

Principles and objectives to progress a National Plan for Rare Diseases

1. **Rare diseases need to be recognised as a national health priority.** The burden of rare diseases, while largely hidden due to inadequate information systems, is unacceptably high for patients, families and the community.¹ People living with a rare disease have shared concerns and needs that warrant national recognition, leadership and action.
2. **More equitable and timely access to diagnostics, treatments, services and coordinated care for people living with a rare disease.** It is in the national and state interest to establish leadership, direction and action towards more effective national systems and approaches to rare diseases. Appropriate service models should be identified and harmonised across states and territories and developed for regional and remote areas.
3. **Incentives are required to drive a coordinated and collaborative action on rare diseases. A national approach should be established, backed by the Australian government.** There is no shortage of opportunities to improve diagnostics, treatments, services and coordinated care. A challenge is to reach agreement on how best to focus effort. Incentives should bridge efforts at local, state, national and international scales and support integrative approaches which leverage knowledge, skills and capacity.
4. **Leaders from patient, healthcare, research, and government and industry organisations need to work collaboratively to champion a National Plan.** The Plan needs endorsement from all stakeholders including the Australian, state and territory governments. A National Plan requires agreement and commitment to action from all the key stakeholders including Patient Organisations and people living with a rare disease.
5. **The National Plan should identify a set of objectives and enabling strategies to action.** Six objectives are proposed under key themes;
 - i. **National Co-ordinated and Collaborated Approach**
Establish a national platform for dialogue, information exchange, and coordinated and collaborative action on rare diseases.
 - ii. **Data Collection**
Identify and enable approaches to data collection and use that better meet the needs of people living with a rare disease.
 - iii. **Co-ordinated Care**
Identify and enable approaches to coordinated care that better meet the needs of people living with a rare disease.
 - iv. **Equitable Access to Services**
Ensure Australia's health system enables timely, equitable access to appropriate services for people living with a rare disease.
 - v. **Equitable Access to Diagnostics and Treatments**
Ensure Australia's health system enables the development of diagnostics and treatments for rare diseases and facilitates timely, equitable access for patients.
 - vi. **Nationally Co-ordinated Research**
Establish a nationally coordinated program of research on rare diseases that is informed by patients and carers.

¹ An estimated 1.2 -2 million Australians live with a rare disease.