Our vision for genomics and genetic healthcare in Queensland

All Queenslanders will have access to quality and safe genomics and genetic healthcare that is person-centred and responsive.

Priority areas that matter to consumers, carers and families when accessing genomics and genetic healthcare:

Access, health equity and respect

- We have equal access to genomics and genetic healthcare anywhere in Queensland.
- Everyone has a chance to be as healthy as they can be to achieve the best possible outcomes.
- Our values, beliefs and individual needs will be respected along the way.

Health literacy

- Health information is presented to us in a way we understand.
- We can access and understand information in formats and languages that suit us.
- We are empowered to ask questions to make informed decisions that are right for us.

Informed consent and choice

- We have access to the right information to understand our condition and treatment.
- We are informed and understand the benefits, risks, alternative options and limitations prior to consenting.
- Informed consent is not a one-off conversation, it's an ongoing process.

Culturally appropriate and safe care

- We have access to culturally safe, respectful and inclusive healthcare for First Nations people and people from multicultural backgrounds.

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Integrated care

- Our care is planned with healthcare teams who work together in a coordinated, integrated way to ensure we are placed at the centre of our care.

Access to support

- We can easily find information to support us.
- We can access healthcare providers to support us throughout our patient journey.

Healthcare workforce

- Our healthcare team provide evidence-based, high quality care that is right for us.
- We have access to trained and available healthcare providers across Queensland.
- Education and training is provided to healthcare teams to increase capacity and capability to deliver genomics and genetic healthcare.

Data and research

- My health information (data) is safe and secure, and used to provide better health outcomes to help support my journey.
- We are supported to access and participate in research or clinical trials.
- We are supported to partner in the co-design of research and can help share the outcomes.

Feedback and innovation

- The process is open to community feedback to continuously improve services.
- This vision has a set of priority areas, however there will be innovation and we need to be responsive to reflect developments as we progress in the future.

Patient journey

What we expect throughout our genomics and genetic healthcare journey:

1. Referral

- A referral to specialist care or genetic health service.
- Informed consent provided throughout the process.
- The opportunity to ask questions.

2. Consultation

- A clinical assessment provided by genetic services, including pre-assessment counselling.
- Genetic testing.
- The opportunity to ask questions.

3. After assessment

- Test results returned to the treating healthcare team.
- Test results explained to us.
- A shared management plan.
- Ongoing care managed by the healthcare team, which may involve a genetic counsellor and social worker.
- The opportunity for our genetic data to be reanalysed with emerging evidence for improved diagnostics and treatment options.
- Informed about possible follow up options for patients and affected family members.
- The opportunity to ask questions.

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