

# RARE VOICES AUSTRALIA – THE NAVIGATOR PROJECT

## EXPRESSIONS OF INTEREST

### FOR CONSUMER-LED RARE AND COMPLEX DISEASE ORGANISATIONS

#### 1. Purpose of the Expressions of Interest Process

Rare Voices Australia (RVA) is seeking Expressions of Interest (EOI) from experienced consumer-led rare and complex disease organisations to implement the third component of **The Navigator Project**. Upon the completion of the EOI process, three organisations will be selected to work with RVA to provide specific services. Selection will be based on an open competitive process.

#### 2. Background

RVA is pleased to be the lead consortium partner on The Navigator Project, which has been named the recipient of the Rare and Complex Disease Telehealth Nurse Program grant. Read more about the grant on [RVA's website](#). You can also read the Australian Government's media release on the [Department of Health and Aged Care's website](#).

RVA is the national peak body for Australians living with a rare disease. RVA's work is non-disease specific and is based on the commonalities of rare disease. Our advocacy focuses on rare disease policy, processes and systems. RVA's person-centred focus sees us working with all key stakeholders, including people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry. We advocate for the best outcomes for Australians living with a rare disease.

The Navigator Project will support the estimated two million Australians living with a rare disease to navigate the health system, including via the assistance of telehealth nurses. This activity is scheduled to run over three years commencing from June 2023.

#### The Navigator Project and the Australian Government's National Strategic Action Plan for Rare Diseases

The Navigator Project responds to several priorities, actions and implementation areas identified in the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). Importantly, this work will accelerate progress towards achieving the Action Plan's vision, 'The best possible health and wellbeing outcomes for Australians living with a rare disease.'

The Navigator Project also responds to ongoing stakeholder feedback from various consultations and projects regarding the gap in equity for Australians living with a rare disease. 'Equity of access' is a foundation principle of the Action Plan.

The Navigator Project has three core components:

1. RARE Helpline
2. Telehealth nurse service navigation trial sites
3. Engagement with three consumer-led rare and complex disease organisations

### *1. RARE Helpline*

**Purpose:** To provide service navigation support to Australians living with a rare disease.

The RARE Helpline will provide **timely access to information** and **answer key questions** people living with a rare disease often face. The RARE Helpline will:

- Support people to connect with existing information that is reliable
- Provide resources that respond to people's specific needs
- Help to increase people's health literacy and engagement with care and support services
- Assist in connecting people with existing health services and/or professionals where possible

The RARE Helpline will complement work already being undertaken on the [Rare Awareness Rare Education \(RARE\) Portal](#) for rare diseases. An interim RARE Helpline has been operating since July 2023.

### *2. Telehealth nurse service navigation trial sites*

**Purpose:** To provide targeted nurse-led support for people with highly complex conditions or issues where information and access to services may be restricted or particularly challenging.

Rare diseases typically display high levels of symptom complexity and in some cases, navigating people to well defined care and support services is not possible. The two telehealth trial sites will be staffed by people with **specialist rare disease expertise and experience**, particularly in relation to working with several of the priority populations identified in the Action Plan, including:

- Those with an undiagnosed rare disease
- People living in regional, rural and remote areas
- Aboriginal and Torres Strait Islander people
- Those living with an intellectual disability

This is a unique model as this service will be embedded within existing clinical services and provide broad equity of access.

### *3. Engagement with three consumer-led rare and complex disease organisations*

**Purpose:** To establish the benefits of an existing patient navigation model and contribute to The Navigator Project's overall data collection and reporting.

RVA will engage with three consumer-led rare and complex disease organisations **already providing disease-specific telehealth service navigation**. The purpose of this activity is information sharing to support continuous improvement of telehealth nurse-led services for people/families living with a rare and complex disease, while also providing an evidence base for alternate patient navigation models for rare and complex diseases.

This component of The Navigator Project acknowledges that some rare and complex disease organisations are currently providing disease-specific telehealth service navigation services to support their cohort. While The Navigator Project trial sites are focused on non-disease specific support embedded within existing clinical services, this element will explore the potential benefit of complementary navigation services, embedded within organisations.

The three successful organisations will benefit from participation in The Navigator Project through representation on the Expert Advisory Group and as such, will support a community of best practice telehealth care and navigation. The successful organisations will be required to share aggregated data, which will inform an evidence base on the benefit of telehealth nurse navigation services through this model. Further, the successful organisations will have the opportunity for their model to be included as part of the broader evaluation of The Navigator Project, which is intended to inform future policy and government investment. The successful organisations will also have access to project learnings, advice, support and exchange of knowledge through the Expert Advisory Group and/or consortia partners to support organisational capacity and capability building.

Three organisations will receive funding (see point 4 below for the specifics) through The Navigator Project over three years.

### 3. EOI Details

Key details are as follows:

<b>Submission time/date</b>	5pm (AEST time), 22 September 2023 Please email: <a href="mailto:navigatorproject@rarevoices.org.au">navigatorproject@rarevoices.org.au</a>
<b>Proposal template</b>	See Annex 1 for the template to use for the EOI
<b>Estimated notification date of shortlisted EOIs</b>	Early October 2023. Following the determination of a shortlisted EOI, a virtual meeting will be organised with RVA. If the EOI is successful, an Agreement will be prepared by RVA to be reviewed and signed by the successful candidate.
<b>EOI Submission</b>	Annex 1 to be submitted in PDF format to <a href="mailto:navigatorproject@rarevoices.org.au">navigatorproject@rarevoices.org.au</a> with the subject line, "EOI – The Navigator Project"
<b>Enquiries</b>	If you have any queries, email <a href="mailto:navigatorproject@rarevoices.org.au">navigatorproject@rarevoices.org.au</a> with the subject line, "EOI Query – The Navigator Project"
<b>Estimated decision communicated by RVA</b>	October 2023

#### 4. Summary of Collaboration

<b>Project requirements</b>	<ul style="list-style-type: none"> <li>• Share data (de-identified) with RVA (specific details regarding frequency and type of data to be agreed)</li> <li>• Report (e.g., six-monthly) to RVA regarding telehealth services provided</li> <li>• Provide advice to The Navigator Project, primarily through participation in The Navigator Project’s Expert Advisory Group (e.g., quarterly meetings from September 2023 to November 2026)</li> <li>• Participation in meetings with The Navigator Project evaluators</li> </ul> <p>An Agreement will be established to detail the relevant terms and conditions.</p> <p><b>Note: funding provided for component three of The Navigator Project is <u>not</u> for service provision. Service provision is to be funded using your organisation’s own resources.</b></p>
<b>Benefits for the successful organisations</b>	<ul style="list-style-type: none"> <li>• Access to project learnings, advice, support and exchange of knowledge through the Expert Advisory Group or consortia partners to support organisational capacity and capability building</li> <li>• An opportunity for your organisation’s model to be included in a broader evaluation intended to inform future policy and government investment</li> </ul>
<b>Timeframe</b>	<p>Funding for the duration of RVA’s grant with the Department of Health and Aged Care (July 2023 – June 2026), with reporting and Expert Advisory Group participation expected to extend up to November 2026</p>
<b>Funding</b>	<p>\$20,000 (plus GST) per grant year for three years, totalling a maximum amount of \$60,000 (plus GST)</p>

#### 5. Selection Criteria

Applications will be assessed against the following selection criteria. (Further details are outlined in the response template at Annex 1.)

- (i) The organisation is appropriately established and registered in Australia.
- (ii) The organisation’s purpose/goals support, or are not inconsistent with, the Action Plan.
- (iii) The organisation provides a sustainable (for the duration of the grant at a minimum) existing disease-specific telehealth service navigation.
- (iv) The organisation has the operational systems and/or capacity to provide:
  - a) Data collection that is systematic, complete and accurate
  - b) Timely and accurate reporting of data collected from helpline services
  - c) Advice to The Navigator Project, including an appropriate representative that will be appointed to The Navigator’s Project’s Expert Advisory Group

## Annex 1: Expressions of Interest Application Form

### 6.1 Organisation Details

	Requested information	Response
a)	<i>Legal/registered entity name of the organisation</i>	
b)	<i>Registered business address</i>	
c)	<i>ABN and GST registration status</i>	
d)	<i>Is the organisation registered with the Australian Charities and Not-for-profits Commission?</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
e)	<i>Name and position of authorised contact</i>	
f)	<i>Email and phone details of authorised contact</i>	

### 6.2 Organisation Information (guide: <200 words per sub-section)

	Requested information	Response
a)	<i>Summary of organisation's goals/purpose/governance</i>	
b)	<i>Summary of organisation's key activities</i>	
c)	<i>Has there been any adverse information on any relevant person associated with the entity in the previous 5 years (e.g., governance investigation, bankruptcy, litigation)?</i>	<input type="checkbox"/> Yes (please provide details) <input type="checkbox"/> No
d)	<i>State any potential, perceived or actual conflicts of interest that may occur related to or from this funding</i>	

### 6.3 Details of Existing Disease-Specific Telehealth Service Navigation Provided (guide: <200 words per sub-section)

	Requested information	Response
a)	<i>What is the model of telehealth service navigation being provided (i.e., disease-specific, nurse-led, health literacy, care</i>	

	<b>Requested information</b>	<b>Response</b>
	<i>coordination or case management?)</i>	
b)	<i>What is the type and scale (e.g., hours of operation, target group, monthly calls/interactions) of telehealth services currently provided?</i>	
c)	<i>What resources (e.g., staffing, funding) are available to provide these services to ensure sustainability for the duration of the grant (June 2023 – July 2026)?</i>	
d)	<i>What experience does the organisation have in providing these services?</i>	
e)	<i>What policies/procedures are in place regarding how telehealth services are administered?</i>	

#### **6.4 Operational Capacity and Systems (guide: <200 words per sub-section)**

	<b>Requested information</b>	<b>Response</b>
a)	<i><u>Data collection:</u> What data is currently collected? What capacity does your organisation have to collect additional data and share this information?</i>	
b)	<i>What processes are in place to ensure that the management of an individual's health information and data is ethical, legal and socially responsible?</i>	
c)	<i><u>Reporting:</u> What processes are in place to ensure reporting is based on data that is accurate, entered in a timely manner and complete?</i>	
d)	<i><u>Advisory consultation:</u> What is the organisation's capacity to provide advice to The Navigator Project's Expert Advisory Group (e.g., at quarterly Expert Advisory Group meetings?)</i>	

	<b>Requested information</b>	<b>Response</b>
e)	<i>Telehealth services of the organisation:</i>	<p>Complies with Privacy Law?  <input type="checkbox"/> Yes      <input type="checkbox"/> No      <input type="checkbox"/> Other (please explain further)</p> <p>Offered without discrimination?  <input type="checkbox"/> Yes      <input type="checkbox"/> No      <input type="checkbox"/> Other (please explain further)</p> <p>Provided from a location in Australia and to people living in Australia?  <input type="checkbox"/> Yes      <input type="checkbox"/> No      <input type="checkbox"/> Other (please explain further)</p> <p>Are processes in place to ensure children/vulnerable persons<sup>1</sup> accessing the service are protected?  <input type="checkbox"/> Yes      <input type="checkbox"/> No      <input type="checkbox"/> Other (please explain further)</p>
f)	<i>Why is your organisation interested in participating in The Navigator Project, and how do you believe your organisation will benefit?</i>	
g)	<i>(Optional) Any other comments to support the application.</i>	

**Declaration**

I declare that:

- The information contained in this application is true and correct.
- I am authorised to make this submission on behalf of the organisation.

**Signature of Authorised Officer:**

**Name of Authorised Officer:**

**Date:**

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<sup>1</sup> For example, an individual aged 18 years and above who is or may be unable to take care of themselves, or is unable to protect themselves against harm or exploitation for any reason, including age, physical or mental illness, trauma or disability etc.