

What Makes a Quality Genetics Service?

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Consumers Say:

1. A supportive, empathetic, caring person.
2. Respect.
3. Two-way communication.
4. A holistic approach (more than the condition).
5. Appropriate language and clarity of speech (use of layman terms).
6. Respect for parents' knowledge.
7. Tailored sessions (for children, parent and spouse).
8. Being encouraged to ask questions.
9. Responsiveness to consumer needs.
10. Sufficient time for consultation.

Service Providers Say:

1. Effective communication skills (verbal and non-verbal).
2. Awareness of expectations from both sides.
3. Accurate and realistic information about condition and testing.
4. Empathy, trust and rapport, patience.
5. Cohesive team approach.
6. Good follow-up.
7. Establishing the consumer's agenda for the consultation process.
8. Adequate physical setting (privacy, time, childcare).
9. Respecting client's wishes and views.
10. Setting of a realistic contract.

As part of their 2002 strategic plan, Genetic Health Services Victoria are collaborating with the Genetic Support Network of Victoria (a consumer support and advocacy organisation) to develop responsive, consumer-focused clinical genetics services. In order to do this, we first needed to identify and prioritise the concerns of consumers and health care providers with regards to service provision.

The question asked was **"From your perspective, what makes for a good clinical genetics service?"** and it was answered using the Nominal Group Technique at two sessions – one which involved 26 consumers (at the Genetic Support Network of Victoria's inaugural conference), and one which involved 33 service providers (at the regular weekly Genetic Health seminar). At each session, the participants broke into small groups and discussed the question. Each group was then asked to come back to the entire group with a list of four or five major answers to the question. Each small group provided one idea at a time from these lists. Once the twenty or so ideas had been recorded (projected onto a large screen) a few more important ideas were added from participants. The consumer session came up with a list of 27 items, the service provider session came up with a list of 26 items.

Participants were then asked to individually choose the ten most important items and to rank them in order of importance on an anonymous ballot paper. (Service providers who were unable to attend the seminar were emailed the list and ballot paper and were given the option to vote during the following week.)

These ballot papers were collated and scored, with items being listed as high priority receiving high scores, and the low priority items receiving lower scores. The final rankings, according to these scores, provided the top ten most important factors for a quality genetics service from the point of view of each group.

These lists will now be used to help identify priority areas for planning services and to understand the needs of both groups of stakeholders. This project is a step towards equal involvement of consumers in planning the services we provide for them.

Support Groups Represented at Consumer Session

Androgen Insensitivity Syndrome Support Group of Australia
Australian Leukodystrophy Support Group
Australian Primary Immunodeficiency Network
Cardiomyopathy Association of Australia
Cleft Palate and Lip Society of Victoria
Congenital Adrenal Hyperplasia Support Group Australia
Dialysis and Transplant Association
Fibrodysplasia Ossificans Progressiva Australia
Haemophilia Foundation of Victoria
HeartKids Victoria
Marfan Association Victoria
Metabolic Dietary Disorders Association
Neurofibromatosis Support Group Gippsland
Short Statured People of Australia
Thalassaemia Society
Unique in Australia
Victorian Turner Syndrome Association

Professionals Represented at Service Provider Session

Administration Staff
Genetic Counsellors
Genetics Fellows
Management Staff
Medical Geneticists
Medical Scientists
Metabolic Physicians
Social Workers

Reference

Wertz DC, Gregg R. Genetics services in a social, ethical and policy context: a collaboration between consumers and providers. *Journal of Medical Ethics* 2000;**26**:261-265.