Rare Disease Awareness, Education, Support and Training (RArEST)

Under the Commonwealth Department of Health grant funding agreement, the University of New South Wales, committed to delivering Rare Disease Awareness, Education, Support and Training though:

- the development of resources to improve awareness of rare diseases,
- a nationally coherent and evidence-based plan to improve clinician education around rare diseases (pre- and post-graduate),
- guidelines for models of care including psychosocial support,
- national infrastructure to improve health literacy for rare diseases.

Health Professional Education and Training, Stream 2, of RArEST's objectives are to:

- raise awareness of, and educate health professionals about, rare diseases (RD)
- equip and encourage health professionals to provide timely care and support that is integrated and appropriate for all Australians living with a RD, while being both person and family-centred
- integrate mental health, and social and emotional wellbeing, into Rare Disease care and support.

Leading to the following outcomes:

- increased access to Rare Disease education, information, and resources for health professionals to improve Rare Diseases diagnosis, care and support that is timely, accurate, and accessible, as well as culturally safe and appropriate.

Health Professional Education and Training Working Group

1. Constitution

The RArEST Health Professional Education and Training Working Group supports the RArEST steering committee through delivery of Stream 2 “Health Professional Education” activities under the Commonwealth Department of Health RArEST funding from 2021 – 2024.

2. Terms of Reference

a. Purpose

To codevelop with consumers, representing all Rare Disease priority populations, health care professionals, medical education experts and relevant stakeholders a National Recommendations for Rare Disease Practice.

b. Objectives

- To liaise and consult relevant stakeholders to co-develop National Recommendations for Rare Disease Practice.
- The National Recommendations for Rare Disease Practice are to inform curricula development for health professionals:
  - Rare Disease online educational program targeting training and practising doctors (M4RD),
  - Rare Disease Health professional communities of learning program (teleECHO)
  - The tailored Rare Disease training programs for priority populations.
- To conduct a dedicated communication strategy to maximise reach and uptake of National Recommendations, including on the Rare Voices Australia website.
- To commission an evaluation report of uptake, use and feedback on impact of National Recommendations from consumers, health professionals, health service executives and policy makers, and plan for future reviews and adaptation.
- Other activities as relevant to the RArEST grant, to support the implementation of the National Strategic Action Plan for Rare Diseases.

c. Membership

- RArEST Chief Investigator – Chair
- RArEST Manager/Stream 2 Project Lead – Coordination
- Health care professional representation
- GP representation
- Medical education experts – Pedagogy Consultant
- RArEST Grant Associate Investigators
- Evaluation post-doctoral fellow
- Up to 3 other stakeholders

d. Quorum

The quorum for the Health Professional Education and Training Working Group is four.

e. Attendance by members

The Chair of the Working Group will be expected to attend 100% of the meetings. Other Working Group members will be required to attend a minimum of 80% of all meetings and be allowed to send a representative.

f. Roles and responsibilities

- Provide constructive feedback on the development, implementation and evaluation of Clinical Education.
- Allocate resource and time to create relevant resources and activities related to the delivery of Working Group activities as appropriate.

3. Accountability and reporting arrangements

- The Working Group will be accountable to the RArEST Steering Committee.
- The Stakeholder Reference Group members will be engaged and reimbursed to support codesign of working group materials at up to six instances over the course of the Project.
- The minutes and relevant documentation of each meeting will be provided to Chair of the RArEST Steering Committee, the RArEST Chief Investigator, and other Investigators.

4. Frequency

- Meetings shall be held quarterly.
- Additional meetings may be arranged when required to support the effective functioning of the RArEST Stream 2 activities.

5. Monitoring effectiveness

The Working Group will undertake a bi-annual review of its performance against its work plan in order to evaluate the achievement of its duties. This review will inform the RArEST Steering Committees bi-annual report to the Commonwealth Department of Health.

6. Other matters

The Working Group shall be supported administratively by the RArEST Manager/Stream 2 Project Lead, whose duties in this respect will include:

- Agreement of the agenda with the Chair and attendees
- Collation of the papers
- Taking the minutes and keeping a record of the matters arising and issues to be carried forward, and
- Advising the Committee on pertinent areas.

7. Review

These Terms of Reference and the functioning of the Working Group should be subject to a periodic review by the RArEST Steering Committee, including self-assessment by the Working Group, to ensure that it is operating effectively and fulfilling its functions.