



## Response template for the proposed Interprofessional Collaborative Practice Statement of Intent public consultation

June 2023

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This response template is the preferred way to submit your response to the public consultation on the draft proposed **Interprofessional Collaborative Practice (IPCP) Statement of Intent**.

Please provide any feedback in this document, including your responses to all or some of the questions in the text boxes on the following pages. The boxes will expand to accommodate your response. You do not need to respond to a question if you have no comment.

### Making a submission

Please complete this response template and email to [AC\\_consultation@ahpra.gov.au](mailto:AC_consultation@ahpra.gov.au) using the subject line 'Feedback: Proposed Interprofessional Collaborative Practice Statement of Intent'. **Submissions are due by COB 8 August 2023**

### Publication of submissions

We publish submissions at our discretion. We generally publish submissions on our [website](#) to encourage discussion and inform the community and stakeholders about consultation responses. Please let us know if you do not want your submission published.

We will not place on our website, or make available to the public, submissions that contain offensive or defamatory comments or which are outside the scope of the subject of the consultation. Before publication, we may remove personally identifying information from submissions, including contact details.

We can accept submissions made in confidence. These submissions will not be published on the website or elsewhere. Submissions may be confidential because they include personal experiences or other sensitive information. A request for access to a confidential submission will be determined in accordance with the *Freedom of Information Act 1982* (Cth), which has provisions designed to protect personal information and information given in confidence. Please let us know if you do not want us to publish your submission or if you want us to treat all or part of it as confidential.

**Published submissions will include the names of the individuals and/or the organisations that made the submission unless confidentiality is expressly requested.**

Do you want your responses to be published?

- Yes – Please publish my response with my name
- Yes – Please publish my response but don't publish my name
- No I do not want my responses to be published

## Stakeholder details

Please provide your details in the following table:

<b>Name:</b>	[Falak Helwani]
<b>Organisation name:</b>	[Rare Voices Australia]
<b>Interest in joining as a signatory to the final statement</b>	Is your organisation interested in being invited to sign the final statement? [Yes]

## Your responses to the consultation questions

<p><b>1. Is the content, language and structure of the proposed statement clear and relevant? Why or why not?</b></p>
<p>The content in the proposed statement is clear and easy to follow. <a href="#">Rare Voices Australia</a> (RVA), the national peak body for Australians living with a rare disease, welcomes the proposed statement for Interprofessional Collaborative Practice (IPCP) as an important step to formalising such practice and facilitating the establishment of formal rare disease networks of expertise for the best possible health and wellbeing outcomes for Australians living with rare disease.</p> <p>The idea of IPCP is highly relevant for Australians living with rare disease. The Australian Government's <a href="#">National Strategic Action Plan for Rare Diseases</a> highlights the critical need for multidisciplinary teams of doctors, nurses, and allied health professionals in managing the complex problems and disabilities experienced by people living with a rare disease. Interdisciplinary clinics, care coordination, and interconnected clinical networks and communities of practice to support shared learning are important enablers of flexible integrated rare disease care models.</p> <p>Clinical networks of rare disease expertise are vital to ensuring Australians living with a rare disease receive the best care informed by the best expertise regardless of where they live. This emphasises the importance of ensuring that this statement of intent for IPCP includes mention of the need to embed IPCP systemically to prevent inequities in healthcare delivery. It is worth noting that access to the right medical expertise as well connected and coordinated multidisciplinary care, which are all closely linked with IPCP, form part of the recommendations in the <a href="#">National Strategy for Australia's Rare Metabolic Disease Workforce</a> (the Strategy). This Strategy was informed by research findings presented in the <a href="#">Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia</a>, together with multistakeholder consultation with clinicians, industry, researchers, professional medical bodies and consumer representatives.</p>

<p><b>2. Is there anything else the accreditation committee should consider that would be helpful to include in the proposed statement? If so, please provide details.</b></p>
<p>Embedding research and innovation into regular clinical care for people living with a rare disease is vital for best practice care. With fewer than 5% of known rare diseases having an approved treatment, many people living with a rare disease rely on clinical trials as the only way to access treatment. Explicit mention of <i>research</i> in the shared vision of the proposed statement, in addition to education, training, clinical governance and practice, would further highlight the importance of research and enable research to be embedded into IPCP. Embedding research into clinical care was also recently highlighted by the Medical Research Future Fund and the National Health and Medical Research Council Discussion Paper on improving coordination and alignment of the MRFF and the Medical Research Endowment Account as a way to strengthen health and medical research in Australia.</p> <p>Individually rare; collectively common. Rare disease affects approximately 2 million Australians and their families and carers. There are over 7000 known rare diseases making it challenging to find experts with knowledge of each individual disease. In Australia, geographically dispersed populations and state and territory borders further compound the challenges around the inherent rarity of rare</p>

disease patients and available expertise. Clinical centres of rare disease expertise and formalised networks of expertise are one way to manage these challenges. In working towards the shared goals in the proposed statement, to align education, training clinical governance and practice (as well as research as recommended above), it is important to capture the need for building, identifying and formalising clinical centres of expertise, both bricks and mortar and virtual. This will support and enable IPCP and the co-design of best practice models of care. From a rare disease perspective, and as highlighted in the Australian Government's National Strategic Action Plan for Rare Diseases, supporting partnerships between researchers and clinicians is vital because these links strengthen and enable the implementation of innovation in clinical care. Indeed, most rare disease clinicians are also researchers; however, these partnerships, while often present, are not formalised or well resourced. A commitment to including research as part of IPCP is vital for sustainable and systemic access to innovative care.

RVA would also like to highlight a potential opportunity to include how the proposed statement responds to and leverages existing policies, frameworks and strategies, including the National Medical Workforce Strategy 2021–2031. Highlighting any such existing enablers for implementing IPCP may strengthen this proposed statement. RVA also strongly recommends including the need for a systemic response to implementing IPCP to prevent inequities in healthcare delivery.

Although outside RVA's area of expertise, other potential enablers of IPCP, which may be worth mentioning, include digital health technologies, data collection and data sharing.

Under the shared goals of the proposed statement there is mention of improving health services for vulnerable groups. From RVA's perspective it is important to explicitly highlight that these vulnerable groups include people living with high levels of unmet medical need in order to represent the 2 million Australians living with rare diseases. RVA also noted the use of the words 'interprofessional care that is free of racism'. Racism may be too narrow and should be extended to encapsulate discrimination more broadly.

As part of the solution, under bullet point '*reducing duplication, gaps and discontinuity experienced by individuals accessing health services*' it would be helpful to mention that duplication can be avoided, and some gaps and discontinuity can be managed through building or enabling formal networks of expertise. These would ensure that knowledge gained is not lost when experts retire or move on, and patients have access to the right expertise regardless of where they live. Currently, access to care for many Australians living with rare disease is reliant on their postcode.

The final bullet point in the list of shared goals '*establishing strategies and policies that facilitate and support opportunities to embed interprofessional collaborative practice, based on best available evidence*', should include the need for adequate resources, such as infrastructure and workforce, as well as mention of leveraging existing strategies and policies. There are significant gaps and challenges in the rare disease workforce in Australia. 'Sustainable systems and workforce' is a foundation principle and key priority of the National Strategic Action Plan for Rare Diseases. Ensuring that this proposed statement highlights workforce as an important enabler of the shared goals and vision is critical for driving implementation.

Under the '*shared values*' heading, the first bullet point should include mention of accountability and transparency. Transparent and open communication and formalised recording of IPCP will enable the establishment, growth and visibility of clinical networks of expertise, which is critical for equitable access to the right medical expertise for all Australians. Expert clinicians and clinical centres should also be adequately resourced to develop networks, collaborate and share knowledge.

Under the '*our commitment*' heading of the proposed statement and in line with RVA's previous comment, it is importance to mention person-centred care that is free from discrimination (not only racism), more broadly.

### **3. Do you have any general comments or other feedback about the proposed statement?**

Rare diseases are often complex multisystemic disorders requiring the care of a multidisciplinary team. Many people living with a rare disease often coordinate their own care. Recognising, formalising and implementing IPCP will support people living with a rare disease to have more streamlined care pathways, with access to the right specialist expertise and much needed care coordination.