

Implementing the National Strategic Action Plan for Rare Diseases

Sector-Wide Activity Scan

The Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan) is the first nationally coordinated effort to address rare diseases in Australia. Implementation of the Action Plan is the shared responsibility of the entire rare disease sector, including people living with a rare disease, governments, key peak bodies, clinicians, researchers and industry. As the national peak body for Australians living with a rare disease, Rare Voices Australia (RVA) is leading the collaborative implementation of the Action Plan.



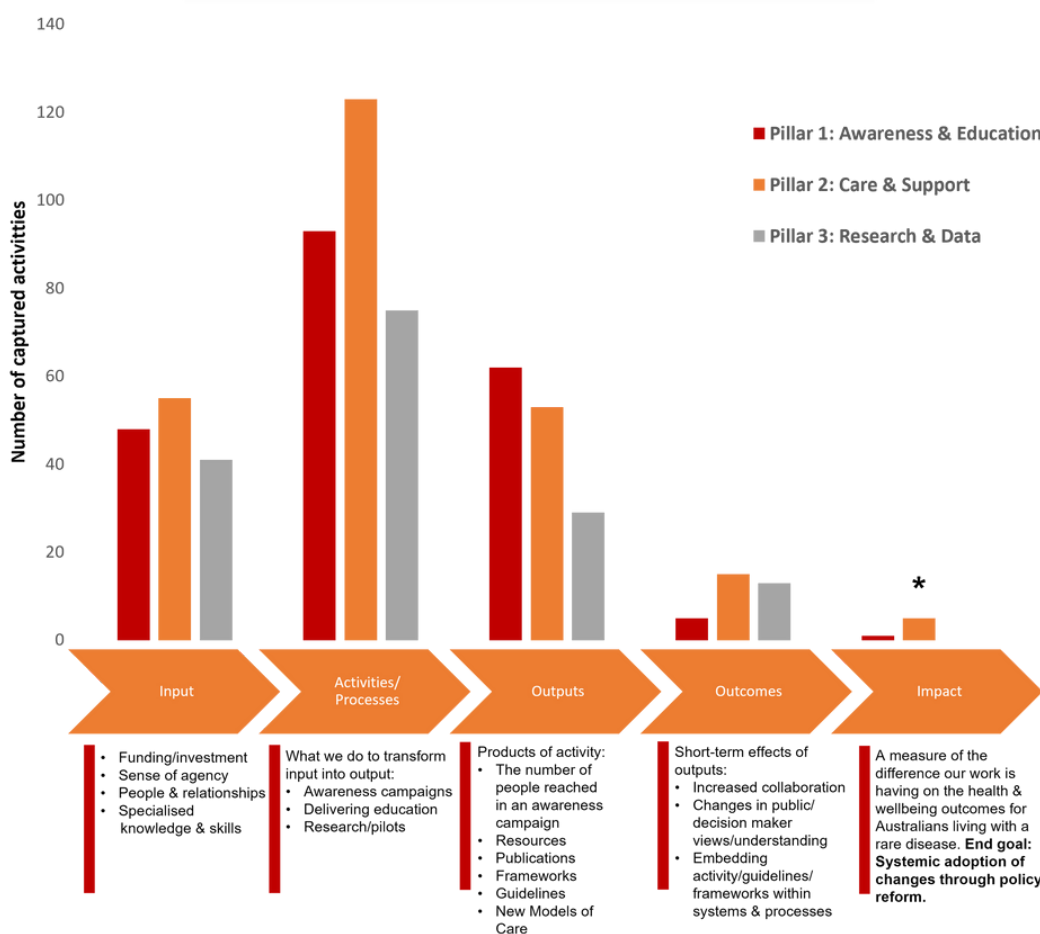
National Strategic
Action Plan for
Rare Diseases
(the Action Plan)

Measuring Sector Progress

In 2022 and the beginning of 2023, RVA conducted an activity scan, inviting rare disease stakeholders to share their projects, initiatives and achievements since the Action Plan's launch in 2020.

The activity scan captured hundreds of activities aligning with the Action Plan. These activities were categorised according to five key elements of progress—input, activities or processes, outputs, outcomes and impact—and also aligned against the eight key themes in the Action Plan, which are descriptive indicators of sector progress.

Captured activities aligned to 5 key elements of progress



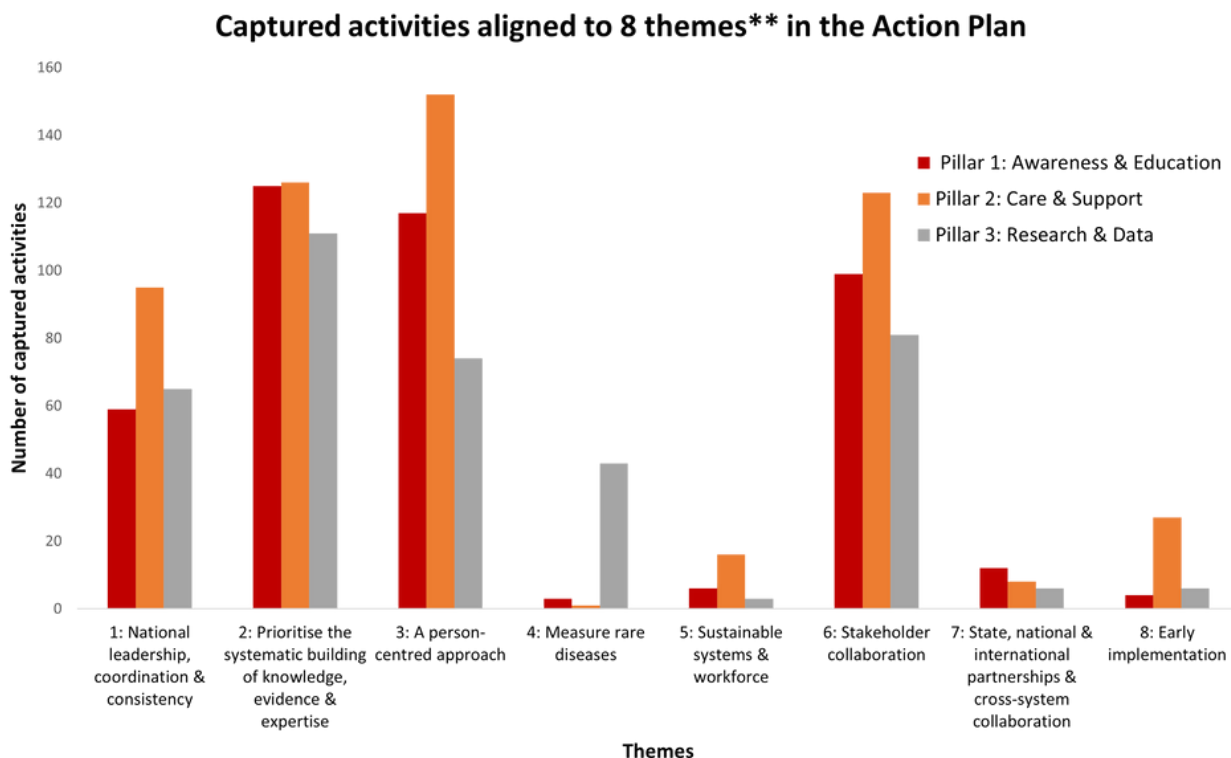
*Impact of sector activities is difficult to measure at this early stage. Greater levels of impact are anticipated in the 23/24 activity scan.



Visit Rare Voices Australia's website: www.rarevoices.org.au

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**Themes are descriptive measures of Action Plan progress.

What do the captured activities say about implementation progress?

- Rare disease sector activities strongly align with Action Plan Pillars, Priorities, Actions and Themes. The Action Plan has mobilised the sector to work on targeted/common goals
- Some activities are being translated into output and outcomes—an increase in output and outcomes is anticipated in the near future
- At this early stage, impact is difficult to measure—achieving impact requires systemic adoption of evidence-based strategies through policy reform
- Gaps in Action Plan implementation have been identified across Themes 4, 5, 7 and 8.

To interpret the data in greater detail, scan the QR code on page 1 to read about the priorities, actions and implementation areas under each pillar of the Action Plan and the eight themes developed as measures of Action Plan progress.

Next Steps

The rare disease sector should collaboratively:

- Respond to gaps in Action Plan implementation and avoid duplication;
- Foster a culture of evaluation to ensure input and activities are being translated to outcomes and impact; and
- Monitor, evaluate and report on progress regularly to ensure continual alignment with the Action Plan.

As the national peak body for Australians living with a rare disease, RVA will aim to regularly report on Action Plan implementation progress to drive the best possible health and wellbeing outcomes for Australians living with a rare disease.



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