



System navigation across the rare, genetic and undiagnosed community of Western Australia.

The Western Australia Department of Health, Office of Population Health Genomics are currently reviewing the supports, services and systems available to those living with rare, genetic and undiagnosed conditions and their families, and how the community navigate these systems.

We would like to know more about your or your family's experience, from the time of diagnosis or through the diagnostic odyssey, and the journey that followed.

- What does 'system navigation' mean to you and your family?
- How did you find services, support and information?
- Was it easy or difficult to find services, support and information about the condition?
- Did the services and supports meet yours or your family's needs?
- How did you feel about navigating the systems following diagnosis and beyond, such as the NDIS and Centrelink? Was it difficult?
- Where do you think there are gaps in the information, support and services for those living with rare, genetic and undiagnosed conditions and their families?

Community Stakeholder Consultation

We are holding a series of stakeholder consultation focus groups for those living in Western Australia with a rare, genetic or undiagnosed condition and/or their families. If this is you, share your experiences and thoughts to help shape the future system navigation services for those living with genetic, rare and undiagnosed conditions across Western Australia.

What: Stakeholder consultation focus groups to hear from WA's rare, genetic and undiagnosed community.

Where: Face to face in Perth CBD (address to be provided) with online video conference options available.

When: Participants may choose from a morning or evening session on 2nd, 3rd, 8th or 9th of February.

Why: Community input plays a critical role in how future services are designed to create better outcomes.

How: Face to face or online video conference

You will be remunerated for your time, so to learn more or register your interest please email

genomics@health.wa.gov.au or call 08 9222 2239. We appreciate your time.