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Response to Guiding Principles: Ensuring Culturally Safe Health Genomics in Partnership with Aboriginal and Torres Strait Islander Peoples

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Background

Rare Voices Australia (RVA) is the national peak body representing Australians living with a rare disease. RVA led the collaborative development of the National Strategic Action Plan for Rare Diseases (the Action Plan) which was launched by the Commonwealth Government in 2020. The National Strategic Action Plan for Rare Diseases is the first nationally coordinated effort to address rare diseases in Australia. Rare diseases are complex but share countless commonalities. This Action Plan addresses this common ground. It outlines a comprehensive, collaborative and evidence-based approach built on 3 principles: person-centred; equity of access; and, sustainable systems and workforce. Its content is sorted into three interrelated pillars: Awareness and Education; Care and Support; and, Research and Data

Aboriginal and Torres Strait Islander peoples are identified as a priority population in the Action Plan, which was prepared in alignment with the *National Aboriginal and Torres Strait Islander Health Plan 2013—2023.*

RVA Feedback

RVA welcomes the opportunity to provide feedback on these Draft Guiding Principles. Overall RVA is impressed with the Draft Guiding Principles, however believe they would be potentially further strengthened by highlighting alignment with the National Strategic Action Plan for Rare Diseases.

The Action Plan recognises that while Aboriginal and Torres Strait Islander people are not necessarily at greater risk of rare diseases, several factors increase the potential impact of rare diseases on Aboriginal and Torres Strait Islander people. The lack of research into rare diseases means our knowledge on which rare diseases are most prevalent within Aboriginal and Torres Strait Islander people is incomplete. Given the genetic basis of most rare diseases, research exploring this is vital. The Action Plan notes that there is a gap in data and genomic knowledge for Aboriginal and Torres Strait Islander Peoples and the draft Guidelines may benefit from a stronger emphasis on this.

As outlined in the Action Plan, the following factors further contribute to the unique challenges faced by Aboriginal and Torres Strait Islander people:

- while the areas of genetics and genomics are expanding rapidly, inequity exists in the inclusion of Aboriginal and Torres Strait Islander people genetics, genomics, and clinical phenotype diagnostic support tools;
- many Aboriginal and Torres Strait Islander people have Indigenous language/s as their first language/s. As a result, diagnostic and clinical concepts, including around emerging health technologies, can be challenging for non- Indigenous Australian practitioners to adequately convey;
- more work is required to understand the health information needs of Aboriginal and Torres Strait Islander people with rare diseases (and their families and kinship groups) to ensure available information and services are both culturally safe and appropriate; and
- proportionately, more Aboriginal and Torres Strait Islander people live in regional, rural and remote areas, which can pose significant challenges to their ability to access services.

Relevant excerpts from the Action Plan

Under each Pillar and for every priority in the Action Plan, Aboriginal and Torres Strait Islander communities are identified as a priority population for the implementation of key actions.

Pillar 1 Awareness and Education

Priority 1.1

Increase every Australian's awareness of rare diseases including, where applicable, relevant prevention measures.

Action 1.1.1

Develop and conduct national awareness and education activities for rare diseases.

Implementation

1.1.1.4. Collaborate with targeted stakeholders to maximise the reach and appropriateness of materials to Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

Priority 1.3

Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics.

Action 1.3.1

Develop a national rare disease workforce strategy.

Implementation

1.3.1.3. Ensure the strategy includes measures to empower practitioners to provide culturally safe and appropriate care and support to Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

1.3.2.3. Develop awareness and education that empowers frontline health professionals to provide culturally safe and appropriate care and support to Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

Pillar 2 Care and Support

Priority 2.1

Provide rare disease care and support that is integrated and appropriate for all Australians living with a rare disease, while being both person and family-centred.

Action 2.1.1

Provide rare disease care and support that is integrated, incorporating clear pathways throughout health, disability and other systems.

Implementation

2.1.1.4. Ensure care and support is responsive to the specific needs of rural and remote communities and health services, Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

Action 2.1.2

Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.

Implementation

2.1.2.3. Through regular stakeholder consultations, determine strategies to improve access to rare disease care and support services for Aboriginal and Torres

Strait Islander people, those with CALD backgrounds, those living in rural and remote areas, and other priority populations.

Action 2.1.3

Ensure services support people living with a rare disease through significant life-stage transitions.

Implementation

2.1.3.4. Ensure transition services are culturally safe and appropriate, in recognition of unique life-stage challenges faced by Aboriginal and Torres Strait Islander people.

Action 2.1.4

Develop the capacity of rare disease organisations to represent and advocate for people living with a rare disease and their families.

Implementation

2.1.4.2. Ensure consultation with targeted stakeholders to strengthen the capacity of rare disease organisations to appropriately represent and advocate for Aboriginal and Torres Strait Islander people living with a rare disease and their families.

Action 2.1.5

Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases.

Implementation

2.1.5.2. Enhance culturally safe and appropriate approaches for Aboriginal and Torres Strait Islander people, including aligning with existing initiatives to develop and implement ways to integrate Indigenous Australian languages to equitably enhance care and support.

Priority 2.2

Ensure diagnosis of a rare disease is timely and accurate.

Action 2.2.1

Ensure all Australians have equitable access to a range of diagnostic tools and tests, providing the best chance of early and accurate diagnosis.

Implementation

2.2.1.1. Further the development of, and investment into, the range of existing specialist diagnostic responses, such as genomics technology, including for Aboriginal and Torres Strait Islander people; interdisciplinary undiagnosed disease programs; clinical phenotype diagnostic support tools; centres of expertise; genetic counsellors and peer support groups.

2.2.1.3. Enhance culturally safe and appropriate approaches for Aboriginal and Torres Strait Islander people, including aligning with existing initiatives to develop and implement ways to integrate Indigenous Australian languages to equitably enhance diagnosis.

Action 2.2.4

Support people with a suspected but undiagnosed rare disease on their diagnostic journey.

2.2.4.4. Ensure consultation with targeted stakeholders to maximise appropriateness of this support for Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

Priority 2.5

Integrate mental health, and social and emotional wellbeing, into rare disease care and support.

Action 2.5.1

Ensure people living with a rare disease, including their families and carers, receive the community, clinical and digital mental health supports and services they need.

Implementation

2.5.1.2. Ensure Aboriginal and Torres Strait Islander people living with a rare disease have access to customised resources (including digital), in recognition of the greater challenges to achieving the best possible social and emotional wellbeing support outcomes for Aboriginal and Torres Strait Islander people.

Action 2.5.2

Implement care and support systems to address the mental health and wellbeing of Australians impacted by a rare disease.

Implementation

2.5.2.1. Empower rare disease care and support providers to deliver the best possible mental health and social and emotional wellbeing support outcomes through a range of initiatives, including:

- access to evidence that aids providers in their understanding of and ability to respond to mental health and social and emotional wellbeing support needs, such as a rare disease mental health checklist;
- awareness around the existing range of free or low cost digital mental health services that provide support, such as Head to Health;
- education about how to access and utilise these services; and
- cultural competency education that empowers providers to effectively support Aboriginal and Torres Strait Islander people.

Action 2.5.3

Develop the capacity of rare disease organisations to provide wellbeing and mental health support.

Implementation

2.5.3.3. Undertake targeted stakeholder consultations to ensure appropriate social and emotional wellbeing support, including appropriate referral to GPs, for Aboriginal and Torres Strait Islander people, those with CALD backgrounds, those living in rural and remote areas, and other priority populations.

Pillar 3 Data and Research

Priority 3.1

Enable coordinated and collaborative data collection to facilitate the monitoring and cumulative knowledge of rare diseases, informing care management, research and health system planning.

Action 3.1.1

Health information systems identify and measure rare diseases and undiagnosed rare diseases.

Implementation

3.1.1.4. Ensure rare disease and undiagnosed rare disease codes link with a person's Aboriginal and Torres Strait Islander status to allow for culturally appropriate care, and to build evidence of rare disease epidemiology among Aboriginal and Torres Strait Islander people.

Action 3.1.2

Undertake broad epidemiological surveillance of rare diseases to support decision-makers to access the information they need to improve the health and wellbeing of Australians living with a rare disease.

3.1.2.2. Establish a dedicated Rare Disease Office within the AIHW that publishes periodic national reports on the epidemiology of rare diseases and undiagnosed rare diseases in Australia, including among Aboriginal and Torres Strait Islander people.

Priority 3.3

Ensure research into rare diseases is collaborative and person-centred.

Action 3.3.1

Provide people living with a rare disease or an undiagnosed rare disease with the opportunity and support to participate in research.

Implementation

3.3.1.1. Health professionals inform and connect people living with a rare disease to research as part of their ongoing care.

3.3.1.2. Develop opportunities for individuals to share their lived experience to contribute to research. Rare disease organisations can promote this by increasing their liaison with researchers and clinicians, and by disseminating information.

3.3.1.3. Promote culturally safe and appropriate approaches for Aboriginal and Torres Strait Islander people.