Delivering quality care more efficiently inquiry

Questionnaire response 11

Name: Anonymous

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Participant background

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

   I am a consumer or user of care services (consumer)

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

   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.

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?

- There is limited focus from the formal healthcare system on supporting patients to self-manage chronic conditions such as autoimmune diseases.
These conditions are not amenable to primary prevention (that is, there is nothing I could have done to avoid getting my autoimmune condition) which means that tertiary prevention is critically important. By self-managing my condition I am currently able to still work full time and contribute to the economy and I am minimising my demands on the healthcare system.
However, specialists don't generally have time to provide advice on broader self-management of conditions, and GPs don't have the in-depth knowledge of rare conditions to be able to provide up to date advice about ways to self-manage.
In my case I received limited information from my specialists about how to self-manage or seek support for my condition beyond medication and regular specialist check-ups. I had to rely on my own research and advocacy to find support groups, allied health experts (to assist with exercise and other preventive actions) and information (about exercise, diet, fatigue management, wound prevention and general well-being when living with a rare autoimmune condition). I have now started my own support group for my condition in my region which is helping to share information and boost well-being among other people with the condition.

- There is limited evidence and limited research on the value of support programs that assist patients to self-manage chronic conditions such as autoimmune diseases.
Research and research funding seem to be focused on treatment and disease mechanisms, therefore there is little evidence to build a case for investment from government in self-management and support programs. This becomes a vicious cycle - without research there is no investment in support programs, and without visible support programs there is unlikely to be research undertaken.

- Support programs are generally provided by volunteer organisations who lack the funds and the expertise to promote the programs and their benefits to government or to advocate for government investment in these programs.
Scleroderma Australia and its international equivalents (eg spinsclero.com) fund research into self-management and support programs but this is limited and slow and the outcomes may not make it to government to be taken into consideration in policy development.
Support groups such as the one I run are very local and have limited visibility outside our community so we don't have a mechanism to promote the benefits of such support groups to government.

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

- The Pathways Telehealth Nurse service is an Australian innovation that places a trained registered nurse within a patient organisation, to provide specialist care and health system navigation to communities with rare, genetic, and complex conditions.
The program was developed by an Australian nurse, Kate Holliday who is a researcher, Chief Executive and founder of the Centre for Community-Driven Research.
Funding is provided by the patient organisation – in the case of Scleroderma Australia,

funding was gathered through fundraising efforts by the scleroderma community.
A pilot was undertaken in around 2019 but I don't have access to the results. However, the Pathways Nurse website has some of the findings from the pilot: https://pathwaysnurse.org/. Information about the Scleroderma Australia Pathways Telehealth Nurse is here: https://www.sclerodermaaustralia.com.au/scleroderma-australia-pathways-telehealth-nurse-2024/

- The Scleroderma Patient-centered Intervention Network (SPIN) is an organisation of researchers, health care providers, and people living with scleroderma from around the world.
Individuals and organizations involved in SPIN are working on a novel research project with the goal to develop, adapt and test new and existing programs to help people with scleroderma cope with their illness and manage their daily lives. The areas covered by the programs developed by SPIN include, but are not limited to, managing symptoms, daily tasks, and emotions related to illness, as well as balancing activity and rest.
The program is sponsored by a number of patient organisations from around the world, including Scleroderma Australia and its state chapters.
SPIN is based in Canada. Information about SPIN is available on their website at https://www.spinsclero.com/. This also includes a list of peer-reviewed publications about their research at https://www.spinsclero.com/publications-1.

- Volunteer-led support groups are run by many patient organisations to provide connection and assistance for patients.
As a single (non-representative) example, I'll focus on the support group that I established in 2022 but will also mention associated support groups.
My support group is for people with scleroderma (a rare, progressive autoimmune condition) who live in and around the ACT. The group also includes people in regional NSW as far away as Dubbo and Eden who use Canberra as their medical hub. The group meets in person once a month in an informal setting to share information and experiences. There are around 24 people listed as members, but monthly attendance ranges from 2 people to 8 people depending on everyone's availability.
The group doesn't receive any funding and is managed by me in a voluntary capacity.
The group has not been evaluated, but participants have shared their experiences in the group including this from an anonymous member: "I joined the support group as I was at my wits' end trying to understand the scleroderma diagnosis and the ramifications it was to have on my life. I had found that the limited time with specialists did not give me the information and reassurance I needed. Having a group of people who were able to do that has been wonderful. The monthly cuppas are a set date in my calendar and a high priority for me".
There are about 10 other scleroderma support groups around Australia, including an online group and a men's group. Scleroderma Australia also runs a regular online meeting for the leaders of the support groups, allowing us to provide each other with support, advice and mentoring.

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

- The healthcare sector(s) should be encouraged to consider patient well-being in a holistic way and offer advice and support beyond medication and check-ups.
This may require dedicated resources such as a telehealth nurse service for different conditions. This could operate similar to the Pathways Telehealth Nurse initiative

outlined above, or could be an offshoot of the expanded 1800MEDICARE initiative but staffed by nurses with specific knowledge of particular conditions. They could provide accessible advice and information to patients in a way that GPs don't have the expertise to do (because these are often rare conditions and GPs can't be expected to have specialist knowledge of all of them) and that medical specialists don't have time to do.

- Governments should engage with patient support organisations (like Scleroderma Australia, the Myositis Association Australia Inc and Rare Voices Australia) to understand what self-management and support programs they run and how they are assisting patients.
Funding could be offered to researchers (for example through NHMRC) to undertake reviews of some of the programs offered by volunteer organisations as well as a systematic review of the global evidence on patient self-management to build an evidence base about which kind of support programs are most effective. This evidence should be used as the basis for new programs and initiatives, or to provide funding for patient support organisations to continue and expand their work.

- Research funding should be dedicated to tertiary prevention of conditions such as autoimmune diseases.
Research is needed to understand how patients self-manage their conditions, the drivers or barriers of self-management and the most successful interventions to support patients to self-manage.
A dedicated research fund for studies of patient self-management programs would go a long way to helping researchers consider these research questions and increase the profile of this kind of research.

- Government should support and promote community support groups.
Funding for these support groups would be difficult for volunteers to manage and is not really necessary. However, a network of advice, support and assistance for support group leaders would be incredibly useful – for example free training and mentorship for support group leaders and evidence-based information on best practice for support groups.
It would also be useful for government to provide general promotion of the value of joining a support group, directing people to patient organisations for information about how to join a relevant group for their situation. This could usefully include a brochure that specialists and GPs could give to patients when newly diagnosed, providing them with advice on where to find support.