

CONTENT OF THE TOOLKIT

Patient-reported outcome and experience measures

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Still abstract ?

See more examples in our popularization capsules!

Video PREMS



Video PROMS



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PROMs, PREM s or not?

Although most professional or patient organizations claim to incorporate the concept of Patient-Reported Outcome Measures (**PROMs**) or Patient-Reported Experience Measures (**PREMs**), how the information is collected is not necessarily adequate.^{1,2} PROMs and PREMs must be measured using scientifically validated tools to be compliant. They must be completed by patients.³ Let's see the definition of PROMs and PREMs and what characterizes them.

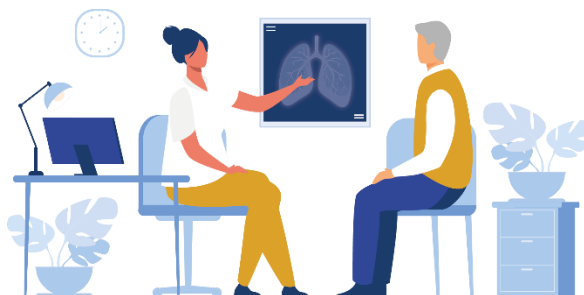
Definitions

What is a PROM?

PROMs are the measures of health outcomes perceived by patients without the interpretation of a health care professional. These outcomes reflect their view of the disease and treatments.^{4,5}

What is a PREM?

PREMs are measures of perceived care experience reported by patients, providing a more comprehensive view of the quality of care.⁶



PROMs/PREMs are^{1,4-8} :

- ✓ Patient's perception of their health status or health services received
- ✓ Issued from validated questionnaires constructed using a rigorous method in collaboration with patients
- ✓ Issued from questionnaires completed by patients or with the help of another person but without interpretation
- ✓ Quantitative and have an accessible literacy level
- ✓ Applicable to different populations

PROMs/PREMs are not^{1,4-8} :

- ✗ Issued from "in-house" questionnaire not validated
- ✗ Issued from a conversation with a patient
- ✗ Based on questionnaires completed by professional staff rather than by a patient

References : 1. Wong, Johnston et al. 2019; 2. Berta, Barnsley et al. 2008; 3. Veillard, Dhalla et al. 2015; 4. Minvielle, Fourcade et al. 2019; 5. FDA, 2006; 6. OECD, 2017; 7. Boyce, Browne et al. 2014; 8. Dawson, Doll et al. 2010.

PROMs and PREM's : Why are they a key to improving health care and services ?



Reminder

What is a PROM?

A tool that measures patients' perspective of their health situation or how they evaluate their health status.^{1,2}

What is a PREM?

A tool that measures patients' perspectives on their care experience, how they care, or how they evaluate the health care they receive.³

A powerful measure

The perspective of patients is often absent from the redesign of primary care policies and services⁵ even though it has the potential to guide them so that they better meet their needs⁶ for the implementation of:

- Intervention plans focused on the real needs of patients⁷
- Support for healthcare professionals to integrate the patient perspective into their professional practice^{8,9}
- Health policies that better meet the needs of people with common characteristics^{9,10}

PROMs and PREM's allow :

- ✓ A better understanding by the professional staff of the symptoms experienced by patients^{7,11}
- ✓ Improved interprofessional communication and the one with patients^{7,8}
- ✓ A person-centred follow-up^{7,8}
- ✓ A reduction in the presence and intensity of encounters⁷
- ✓ Improved emotional and psychological quality of life and shared decision-making⁷
- ✓ A more coherent and efficient care offer^{9,11,12}

Although answering questions about the PROMs and PREM's measurement tools may require the help of another person, these must be completed by the patients.

*Thus, they **DO NOT INCREASE THE WORKLOAD OF CLINICIANS**. These tools can be completed before or after an appointment by the patient or with the help of the administrative staff or a caregiver.*



References : 1. Minvielle, Fourcade et al. 2019; 2. FDA, 2006; 3. OECD, 2017; 4. Boyce, Browne et al. 2014; 5. Berta, Barnsley et al. 2008; 6. Wong, Johnston et al. 2019; 7. Rotenstein, Huckman et al. 2017; 8. Dawson, Doll et al. 2010; 9. Øvretveit, Zubkoff et al. 2017; 10. Snyder and Brundage 2010; 11. Atkinson, Ryan et al. 2016; 12. Santana and Feeny 2014.

Possible barriers to the integration of PROMs and PREMs and the means to put in place to overcome them

BARRIERS	ENABLERS
Patient	
Lack of motivation to complete the questionnaire	<ul style="list-style-type: none"> Provide patients with sufficient information to ensure the objective is well understood.^{1,2} Discuss the results with patients to maintain long-term commitment.^{2,3} Use a video or flyer to explain what the questionnaire is for and how to complete it. You may want to enlist a patient partner to complete this task.⁴ Suggest several methods for administering the questionnaire and consider enlisting the help of a family member, loved one or professional if needed.³
Lack of time for fill the questionnaire	<ul style="list-style-type: none"> Professional staff should select an appropriate questionnaire that collects only data relevant to patients in the practice setting being assessed.⁵ Professional staff should favour a simple and short questionnaire.⁵ However, it must remain clinically relevant. Otherwise, it must be replaced by a more exhaustive questionnaire that meets the needs of the assessment.⁴
Insufficient computer skills	<ul style="list-style-type: none"> Have a user-friendly and easily accessible collection system for PROMs and PREMs.^{1,3} Provide patients with adequate technological support (training, information brochure, tutorials, availability of professional staff, etc.).^{1,3,6}
Professional Staff	
Lack of motivation to integrate the questionnaires into routine practice	<ul style="list-style-type: none"> Provide sufficient information to professional staff to demonstrate that PROMs help in clinical practice and PREMs in improving care organization.^{7,8} Sensitize professional staff to use the questionnaires in daily practice and encourage them to discuss the results with patients.^{3,7} Having a straightforward and user-friendly interface for collecting and displaying data can help engage professional staff and help them better use and interpret data (e.g. dashboard, threshold line, graphs, colour coding, etc.).^{4,7}
Lack of knowledge on how to interpret and integrate PROMs and PREMs into clinical practice / perceived uselessness	<ul style="list-style-type: none"> Adequately train professional staff on using and interpreting measurement tools from the first stages of implementation in clinical settings.^{7,10,11} Provide professional staff with a clear objective for data use.^{7,10} Determine threshold values for PROMs results to target actionable triggers.⁷ Select PROMs and PREMs relevant to patients.⁷
Fear of adding administrative burden and reducing time for clinical activities	<ul style="list-style-type: none"> Evaluate the actual time required to complete the questionnaires. PROMs and PREMs are complementary tools to the practice and should not be seen as an add-on. In the medium to long term, there are even a time savings to using them.^{2,4,7} Send measurement questionnaires to patients by email before the consultation. A paper or tablet version may also be available to patients in the clinic.¹² Integrate PROMs and PREMs directly into the electronic medical record to avoid duplicating the information to be collected.^{2,9,12}
Lack of knowledge of the tools available (English, French, free access)	<ul style="list-style-type: none"> Train professional staff to search for and identify tools in measuring tool directories.¹¹
Lack of human resources	<ul style="list-style-type: none"> The use of PROMs and PREMs does not require additional staff.⁴ Patients must complete the questionnaire alone or with the help of a family member or loved one. Administrative staff can also support them if needed.⁶
Organizational	
Organizational decisions limiting the implementation	<ul style="list-style-type: none"> Monitor scientific publications demonstrating the relevance of integrating PROMs and PREMs into care settings. The management committees are regularly mobilized to implement innovations in good health practices.^{3,4,13}
Lack of financial resources	<ul style="list-style-type: none"> Considering the integration of PROMs and PREMs within the framework of scientific projects can allow the institution to reduce the financial contribution (e.g., doctoral work) if the project is funded via a research grant.^{3,13}
Lack of uniformity in the computer tools used by professional staff (CISSS and CIUSSS, out of network, private, etc.)	<ul style="list-style-type: none"> Have an adequate information technology infrastructure by granting the professional, financial and administrative resources for the development of such a system.^{7,13}

References : 1. Wang, Samuel et al. 2018; 2. Girgis, Durcinoska et al. 2017; 3. Baeksted, Pappot et al. 2017; 4. Poitras, Haggerty et al. 2022; 5. Dawson, Doll, Fitzpatrick, Jenkinson, & Carr, 2010; 6. Howell, Molloy et al. 2015; 7. Kanatas, Mehanna et al. 2009; 8. Santana, Haverman et al. 2015; 9. Baeksted, Pappot et al. 2017; 10. Gerhardt, Mara et al. 2018; 11. LeBlanc & Abernethy, 2017; 12. Rotenstein, Huckman, & Wagle, 2017; 13. Schepers, Haverman et al. 2016.

PROMs and PREMs

Relevant general documentation

WEBSITES*

- **Agency for Healthcare Research and Quality:**
<https://www.ahrq.gov/cahps/surveys-guidance/index.html>
- **Code Technology:**
codetechnology.com/resource-center/?ref=side_nav
- **Government of United Kingdom:**
gov.uk/guidance/patient-reported-outcomes-and-experiences-study
- **HealthMeasures:**
<https://www.healthmeasures.net/index.php>
- **International Consortium for Health Outcomes Measurement:**
ichom.org/
- **Canadian Institute for Health Information:**
<https://www.cihi.ca/en/patient-reported-outcome-measures-proms>
- **National Health Service Digital:**
digital.nhs.uk/data-and-information/data-tools-and-services/data-services/patient-reported-outcome-measures-proms
- **National Institutes of Health:**
commonfund.nih.gov/promis/websites
- **Organisation for Economic Co-operation and Development:**
<https://www.oecd.org/health/paris/>
- **Patient Reported Outcomes Measurement Information System – Canada:**
mcgill.ca/can-pro-network/promis-canada
- **Remecare:**
remecare.eu/blog/everything-you-need-to-know-about-proms-and-prems
- **SKEZI:**
<https://skezi.eu/donnees-recueillies>

DOCUMENTS*

- [ICIS-Information Document on PROMs](#)
- [KCE-Use of patient-reported outcome and experience measures in patient care and policy](#)
- [Measures of rheumatoid arthritis disease activity](#)
- [National and cross-national surveys of patient experiences](#)
- [OECD-Patients-reported indicators for assessing health system performance](#)
- [User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice](#)

*Non-exhaustive lists

EXAMPLES OF RESOURCES

PROMs

Exemples of **generic** tools for measuring PROMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References	
Mental wellbeing	WHO Well-being Index (WHO-5)	Mood Relaxation Energy Daily life Sleep	5	Lara-Cabrera et al. (2022) [1] https://www.psykiatri-regionh.dk/who-5/Documents/WHO5_French.pdf	
Overall health status	PROMIS Global Health (PROMIS-10)	Physical Health	10	Bevans et al. (2014) [2] https://orthotoolkit.com/promis-10/	
		Mental Health			<ul style="list-style-type: none"> • Functioning • Pain (intensity) • Pain (interference) • Fatigue • Sleep
		Social Health			<ul style="list-style-type: none"> • Depression • Anxiety • Anger • Cognitive function • Alcohol • Psychosocial disorders • Self-efficacy • Smoking
Quality of life	36 item Short Form Survey (SF-36)	Physical Health	36	Ware (2000) [3] https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/survey-instrument.html	
		Mental Health			<ul style="list-style-type: none"> • Social functioning • Satisfaction • Social support • Social isolation • Support
	12 item Short Form Survey (SF-12)	Physical Health			<ul style="list-style-type: none"> • Functioning • Physical role • Pain • General health
		Mental Health	<ul style="list-style-type: none"> • Vitality • Functioning • Emotional role • Mental health 		
		Physical Health	12	Ware et al. (1996) [4] https://www.qualitymetric.com/health-surveys/the-sf-12v2-pro-health-survey/	
		Mental Health			<ul style="list-style-type: none"> • Functioning • Physical role • Pain • General health
		Mental Health	<ul style="list-style-type: none"> • Vitality • Functioning • Emotional role • Mental health 		

EXAMPLES OF RESOURCES

PROMs

Examples of **generic** tools for measuring PROMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References
Health-related quality of life	EuroQoL (EQ-5D-5L)	<ul style="list-style-type: none"> • Mobility • Self-care • Activities of Daily Living • Pain/Comfort • Anxiety/Depression 	5	<p>Feng et al. (2021) [5] https://euroqol.org/eq-5d-instruments/sample-demo/</p>
	AQoL-8D	<ul style="list-style-type: none"> • Autonomy • Happiness • Mental health • Adaptation • Relationships • Self-esteem • Pain • Sense 	35	<p>Hoi yau Chan et al. (2022) [6] http://www.aqol.com.au/documents/AQoL-8D/AQoL-8D_simplified_Data_Collection_v12.pdf</p>
	Health Utilities Index (HUI3)	<ul style="list-style-type: none"> • Vision • Hearing • Language • Mobility • Dexterity • Emotion • Cognition 	8	<p>Horsman et al. (2003) [7] http://www.healthutilities.com/</p>
	15 Dimension (15D)	<ul style="list-style-type: none"> • Mobility • Vision • Hearing • Breathing • Sleep • Eating • Language • Elimination 	<ul style="list-style-type: none"> • Usual activities • Cognition • Discomfort • Symptoms • Depression • Distress • Vitality • Sexuality 	15

EXAMPLES OF RESOURCES

PROMs

Examples of **specific** tools for measuring PROMs

Measured Concept	Nom de l'outil	Domain(s)	Nb items	Références
Diabetes				
Impact of diabetes on daily social and emotional functioning	Diabetes Health Profile (DHP-18)	<ul style="list-style-type: none"> Psychological distress Barriers to activities Uninhibited eating 	18	<p>Tan et al. (2016) [9] https://innovation.ox.ac.uk/wp-content/uploads/2014/09/DHP-18_English_UK_SAMPLE-2019.pdf</p>
Pain				
Acceptance of pain	Chronic Pain Acceptance Questionnaire (CPAQ-8)	<ul style="list-style-type: none"> Participation in activities Willingness to fight pain 	8	<p>Rovner et al. (2014) [10] https://www.researchgate.net/publication/330181601_Chronic_Pain_Acceptance_Questionnaire_8_CPAQ-8</p>
Attitude towards pain	Pain Catastrophizing Scale (PCS)	<ul style="list-style-type: none"> Rumination Impotence Amplification 	13	<p>Sullivan et al. (1995) [11] https://www.oregon.gov/oha/HPA/dsi-pmc/PainCareToolbox/Pain%20Catastrophizing%20Scale.pdf</p>
Pain severity and functional impact	Brief Pain Inventory – Short Form (BPI-SF)	<ul style="list-style-type: none"> Pain (intensity) Pain (interference) 	9	<p>Andres et al. (2015) [12] http://www.npcrc.org/files/news/briefpain_short.pdf</p>

EXAMPLES OF RESOURCES

PROMs

Examples of **specific** tools for measuring PROMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References
Orthopedics				
Amplitude of movement of the knee	Copenhagen Knee ROM Scale	<ul style="list-style-type: none"> Flexion Extension 	2	<p>Mørup-Petersen et al. (2018) [13]</p> <p>https://www.procordo.com/docs/copenhagen_rom/Copenhagen%20Knee%20ROM%20Scale%20(English).pdf</p>
Knee injury and treatment results	Knee Injury and Osteoarthritis Outcome Score (KOOS)	<ul style="list-style-type: none"> Symptoms Pain Rigidity Function (daily) Function (sports) Quality of life 	42	<p>Roos et al. (1998) [14]</p> <p>Free Online KOOS Score Calculator - OrthoToolKit</p>
Respiratory Problems				
Quality of life of people living with asthma	Asthma Quality of Life Questionnaire (AQLQ)	<ul style="list-style-type: none"> Symptoms Physical Limitations Emotional functioning Environmental exposure 	32	<p>Aburuz et al. (2007) [15]</p> <p>http://www.qoltech.co.uk/aqlq.html</p>
Neurological disorders				
Quality of life of people living with Alzheimer's	Dementia Quality of Life Instrument (DEMQOL)	<ul style="list-style-type: none"> Health and well-being Cognitive Functioning Daily activities Social relationships Self-image 	29	<p>Hendriks et al. (2017) [16]</p> <p>https://www.bsms.ac.uk/_pdf/cds/demqol-questionnaire.pdf</p>

EXAMPLES OF RESOURCES

PREMs

Examples of **generic** tools for measuring PREMs

Measured Concept	Tool Name	Domains)	Nb Items	References
Experience of care	Consumer Quality Index In patient Hospital Care Questionnaire (CQ-Index)	<ul style="list-style-type: none"> • Admission • Communication(s) • Involvement • Explanation of treatment • Pain management • Safety • Return home 	50	<p>Smirnova et al. (2017) [17] https://www.infinicare.com/en/cq-index/#:~:text=The%20Consumer%20Quality%20Index%20(CQ,the%20care%20they%20have%20received.</p>
	Canadian Patient Experiences Survey – Inpatient Care (CPES-IC)	<ul style="list-style-type: none"> • Admission • Communication(s) • Decision-making involvement • Respect for preferences • Coordination of care • Hospital discharge • Overall experience 	49	<p>Hadibhai et al. (2018) [18] https://www.cihi.ca/sites/default/files/document/patient_expsurvey_inpatient_en.pdf</p>
	HowRwe	<ul style="list-style-type: none"> • Compassion • Communication • Accessibility • Organization 	4	<p>Benson et al. (2014) [19] https://r-outcomes.com/patient/patient-experience/</p>

Experience in communicating with hospital staff

Health Care Communication Questionnaire (HCCQ)

- Problem solving
- Respect
- Lack of hostility
- Non-verbal

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Gremigni et al. (2008) [20]

https://www.researchgate.net/publication/264195085_HC_CQ-English

EXAMPLES OF RESOURCES

PREMs

Examples of **generic** tools for measuring PREMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References
Ambulatory care experience	Consumer Assessment of Healthcare Providers and Systems – Clinician and Group Survey (CG-CAHPS)	<ul style="list-style-type: none"> • Access to care • Communication with the doctor • Courteous and helpful staff • Physician's assessment • Physician's recommendation 	28	<p>Dyer et al. (2012) [21]</p> <p>https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/survey-guidance/cg/adult-english-cg-3-1-2351a.pdf</p>
Care safety experience	Patient Reported Experiences and Outcomes of Safety in Primary Care (PREOS-PC)	<ul style="list-style-type: none"> • Measures implemented • Experience • Harms • General perception 	58	<p>Ricci-Cabello et al. (2016) [22]</p> <p>https://innovation.ox.ac.uk/wp-content/uploads/2018/07/PREOS-PC-27-item-version-SAMPLE.pdf</p>
Experience of healthcare accessibility	GP Patient Survey (GPPS)	<ul style="list-style-type: none"> • Health Center • Call results • Consulting a physician • Waiting Time • Physician Preference • Hours of operation • Consultation(s) • Care Planning • Overall satisfaction 	51	<p>Campbell et al. (2009) [23]</p> <p>https://moderngov.southwark.gov.uk/documents/s43536/GP%20Patient%20Survey%20questionnaire%20example.pdf</p>

EXAMPLES OF RESOURCES

PREMs

Examples of **specific** tools for measuring PREMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References
Patient engagement				
Patient engagement experience	Patient Participation Questionnaire	<ul style="list-style-type: none"> Participation Information Communication Relation with the staff 	18	<p>Berg et al. (2020) [24] https://www.semanticscholar.org/paper/Questionnaire-measuring-patient-participation-in-Berg-F%C3%A6rçh/544bba1320c4183dd3b4d37e29ab93a40f53d156/figure/0</p>
Care coordination				
Experience coordinating patient-centred care	Person-Centred Coordinated Care Experience Questionnaire (P3CEQ)	<ul style="list-style-type: none"> Information and communication process Care planning Transitions Objectives and results Decision making 	10	<p>Lloyd et al. (2019) [25] https://www.p3c.org/resources</p>
Shared decision making				
Experience using shared decision making	CollaborATE	<ul style="list-style-type: none"> Explanation Solicitation of preferences Integration of preferences 	3	<p>Ubbink et al. (2022) [26] http://www.glynelwyn.com/uploads/2/4/0/4/24040341/collaborate_for%C2%A0patients_v6.pdf</p>
	SDM-Q-9	<ul style="list-style-type: none"> Recognition that a decision must be made Preference(s) Options Advantages/disadvantages Explanations Discussion of options Collaborative choice Common agreement 	9	<p>Kriston et al. (2010) [27] http://www.patient-als-partner.de/media/sdm-q-9_french_version.pdf</p>

EXAMPLES OF RESOURCES

PREMs

Examples of **specific** tools for measuring PREMs

Measured Concept	Tool Name	Domain(s)	Nb Items	References
Mental Health				
Experiences of perceived treatment outcome, quality of interaction with clinician, and information provided	Psychiatric Out-Patient Experiences Questionnaire (POPEQ)	<ul style="list-style-type: none"> Perceived outcome of treatment Quality of the interaction with the clinician Quality of information provision 	11	<p>Olsen et al. (2010) [28]</p> <p>https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-10-282#Sec10</p>
Oncology Care				
Oncology care experience	CAHPS Cancer Care Survey	<ul style="list-style-type: none"> Timely Care Supporting self-management Availability Communication Coordination of care Courteous staff. 	56	<p>Evensen et al. (2019) [29]</p> <p>https://www.aahr.gov/cahps/surveys-guidance/cancer/index.html</p>
Primary Care				
Primary care experience	Primary Care Patient Experience Survey	<ul style="list-style-type: none"> Communications Accessibility Care team Treatment plan and priorities of care Mobility Self-care Daily activities Pain/Discomfort Anxiety/Depression Overall satisfaction 	53	<p>Health Quality Council of Alberta [30]</p> <p>https://hqca.ca/wp-content/uploads/2019/03/Dr.-Sample-Physician-Report-Final-JB.pdf</p>
Experience providing patient-centered care	Patient-Centred Primary Care Measure (PCPCM)	<ul style="list-style-type: none"> Accessibility Advocacy Community Context Continuity Coordination Family Context Goal Oriented Care Health Promotion Integration and relationships Comprehensive Care 	11	<p>Tse et al. (2021) [31]</p> <p>https://static1.squarespace.com/static/5d7ff8184cf0e01e4566cb02/t/608ab2859602525676ee51e2/1619702406481/PCPCM-French2021.pdf</p>

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Recommendations

The PaRIS-Québec study team conducted an environmental scan of Quebec organizations representing healthcare professionals and patients. This scan provided a current picture of the integration of self-reported indicators by patients regarding their health status (PROMs) and care experience (PREMs).

Based on the results of this study, we propose recommendations that will facilitate reflection and the implementation of action strategies to promote the inclusion of PROMs and PREMs in clinical settings.

Clinical settings



- Provide compatible technological tools to collect and analyze PROMs and PREMs while making them accessible to professional staff and patients.
- Provide continuous professional development on the usefulness and best practices of PROMs and PREMs, the validated tools available to collect them and how to interpret these data.

Professional organizations



- Provide continuous professional development on the best practices for PROMs and PREMs, the validated tools available to collect them and how to interpret these data.
- Promote the importance of using PROMs and PREMs appropriately.
- Relay to members the information related to PROMs and PREMs.

Patient organizations



- Promote the importance of using PROMs and PREMs appropriately.
- Legitimize the time required to complete a questionnaire.

Academic organizations



- Teach the concept and best practices for PROMs and PREMs.
- Raise awareness in the student community of the usefulness of PROMs and PREMs in clinical practice.
- Provide learning opportunities to integrate PROMs and PREMs (practical work, use in the electronic medical record, etc.).

Awareness of the relevance of integrating PROMs and PREMs must be raised among all key players in the health system to enhance practices and provide person-centred care.

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