**SUPPLEMENTARY ONLINE MATERIAL**

Table VI: Groups of people represented in the nominal group technique sessions.

**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
- Hemophilia 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 counselors
- Genetics fellows
• Management staff
• Medical geneticists
• Medical scientists
• Metabolic physicians
• Social workers