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The RARE Helpline:

- Supports people to connect with existing information that is reliable
- Provides resources that respond to people's specific needs
- Helps to increase people's health literacy and engagement with care and support services
- Assists in connecting people with existing health services and/or professionals where possible

Additionally, the RARE Helpline has been designed to:

- Collect data on gaps in support and care for people living with a rare disease
- Provide emotional and psychosocial support
- Connect people with complex service navigation needs to a telehealth nurse embedded in the healthcare system
- Provide evidence to address key gaps in support for people living with a rare disease
- Accelerate diagnosis and access to appropriate care by flagging a genetic diagnosis pathways sooner

Interim RARE Helpline Progress

- The Interim RARE Helpline has commenced with soft launch
- [The Interim RARE Helpline page is on the RARE Portal](#)
- Recruitment for a Project Manager and RARE Helpline Manager is in progress

Helpline not yet fully staffed or formally promoted – this will happen later this month

As such still only small number of enquiries ie <100

However data is being collected on priority populations as well as areas of unmet need/ specific gaps

Interim Helpline stats to date

- 50% queries - from a person with a rare and /or complex disease
- 40% queries – from carer/ family member
- 10% queries – Health care professional

10% of the people were seeking a diagnosis

About a third of people were seeking information about a particular disease

About a quarter of the people were looking for a support organisation

About a fifth of the people were seeking a clinical referral/ information

Helpline provided emotional support to 30% of people

We have noticed that more than a third of the people who contacted the Helpline have a diseases for which there is no existing support group in Australia.

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Interim Helpline Data (updated)

- In the interim period the helpline provided **information about 46 different diseases**
- Approximately 12% of requests came from people who are seeking a diagnosis
- 62% of enquiries were from people who are living with a rare or complex disease
- 23% were from parents and carers
- 10% from health care professionals supporting some with a rare disease
- 5% other
- Requests from support have come from every state and territory in Australia
- 31% of people wanted information about a specific rare disease
- 45% requested information about support organisations
- 20% were looking for information about clinical centres
- 36% were provided with emotional support
- More than half did not have a disease specific support group they could be referred to

Quotes:

From RARE Helpline service user:

"Thank you so much for the email back. I will read through all the links etc. I really appreciate the time you have taken to find links and information, just fantastic".

From person living with a rare disease (member of the Stakeholder Reference Group for the RAREST Project - another Commonwealth DOH funded project that RVA is involved in):

"We need like... a rare disease line... it would be good if I knew I was guiding people somewhere that has some training in rare [disease] and the challenges that us rare people face."

From Rare Voices Australia CEO: Nicole Millis

"The RARE Helpline provides service navigation support to Australians living with rare and complex diseases. The great complexity, unmet need and uncertainty in rare and complex diseases can be incredibly overwhelming. The RARE Helpline provides timely access to information and answers key questions people living with rare and complex diseases often face."

"Complementing the work already being undertaken on the [Rare Awareness Rare Education \(RARE\) Portal](#) for rare diseases, the RARE Helpline supports people to connect with existing information that is reliable; provides resources that respond to people's specific needs; helps to increase people's health literacy and engagement with care and support services; and assists in connecting people with existing health services and/or professionals where possible."

"To date, the majority of people have contacted the RARE Helpline about diseases for which there is no specific patient support group. The RARE Helpline is helping to reach the most vulnerable individuals – who otherwise would have nowhere else to go."

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From: Nicole Millis s47F
Sent: Tuesday, 16 January 2024 1:18 PM
To: s22
Cc: s47F s22
Subject: RE: Navigator Program statistics [SEC=OFFICIAL]

REMINDER: Think before you click! This email originated from outside our organisation. Only click links or open attachments if you recognise the sender and know the content is safe.

Hi all
We have tweaked the wording slightly...

- Since the RARE Helpline began operating, it has assisted 143 people, covering 116 rare, complex and undiagnosed diseases via a telehealth service

Thanks
Nicole

Nicole Millis
Chief Executive Officer
RARE VOICES AUSTRALIA
www.rarevoices.org.au

Mobile s47F
Email s47F

Advocating for the best outcomes for Australians living with a rare disease

[Read the National Strategic Action Plan for Rare Diseases](#)

RVA acknowledges Aboriginal and Torres Strait Islander people as the Traditional Owners of Country throughout Australia and as a priority population of the rare disease sector. We pay our respects to Elders past, present and emerging.

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