Monash Partners
ACADEMIC HEALTH SCIENCE CENTRE

Developing a state-wide plan for a model of healthcare for people affected by Prader Willi Syndrome

The project

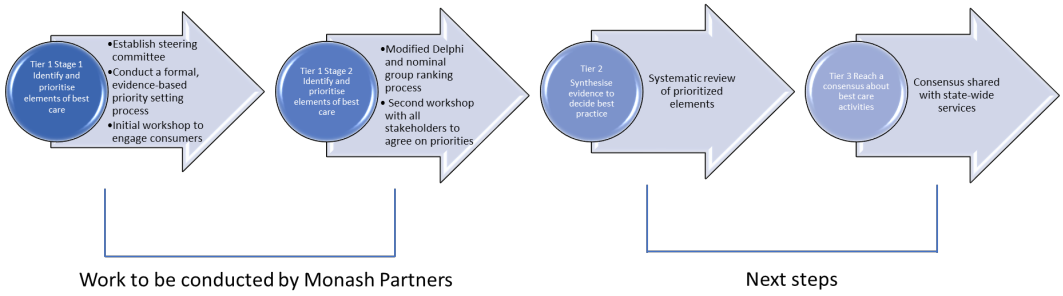
A state-wide plan for a model of healthcare for people affected by Prader Willi Syndrome is a collaboration between Prader Willi Syndrome Association of Victoria (PWSA Vic), Monash Children's Hospital and the Royal Children's Hospital, supported by Monash Partners Academic Health Science Centre (Monash Partners). Funding has been provided by the PWSA Vic.

The project is led by Professor Katrina Williams at the Department of Paediatrics at Monash University in close consultation with Associate Professor Tom Connell from the Royal Children's Hospital. Monash Partners (www.monashpartners.org.au), is supporting development of the state-wide plan by working with all stakeholders, including children, families, carers and front-line clinicians, to identify and prioritise elements of best care.

Aim

The aim of the project is to develop a Prader Willi Syndrome (PWS) state-wide plan for children to deliver best care to every child, and their families, in Victoria regardless of where they live.

Methods



"I guess the challenge is that because it's such a rare syndrome, there's not really many people out in the community that have even heard of Prader Willi Syndrome."

Consultation with carers of people with Prader Willi Syndrome.

Following review and approval by the Monash Health Human Research and Ethics Committee, the Prader-Willi Syndrome community was invited to participate in a Loomio discussion platform and/or Zoom meetings.

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Results from consultation with the community – the community perspective:

The consultation with the community identified key elements of a state-wide model of care:

Coordination of care

- Enhanced coordination of care through an overarching care co-ordination role such as a complex care liaison role and/or a potential Clinical Nurse Consultant role.
- A multidisciplinary approach to care. As this is a rare condition, there is an opportunity for key health services to explore a virtual care clinic shared between the key health services, drawing on expertise and optimising clinical care for carers and people affected by PWS.

Communication

- Maintaining effective communication between all providers and between providers and people living with PWS is essential.
- Building capacity for effective communication with carers and clinicians.
- Engaging with networking and advocacy groups such as PWS Association Vic.

Education

- Provision of standardised information templates to families and inclusion of a "My team" page in the information provided may be useful.
- Development of online education resources and tools that can be tailored and shared with day care, preschool, kindergartens and schools to inform carers of specific health needs.
- Building ongoing community awareness of PWS.

Best practice interventions

- Standards of practice that guide decision making and become living guidelines. With the limited evidence available this may require an international virtual centre of excellence, possibly using the Orphanet framework and support.
- Research that addresses the current gaps in knowledge and also includes a focus on services and interventions for adults living with PWS.

> "Communication is very important in any care plan, and sometimes due to having so many specialists, it can be missing."

Next steps – obtaining the clinician perspective

The next step is consultation with clinicians supporting people with Prader Willi Syndrome to identify best practice in the priority areas identified by the PWS community. Following this consultation, we will bring the two sets of feedback together and a prioritisation process will be used to identify key elements that can be implemented in the short, medium and long term.

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