



# Guidelines for Selecting Patient-Reported Measures

## Definitions

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### Patient-reported Experience Measures (PREMs)

PREMs are generic tools that ask patients to provide information about their satisfaction with and experience of receiving health care. They are focused on the processes of care and how that impacts the patients' perceptions of their experience rather than experience related to a specific disease<sup>1,2</sup>. They are primarily used to measure and monitor service quality<sup>1</sup>.

### Patient-reported Outcome Measures (PROMs)

PROMs ask patients to provide information on aspects of their health (symptoms; function; physical, mental, social health) that are relevant to their quality of life and provide insight on the effectiveness of care from the patients' perspective without interpretation from a physician or anyone else<sup>1</sup>.

**Generic PROMs:** Ask general questions about the well-being of a patient. They allow comparisons between and within different diseases and sectors of care and can be used for comparisons with population norms and generally produce utility scores that can be used for cost-effectiveness analysis. While they facilitate comparisons across different patient populations, they are less sensitive to health outcomes that are relevant to a specific disease, disability or surgery.<sup>1</sup>

**Condition-specific PROMs:** Ask questions that are specific to a particular disease or sector of care. They are more sensitive to change over time and differences between groups of people who have the same condition. They generally do not produce utility scores and do not facilitate the comparison of health outcomes with those of the general population or across different clinical conditions.<sup>1,2</sup>

## Recommendation #1

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The EQ5D-5L is the provincial generic PROM for use across health sectors.

The following features of the EQ5D-5L tool were taken into consideration when making this recommendation:

- **Level of psychometric evidence** – The EQ5D-5L has been proven to be valid, reliable and responsive in numerous conditions and populations.<sup>3</sup>
- **Track record** – One of the most widely used health utility PROMs in the world, it includes benchmarks to guide interpretation and will allow us to make national and international comparisons. EQ5D-5L is the generic tool that is part of CIHI's national standards for hip/knee arthroplasty PROMs.<sup>4</sup>
- **Instrument content** – Includes questions about mental, physical, social, and general health and produces an overall health utility score to support economic evaluations - one of the only generic PROMs that have utility scores derived from a Canadian sample and supply Canadian population norms.<sup>5</sup>



- **Patient acceptance** – Response burden is low (only 5 questions), extensive translation including Canadian English and French, high cross-cultural validity, and multiple modes of administration are available including proxy versions for patients who are unable to complete surveys themselves.
- **Licensing** – No cost to use the paper version of EQ5D-5L for collection in routine care. CIHI holds the national license for this tool and it may be able to sub-license to Shared Health for users in Manitoba.
- **Ease of Administration** – Overall low administration burden compared to other generic PROMs due to few questions (5) and validity across multiple modes of administration.

Overall selection of a generic PROM requires consideration of several sources of imperfect and evolving evidence. The provincial Patient-Reported Measurement Strategy will be regularly reassessed and will evolve along with the national and international PROMs environment.

In different disease sectors and populations, there may be limited evidence of validity of EQ5D-5L and other generic PROMs may be more commonly used. This recommendation does not preclude the use of other generic PROM tools. However, we strongly encourage the administration of the EQ5D-5L to facilitate comparisons within and across different diseases, health sectors and populations within Manitoba.

## Recommendation #2

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Where possible, it is recommended that both a generic and condition-specific PROM be used together as they provide complementary information.

## Recommendation #3

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The selection of patient-reported measures requires consideration of a number of important factors and will vary depending on how they are being collected and used. It is important to use the literature to guide decisions around using different tools. The following checklist provides general criteria for selecting patient-reported outcome and experience measures.



## Checklist for Selecting PROMs and PREMs<sup>1,6</sup>

- Level of psychometric evidence (reliability, validity, responsiveness).<sup>1,7</sup>
- Track record of widespread use and successful implementation.<sup>1</sup>
- Questionnaire content (questions will provide the right data to respond to a specific objective). When selecting a PROM, both a generic and condition-specific PROM should be used together.
- Patient acceptance (cultural appropriateness, response burden, appropriate literacy level).<sup>8</sup> Selection of the questionnaire content should consider clinician and patient needs.<sup>9</sup>
- Validated in multiple languages.<sup>1,6</sup>
- Feasibility (licensing fees, data reporting requirements, costs to implement, administration time and resources, and patient response burden).<sup>1,8</sup>
- Potential for Canadian norm comparisons and international comparability. Benchmarks available to guide interpretation.<sup>1,5</sup>
- Clinical and health system applicability.
- Patient engagement in development.<sup>5</sup>



## References

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