

**Draft National Clinical Quality Registry Strategy: Consultation Questions**

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| <p><b>National Principles</b><br/>(p5)</p>  | <ul style="list-style-type: none"> <li>• Are there other important principles that need to be included?</li> </ul> <p>Overall: There is a gap in articulating how clinical outcomes are understood in a detailed manner (i.e. patterns identified, outliers investigated) and how they are improved in a systematic manner (i.e. through research, pilot programs, testing interventions, etc. Suggest the addition of a Principle to the effect: High functioning, mature, prioritised, national CQRs <b>enable researchers / policy makers to leverage off the existing infrastructure and conduct research / clinical trials, run pilot programs, test interventions etc.</b></p> <p>Principle 4: 4. provide direct, timely access to data and/or tailored information to patients, health care providers, health system managers and funders, <b>and research institutions / individual researchers</b> to maximise the value of national CQR data and information, in accordance with privacy legislation and the 2013 National Health Information Agreement;</p>   |
| <p><b>Strategy Objectives</b><br/>(p22-32)</p>  | <ul style="list-style-type: none"> <li>• Are there other important objectives that need to be included?</li> </ul>   |
| <ul style="list-style-type: none"> <li>• National CQRs are based on clinician/patient partnerships (p25)</li> </ul> | <ul style="list-style-type: none"> <li>• What key actions would facilitate:             <ul style="list-style-type: none"> <li>○ clinician/patient partnerships?</li> </ul> <p>It is critical to ensure patients have a strong voice in their relationship with their clinicians. Rare Voices Australia advocates for patient-centric care and support models, where patients are viewed through a strengths-based lens and treated as equal partners in their care and support.</p> <p>Rachel Callander’s Health Language Matrix outlines the importance of “POSITIVE INFORMATIVE” language in the clinician/patient partnership (see: <a href="https://static1.squarespace.com/static/5553f79ae4b01ea315d07df1/t/5a6eae0e4966b35d93a657f/1517203285676/Effective+Communication+-+A+White+Paper+by+Rachel+Callander.pdf">https://static1.squarespace.com/static/5553f79ae4b01ea315d07df1/t/5a6eae0e4966b35d93a657f/1517203285676/Effective+Communication+-+A+White+Paper+by+Rachel+Callander.pdf</a>)</p> <ul style="list-style-type: none"> <li>○ the development of CQR PROMs and PREMs?</li> </ul> </li> </ul> |

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|  | <p>Rare Voices Australia advocates for the consideration of a broad range of outcome and experience measures that goes beyond strictly clinical / medical outcomes and experiences to include measures that reflect the person’s wellbeing and mental health, and the social determinants of health, such as social supports, employment, education, physical environment, i.e. housing etc.</p> <ul style="list-style-type: none"> <li>○ greater clinician/patient interaction with CQRs?</li> </ul> <p>Patient access and input to their entry in a CQR is central to truly patient-centred care and outcomes. This could be achieved by ensuring there is a platforms for the patient to engage and interact with the CQR, such as an app that enables them to enter data, including as related to the above point.</p> <p>Clinician interaction with CQRs could be facilitated by the inclusion of a research element in patient care management. This would trigger them to have conversations with their patients about their involvement in research, including CQRs.</p> <ul style="list-style-type: none"> <li>○ the development of interactive CQRs?</li> </ul> <p>It is important to outline the avenues through which CQRs can become interactive, i.e. what are the platforms that facilitate this?</p> <ul style="list-style-type: none"> <li>● What other key actions would facilitate CQR contribution to patient centred care?</li> </ul> <p>Rare Voices Australia advocates for the involvement of patients in making decisions around shaping CQRs. It is critical to ask patients what clinical quality means to them in various contexts, and then develop the CQs accordingly. It is important to recognise that the patient is central to much more than their care episode, and to view their life as holistically as possible. What does clinical care impact on for the patient, outside of the care episode? For example, is may be important to patients to consider clinical quality from the perspective of impacts on their ability to participate in employment or education.</p> |
| <ul style="list-style-type: none"> <li>● National CQRS are quality assured, efficient and cost effective (p26-27)</li> </ul> | <ul style="list-style-type: none"> <li>● What key actions would facilitate: <ul style="list-style-type: none"> <li>○ the development of a CQR standard and accreditation scheme?</li> </ul> <p>Rare Voices Australia advocates for the involvement of the National Alliance of Rare Disease Registries (see <a href="http://www.rarevoices.org.au/page/132/national-alliance-of-rare-disease-registries">http://www.rarevoices.org.au/page/132/national-alliance-of-rare-disease-registries</a>) the development of a CQR standard and accreditation scheme.</p> <p>Rare Voices Australia advocates for consistency with the 10 key principles for RD Registries jointly declared by the European Organisation for Rare Diseases (EURORDIS), the National Organization for Rare Disorders (NORD) and the Canadian Organization for Rare Disorders (CORD). See Rare disease registries: a call to action, Lacaze, P., Millis, N., Fookes, M., Zurynski, Y.,</p> </li> </ul>  |

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|  | <p>Jaffe, A., Bellgard, M., Winship, I., McNeil, J. and Bittles, A.H., 10 September 2017, accessed from <a href="https://onlinelibrary.wiley.com/doi/full/10.1111/imj.13528">https://onlinelibrary.wiley.com/doi/full/10.1111/imj.13528</a></p> <ul style="list-style-type: none"> <li>○ national CQR communication and collaboration?</li> </ul> <p>Rare Voices Australia advocates for the involvement of the National Alliance of Rare Disease Registries (see <a href="http://www.rarevoices.org.au/page/132/national-alliance-of-rare-disease-registries">http://www.rarevoices.org.au/page/132/national-alliance-of-rare-disease-registries</a>) to ensure national CQR communication and collaboration.</p> <p>Rare Voices Australia advocates for the inclusion of research institutes, research funding bodies, researchers / academics and the health technology industry (i.e. pharmaceutical companies) to be included in communications and collaboration.</p> <ul style="list-style-type: none"> <li>○ streamlining of external barriers such as ethics approval, site governance and data collection processes?</li> </ul> <ul style="list-style-type: none"> <li>● What other key actions would facilitate a quality assured, efficient and effective CQR sector?</li> </ul> |
| <ul style="list-style-type: none"> <li>● The potential value of national CQR data is maximised (p28-30)</li> </ul> | <ul style="list-style-type: none"> <li>● What key actions would facilitate the creation of an environment that supports access to tailored CQR information for consumers, health care providers and funders?<br/>It is critical that this information is available in relevant forums and formats, and that it is pushed through to the target audience.</li> <li>● What key actions would facilitate national CQR data linkage, interoperability and integration with Australia’s health information systems and infrastructure?</li> <li>● What key actions would facilitate the use of CQR data for: <ul style="list-style-type: none"> <li>○ clinical care improvements via benchmarking?</li> <li>○ quality and safety monitoring?</li> </ul> </li> </ul> <p>It is critical to ensure alignment with existing quality and safety monitoring requirements, including the TGA’s Post Marketing Surveillance requirements. It is important to ensure there is no / minimal overlap between existing reporting requirements and any new requirements under emerging CQRs.</p>   |

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|  | <ul style="list-style-type: none"> <li>○ clinical trials and research purposes?</li> </ul> <p>Specifying a requirement or preference to use CQR data for clinical trials and research purposes can be a useful action, i.e. like the 2017 MRFF grant program <i>Rare Cancers, Rare Diseases and Unmet Need Clinical Trials Program</i>.</p> <p>For all three of these purposes, it is again important that the information is pushed through to the target audiences.</p> <ul style="list-style-type: none"> <li>• What other key actions would maximise the potential value of CQR data?<br/>The health technology industry, i.e. pharmaceutical companies, may be interested in accessing the CQR data, with a view to generating health technology improvements.</li> </ul>   |
| <ul style="list-style-type: none"> <li>• National, prioritised CQRs are sustainably funded (p31-32)</li> </ul> | <ul style="list-style-type: none"> <li>• What key criteria should be used to finalise a list of national, prioritised CQRs? <ul style="list-style-type: none"> <li>○ The Australian Commission on Safety and Quality in Health Care's, '<a href="#">Prioritised list of clinical domains for clinical quality registry development</a>', includes prioritisation criteria and a prioritised list of clinical domains.</li> </ul> <p>Rare Voices Australia advocates for the prioritisation of CQRs that incorporate rare diseases; it can often be easier to capture high / full coverage of the entire, national clinical population of a certain rare disease, due to their lower numbers than other diseases, and there are significant opportunities for improvement in clinical care and cost effectiveness in the rare disease space.</p> <ul style="list-style-type: none"> <li>• What key criteria should be included in a sustainable CQR funding model for national, prioritised CQRs?</li> <li>• What key actions would facilitate a: <ul style="list-style-type: none"> <li>○ co-ordinated, prioritised approach to the funding of CQRs?<br/>Ensure that all impacted stakeholders are involved in discussions about funding CQRs, including researchers and health technology (i.e. pharmaceutical) industry.</li> <li>○ sustainable funding model for national, prioritised CQRs?<br/>There may be potential to attract funding from industry (health technology industry, i.e. pharmaceuticals) if requirements for Post-Marketing Surveillance were minimised / removed due to the capture of this same information in other CQRs. A sustainable funding model would need to consider a 'tax-like' model, where Sponsors contribute funding in line with the proportion of the market that their products occupies.</li> </ul> </li> </ul> </li> </ul> |

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| <ul style="list-style-type: none"> <li><b>General comments</b></li> </ul> | <ul style="list-style-type: none"> <li>Do you have any general comments about the draft Strategy?</li> </ul> <p>Rare Voices Australia acknowledges the Strategy's focus on patient-centred health care and outcomes; this focus is of great importance and is strongly supported by Rare Voices Australia.</p> <p>The critical role of research in the CQR feedback loop (p.11) could be strengthened throughout the Strategy; research plays a critical role in improving the quality of care, based on the data present within CQRs.</p> |
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