

Summary: Health System Simulation Workshops

Why do health systems need to consider rare diseases?

1. Individually rare, but collectively common. A rare disease affects less than five in 10,000 people but there are at least 7000 different rare diseases.¹⁻²
2. While there are few people with individual rare diseases, the total number of Australians living with a rare disease is approximately 2 million, or about 8% of the Australian population.³
3. Rare diseases are chronic and complex, and people living with a rare disease often need care from multiple specialised teams of healthcare professionals and access support across many different sectors including social care, disability and education.
4. Rare diseases have significant socio-economic impacts on people living with a rare disease and an economic impact on our health systems.⁴

What is a Health System Simulation Workshop and how are they relevant to rare diseases?

Health System Simulation Workshops were designed by Professor Jeffrey Braithwaite, the Director of the Australian Institute of Health Innovation at Macquarie University, and the first simulation workshops were held in 2014. The workshops have been delivered in many different countries including at Oxford and Harvard Universities and at departments of health in Canada and Australia. Stream 3 of the Rare Disease Awareness, Education, Support and Training (RAReST) Project adopted the health system simulation model and applied it to the rare disease context.

Health System Simulation Workshops are designed to convene multiple stakeholders who are a part of or interact with the health system or who have influence on the health system, whether it is through their lived experience of rare disease, health care design, delivery or evaluation. Stakeholders within the rare disease sector include people living with a rare disease, carers and family members, rare disease organisations and peak bodies, other not-for-profit organisations, health care professionals, researchers, policymakers, industry, and the media.

Each RAReST Health System Simulation Workshop has a specific focus relevant to rare disease health care. Participants are challenged to solve a challenging problem while taking a different perspective to their usual, familiar perspectives, and to “step outside of their usual silos”. Participants are arbitrarily assigned to a stakeholder group that is different from their usual real-life role. For example, a health manager, a nurse, a physiotherapist and a person with lived experience may be assigned to role play the decision-makers working in the department of health.

Apart from challenging participants to think differently and to consider a given problem from different perspectives, Health System Simulation Workshops are always a lot of fun and generate a lot of interesting and spirited discussions! Most importantly, they bring different stakeholders together to experience each other’s expertise, ways of working and perspectives in a simulated complex system scenario.

What are the outcomes of a Health System Simulation Workshop?

As an exercise, Health System Simulation Workshops help multiple different stakeholders understand the roles of others in the health sector, and the need for multi-stakeholder collaboration to address complex and challenging problems that cannot be solved by any single stakeholder group. Outcomes include:

- Capacity building
- Collaboration
- Networking
- Awareness and education

All stakeholder groups then reconvene to share their learnings and interactions from new perspectives. The facilitator then debriefs on the session with the following five 'Big Lessons':

1. The solutions to problems in complex systems are not achieved overnight.
2. In a complex adaptive system, stakeholders push and pull, and priorities compete.
3. Parts of the system continuously interact and affect each other.
4. People can feel overwhelmed by complexity, so everyone must work together.
5. A complex system can be shaped and influenced over time.
6. People living with a rare disease and their families/carers must be at the centre of health care design, delivery and evaluation.

that is holistic, person-centred and multi-sectoral. A word cloud (above) produced by workshop participants reflects opportunities to improve integrated care for people living with a rare disease.

Many groups also reflected a need for funding and resourcing. This would allow for sharing data across systems, which would enable integrated care for people living with a rare disease. They talked about the importance of primary care, especially supporting the primary care workforce to build capacity. They also talked about greater cross-sectoral collaboration within the health system and outside of the health system – for example, greater collaboration with the disability and education sectors. The need for trials of new integrated models of care and sustainment of effective models was prioritised.

Essentially, participants wanted to break down siloed barriers in the health system (for example, inability to share medical records across primary care and hospitals, or across state borders) that prevent integrated care, and they wanted to do this through collaboration, shared knowledge and resources and adequate infrastructure that would enable them to fulfill their role effectively.

To read more please see a [blog post](#) on the International Foundation for Integrated Care website.



Simulation 2 - Co-designing integrated care transition for young people living with a rare disease

The second Health System Simulation Workshop under Stream 3 of the RrEST Project was held at Macquarie University, in Sydney, in March 2024. Given this was an open event, it attracted many different stakeholders within the rare disease sector, and health sector broadly.

Who attended?

A total of 38 people attended this workshop, each from various stakeholder groups within the rare disease sector. Most participants were from outside of the health sector (13) which included rare disease organisation leaders and people with lived experience of a rare disease. Other participants included doctors, nurses and allied health professionals (9), academics and researchers (8), people from policy and government (3), and people from the public health sector (3) and private health sector (2).

What was the focus of this workshop, and what was discussed?

Participants were challenged to address a fragmented care by designing a collaborative, integrated and compassionate health system for young people living with a rare disease. They were asked:

How would you improve care integration and transitions for young people living with rare conditions?

Given many young people living with a rare disease experience challenges with transitioning from paediatric to adult care, this issue is an important topic of discussion for the rare disease sector, whether they are involved in health care, education, or disability support.

Participants were introduced to concepts of a complex adaptive system by Professor Jeffrey Braithwaite, and how system complexities overlap with the complexities of living with a rare disease. Professor Yvonne Zurynski elucidated on this concept by talking about some of the specific challenges of living with a rare disease, including underdiagnosis, misdiagnosis and challenges related to care transition. Clare Stuart from Mito Foundation generously offered her lived experience of a sibling of a person living with a rare disease who had undergone transition. These experiences highlighted some of the key themes mentioned by Professor Braithwaite and Professor Zurynski. The full presentation can be accessed [here](#).

What happened during the workshop?

Participants were randomly assigned to the following stakeholder groups:

1. People living with a rare disease, rare disease organisations and peak bodies
2. Minister for Health, Australian Government Department of Health and policy staff
3. State Health Systems (Departments of Health, Local Health Districts and networks)
4. General practitioners and Primary Health Networks
5. Allied health professionals
6. The media
7. Specialist doctors and professional organisations (Royal Colleges)
8. Nurses and midwives
9. Industry and Commercial organisations (pharmaceutical companies and medical technology developers)
10. Academics and researchers

Many groups discussed the challenge among themselves. As so often happens in real-life, it took some time for groups to approach other groups, to share ideas, understand what other groups needed and how they could join forces. Interestingly the “Department of Health” and the “State departments of health” joined forces relatively quickly. Some groups did not actively seek out discussion with other groups, but instead waited to be

Simulation 3 - Co-ordinated, whole-of-life care for people living with a rare disease in rural, regional and remote areas

The third Health System Simulation Workshop under Stream 3 of the RrEST Project was held at the Harry Perkins Institute of Medical Research, in Perth, in May 2024. This workshop was co-hosted with the Rare Care Centre. This was an open event, which meant it attracted many different stakeholders within the rare disease sector, and health sector broadly. Many attendees had lived experience and were part of the Rare Care Centre community, which made for a particularly rich discussion.

Who attended?

A total of 42 people attended this workshop, each from various stakeholder groups within the rare disease sector. Many participants had lived experience of living with a rare disease (15), as well as belonging to other stakeholder groups. Other groups included rare disease organisations (7), academics and researchers (5), doctors (2), nurses (7), allied health professionals (7) and those working in the public health (7) and private health (2) sectors.

What was the focus of this workshop, and what was discussed?

Participants were challenged to address a fragmented and inequitable health care system for people living with a rare disease in rural, regional and remote Australia. They were asked:

How would you improve care coordination and whole-of-life care for people living with a rare disease in rural, regional and remote areas of Western Australia?

There is a significant gap in access to health care between people living with a rare disease in rural, regional or remote areas, and those living in metropolitan areas. Many people living outside of metropolitan areas often travel long distances to receive care, and this care is often costly, and not consistent or coordinated.

Professor Yvonne Zurynski introduced participants to concepts of a complex adaptive system and how these system complexities overlap with complexities of living with a rare disease and living in rural, regional or remote areas of Western Australia. Kaila Stevens spoke about the wonderful work being conducted with families from the Rare Care Centre, including highlighting some of the successes they have had with care coordination and patient support in rural, regional and remote parts of Western Australia. Andrew Bannister, Amanda Gilpin and Cristian Rapanaro generously shared their lived experience of rare disease as an individual, mother, and father. Each speaker kindly provided important insights about living with a rare disease, including challenges, learnings and shedding light on their involvement in rare disease advocacy and awareness. The full presentation can be accessed [here](#).

What happened during the workshop?

Participants were randomly assigned to the following stakeholder groups:

1. People living with a rare disease, rare disease organisations and peak bodies
2. Minister for Health, Australian Government Department of Health and policy staff
3. State Health Systems (Departments of Health, Local Health Districts and networks)
4. General practitioners and Primary Health Networks
5. Allied health professionals
6. The media
7. Specialist doctors and professional organisations (Royal Colleges)
8. Nurses and midwives
9. Industry and Commercial organisations (pharmaceutical companies and medical technology developers)
10. Academics and researchers

Many groups discussed among themselves initially, however, most groups split up and sat with different groups to discuss the problem. In a few instances, one table had several stakeholder groups at once discussing the

References

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4. Teutsch, Suzy et al. “Australian children living with rare diseases: health service use and barriers to accessing care.” *World journal of pediatrics: WJP* vol. 19,7 (2023): 701-709. doi:10.1007/s12519-022-00675-6