



# PROM toolbox

The **Patient Reported Outcome Measure (PROM)** toolbox holds the following tools:

- The **PROM-guide**
- The literature review on the use of PROMs
- The **PROM-cycle**
- The **Linnean menu**
- The **PROM-links**
- The making of the **PROM-overview & PROM-select app**
- The **PROM-overview**
- The **PROM-select app**
- The **PROM-select app usability test report**
- The **PROM toolbox presentation (HTx Expert Forum meeting 25-11-2021)**

The **PROM toolbox** consists of the **PROM-guide**, step 3 accompanied by **The literature review on the use of PROMs**, and the **PROM-cycle**. of which step 2 and 3 are supplemented with generic PROMs in **the Linnean menu**. The **PROM-links** tool provides links to useful websites. In addition, the **PROM-overview** is an Excel database containing PROMs accompanied by relevant information made available via a user-friendly web-application helping users to select PROMs: **The PROM-select app**. **The making of the PROM-overview & PROM-select app** is a report describing their development.

The **PROM-guide** deals with orientation and preparation for the use of PROMs. Step 3 is about how and when PROMs work and is accompanied by **The literature review on the use of PROMs: Current knowledge and scientific evidence for the use of Patient-Reported Outcome Measures; an overview of the ‘mechanisms of action’ or expectations about ‘how it works’**.

The assessment framework **the PROM-cycle**<sup>4</sup> is about the selection and application of PROMs. **The Linnean menu** is a supplement to **the PROM-cycle**<sup>4</sup> and aligns to steps 2 and 3, the process of selecting PROs and PROMs.

The **PROM-links** tool provides links to useful websites.

**The making of the PROM-overview & PROM-select app** describes the development of the Excel database containing Patient or Person-Reported Outcome Measures (PROMs) recently used in the EU in i.e. in the fields of our HTx case studies: Head and Neck Cancer, Diabetes Mellitus, Multiple Sclerosis, MyeloDysplastic Syndrome, (Long lasting) COVID and in general. The **PROM-overview** is made available via a user-friendly web-application helping users to select PROMs: **The PROM-select app**: <https://www.prom-select.eu>.

Dr. Elise H. Quik  
The National Health Care Institute  
Willem Dudokhof 1  
1112 ZA Diemen  
The Netherlands  
Contact: [EQuik@zinl.nl](mailto:EQuik@zinl.nl)

**PROM toolbox**: [PROM-toolbox](#); [PROM-wijzer en PROM-cyclus](#) | [Zorginzicht](#)  
HTx project: [www.htx-h2020.eu](http://www.htx-h2020.eu); [HTx Project](#) | [Publications \(htx-h2020.eu\)](#)



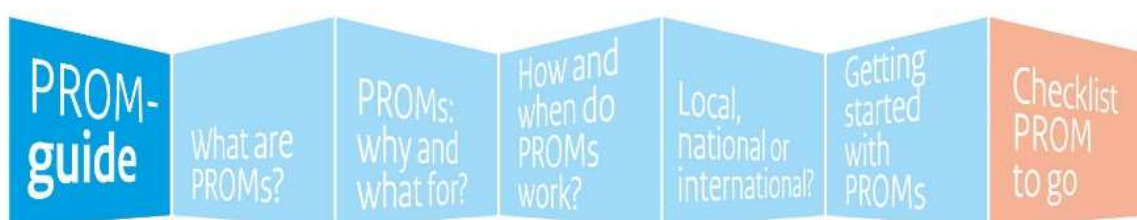
# Content

<b>1 What is the PROM-guide?</b>	<b>3</b>
<b>2 What is the PROM-cycle?</b>	<b>4</b>
<b>3 What is the PROM-Overview?</b>	<b>5</b>
<b>4 What is the PROM-select app?</b>	<b>5</b>
<b>5 PROM toolbox Glossary</b>	<b>6</b>
<b>6 Documents</b>	<b>7</b>
<b>7 Funding statement</b>	<b>7</b>



# 1 What is the PROM-guide?

The **PROM-guide** is part of the **PROM toolbox** and deals with orientation and preparation for the use of PROMs. In terms of sequencing, the **PROM-guide** therefore comes before the **PROM-cycle**, which is intended for the selection and application of PROMs in healthcare.



## PROM-guide

- 1. What are PROMs?
- 2. PROMs: why and what for?
- 3. How and when do PROMs work?

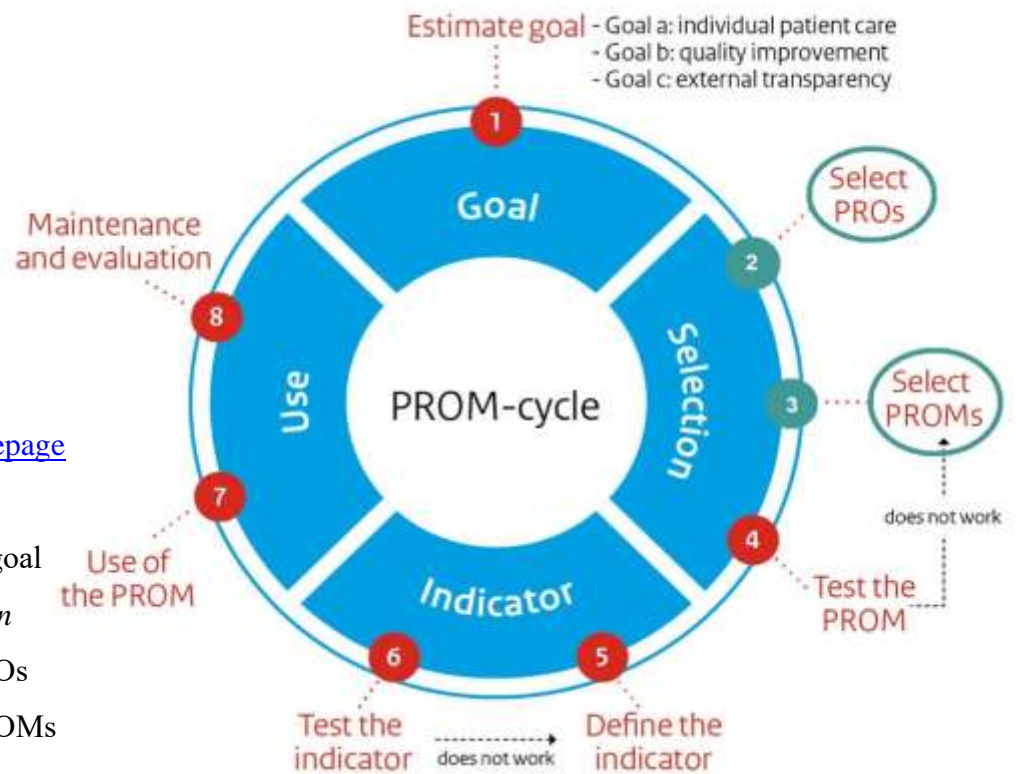
Parties that start working with PROMs would be wise to clarify how they want the PROMs to contribute to the quality of care and quality of life. We provide an overview of the ‘mechanisms of action’ or expectations about ‘how it works’ described in **The literature review on the use of PROMs: Current knowledge and scientific evidence for the use of Patient-Reported Outcome Measures. The literature review on the use of PROMs** contains ways in which PROMs can contribute to better individual patient care, internal quality improvement and quality improvement through external quality information (accountability or transparency).

- 4. Local, national or international?
- 5. Getting started with PROMs
- 6. Checklist PROM to go



## 2 What is the PROM-cycle?

The **PROM-cycle** is part of the **PROM toolbox** and deals with the selection and application of PROMs in healthcare. In terms of sequencing, the **PROM-cycle** therefore comes after the **PROM-guide**, which is intended for the orientation and preparation for the use of PROMs.



[PROM-cycle homepage](#)

*# Phase 1: Goal*

- Step 1: Estimate goal

*# Phase 2: Selection*

- Step 2: Select PROs
- Step 3: Select PROMs

The Linnean Initiative developed **The Linnean menu** of generic PROMs. The menu is advisory in nature and contains a list of outcomes that are relevant to many patients with different conditions (PROs). For each of these PROs some outcome measurement instruments (generic PROMs) are offered in order to help people to select PROs and PROMs and support the use of PROMs in the consulting room and in health care.

- Step 4: Test the PROM

*# Phase 3: Indicator*

- Step 5: Define the indicator
- Step 6: Test the indicator

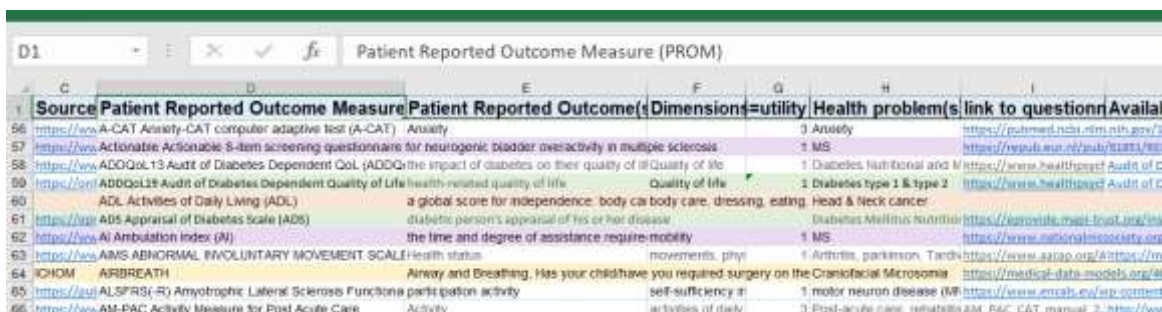
*# Phase 4: Use*

- Step 7: Use of the PROM
- Step 8: Maintenance and evaluation



### 3 What is the PROM-Overview?

Sometimes there is not much time and/or resources to check if a certain PROM is rather well suited for the target group and meets the requirements. Then a systematic literature search for relevant PROMs may take too much time. In order to help you save time, we made an overview of PROMs, their relevant scientific literature and other sources where you may find relevant information about those PROMs.



	Source	Patient Reported Outcome Measure	Patient Reported Outcome	Dimensions	utility	Health problem(s)	link to question	Available
56	<a href="https://www.a-cat.com">https://www.a-cat.com</a>	A-CAT Anxiety-CAT computer adaptive test (A-CAT)	Anxiety		3	Anxiety	<a href="https://pubmed.ncbi.nlm.nih.gov/">https://pubmed.ncbi.nlm.nih.gov/</a>	
57	<a href="https://www.actionableactionable.com">https://www.actionableactionable.com</a>	Actionable Actionable 8-item screening questionnaire for neurogenic bladder overactivity in multiple sclerosis			1	MS	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/</a>	
58	<a href="https://www.addqol.com">https://www.addqol.com</a>	ADDQoL 13 Audit of Diabetes Dependent CoL (ADDQoL) the impact of diabetes on their quality of life	Quality of life		1	Diabetes, Nutritional and I	<a href="https://www.healthtrust.org.uk/">https://www.healthtrust.org.uk/</a>	
59	<a href="https://www.addqol.com">https://www.addqol.com</a>	ADDQoL13 Audit of Diabetes Dependent Quality of Life	health-related quality of life	Quality of life	1	Diabetes type 1 & type 2	<a href="https://www.healthtrust.org.uk/">https://www.healthtrust.org.uk/</a>	
60		ADL Activities of Daily Living (ADL)	a global score for independence: body care, body care, dressing, eating			Head & Neck cancer		
61	<a href="https://www.ad5.com">https://www.ad5.com</a>	AD5 Appraisal of Diabetes Scale (AD5)	diabetic person's appraisal of his or her disease			Diabetes Mellitus Nutrition	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/</a>	
62	<a href="https://www.ai-ambulation.com">https://www.ai-ambulation.com</a>	Ai Ambulation Index (Ai)	the time and degree of assistance require	mobility	1	MS	<a href="https://www.nationalmsociety.org/">https://www.nationalmsociety.org/</a>	
63	<a href="https://www.aims-abnormal.com">https://www.aims-abnormal.com</a>	AIMS ABNORMAL INVOLUNTARY MOVEMENT SCALE	health status	movements, phys	1	Arthritis, parkinson, Tardiv	<a href="https://www.aapap.org/">https://www.aapap.org/</a>	
64		AIBREATH	Airway and Breathing. Has your child	have you required surgery on the		Craniofacial Microsomia	<a href="https://medical-data-models.org/">https://medical-data-models.org/</a>	
65	<a href="https://www.alsfrs.com">https://www.alsfrs.com</a>	ALSFRS (R) Amyotrophic Lateral Sclerosis Functional	patient activity	self-sufficiency of	1	motor neuron disease (M	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/</a>	
66	<a href="https://www.am-pac.com">https://www.am-pac.com</a>	AM-PAC Activity Measure for Post Acute Care	Activity	activities of daily	3	Post-acute care, rehabilitation, PAC, CAT, manual 2	<a href="https://www.am-pac.com/">https://www.am-pac.com/</a>	

The **PROM-overview** is an Excel database containing Patient-Reported Outcome Measures (PROMs) recently used in the EU in i.e. in the fields of our HTx case studies: Head and Neck Cancer, Diabetes Mellitus, Multiple Sclerosis, MyeloDysplastic Syndrome, (Long lasting) COVID and in general. This **PROM-overview** is made available in this user-friendly web-application helping users to select PROMs: this **PROM-select app**.

### 4 What is the PROM-select app?

First check out our **PROM-guide** for more basic information on PRO's and PROM's. Next, we provide an overview of the eight steps (divided into four phases) that should be completed in the selection and implementation of PROMs in healthcare. These phases and steps described in detail in the **PROM-cycle**.

Then, using this **PROM-select app** you may choose your selected PRO you want to measure and relevant health problem or patient group/population. When selected a PRO and health problem you'll get a list of relevant PROMs.

When clicking on a PROM, you will find an overview of relevant information about the PROM and links to more information.

If you are interested in more information about PROMs and how the **PROM-overview** and the **PROM-select app** came to be, then you can read more about it in: **the making of the PROM-overview & PROM-select app**.

The **PROM-links** tool provides links to useful websites.



## 5 PROM toolbox Glossary

Glossary of terms commonly used in the **PROM toolbox**.

### Implementation

Planned implementation of changes with the aim of ensuring that they are given a structural place in the course of action.

### Indicator

An indication of any differences in quality of care. Results of PROMs can be converted into an indicator.

### Item bank

A set of questions that all measure the same concept (e.g. depression, fatigue, pain, emotional support, etc.). These questions can be used to measure physical, mental and social aspects of health and well-being.

### PRO

Patient-reported outcome or Person-reported outcome. A patient-reported aspect of perceived health. PROs reflect the person's opinion and assessment of their health.

### PROM

Patient-reported outcome measure or person-reported outcome measure. A questionnaire that measures PROs and that allows the patient (or their next of kin) to assess their health status.

### PROM-guide

Orientation and preparation for measuring patient-reported outcomes with Patient-Reported Outcome Measures

### PROM-cycle

Selection and application of Patient-Reported Outcomes and Measures

### PROMIS®

Patient-reported outcomes measurement information system. This is a computer system that uses adaptive testing. This will guide respondents through a set of PROM questions in a faster and smarter way. The aim is to obtain precise measurements of the most relevant PROs with as few questions as possible. Based on the answer to a question (can you get in and out of bed?), the computer determines the next question (is it easy or difficult for you to run 5 km?) PROMIS consists of a dynamic system of item banks and was originally developed in the United States.

### The Linnean menu

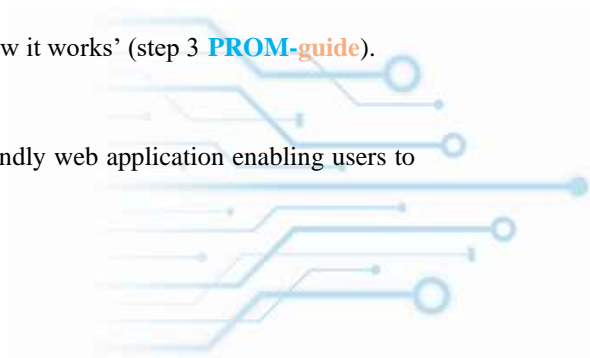
A supplement to the **PROM toolbox** and aligns to steps 2 and 3 of the **PROM-cycle**.

**The literature review on the use of PROMs** Current knowledge and scientific evidence for the use of Patient-Reported Outcome Measures

An overview of the 'mechanisms of action' or expectations about 'how it works' (step 3 **PROM-guide**).

### The **PROM-select** app

the **PROM-overview** Excel database, made available via a user-friendly web application enabling users to select PROMs.



## 6 Documents

- The **PROM-guide**
- The literature review on the use of PROMs
- The **PROM-cycle**
- The **Linnean menu**
- The **PROM-links**
- The making of the **PROM-overview & PROM-select app**
- The **PROM-overview**
- The **PROM-select app**
- The **PROM-select app usability test report (coming soon)**
- The **PROM toolbox presentation (HTx Expert Forum meeting 25-11-2021, coming soon)**

## 7 Funding statement

HTx is a Horizon 2020 project supported by the European Union lasting for 5 years from January 2019. The main aim of HTx is to create a framework for the Next Generation Health Technology Assessment (HTA) to support patient-centered, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

The HTx project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 825162.

