consumer representatives could contribute as associate investigators, including by advising on patient-facing materials, recruitment, outcome relevance, dissemination and implementation.

- The group supported stronger evidence for early intervention and conservative care, particularly where childhood treatment may reduce severity or prevent worsening.
- The group discussed the need to compare people with PE against appropriate age-, sex-, height- and weight-matched normative data, particularly for exercise capacity and function.
- Consumer questions for future evidence summaries included surgical options, testing pathways, adult vacuum bell use, and practical guidance for navigating care.

Priority Areas

- Develop an initial PE website with evidence-informed information, consumer group updates and downloadable resources.
- Create a clinician-facing one-page resource to support recognition, assessment and appropriate referral.
- Strengthen messaging that PE can have physical, psychological and functional impacts and should not be dismissed as purely cosmetic.
- Build evidence summaries or “question spotlights” responding to consumer-prioritised topics.
- Improve understanding of assessment pathways, including CPET, and how testing relates to function and treatment decisions.
- Ensure future research includes consumer perspectives across the lifespan, including adults, females, parents/carers and people with associated conditions.

- Explore collaboration with Musculoskeletal Health Australia to increase awareness, reach and access to evidence-based information for people affected by PE.
- Strengthen links with organisations and communities focused on connective tissue disorders, where there are shared issues, aligned support needs and potential opportunities for cross-referral or shared resources.

Role of Consumer Involvement

Consumer involvement was again recognised as central to the group's purpose. A/Prof Simic invited interested consumers, including adults with PE and parents/carers of children with PE, to consider formal involvement as associate investigators in consumer-led grant applications. The group also discussed the potential for linking with related organisations and supports, including Musculoskeletal Health Australia and organisations supporting people with connective tissue disorders, where there may be strong alignment in advocacy, education and consumer-facing resources.

Key decisions and agreed outcomes

- Proceed with drafting an initial outline for a public PE website and circulate it to the group for comment.
- Develop a draft one-page PE information leaflet/resource for review by the consumer group and relevant clinicians.
- Seek multidisciplinary clinical input before publishing public health information.
- Explore ways to capture website engagement, such as downloads or page visits, to demonstrate community need and support advocacy.
- Continue developing the consumer-led grant applications and invite interested consumers to contribute formally as associate investigators.
- Identify consumer-prioritised questions that could be addressed through short evidence summaries or website content.
- Continue monthly group meetings, with the option of a shorter 45-minute format if preferred.
- Continue discussions with Musculoskeletal Health Australia regarding potential collaboration, partnership, advocacy support, resource sharing and opportunities to improve awareness and access to evidence-based information for people with PE.
- Explore alignment with connective tissue disorder organisations and resources, recognising similarities in consumer support needs and the potential value of cross-linking information.

Contact

Associate Professor Milena Simic

Faculty of Medicine and Health

School of Health Sciences

Discipline of Physiotherapy

Address: Level 7 East, D18 - Susan Wakil Health Building, Western Avenue, The University of Sydney, NSW 2006

Email: Milena.simic@sydney.edu.au

sydney.edu.au | CRICOS 00026A