

**Project Title: Next Generation Health Technology Assessment
to support patient-centred, societally oriented, real-time
decision-making on access and reimbursement for health
technologies throughout Europe**

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Deliverable Title: Web application enabling users to select
PROMs: **The PROM-select app** <https://www.prom-select.eu/>

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DOCUMENT INFORMATION

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Description of the deliverable	Web application to select PROMS Task 4.3.1 Preparing a user-friendly PROMs overview (Lead Partner: ZIN) (M1-48): The PROM-select app , https://www.prom-select.eu
Key words	Patient Reported Outcome (PRO) Measures (PROMs)

DOCUMENT HISTORY

NAME	DATE	VERSION	DESCRIPTION
Elise Quik	29-11-2021	1.0	First draft
SC Members	21-12-2021	2.0	Comments
Elise Quik	10-01-2022	3.0	Final Document

EXECUTIVE SUMMARY

Task 4.3.1 Preparing a user-friendly PROMs overview

(Lead Partner: ZIN; Collaborating partner: UU) (M1-48)

The basis for the selection of Patient/Person Reported Outcome (PRO) Measures (PROMs) is the scoping review on patient involvement in PROM development, conducted by Wiering et al, 2017¹. This selection of 193 PROMs was complemented with PROMs in ICHOM-sets and PROMs that are relevant for the case studies in WP1 and (long lasting) COVID.

ZIN started by constructing a framework for the assessment of PROMs, derived from the guidance provided by Cella et al., 2012² and other relevant publications, see **PROM toolbox**³. This initial framework, **the PROM-cycle**⁴, was discussed with relevant partners in the project and tested for a subset of PROMs by the Linnean Initiative. This resulted in a final version of the assessment framework, **the PROM-cycle**⁴. This was framework was used for the development of **the PROM-overview**, which resulted in a web-based PROMS interface; **The PROM-select app** (Deliverable 4.6).

PubMed, EMBASE, MEDLINE, the Cochrane Methodology Register and many other scientific literature sources were searched for publications describing the development of the selected PROMs, and their methodological and statistical properties. In addition, the literature search focused on selecting examples of different forms of use of the selected PROMs. Because of the large amount of publications in which the selected PROMs are used, this search was limited, e.g. to recent years and/or to EU countries. In the following phase, the relevant information was extracted from the selected publications and analysed using the assessment framework; **the PROM-cycle**⁴. The assessment framework was used as the basis for the description of the characteristics of the selected PROMs. This resulted in **the PROM-overview** Excel database, made available via a user-friendly web application enabling users to select PROMs; **The PROM-select app**, <https://www.prom-select.eu/>. This web application; **The PROM-select app**⁴, will be maintained and updated annually by ZIN during the HTx project. Depending on the demand for this service, ZIN is willing to maintain and update the application also after the end of this project.



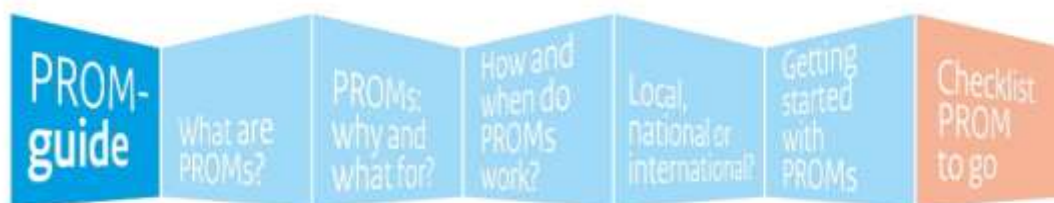
INTRODUCTION

The chosen health technology for diagnosis or treatment should be appropriate for the patient as a person with his/ her individual values, needs and preferences. Therefore, in order to make healthcare provision more patient/centred, it is important to take these preferences and values into account when appraising health technologies and in clinical decision-making.

Patient-centricity in appraising health technologies.

In order to increase the value of healthcare, the effectiveness of interventions should be assessed by analysing or comparing outcomes that matter most to patients. Patient/Person Reported Outcome Measures (PROMs) have been developed to capture outcomes from the perspective of patients, including outcomes that can only be reported by patients themselves (e.g. pain or fatigue). However, that does not necessarily mean that PROMs measure outcomes that are relevant for patients. Clinicians, patient organizations and researchers need better guidance about how to develop and select generic and/or more specific outcome measures that are relevant to patients. In addition, guidance is needed to help clinicians, patients and researchers choose PROMs that are fit-for-purpose.

A Patient/Person-Reported Outcome (PRO) is a patient-reported aspect of perceived health. PROs reflect the patient's opinion and self-assessment of their health. A PROM is a questionnaire that measures PROs. PROMs have been developed to capture outcomes that can only be reported by patients themselves, or their next of kin, such as pain, quality of life or fatigue. More information can be found in the [PROM-guide](#)⁵.



IMPLEMENTATION

The basis for the selection of PROMs was the scoping review on patient involvement in PROM development, conducted by Wiering et al., 2017¹. This selection of 193 PROMs was complemented with PROMs in ICHOM-sets and PROMs that are relevant for the case studies in WP1 and in addition (long lasting) COVID.

ZIN started by constructing a framework for the assessment of PROMs, derived from the guidance provided by Cella et al, 2012² and other relevant publications (see [PROM toolbox](#)³). This initial framework was discussed with e.g. ZiN (OWIZ, value based healthcare), OECD/ParIS, ICHOM, the Linnean initiative, Sandra Beurskens of “meetinstrumenten in de zorg”, KEMTA of the MUMC, KLIK/VUmc, many others and relevant partners in the HTx project and tested for a subset of PROMs ([The Linnean menu](#)⁶). This resulted in a final version of the assessment framework: [the PROM-cycle](#)⁴.

COSMIN Database of systematic reviews of outcome measurement instruments, PubMed, Google, Google scholar, Bing were searched for reviews and publications describing the development of PROMs, and their methodological and statistical properties, recent articles and HTA related articles. In addition, a literature search focussed on selecting examples of different forms of use of the selected PROMs was performed.

Because of the expected large amount of publications in which the selected PROMs are used, the searches were limited to recent years and preferably use of PROMs within the EU countries.

In the following phase, the relevant links to the selected publications was pasted in **the PROM-overview**. Articles were selected by using the assessment framework: **the PROM-cycle**⁴. In addition, the assessment framework **the PROM-cycle**⁴ was used as the basis for the description of the characteristics of the selected PROMs. This resulted in **the PROM-overview** Excel file.



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. **The PROM-overview** is made available via.

To implement our **PROM-overview** data, a web application was built to implement the novel methods, apply them to real-world practice, evaluate their performance and transfer to other settings. This user-friendly web application will enable users to select PROMs by choosing between different patient reported health outcomes in combination with health problem/disease/patient population. Then a list of PROMs will be optional to choose from and when clicking on a PROM in the list, properties available in **the PROM-overview** Excel sheet will be given in a user-friendly way. This web application will function as a user-friendly interface between user and **PROM-overview** Excel sheet(s), making the data even patient friendly next to clinician, researcher/other user-friendly. This for usability tested, user-friendly web-application helping users to select PROMs is deliverable 4.6 and called **the PROM-select app**.

This web application, **the PROM-select app** will be maintained and updated annually by ZIN during the HTx project. Depending on the demand for this service, ZIN is willing to maintain and update the application also after the end of our HTx project.

The PROM-select app (D4.6) is available at:

<https://www.prom-select.eu>

RESULTS

The **PROM** toolbox holds the following tools:

- Annex 1: the PROM toolbox homepage
- Annex 2: the **PROM-guide**
- Annex 3: The literature review on the use of PROMs
- Annex 4: The **PROM-cycle**
- Annex 5: **The Linnean menu**
- The **PROM-links**
- Annex 6: The making of the **PROM-overview** & **PROM-select app**
- Annex 7: The **PROM-overview**
- Annex 8 and 9: The **PROM-select app**
- Annex 10: The **PROM-select app usability test report**
- Annex 11: The **PROM** toolbox presentation (HTx Expert Forum meeting 25-11)

The **PROM** toolbox consists of the **PROM-guide**, step 3 accompanied by **The literature review on the use of PROMs**, and the **PROM-cycle**⁴. 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 **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**⁴ is about the selection and application of PROMs. **The Linnean menu** is a supplement to **the PROM-cycle**⁴ 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 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>.



CONCLUSIONS

The making of the **PROM-overview & PROM-select app** describes the development of a user-friendly web app for selecting PROMs: The **PROM-overview** interface called **the PROM-select app**. All tools and steps we took, such as **the PROM-cycle**⁴ to develop **the PROM-select app** are available in **the PROM toolbox**.

Using **the 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.

REFERENCES

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4. <https://www.zorginzicht.nl/ondersteuning/prom-toolbox-summary-in-english>
5. <https://www.prom-select.eu/>
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7. <https://www.zorginzicht.nl/binaries/content/assets/zorginzicht/algemeen-ondersteuning/generic-proms-menu---advice---linnean.pdf>

ANNEXES

- **Annex 1: the PROM toolbox homepage**
- **Annex 2: the PROM-guide**
- **Annex 3: The literature review on the use of PROMs**
- **Annex 4: The PROM-cycle**
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- **The PROM-links**
- **Annex 6: The making of the PROM-overview & PROM-select app**
- **Annex 7: The PROM-overview**
- **Annex 8 and 9: The PROM-select app**
- **Annex 10: The PROM-select app usability test report**
- **Annex 11: The PROM toolbox presentation (HTx Expert Forum meeting 25-11-2021)**