Delivering quality care more efficiently inquiry

Questionnaire response 67

Name: Scleroderma Australia

Submission date: 6/06/2025

Participant background

1. For the purposes of this consultation, which of the following best describes you:

   I am an industry or advocacy organisation, professional association or peak body

2. Which of the following care sectors will your feedback relate to? Please select all that apply.

   Aged care; Disability; Health

3. What kind of care supports, services and programs do you have experience with, and in what jurisdictions?

   The participant did not respond to this question.

1. Reform of quality and safety regulation to support a more cohesive care economy

1. To what extent do differences in quality and safety regulation make it costly or complex to provide or access care services?

   The participant did not respond to this question.

2. What are the reasons for your answer?

   The participant did not respond to this question.

3. To what extent should quality and safety regulations be more aligned across the different care service sectors and jurisdictions?

   The participant did not respond to this question.

4. What are the reasons for your answer?

   The participant did not respond to this question.

2. Embed collaborative commissioning to increase the integration of care services

1. What is your experience with collaborative commissioning

   The participant did not respond to this question.

2. What are the benefits of pursuing greater collaborative commissioning?

   The participant did not respond to this question.

3. What are the barriers to collaborative commissioning, and do you have any suggestions for solutions that would lead to better collaboration in the commissioning of care services?

   The participant did not respond to this question.

Survey responses from the Productivity Commission's Delivering quality care more efficiently inquiry are publicly available on the PC's website: **pc.gov.au**. Copyright and the views expressed belong to the submitter(s), not the PC.

3. A national framework to support government investment in prevention

1. What are the main barriers to governments investing in evidence-based prevention programs across the care economy?

1. Fragmented Systems and Disconnected Care
People living with complex conditions like scleroderma often navigate multiple care sectors - public and private specialists, general practitioners, disability services, and aged care. Each sector operates under different regulations and funding models, leading to confusion, inefficiencies, and misaligned priorities.
One of many personal stories to highlight this disparity:
“When I was diagnosed in Victoria, I was quickly referred to the Scleroderma Clinic in Melbourne. There, I received coordinated, best-practice care from a knowledgeable team. This allowed me to actively participate in my treatment and feel confident in the system. However, after moving to Queensland, I had to rebuild my care team from scratch and educate them about my condition—something many patients are not equipped to do.”
People with scleroderma living in rural and regional Australia face compounded challenges due to both the complexity of their condition and the structural limitations of the healthcare system in non-metropolitan areas.
People living outside metropolitan areas often face:
• Long travel times to access specialists
• Limited availability of rheumatologists or allied health professionals
• Poor digital infrastructure that hinders telehealth access
“I live in a rural town and the nearest specialist is over 300km away. I can’t afford to travel that often, so I just go without.”
2. Limited Awareness and Investment in Specialist Services
Specialties like rheumatology and rare disease care are underfunded and under-recognised. They attract fewer trainees and lack visibility in mainstream health planning. Embedding specialty clinics in major hospitals and offering student placements can help build future workforce capacity.

2. What are some examples of successful prevention programs (this could include discontinued programs)?

Multidisciplinary Team (MDT) Clinics for Scleroderma
Operating in Melbourne, Sydney, Perth, Tasmania, Adelaide, and the Gold Coast, these clinics offer a proven, scalable model for managing complex conditions. As a small not-for-profit with no government funding, Scleroderma Australia raises money to part-fund these clinics, where they benefit the health system by:
• Reducing emergency presentations
• Enabling timely referrals and coordinated care
• Creating opportunities for research and clinical trials
Many people with scleroderma are left to coordinate their own care due to a lack of integrated services. Without a central point of contact, they must:
• Educate each new provider about their condition
• Manage multiple appointments across specialties
• Advocate for referrals and follow-ups themselves
“I had to explain my condition to every new doctor. There was no continuity of care, and I often felt like I was starting from scratch. Over time, this constant retelling became emotionally exhausting. I began to delay appointments just to avoid the stress, which led to worsening symptoms and missed opportunities for early intervention. The lack of

coordinated care didn't just affect my physical health, it took a serious toll on my mental wellbeing too."

Many people living with scleroderma face the additional challenge of limited health literacy, which significantly affects their ability to navigate fragmented healthcare systems. Understanding complex medical terminology, managing multiple appointments, interpreting test results, and advocating for appropriate care can be overwhelming, especially without coordinated support.

"I was fortunate to have a high level of health literacy, which helped me rebuild my care team after moving interstate. But many others in our community don't have that advantage. They're left to manage a complex disease with little guidance or support."

This gap in health literacy can lead to:

• Missed or delayed diagnoses
• Poor adherence to treatment plans
• Increased anxiety and confusion
• Greater reliance on emergency services due to unmanaged symptoms

Multidisciplinary clinics and nurse-led services play a crucial role in bridging this gap. They provide:

• Clear, accessible education tailored to the patient's level of understanding
• Ongoing support to reinforce self-management strategies
• A single point of contact to help patients navigate the system confidently
• Connection to peak organisations such as Scleroderma Australia for support groups and resources

Investing in these models is not just about improving outcomes, it's about equity. Everyone deserves the chance to manage their health effectively, regardless of their background or education level.

While the financial benefits of MDT clinics are more visible in the medium to long term, the immediate improvement in patient quality of life is undeniable. These clinics also foster research, as seen in the work of the Australian Scleroderma Interest Group (ASIG) in their Australian Scleroderma Cohort Study (ASCS).

3. How can governments better support investment in prevention activities that have broad and long-term benefits for the Australian community?

• Partner with Patient Organisations:

Patient organisations like Scleroderma Australia offer deep, real-world insights into the lived experience of people with complex, chronic conditions. They are trusted by their communities and have direct access to patient voices, making them essential partners in designing and evaluating effective care models.

Recommendation:

• Establish formal partnerships with patient organisations to co-design national models of care for rare and complex conditions.
• Involve these organisations in policy development, service planning, and evaluation to ensure programs are grounded in patient needs.
• Provide core funding to support their capacity to contribute meaningfully to system reform, including data collection, patient education, and peer support initiatives.
• Recognise patient organisations as critical infrastructure in the preventive health ecosystem—not just advocacy groups.

Encourage Cross-Sector Collaboration:

People with scleroderma often interact with multiple sectors—primary care, specialist care, allied health, disability services, and aged care. Without coordination, care becomes fragmented, inefficient, and burdensome for patients. Bring together GPs,

specialists, and allied health professionals to co-design care pathways using the MDT model.

Recommendations:

• Facilitate interdisciplinary working groups that include GPs, specialists (e.g. rheumatologists), nurses, allied health professionals, and patient representatives to co-design care pathways.

• Pilot regional MDT hubs that integrate services across sectors and use shared care plans to ensure continuity.

• Develop interoperable digital health systems that allow providers across sectors to access and contribute to a unified patient record.

• Provide incentives for collaboration, such as bundled payments or shared outcome-based funding models.

Invest in Research and Evaluation:

Despite strong anecdotal and international evidence, there is limited Australian data on the cost-effectiveness and outcomes of MDT clinics and nurse-led models for rare diseases. This evidence gap hinders policy uptake and sustainable funding.

Recommendations:

Provide funding through bodies like the NHMRC to:

• Fund the evaluation of existing MDT clinics (e.g. those supported by Scleroderma Australia) to measure outcomes such as reduced hospitalisations, improved quality of life, and patient satisfaction.

• Commission systematic reviews and meta-analyses of global evidence on MDT and nurse-led care models, particularly in rare and autoimmune conditions.

• Establish a national outcomes registry for rare diseases like scleroderma to track long-term health and economic impacts of coordinated care.

• Support implementation research to identify best practices for scaling MDT clinics across diverse settings, including rural and remote areas.

Cover sheet: Supporting document #1

Submission to the Productivity Commission: Investing in Prevention for People with Scleroderma

From: Scleroderma Australia
Date: June 5, 2025
Contact: Amanda Lawrie-Jones – Chair of the Board

Introduction

Scleroderma is a rare, chronic autoimmune condition that requires lifelong management. While primary prevention is not possible, tertiary prevention, supporting individuals to manage their condition effectively, is critical. This submission outlines key opportunities for investment in nurse-led clinics, workforce participation, and improved data collection to enhance outcomes for people with scleroderma and similar chronic conditions.

1. Nurse-Led Clinics: A Proven Model for Chronic Disease Management

Nurse-led clinics offer a scalable and effective way to support people with rare and complex conditions. The benefits are listed below:

a) Holistic, Patient-Centred Care

- Nurses trained in chronic disease management can address the **whole person**, not just the disease.
- They can provide guidance on **fatigue management, nutrition, exercise, mental health, and wound care**, which are often overlooked in specialist appointments.

b) Improved Access and Continuity of Care

- Telehealth nurse clinics reduce barriers for people in **regional and remote areas**, who may have limited access to specialists.
- They offer **continuity of care** between specialist visits, helping patients stay on track with self-management plans.

c) Health System Navigation

- Nurse-led services can help patients **navigate complex healthcare systems**, including referrals to allied health professionals, community services, and support groups.
- This is especially valuable for people with rare conditions who often face fragmented care.

d) Early Intervention and Tertiary Prevention

- Nurses can detect early signs of complications or disease progression and intervene before hospitalisation is needed.
- This reduces emergency department visits and hospital admissions, saving costs and improving quality of life.

e) Empowerment and Education

- Patients receive **personalised education** about their condition, medications, and lifestyle adjustments.
- This empowers them to take control of their health, improving adherence and outcomes.
- Reduced Burden on **GPs** and Specialists
- Nurse-led clinics can handle routine monitoring, education, and support, freeing up GPs and specialists to focus on complex medical decisions.
- This team-based approach enhances efficiency and patient satisfaction.

f) Evidence of Effectiveness

- Programs like the *Pathways Telehealth Nurse* have shown promising results in improving patient outcomes and satisfaction.
- International models, such as nurse-led rheumatology clinics in the UK and Canada, have demonstrated **cost-effectiveness and improved disease management**.

Recommendation:

Expand funding for nurse-led telehealth clinics tailored to rare and autoimmune conditions. These services should be integrated into the broader healthcare system and supported through Medicare or similar funding mechanisms.

2. Supporting Workforce Participation

Many people with scleroderma can and want to remain in the workforce. Effective self-management, supported by access to information, allied health services, and peer support, enables continued employment and economic contribution.

Barriers include:

- Lack of accessible, tailored advice on managing fatigue, pain, and mobility.
- Limited employer awareness of fluctuating conditions.
- Inadequate workplace accommodations.

Recommendation:
Invest in programs that support flexible work arrangements and educate employers about chronic conditions. Include self-management support as a core component of employment retention strategies for people with chronic illnesses.

3. Improving Data and Evidence for Prevention Investment

There is a significant gap in research and data on the effectiveness of self-management and peer support programs for rare diseases like scleroderma. This lack of evidence hinders government investment.

Recommendation:

- Establish a dedicated research fund focused on tertiary prevention and self-management.
- Partner with patient organisations to evaluate existing support programs.
- Promote systematic reviews of global evidence to inform policy and funding decisions.

4. Community Support Groups: Low-Cost, High-Impact Prevention

Volunteer-led support groups, provide vital peer support, reduce isolation, and improve mental health. These groups operate with minimal resources but deliver significant value.

Recommendation:

- Provide non-financial support such as training, mentorship, and promotional materials for support group leaders.
- Develop a national directory of support groups and distribute information through GPs and specialists.
- Recognise and promote the role of peer support in chronic disease management.

5. Addressing Health Equity and Rural Access

Australia has a vast population of people living in rural and regional areas, where access to preventive health services is often limited. People with rare and complex chronic conditions like scleroderma are disproportionately affected by these barriers.

Recommendations:

- Invest in Digital Health Infrastructure: Improve internet access and digital literacy in rural areas to support telehealth and remote monitoring. Provide training for patients and carers to use digital tools effectively.
- Support Community-Led Peer Networks: Recognise and fund rural peer support groups as essential components of the preventive health ecosystem. Provide training, mentorship, and resources to enable sustainability and local leadership.

- Embed Health Equity in Preventive Health Planning: Use disaggregated data to identify service gaps and prioritise funding based on need, not just population size.

Conclusion

Investing in tertiary prevention for people with scleroderma through nurse-led clinics, workforce support, improved data collection, and community-based peer support offers long-term benefits for individuals and the healthcare system. These initiatives are cost-effective, scalable, and aligned with a patient-centred approach to care.

Importantly, these investments must prioritise rural and remote communities, where access to specialist care and support services is often limited. Telehealth-enabled nurse-led clinics, digital health infrastructure, and community-led peer networks are essential to ensuring that people living outside metropolitan areas receive equitable, timely, and effective preventive care. Addressing geographic disparities is not only a matter of fairness—it is a strategic imperative for improving population health outcomes across Tasmania.

Please contact me at chair@sclerodermaaustralia.com.au if you have any questions.

Yours sincerely

Amanda Lawrie-Jones

Chair of the Board