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

Meeting Summary (29 June 2026)

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

Present members:

- 3 Consumer representative (parent of a child with PE), NSW, AU
- 2 Consumer representatives (individual with PE), QLD, AU
- 1 Consumer representative (individual with PE and carer of a child with PE), NZ
- 1 Researcher and consumer representative (parent of a child with PE), NSW, AU

Purpose of the Meeting

The 1st meeting of the consumer advocacy group brought together individuals affected by pectus excavatum and/or their parents/carers to identify key challenges, inform research priorities, and explore opportunities for advocacy and improved care in Australia and New Zealand.

Key Issues and Experiences

Participants described a common pattern of delayed diagnosis, symptoms being minimized, or concerns being dismissed as cosmetic or psychological rather than taken seriously as a health issue. Shared experiences included breathing difficulties, fatigue, reduced function, anxiety about treatment decisions, and the ongoing burden of having to advocate for recognition and appropriate care. The discussion also suggested that support needs vary across children, adolescents, and adults, and that some presentations may be overlooked, including in females and in people whose symptoms are not immediately recognized by health professionals.

Treatment and System Challenges

The meeting highlighted major barriers across the care pathway. These included limited awareness among general healthcare providers, inconsistent access to clinicians with pectus-specific expertise, uncertainty about when surgery is appropriate, and limited access to non-surgical approaches such as vacuum bell therapy and physiotherapy. Participants also raised concerns about insurance and coding arrangements when the condition is treated as cosmetic rather than medical, the broader financial burden of treatment and care, and administrative or regulatory barriers that may delay access to newer products and treatment approaches. Some families had needed to search widely for information and treatment options because they did not feel confident that suitable local options were easy to find.

Research Insights

A/Prof Simic presented some research she has commenced with her teams, including Medicare data showing a 230% increase in pectus excavatum surgeries over 20 years, with surgeries reported as occurring primarily in males. A systematic review and meta-analysis of non-surgical management found that the evidence base is still limited, but suggested that vacuum bell therapy combined with physiotherapy may be promising, with an estimated 38% success rate reported in cohort studies. The meeting also highlighted important evidence gaps, including limited high-quality trials, uncertainty about long-term outcomes, insufficient patient-perspective data, and a need for stronger evidence to guide decisions about non-surgical care and timing of intervention. A/Prof Simic also outlined a proposal for the upcoming MRFF grant application, aiming to apply to conduct a large randomised controlled trial into the effects of a 12 month vacuum bell suction therapy with physiotherapy in children aged 6-17 and evaluate their effects over 2 years with follow-up planned annually. The consumers gave feedback on the design and outcomes to be considered.

Priority Areas

Priority areas identified by the group included earlier recognition and diagnosis, better education for healthcare professionals, and clearer public information about the condition and its potential impact on physical, psychological, and day-to-day functioning. Participants also emphasized the need for better support for caregivers, practical resources for appointments and decision-making, and information tailored to different life stages. Suggested resources included question guides for clinicians, fact sheets for families and support networks, and materials covering comorbidities, mental health impacts, and realistic treatment options.

Role of Consumer Involvement

Consumer input was recognised as essential for shaping research, advocacy efforts, and resource development. Ongoing engagement and regular meetings were supported to maintain momentum. Suggested monthly meetings was supported.

Key decisions and agreed outcomes

- Establish the group formally as a consumer advocacy body with ongoing regular monthly meetings.
- Develop a public-facing website to centralise information, resources, and support.
- Advance a research program, including pursuing funding for a clinical trial of non-surgical interventions.
- Advocate for system-level change, including improved recognition of pectus excavatum as a medical condition, changes to funding pathways, and availability of therapeutic devices for non-surgical and surgical management.
- Produce educational and advocacy resources for patients, families, and healthcare professionals.
- Strengthen collaboration with stakeholders, including clinicians, researchers, industry, and media.

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