

Projects

# Prader-Willi Syndrome Centre of Excellence Health Care Model

Identifying the benefits from a better health care model



## LOCATION

Sydney, NSW

## CLIENT

Prader-Willi Research Foundation of  
Australia

PUBLIC POLICY

## Background

Prader-Willi Syndrome (PWS) is a rare genetic disorder that occurs in approximately one out of every 15,000 births. PWS affects males and females with equal frequency and affects all races and ethnicities. PWS is recognised as the most common genetic cause of life-threatening childhood obesity. The current healthcare delivery in Australia for people living with PWS is fragmented, reactive, and enables crisis events. This has significant negative impacts on the health and well-being of people living with PWS and their families, brings massive financial dis-benefits to affected populations due to inefficiencies, and is a major barrier to health research and development.

Founded in 2015, Prader-Willi Research Foundation of Australia is a registered charity which seeks to improve the lives of people living with PWS. They do this by funding research that is aimed at helping people living with PWS lead independent lives, free from some of the most debilitating aspects of the condition. The Foundation also aims to provide a link between people who have PWS, their families, clinicians, and researchers.

The Foundation is proposing to pilot a new healthcare model, the Prader-Willi Centre of Excellence, to provide better health care to people living with PWS, better support for their families and to improve research into PWS in the future. NineSquared was engaged by the Foundation to help define and assess the benefits of the proposed healthcare model. The engagement was undertaken as part of NineSquared's commitment to the Pledge 1% initiative.

## Our role

NineSquared's role and the objectives of this project were to define the problem statement and current state of delivery of healthcare of people living with PWS, identify benefits of the proposed Centre of Excellence, and recommend further work and strategies to implement a pilot of the new health care model.

This was done using a multifaceted approach which included:

- Desktop research into prior work already done in similar studies and evaluating how learnings from similar projects could apply to setting up the PWSCE in Australia.
- A strategic review to examine the alignment of the proposed health care model with government objectives, including the National Strategic Action Plan for Rare Diseases & the National Disability Strategy 2010-2020.
- Identification of the potential benefits that would arise from implementing the new health care model for people living with PWS and their families. This involved engaging stakeholders through a series of workshops, with participants including medical practitioners, researchers and academics, parents caring for children living with PWS, and health economists, all specialising in PWS or intellectual disability (ID).
- An assessment of the PWS-related financial burden on individuals and families that are living with PWS

Outputs from the work helped the Foundation to engage with key stakeholders on the impacts of PWS and the benefits that of developing a better health care model. Outputs from the work also informed a submission by the Foundation to the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#).

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## FOR FURTHER INFORMATION

For more information, find one of our experts at [ninesquared.com.au/people](https://ninesquared.com.au/people)

## PLEDGE 1%

This project was undertaken on a pro bono basis as part of NineSquared's Pledge 1% commitment.

If you are interested in learning more about our commitment and, if you are a charity in Australia, how we can assist you through applying our expertise and experience please visit our Pledge 1% page at [ninesquared.com.au/about](https://ninesquared.com.au/about).