

The Australian Real World Cancer Evidence Network (Pan Cancer Initiative)

A co-funded partnership between Movember, Cancer Australia & the Department of Health, Disability and Ageing

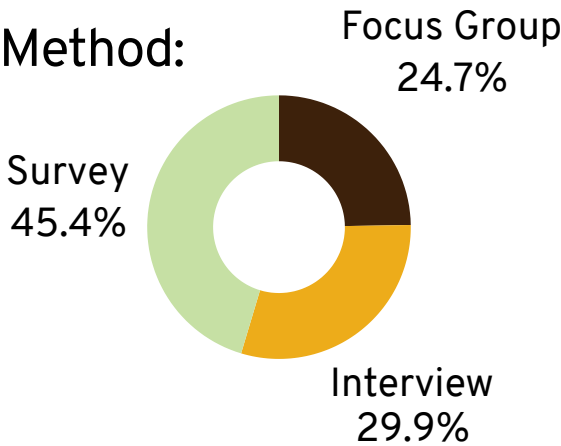
Work Package 1 of the Pan Cancer Initiative aims to identify generic patient-reported outcome and experience measures that should be collected across all cancer types. Sector and lived experience engagement has been a crucial part of the discovery phase.

Lived Experience Engagement

97 people with lived experience told us what was most important to them. Participants represented:



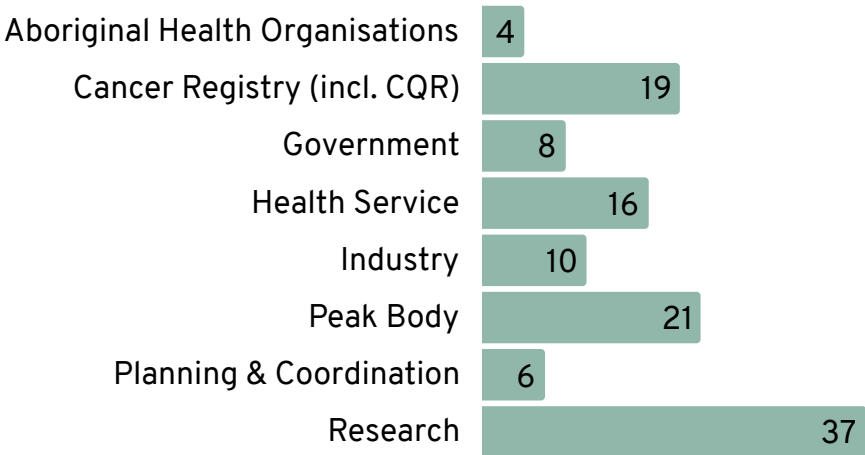
Just ask me
“How are you feeling?”



Priority PROs	Priority PREs
<ul style="list-style-type: none">Physical health: Pain, nausea, sleep, and fatigueMental health & wellbeing: Anxiety, depression, emotional resilience, and fear; culturally relevant holistic and spiritual dimensionsSocio-economic dimensions: Financial toxicity, social support	<ul style="list-style-type: none">Information provision: Both too much and too little was noted, suggesting a domain around information adequacy or overloadExperiential dimensions: Feeling respect and listened to by staff, and the quality of interactions with healthcare professionalsExperiential dimensions: Information provision and use, for treatment, and management of feedback

Sector Engagement

121 stakeholders representing the cancer sector identified the most relevant and critical PRO and PRE domains in cancer care.



Priority PROs		Priority PREs
<ul style="list-style-type: none">Quality of life – globalPsychological wellbeingPhysical health & functioningSocial functioningFinancial toxicitySexual function & wellbeing	<ul style="list-style-type: none">PainFatigueCognitiveOther symptoms & side effectsFearActivities of daily living	<ul style="list-style-type: none">InformationCommunicationPartnershipAccessCoordination & continuity of careCultural safetySupportPerson-centred care

Next Steps

Achieve consensus on a core set of generic patient-reported outcomes and experience measures through a Delphi process.



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