



# Literature review on the use of PROMs

## Current knowledge and scientific evidence for the use of Patient-Reported Outcome Measures

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

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’.

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Table of contents

1. Introduction..... 3

2. Research method..... 4

    2.1. Literature review..... 4

    2.2. Data synthesis ..... 4

    2.3. PROMs in the Netherlands ..... 5

3. PROMs in the Netherlands: history and context..... 6

4. Effectiveness of PROMs..... 10

5. Factors and mechanisms that influence the use of PROMs ..... 15

6. Synthesis of results as a basis for the interviews and decision tree ..... 20

7. PROMs in the Netherlands ..... 25

8. Discussion and conclusions ..... 26

References..... 28

Appendix 1 Literature review search strategies ..... 30



### 1 Introduction

Patient-reported outcomes (PROs) represent the patient's opinion and evaluation of their own health. Examples of PROs are symptoms, physical functioning and quality of life. The questionnaires to measure these outcomes are called PROMs: Patient Reported Outcome Measures. Most PROMs were originally developed for scientific research, mainly in clinical trials. Nowadays, PROMs are increasingly being used in patient care, e.g. for medical case history and diagnostics, joint decision-making and treatment evaluation. At an aggregate level, PROMs are gaining interest as a way of improving and making quality of care more transparent. Often, the aim is to use the PROM for multiple purposes (in individual patient care, improvement information, public information). However, this is not easy because each goal puts different demands on the type of questionnaire, the measuring method, the logistics process, measuring moments and analysis techniques.

In the Netherlands, many parties measure patient-reported outcomes, with large variations in their application. The National Healthcare Institute (Zorginstituut) considers it important for research to be carried out into the usefulness and relevance of measurements using PROMs. This is to prevent a proliferation of measures, avoid unnecessarily burdening patients, and to collect information that is useful and valid for the intended purposes. With the **PROM-toolbox**, the National Healthcare Institute has published a roadmap for the application of PROMs: the PROM-guide. With a project at more of a policy level, the National Healthcare Institute provided guidance to determine when it is useful or not to utilise PROMs for the different goals. This resulted in a 'decision tree' for the use of PROMs: the PROM-cycle.

The assignment of the National Healthcare Institute was to clarify when it makes sense to use PROMs. This resulted in a framework, the PROM-cycle that can help in making choices to measure PROs, – for which patient groups and for which goal(s). This requires an understanding of the scientific and practical situation regarding the use and effects of PROMs.

Three questions have been formulated for this study:

1. What is the current knowledge about using PROMs for the different goals?
2. What are the experiences of early adopters in making choices for the different goals?
3. How can parties be helped in making choices for the meaningful use of PROMs?

In this document, we studied the first research question by means of scientific literature review. The results of this literature review served as the basis for the interviews on practical experience, and as input for the framework developed: the PROM-cycle. Using the PROM-cycle the Linnean menu for generic PROMs was developed. Next to that, an PROM-overview was compiled with scientific and practical information about recently used PROMs in the EU, based on Wiering et al. (2017). To help you select a PROM we made the information collected for the PROM-overview available via a user-friendly web application: the PROM-select app.



## 2 Research method

### 2.1 Literature review

We conducted a literature review to summarise the current knowledge for making choices to use PROMs for the different goals. In summarising the literature, we distinguish between four different uses of PROMs:

- in individual patient care: use in the consulting room for screening/diagnostics, joint decision-making on treatment goals, use during multidisciplinary consultation, monitoring of health outcomes, and evaluation of the care/treatment plan;
- for quality improvement at organisational, locational, departmental and team levels
- for public information / transparency (accountability/selection information).
- in scientific research and as policy information.

The literature review focused on reviews/survey studies of the international literature on PROMs. We used two recent reports as a basis for our literature review. The first report was issued by the Organisation for Economic Cooperation and Development (OECD) on the application of PROMs in an international perspective (OECD 2017). The report describes 13 systematic reviews, of which 12 are quantitative reviews and one is a qualitative review. The second report is a realist review by Greenhalgh and colleagues (2017). They describe the meaningful application of PROMs by means of various operating mechanisms, and the context that affects the success of the mechanisms intended by PROMs. Contextual factors such as history and (financial) incentives may cause the use of PROMs in certain situations to lead to the intended use or intended improvement, and not in other situations.

Next, we updated these survey studies in PubMed. We (partly) used the search strategies of the OECD (2017) and Greenhalgh (2017) to identify and add new studies to the literature review from 2016 up to the present. The search strategy has been attached (see Appendix 1).

The search yielded n=15 reviews and n=29 individual studies, of which 8 and 4 were relevant, respectively. As a final step, we looked at reference lists of the studies that have been included and have supplemented these on the basis of our own knowledge and expertise. In this step, we added four more studies to the literature review.

### 2.2 Data synthesis

First of all, we summarised the quantitative studies on the effectiveness of the application of PROMs in individual patient care and at group level for quality improvement and external transparency. We have made a customised version of the OECD summary table for this purpose, and have briefly described the individual reviews.



Then we summarised the qualitative and reflective exploratory literature, mainly based on Greenhalgh's 'realist review'. We schematically mapped out the contextual factors and operating mechanisms for the application of PROMs.

Finally, we focused on what this means in terms of the choices, dilemmas and factors relevant to the use of PROMs for the different purposes and target groups. We have created a matrix for the use of PROMs for the various purposes in four types of disorders/care: elective interventions (such as hip and knee replacement, cataract surgery), acute disorders/care (such as heart attack or acute injuries), chronic disorders/care (such as diabetes or chronic obstructive pulmonary disease) and oncological disorders/care.

Because the context in which PROMs are used is important, findings from international literature do not need to apply exactly to the Dutch situation. The Dutch context may be different from the one described in the studies. For a good understanding of the Dutch situation, we first describe the Dutch history and context in the results.

### 2.3 PROMs in the Netherlands

In addition to the literature survey, we carried out an inventory of the application of PROMs in the Netherlands, initiated by national and regional parties. We used a previous overview that was prepared by the National Health Care Institute in 2016 and have supplemented this. We specifically looked at the conditions on the Transparency Calendar<sup>1</sup>, and screened websites of scientific associations, DICA, Zorginzicht and patient associations. This resulted in an overview of PROMs applications in the Netherlands.

### 2.4 PROMs in the European Union

For the H2020 HTx project we worked on an overview of PROMs recently used in the EU.

The main aim of the H2020 HTx project<sup>2</sup> is to create a framework for the Next Generation Health Technology Assessment (HTx) to support patient-centered, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

In the **PROM-toolbox** document: **The making of the PROM-overview & PROM-select app** you can find more info about PROMs in the EU.

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<sup>1</sup> <https://www.zorginzicht.nl/bibliotheek/Paginas/Transparantiekalender.aspx>

<sup>2</sup> [HTx Project | Next Generation Health Technology Assessment \(htx-h2020.eu\)](https://www.htx-h2020.eu/)



### 3 PROMs in the Netherlands: history and context

As in many other countries, PROMs have been used in scientific research for a long time in the Netherlands and the use for other purposes has increased in the last ten years. The applications for use in individual care, for internal quality improvement and for external transparency run more or less parallel. The policy is strongly focused on the potential integration of the different purposes to ensure that the application of PROMs is meaningful in individual care, but can also be used at group level for quality improvement and external transparency.

#### History

The application of PROMs was accelerated in 2011 by the creation of the PROMs Nederland Foundation. The purpose of this foundation was to issue questionnaires for a number of disorders for the measurement of patient-reported outcomes. PROMs Nederland was set up by MediQuest, CbusineZ and health insurer De Friesland Zorgverzekeraar. After a few years, the activities were transferred to the Miletus Foundation, a partnership of health insurers. Over the years, PROMs have been added to new or existing quality records of professional associations. One example of this is the Routine Outcome Measurement (ROM) in mental health that is managed by the Benchmark GGZ Foundation.

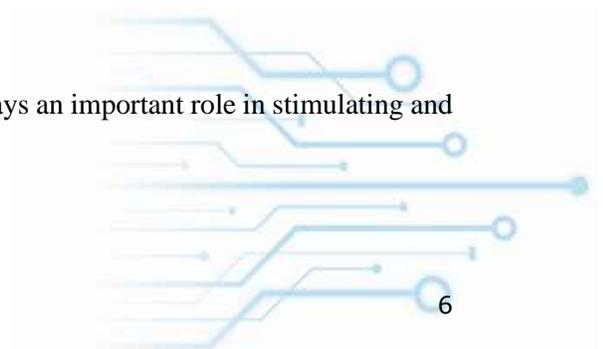
In recent years, various initiatives have been launched at national, regional and local levels in the Netherlands. Participation in national quality records within medical specialist care - where PROMs are also used - is in some cases a mandatory requirement. This requirement may, for example, be imposed by the professional association, the health insurer or the government. In the Netherlands, the Dutch Institute for Clinical Auditing (DICA) is the largest organisation for the management of quality records.

#### PROs expertise network

At the end of 2013, the NFU expertise network PRO was established to combine knowledge. The aim of the PROs expertise network was to increase knowledge on issues for the application of PROMs by exchanging research data, drawing up a research agenda, and jointly writing subsidy proposals. The expertise network's activities have resulted in the NFU manual for the selection of PROs and PROMs, and the Dutch version of the **PROM toolbox** has been developed on behalf of the National Health Care Institute. In 2017-2020, the expertise network proceeded in the form of the PROM platform where patients, practitioners, insurers, scientists and other experts were represented.

#### Transparency calendar

From the (semi) public sector, the National Health Care Institute plays an important role in stimulating and monitoring the application of PROMs in The Netherlands.



It does this in several ways, including the implementation of projects such as the development of the Dutch **PROM toolbox** and the project for the development of a ‘PROM decision tree/framework’. The National Health Care Institute has the legal task of publishing information on the quality of care provided, and manages a register of indicators for measuring the quality of care. The Transparency Calendar states what information must be supplied. PROMs are part of the indicators on the Transparency Calendar.

For the medical specialist care, cooperation agreements have been made for making quality information available. The Federation of Medical Specialists (FMS), Dutch Association of Hospitals (NVZ), Netherlands Federation of Hospitals (NVZ) The Netherlands Federation of University Medical Centres (NFU), Independent Clinics Netherlands (ZKN), Netherlands Patient Federation, the Association of Dutch Healthcare Insurers (ZN), Dutch Nursing Association (V&VN) and the National Health Care Institute are working together to develop quality indicators. The parties meet in the Agency Consultation on Transparency to work together on the implementation of the transparency calendar.

### Joint decision-making

In the parliamentary letter of 12 February 2017, the Minister of Public Health wrote that the government is going to work on making outcomes available for joint decision-making. The programme ‘Outcome Information for Joint Decision-Making’ was set up for this purpose. The essence of that programme is to work on a different registration and processing of data, which will allow patients to share their outcomes with professionals, and enable physicians and patients to jointly use the data from national quality records. Thus, joint decision-making implies the integration of the purposes of PROMs at an individual and group level.

In 2017, during the ICHOM conference in Washington, the National Health Care Institute and the Ministry of Health, Welfare and Sport organised meetings about the use of outcome information for joint decision-making in the Dutch health service. The Linnean Initiative was created on the basis of this (named after the address of the Dutch Embassy in Washington). This initiative used the PROM-cycle to create a menu of generic PROMs: the Linnean menu. They will further elaborate on several themes, including the use of PROMs as well as Patient Reported Experience Measures (PREMs).

### International

The Netherlands is also closely involved in the international application of PROMs. For that reason, we describe three important recent developments below: 1) ICHOM, 2) initiatives from the OECD and 3) H2020 HTx project.

The International Consortium for Health Outcomes Measurement (ICHOM) develops standard sets for measuring outcomes in specific conditions.<sup>3</sup> PROMs take a prominent place within the Standard Sets of

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<sup>3</sup> <http://www.ichom.org/>



outcomes measurements developed by ICHOM. The Netherlands is closely involved in the activities of ICHOM and several Dutch experts participate in the development of ICHOM Standard Sets.

Several hospitals and other healthcare institutions are also involved in setting up an international database for disorders for which the outcomes are measured using the Standard Sets. ICHOM also has a place within the Outcome Information for Joint Decision-making programme. The National Health Care Institute examined whether the Standard Sets of ICHOM were used to enable an acceleration in the availability of outcome information for joint decision-making. The study programme is published online: <https://english.zorginstituutnederland.nl/publications/publications/2017/10/19/programme-%E2%80%98outcome-information-for-shared-decision-making%E2%80%99---factsheet>.<sup>4</sup>

The Organisation for Economic Cooperation and Development (OECD) started preparations for the so-called Patient-Reported Indicator Survey (PaRIS) in 2017. The aim of the PaRIS programme is to measure and make experiences and healthcare outcomes comparable on an international level. The programme has two components. In the first component of the programme, the OECD encourages the use and application of existing PROMs in national measurements that also allow international comparisons. For this purpose, working groups have been set up to advise on the PROMs to be measured and for the measurement protocol for a limited number of conditions including Hip and Knee Replacement and Breast Cancer. The second part of the programme includes the development of an international survey for measuring health outcomes and experiences of patients with complex disorders. Dutch representatives participate in the initiative through the steering committee and the various working groups. In the programme, the OECD collects, analyses and publishes patient-reported outcomes for the purpose of international comparisons.<sup>5</sup>

The main aim of the H2020 HTx project<sup>6</sup> is to create a framework for the Next Generation Health Technology Assessment (HTx) to support patient-centered, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

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. 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). So, PROMs use patients as the source of information. 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. The methodological, statistical and practical issues that PROM users need to take into account, are described comprehensively e.g. by the International Society for

<sup>4</sup> <https://english.zorginstituutnederland.nl/publications/publications/2017/10/19/project-%E2%80%98ichom-as-an-accelerator-for-outcome-information%E2%80%99---factsheet>

<sup>5</sup> <http://www.oecd.org/health/paris.htm>

<sup>6</sup> [HTx Project | Next Generation Health Technology Assessment \(htx-h2020.eu\)](#)



## Literature review on the use of PROMs



Quality of Life Research (ISOQOL). Widely used PROMs were assessed against these methodological, statistical and practical criteria in order to provide the user-friendly PROM-overview for HTA institutes and researchers of how these PROMs perform on aspects such as relevance to patients, measurement of errors, response percentages in various patient groups, case mix factors that need be taken into account, experiences with use for different purposes (clinical outcomes research, performance measurement, routine clinical practice) etc. For the compilation of the PROMs overview by the National Health Care Institute, co-operation with the Patient-Reported Indicators Survey (PaRIS) initiative of the OECD was sought. One of the aims of the PaRIS initiative is to support countries to adopt validated, standardised, internationally-comparable patient-reported indicators. Currently the focus is on hip and knee replacements, breast cancer care, and mental health care. According to the OECD, selected PROMs should be relevant to patients, and acceptable to both physicians and patients. PROMs selection should be “based on strict criteria, which includes taking patients’ priorities into account using focus groups. Instruments should meet methodological requirements of cognitive testing and psychometric properties of validity, reliability and international comparability.” The PROM-overview that was prepared in the HTx project can contribute to this line of work within the OECD.



## 4 Effectiveness of PROMs

Table 1 summarises the results of 14 systematic reviews of the effectiveness of PROMs published from 1999 to September 2017. All reviews focused on the use of PROMs in individual patient care. Two reviews (Chen 2013; Boyce 2013) also examined the effectiveness of the use of PROMs at group level for quality improvement and external transparency. Most reviews focus on oncology care and mental health care. Some reviews (6) did not select a specific target group and report on various patient groups.

Table 1: Summary of 14 systematic reviews of effectiveness of PROMs

Author	Year	Setting	Results	Effects*
<b>Individual healthcare</b>				
Greenhalgh 13 studies	1999	Diverse	Care process Health outcomes	n=10: + ; n=10: 0 n=2: +; n=3: 0
Espallargues 21 studies	2000	Diverse	Care process Health outcomes	n=11: +; n=9: 0 n= 4: + ; n=7: 0
Gilbody 9 studies	2001	Mental health care	Care process Health outcomes	n=4: 0 n=4: 0
Gilbody 9 studies	2002	Mental health care	Care process Health outcomes	n=5: +; n=3: 0 n=1: +; n=4: 0
Gilbody 16 studies	2003	Primary mental health care	Care process Health outcomes	n=4: +; n=10: 0 n=1: +; n=7: 0
Marshall 38 studies	2006	Diverse	Care process Health outcomes	n=11: +; n=9: 0 n=1: +; n=1: 0
Valderas 34 studies	2008	Diverse	Care process Health outcomes	n=10: +; n=11; 0 n=8: +; n=9: 0
Luckett 6 studies	2009	Oncology	Care process Health outcomes	n=1: + n=5: +; n=5: 0
Chen 27 studies	2013	Oncology	Care process Health outcomes	n=47: +; n=2: 0; n=1: - n=13: +; n=2: 0
Boyce 17 studies	2013	Diverse	Health outcomes	n=7: +; n=15: 0
Kotronoulas 24 studies	2014	Oncology	Care process Health outcomes	n=16: +; n=13: 0 n=7: +; n=14: 0
Howell 30 studies	2015	Oncology	Care process Health outcomes	n=13: +; n=2: 0 n=2: + ; n=5: 0
Kendrick 17 studies	2016	Mental health care	Care process Health outcomes	n= 7: 0 n=12: 0
Adam 29 studies	2016	Oncology	Health outcomes	n= 12: +
<b>Quality improvement and transparency</b>				
Chen 27 studies	2013	Oncology	Quality improvement Performance measurement	No studies found No studies found
Boyce 17 studies	2013	Diverse	Quality improvement	N=1: 0

Adapted and supplemented on the basis of OECD 2017; GGZ= Mental Health Care

+ = positive effect, 0 = no effect, - = negative effect, as reported by authors

\*Effects are based on the number of (grouped) outcomes. The number of outcomes can therefore be higher than the number of studies per review.



### Effectiveness of PROMs when used in individual patient care

In Table 1, we have ranked the effectiveness of PROMs in individual care by their impact on the care process and on health outcomes. Impact on the care process involves aspects such as communication between healthcare professional and patient, detection of health problems, and joint decision-making. By impact on health outcomes, we mean whether the application of PROMs also leads to better patient health as a result of the treatment.

In summary, the results show that PROMs are more likely to have a positive effect on parts of the care process than on the health outcomes chosen by the authors. Effects on health are less often measured and show mixed results: sometimes the use of PROMs has a positive effect on aspects of health, but usually not. Below we will discuss the results of the various reviews summarized in Table 1 for the use of PROMs in individual patient care.

#### *Greenhalgh et al. (1999)*

In 1999, Greenhalgh and colleagues conducted a literature review to determine the effectiveness of PROMs and identify the factors that influence effectiveness. The 13 studies found were carried out in different settings with various populations. They conclude that physicians value the information from PROMs. Feedback from the outcomes of PROMs for physicians contributes to recognising mental and functional problems. However, there was little evidence that the use of PROMs subsequently had a substantial impact on the further design of the care process or on patient health outcomes. The authors emphasize that how the PROMs are implemented in daily practice affects the impact and effectiveness of PROMs.

#### *Espallargues et al. (2000)*

This is a literature review of the effectiveness of providing feedback to physicians on patient-reported health outcomes. The authors included 21 studies in their review, conducted in different settings with various populations. Some of the studies were conducted in mental health care (GGZ) for which subgroup analyses were carried out. They conclude that providing feedback to physicians about the patient-reported health outcomes had an effect on the care process, but not on the (functional) health of patients in the longer term. This was particularly the case for information about the mental health status. However, a thorough evaluation of the intervention was not possible because of the limited number of studies.

#### *Gilbody et al. (2001)*

In this article in the BMJ, Gilbody and colleagues investigated the effect of routinely applying questionnaires to detect anxiety and depression in non-psychiatric departments. They also looked at effects on the process and outcomes of care. They included 9 studies and concluded that routine questionnaires about psychosocial problems had none to a modest effect on the screening/detection of anxiety and depression – the effect being mainly found in patients who scored at the upper limit - but subsequently they did not find any effect on the process and outcomes of care. This is likely due to the fact that the behaviour of physicians did not change following the results of the questionnaires that were conducted.

#### *Gilbody et al. (2002)*

Routinely applying a quality-of-life questionnaire can help detect psychosocial problems, contribute to decision-making, help monitor treatment effects over time, and contribute to better doctor-patient



communication. However, the extent to which this instrument is actually used, its costs and the actual benefits have not been clearly identified. That is why Gilbody and colleagues conducted this review. They included 9 studies. The authors conclude that the routine application of quality of life questionnaires (HR-QoL) is costly and that there is no robust evidence for the improvement of psychosocial outcomes for patients. The review could only make statements about non-psychiatric settings.

### *Gilbody et al. (2003)*

This article by Gilbody et al. focuses on assessing the effectiveness of screening as a strategy and the effectiveness of other organisational strategies in improving the detection and management of depression in general practice. One of their conclusions is that routinely applying and providing feedback based on simple questionnaires that measure depression and quality of life has had no impact on the detection, management or outcomes of depression in general practice. They argue that implementation of these interventions requires a substantial organisational change in practice, and a revision of professional tasks between physicians and nurses and practitioners.

### *Marshall et al. (2006)*

Marshall and colleagues are seeking to summarise the literature on the effectiveness of PROMs' routine clinical application, in which they examined whether and how the use of PROMs could improve the practice. In their review of 36 studies, they conclude that there is a general lack of clarity about the purpose and mechanism for achieving the goal. The studies are too heterogeneous to draw clear conclusions, which means that the potential of PROMs is underexploited.

### *Valderas et al. 2008*

Valderas and colleagues investigated the effect of providing information on patient-reported outcomes to physicians. They included 34 studies in different settings and populations. Due to the great heterogeneity of studies and methodological limitations, it was not possible to draw strong conclusions. However, the authors show that most studies have had an effect on at least one of the process measures and that effects on health outcomes have been less frequently researched and demonstrated.

### *Luckett et al. 2009*

The authors found 6 RCTs that researched the impact of PROMs on the outcomes of patients with cancer. There was little evidence that PROMs improved the health outcomes of patients. Next, the authors analysed the interventions used in the individual studies. They made the following recommendations: 1) training is needed to motivate the medical staff to interpret and use PROMs data; 2) patients should be trained or supported in joint decision-making; 3) more specific and individual outcomes should be used; 4) the presentation of data needs to be improved to make it easier to interpret; 5) the use of PROMs should be monitored and encouraged.

### *Chen et al. 2013*

In 2013, Chen and colleagues conducted a review of the routine collection of patient-reported outcomes in an oncology setting. The authors conclude that there is growing evidence that PROMs can be useful in oncology. They identified 27 studies that provided strong evidence that well-implemented patient-reported



outcomes improved doctor-patient communication and had a positive effect on patient satisfaction. There was also evidence that PROMs contribute to monitoring treatment effects and detecting problems. However, the authors also concluded that no or only a weak effect was reported for the process of care delivery, health outcomes, patient behaviour, improving the quality of organisations, transparency, public accountability, and the performance of the care system.

### *Boyce & Browne 2013*

Boyce & Browne conducted a literature review to determine the effectiveness on health outcomes of providing feedback to healthcare providers about patient-reported outcomes. The study focused both on feedback on individual patients and at group level. The review included 17 studies (RCTs), of which 16 studies focused on providing feedback at individual patient level. The perceived effects of PROMs on health outcomes (in the longer term) varied. Boyce & Browne conclude that the effectiveness of PROMs is related to the purpose for which the PROM was deployed. However, the evidence that PROMs have a positive impact is weak and many methodological limitations were found.

### *Kotronoulas et al. 2014*

Kotronoulas researched whether the routine application of PROMs in cancer patient care is related to improvements in care processes and outcomes of care. The review included 24 studies. The study shows that routine use of PROMs increases the frequency with which the outcomes of care are discussed with the patient. The implementation of PROMs is associated with improved symptom monitoring, patient support, and patient satisfaction. However, many results were not statistically significant and the effect sizes were small to moderate.

### *Howell et al. 2015*

This review of 30 studies focused on the effectiveness of the routine use of PROMs in cancer patients. The use of PROMs had a clear impact on the care process through earlier detection of health problems and improved communication between patient and healthcare professional. However, the impact on health outcomes was unclear. The authors concluded that the routine application of PROMs in oncology care is increasing and shows key improvements in the care process. However, several obstacles make further implementation more difficult. The lack of standardisation in the use of PROMs makes it difficult to use the data at group level for monitoring quality of care.

### *Kendrick et al. 2016*

Kendrick et al.'s Cochrane review researched the routine measurement of patient-reported outcomes in mental health care. The review included 17 studies (RCTs). In a meta-analysis of 12 studies, the authors found no difference in health outcomes between giving or not giving feedback to healthcare professionals, with scores of the OQ-45 or ORS as their outcome measure. Nor did they encounter differences in the number of treatment sessions. The authors concluded that the low quality of the studies makes it difficult to draw robust conclusions.

### *Adam et al. 2016*

Adam and colleagues investigated whether patient-reported pain measurements are meaningful in improving pain management in cancer patients. They included 29 studies that used feedback on pain scores



for patients and healthcare professionals, with the aim of improving pain management. Narrative synthesis of the results seems to demonstrate an overall positive effect on the discussion of pain and symptoms by patient and healthcare professional. Meta-analysis of 12 studies shows a reduction in pain (MD: -0.59; 95%CI -0.87 to -0.30) in patients with pain score feedback. The authors conclude that interventions in which pain is measured with feedback on the scores lead to a moderate reduction in pain.

### **Effectiveness of PROMs for quality improvement and transparency**

In Chen's review (2013), there were no studies in which PROMs were used at group level in oncology care, for quality improvement and/or transparency. Boyce (2013) did find a study in her review on the use of PROMs at group level for quality improvement. This study (Weingarten 2000) examined the functional status of older people over a four-year period about which general practitioners were systematically provided feedback. The feedback consisted of a periodic benchmark comparing group data from their own patients with group data from fellow general practitioners. However, feedback from PROMs data on patient groups has not been effective for the quality of care – that was measured with health outcomes.

In addition to the reviews from Table 1, we have found some additional individual studies on the effectiveness of group-level PROMs for quality improvement and external transparency.

A randomized trial published by Boyce and Browne (2015) examined the impact of providing PROM feedback to orthopaedic surgeons on the functioning of their patients. The surgeons from the intervention group were given a feedback report which included a benchmark of their patients' progress against that of their colleagues on different PROM scores. Surgeons also received a training session about the interpretation of the data. No statistically significant differences were found in the quality of care – measured as outcomes of care for the PROMs used.

Varagunam and colleagues (2014) have examined the impact of the launch of the National PROMs Programme in England. The authors analysed data on health outcomes collected with PROMs between 2009 and 2012 after hip and knee replacement, varicose vein procedures and groin fractures. They found little variation between providers of care and saw no significant changes in the performance of providers of care over time. The authors conclude that more attention should be paid to the feedback and interpretation of PROM data to stimulate quality improvement. In another study in which data were analysed over the same period, Varagunam and colleagues (2015) conclude that comparison of outcomes between providers of care based on PROM data is more sensitive than comparison of differences in mortality rates.



### 5 Factors and mechanisms that influence the use of PROMs

#### Boyce et al. 2014

In 2014, a systematic review of Boyce and colleagues was published, covering the experience of healthcare professionals with feedback on PROM data from individuals or patient groups. The review included 16 studies. The authors describe obstacles and stimulating factors in four themes: (1) collection and use of PROM data (practical), (2) experienced added value from PROM data (attitude), (3) interpretation of PROM data (methodological), and (4) use of PROM data to improve care (impact). Professionals value PROMs when they are useful for the clinical decision-making process. Practical barriers to the routine use of PROMs are prominent when the appropriate data collection infrastructure is missing and when their use impedes normal work routines. Technology – such as embedding PROMs measurements in the electronic patient record – is important for processing the information obtained through PROMs measurements. Improving the interpretation of (differences in) outcomes may increase the use of PROMs. Attitudes regarding the use of PROMs can be improved by involving professionals in planning the use, and by understanding the reasons for data collection using PROMs.

#### Greenhalgh et al. 2017

Greenhalgh and colleagues (2017) have published a realist review of underlying mechanisms and contextual factors and mechanisms that influence the use of PROMs. They looked at the types of PROMs, types of disorders, and the different uses of PROMs. The extensive research report was published in 2017, while an article on the use of aggregated data for measuring and improving quality was published a year later (Boyce 2018).

The general outcome of the review is that it is difficult to draw robust conclusions regarding the impact of PROM feedback on the process and outcomes of individual patient care. The context for the measurements is very important for the potential impact of measuring health outcomes with PROMs. It is difficult to determine cause and effect relationships because the context has a major impact on meaningful application. The Greenhalgh review confirms the image that was presented in chapter 4 on the basis of the quantitative analyses. At an individual patient level, PROM feedback has a greater impact on the care process than on health outcomes. PROMs act as a tool for patients to address psychosocial problems during the consultation. This function of PROMs is also appreciated by patients. However, the use of PROMs does not directly lead to substantial changes in the care provided. This requires a change in the perception and behaviour of the healthcare professionals. The use of PROMs can sometimes also interfere with communication, as it hinders an open conversation. Nurses are more open to the use of PROMs to discuss mental and social problems with the patient than are physicians.

Greenhalgh elaborates on the type of PROM in the review. This review distinguishes between standardised and individualized PROMs. Standardised PROMs are fixed questionnaires that are generic (for different populations) or specific (targeted at a particular disease or condition). Individual PROMs are aimed at mapping the individual problems that are reported by the patient. Greenhalgh concludes that standardised



PROMs are particularly useful for patients who provide information through the PROM without having to address sensitive subjects in the conversation with the healthcare professional. Individualised PROMs – in which patients themselves define their health problems – offer more opportunities to discuss individual problems. In mental health care and oncology, standardised PROMs can impede the conversation because the PROM is not specific enough to describe the patient's problems. One disadvantage of individualised PROMs is that they are less suitable for monitoring changes in time between patients due to the personal interpretation of health problems. This also makes individualised PROMs less suitable for quality improvement and transparency.

Greenhalgh's review also shows that the perceived value of using PROMs at group level for quality improvement and transparency is very dependent on confidence in the collected data and its presentation. Healthcare professionals are more inclined to take steps to improve quality if the data is reliable, PROM feedback is given in a timely manner (continuously), and an indication is provided about the quality delivered and the potential improvement. The reliability of the data is related to the accuracy of the data, measurement moments, the right case mix correction and reliability of the organisation providing the PROM feedback. Good presentation of the data is important to get quality improvement going.

The attitude of healthcare professionals is another important factor in the success or failure of the use of PROMs for quality improvement. In a qualitative study, Boyce and colleagues (2014) examined surgeons' experiences of getting feedback on outcomes based on PROMs measurements and their impact on quality improvements. They identified three groups: 'Advocates' had a positive attitude about PROMs and confirmed that the feedback encouraged self-reflection; 'Converts' were uncertain about the added value of PROMs, which made them less inclined to use PROMs; 'Sceptics' had a negative attitude about PROMs and indicated that the feedback did not affect their behaviour. Conceptual, methodological and practical factors were linked to the three typologies.

### Integration of purposes

One important theme in the application of PROMs is the combination of purposes in individual patient care and at an aggregated level for quality improvement and transparency. Figure 1 is a visual image of the integration of goals. In a qualitative study, Van der Wees and colleagues (2014) used interviews with 58 experts from the United States, England and the Netherlands to identify the advantages and disadvantages of integrating goals for PROMs measurements. The integration of purposes has several advantages.

Firstly, the meaningful measurement of PROMs in individual care contributes to support for measuring PROMs for quality improvement and transparency. After all, a direct link is established between the care for individual patients and the measurement of quality of care. In addition, only one measurement system needs to be set up instead of multiple measurement systems side by side. Combining goals also has several disadvantages. These relate to potential differences in the type of PROM suitable for individual versus aggregated use, the design of the measuring system, and the requirements for reliability and validity of the PROM and the PROM measurement. In addition, there may be different interests for different stakeholders, such as patient, practitioner and insurer, and these differences may hinder the integration of goals. The



experts interviewed in Van der Wees' study were in favour of an integrated set of PROM data, but at the same time pointed to the complexity of routinely gathering reliable data and potential tensions between interested parties who have other goals for the same data.

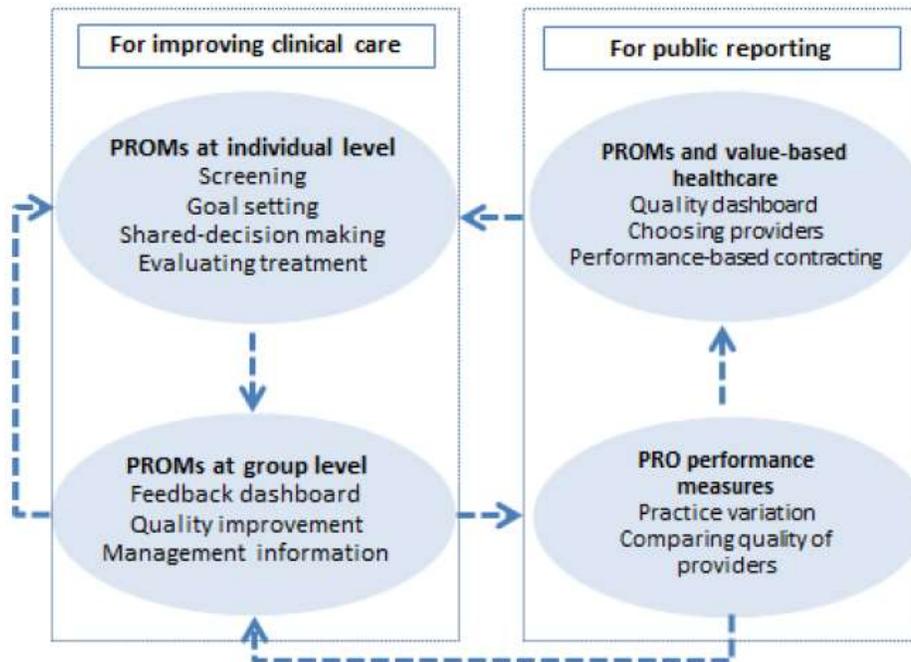


Figure 1: Framework for the integration of PROMs for different goals (Van der Wees, OECD 2017)

### Integration into the electronic patient record

Another important theme is the integration of the data collection into electronic patient records. This is seen as an important condition for achieving a good response from the measurements and for meaningful application in the care for the individual patient. Arguments for this are, on the one hand, logistical: it enables the easy building of routine data collection from the patient record instead of a separate software system. On the other hand, it also encourages meaningful application: the presentation of PROM data in the patient record enables integration with other patient data and thus promotes the interpretation of the data (Greenhalgh 2017).

Wu and colleagues (2013) advocate this integration through a historical description of the rise of PROMs, the emergence of digital patient records and comparative effectiveness studies. Based on that, they identified two dimensions: patient focus and digitisation. Their conclusion is that, in view of the parallel historical developments, the time has now come to integrate PROMs into digital patient records. This allows data to be routinely collected for patient care and for assessing the effectiveness of individual patient treatments. In addition, Mehta et al. (2016) see added value, specifically for the registration of pain, in the use of mobile technology (measurements via smart phones) for the future.

However, there are also arguments in favour of separate data collection outside the electronic patient record for the use of PROM data for external transparency. For comparisons at national or international level, it is easier to give PROM questionnaires to patients and collect the data without the involvement of the healthcare professional. This also prevents potential problems with the validity and reliability of the data. There is less risk of data manipulation by healthcare professionals and it reduces the complexity of data collection because only one database needs to be set up based on a survey. One example of this is the OECD's Patient-Reported Indicators Survey (PaRIS) currently being prepared. At the same time, the OECD also points out the disadvantages of a generic survey, partly because it does not contribute to the involvement of healthcare professionals and there is less potential for using the outcomes for quality improvement (OECD 2017).

### Future scenarios

In the literature, various reflective articles have been published about the future of PROMs application. Without wishing to be exhaustive, we will summarise below a number of articles that will look at the application of PROMs from a 'helicopter view'.

In his 2013 article in the BMJ, Nick Black explains what PROMs are and why they are important. He describes the extent to which the practice uses them (in England), and what, according to him, the five main challenges from PROMs are for the coming years: 1) consider how PROMs can be combined for different user goals; 2) embrace new ways/technologies to collect data so PROMs can be part of everyday care; 3) identify which disorders and treatments have priority in developing and implementing PROMs; 4) solving methodological problems that prevent PROMs from being used properly; 5) taking the opportunity to use PROMs for value-driven care.

Lavallee and colleagues (2016) wrote a reflective article that was published in Health Affairs magazine. In addition to the benefits and challenges that others have already described (such as logistical and technological challenges), they argue for making outcome measurements more user-friendly.

They believe that the measurement methods and questionnaires should be adapted to the target group and should not be too burdensome. In the design phase, a much more 'user-centred design' should be applied and patients with visual limitations, mental problems, or literacy problems should be included.

In a review study in BMC Health Services Research magazine (2015), Schlesinger and colleagues describe the impact of financial incentives on healthcare professionals' use of PROM data. They warn of the danger that over strong pay-for-performance stimuli can come at the expense of caring for the individual patient. If the care provider is too concerned with achieving good outcomes, this can come at the expense of joint decision-making for individual patients. The authors consider the combination and integration of different outcomes and experiences to be important in the awarding of financial incentives, so that the reward is based on an overall view and not on a single outcome. In addition, they advocate stimulating a culture of continuous learning based on the feedback on outcomes.



Wind et al. (2017) conducted a scoping review into benchmarking as a phenomenon, and whether benchmarking leads to quality improvements in specialist hospitals (such as eye hospitals, cancer institutes). Wind et al.'s research (2017) is not specifically focused at using PROMs for benchmarking. They conclude that in some cases quality improvement is achieved by benchmarking, but that the studies are very heterogeneous and the quality of the studies varies, which means that there is no strong evidence for the effectiveness of benchmarking. The authors call for better studies.

Brogan and colleagues (2017) describe whether and how PRO data can be used in different countries to access the oncology technology market – such as pharmaceuticals, decisions on reimbursement of oncology technology, and the use of PRO data for healthcare procurement discussions. They conclude, based on a literature review and additional questionnaire research and interviews, that financiers (insurers) are very open to PRO data, but that the differences between countries are substantial. They see a future for PROMs in decision-making for reimbursements and consider the use of PROMs for calculation models (including risk equalisation) an option. To make decisions about reimbursing (new) oncology technology, PRO data is highly desirable if not mandatory, and scientific research into oncology technology should include PRO data.

In the *International Journal for Quality in Health Care* (2017), Ovretveit and colleagues argue for the use of PROM data for quality improvement. They describe a number of conditional factors for the meaningful application of PROMs. Firstly, the authors say that the use of PROMs for quality improvement is only possible if it is part of a larger system and a ‘hungry’ culture that needs systematic feedback on patient experiences and health outcomes. To promote the use of PROMs, it is important to have support from patients and healthcare professionals. The support in both groups can be increased through targeted feedback that shows the added value of PROM data. To stimulate the use of Proms, care organisations and departments need a champion that excites and motivates. For inspiration, the authors provide examples of quality improvements as a result of feedback from PROM data.

In their article in *Medical Care* (2017), Browne and colleagues focus elsewhere. They recognize the importance of outcome measurements with PROMs, but argue that current applications have led to disappointing results for measuring and improving quality. There is no evidence that PROM data can be used for contracting and continuous quality improvement. The authors argue for a specific link of the outcomes to the care processes. Only then can outcomes be interpreted in a meaningful way and lead to improvements.

The information about outcomes is not sufficient to link them to quality and quality improvement. Their key message is that we should take the time to use PROMs to answer (scientific) questions to understand the meaningful application of PROMs. For now, the focus should not be on comparing the quality of healthcare providers, but on using PROMs for internal quality improvement.



## 6 Synthesis of results as a basis for the interviews and decision tree

To organise the knowledge from the literature and form a basis for the decision tree to be developed, we have mapped out the operating mechanisms and contextual factors for the application of PROMs. We have based this on the realist review by Greenhalgh and colleagues (2017). Table 2 shows the operating mechanisms for the application of PROMs and Table 3 describes the contextual factors. The information in the tables is organised according to the goals for using PROMs.

Table 2: Mechanisms: how the use of PROMs can lead to quality improvement\*

Individual care	Internal quality	External quality
The patient can discuss their problems	Performance feedback drives quality improvement	Wanting to be just as good as or better than colleagues (improve by competition)
Patient uses PROM information for self-management	Performance feedback affects healthcare professionals' behaviour **	Working together on improving quality (improve by learning from each other)
Healthcare professional reviews the completed PROM and discusses it with the patient	Intrinsic motivation to improve	Maintain or increase market share
The PROMs feedback motivates the healthcare professional to take action (along with patient)	Wanting to be just as good as or better than colleagues (improve by competition)	Protecting the professional or organisational reputation
PROMs feedback is discussed between healthcare professionals and action is undertaken (without the patient)	Working together on improving quality (improve by learning from each other)	Increase income
		Accountable to stakeholders for the quality delivered
		Unintended or undesirable consequences: gaming, tunnel vision (only improving what is measured), threshold effects (the best are decreasing toward the average), and avoiding more sickly patients.

\*Note: multiple mechanisms can play a role at the same time

\*\* Research showed only a difference between effects of confidential or public feedback if there is an erroneous interpretation of data or misreporting in the media



## Mechanisms

Mechanisms in individual care relate to the use of PROMs by patients - for instance about making problems negotiable; by patients and healthcare professionals jointly – in discussing outcomes; and by healthcare professionals among themselves – in, for example, multidisciplinary consultation. For internal quality, feedback on outcomes can stimulate quality improvement or promote collaboration. For external quality, mechanisms such as competition, market share or professional reputation can play a role (Table 2).

Table 3: Contextual factors that can influence the mechanisms

Individual care	Internal and external quality		
	Data credibility	Opportunity for ‘action’	Incentives or sanctions
Structure and format of the PROM	Suitability of the data for measuring quality	Direct (online) data feedback	Financial incentives or sanctions (data as indicator for quality or as a settlement instrument)
Clear presentation and interpretation	Adequate case-mix correction	Clear presentation and interpretability of the data	Standardisation yes or no
Feasibility for completing PROM	Sensible measuring moments	The extent to which healthcare professionals see opportunities for quality improvement within their span of control (problem identification + interpretation of duties)	Mandatory or voluntary
Relationship between healthcare professional and patient (PROM strengthens or devalues)	Completeness of data collection (including clinical outcomes)	Focus on outliers or general quality promotion	Media coverage
Physician and nurse’s interpretation of duties	Level of analysis (institution vs. healthcare professional)	Support for quality improvement	
Financial incentives or sanctions	Confidence in the initiator	Resources available for quality improvement	
The extent to which PROMs are used for multiple purposes	Involvement and support of physicians	Attention to ‘easy aspects’ versus elements that are difficult to change	
Involvement of physicians		Degree of variation between healthcare professionals or providers (little variation, little incentive for improvement)	

## Contextual factors

Contextual factors that can influence the mechanisms are shown in Table 3. The feasibility of measurements and practical applicability play a major role in individual care. In addition, healthcare professionals’



interpretation of their duties can play an important role in whether or not PROMs are used. The factors for internal and external quality have been combined, and factors for these objectives are divided into three categories: data credibility, opportunity for action, incentives or sanctions. Providing clear presentation and feedback on patient-reported outcomes from patient groups is an important factor for taking action, for example to improve quality (internal quality) or to select a healthcare professional or institution (external quality).

### Relationship between disorder, objective and characteristic PROM

We then created a matrix (Table 4) in which we related the objectives of using PROMs and the required characteristics of the PROM and PROM measurement to four types of disorders/care: elective interventions, acute disorders, chronic disorders and oncology disorders. It is not an absolute classification, but a global typing to estimate the possible differences in the characteristics of the PROM (measurement) for the various purposes and disorders. Science/research has also been taken into account as an objective.

For example, this format shows that data comparability (between healthcare professionals or institutions) does not play a primary role in individual patient care, but does play a primary role in internal and external quality and science. There are small differences between the different types of disorder/care and objectives when it comes to the necessary properties of the PROM and the PROM measurements. For example, screening is not a primary goal in elective procedures, and the measurement moments between the types of disorders/care can differ. The importance of reliability and validity of the PROM and the comparability of the PROM measurement increases when used for external quality and science.

Table 4: Matrix of required PROM characteristics according to intended usage and type of disorder/care

Elective procedures (hip replacement, knee replacement, cataract surgery, etc.)						
PROM and PROM measurement characteristics	Individual patient care			Quality improvement		Science
	Screening Diagnosis	Joint decision-making	Evaluating Monitoring	Internal	External	Research
Validity (content)		V	V	V	V	V
Validity (other)			(V)	(V)	V	V
Reliability			(V)	(V)	V	V
Responsiveness			V	V	V	V
Comparability (case mix)				(V)	V	V
Comparability (registration)				(V)	V	V
Comparability (sample)				(V)	V	V
Ability to distinguish				(V)	V	V
Disease-specific		V	V	V	V	V
Generic				V	V	V
Single measurement	V	V				V
Before/after measurement			V	V	V	V
Monitoring/follow-up			V	V	V	V
Individual level (patient)		V	V			
Aggregated level:						
specialist				V		
team/department				V	V	V
organisation				V	V	V

Acute disorders (cardiac arrest, cerebral haemorrhage, etc.)						
PROM and PROM measurement characteristic	Individual patient care			Quality improvement		Science
	Screening	Setting goals / Joint decision-making	Evaluation	Internal	External	
Validity (content)	V	V	V	V	V	V
Validity (other)			(V)	(V)	V	V
Reliability			(V)	(V)	V	V
Responsiveness			V	V	V	V
Comparability (case mix)				(V)	V	V
Comparability (registration)				(V)	V	V
Comparability (sample)				(V)	V	V
Ability to distinguish				(V)	V	V
Disease-specific	V	V	V	V	V	V
Generic					V	V
Single measurement	V	V				
Before/after measurement				V	V	V
Monitoring/follow-up			V	(V)	(V)	V
Individual level (patient)	V	V	V	V		
Aggregated level: specialist			V	V		
team/department				V	V	V
organisation				V	V	V
Chronic disorders (diabetes, COPD, etc.)						
PROM and PROM measurement characteristic	Individual patient care			Quality improvement		Science
	Screening	Setting goals / Joint decision-making	Evaluation	Internal	External	
Validity (content)	V	V	V	V	V	V
Validity (other)			(V)	(V)	V	V
Reliability			(V)	(V)	V	V
Responsiveness			V	V	V	V
Comparability (case mix)				(V)	V	V
Comparability (registration)				(V)	V	V
Comparability (sample)				(V)	V	V
Ability to distinguish				(V)	V	V
Disease-specific	V	V	V	V	V	V
Generic				V	V	V
Single measurement						
Before/after measurement						
Monitoring/follow-up	V	V	V	V	V	V
Individual level (patient)	V	V	V			
Aggregated level: specialist				V		
team/department				V	V	V
organisation				V	V	V



Oncology disorders						
PROM and PROM measurement characteristic	Individual patient care			Quality improvement		Science
	Screening	Setting goals / Joint decision-making	Evaluation	Internal	External	
Validity (content)	V	V	V	V	V	V
Validity (other)			(V)	(V)	V	V
Reliability			(V)	(V)	V	V
Responsiveness			V	V	V	V
Comparability (case mix)				(V)	V	V
Comparability (registration)				(V)	V	V
Comparability (sample)				(V)	V	V
Ability to distinguish				(V)	V	V
Disease-specific	V	V	V	V	V	V
Generic				V	V	V
Single measurement						
Before/after measurement						
Monitoring/follow-up	V	V	V	V	V	V
Individual level (patient)	V	V	V			
Aggregated level:						
specialist				V		
team/department				V	V	V
organisation				V	V	V



### 7 PROMs in the Netherlands

The overview of the applications of PROMs in the Netherlands, including the disorders on the Transparency Calendar, is presented in a separate Excel Worksheet:



Appendix  
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The document provides an overview of PROMs for specific disorders. We have classified the disorders into the following categories: disorders for elective care, oncology disorders, chronic conditions and mental health care. Although mental health care is not directly within the scope of this project, we have taken that application into account to create the most complete overview possible. In addition, we have made an overview of generic PROMs used in the Netherlands and PROMs used for measuring pain.

In the overview, we have organised the following information in columns:

- Information about the PROM
- National registration measurement (if applicable)
- Administrator of the PROM measurement
- Transparency Calendar (does the PROM appear on the calendar yes/no)
- Register National Health Care Institute (is the PROM in the register yes/no)
- Application (national/regional)
- Goal (patient care, quality improvement, transparency)



### 8 Discussion and conclusions

The National Health Care Institute's mission was to develop tools (decision tree, framework and selection guide) to determine if and when it makes sense to use PROMs. This resulted in a 'decision tree/framework' that can help in making choices to measure PROs, – for which patient groups and for which goal(s). This requires an understanding of the scientific and practical situation regarding the use and effects of PROMs. In the previous chapters, we focused on the question: What is the current knowledge about using PROMs for the different goals? Based on a description of the Dutch context and Dutch (policy) initiatives, an overview of the scientific literature and an overview of the applications of PROMs in the Netherlands, we describe our conclusions in this section.

#### **The use of PROMs does not directly lead to substantial changes in the care provided**

In general, there is more knowledge about the effectiveness of PROMs on the care process than on health outcomes. Several studies show positive effects of PROMs on doctor/patient communication, goal setting, joint decision-making, and the detection of problems that would otherwise not have been identified. However, the use of PROMs does not directly lead to substantial changes in the actual treatment. Effects on health outcomes are less often measured and show mixed results: sometimes the use of PROMs has a positive effect on aspects of health and sometimes it does not.

#### **The use of PROMs for quality improvement and transparency is still unexplored territory**

There are not enough studies to make statements about the effectiveness of PROMs for quality improvement at group level and for transparency for healthcare purchasing or selection information. The introduction of the national PROMs programme in England (hip and knee replacement, procedures for varicose veins and inguinal hernia) showed little variation between providers of care, and no significant changes in the performance of providers over time. More attention should be paid to the feedback and interpretation of PROM data to stimulate quality improvement.

#### **The context in which PROMs are used is of great importance for decision making**

The purpose of the PROM, operating mechanism(s) and context seem to be of great importance to the decision making process and the success of PROM measurements. The changing context makes it difficult to draw strong conclusions about when the application of PROMs is meaningful or not. There is not much evidence available yet and a lot of evidence is taken from other applications for measuring and improving the quality of care, such as patient experiences with the care process using PREMs.



### **Support among healthcare professionals and patients is essential**

What makes sense for one patient or healthcare professional does not necessarily make sense for another. The attitude of patients and healthcare professionals about the application of PROMs is an important point of reference for motivating meaningful application.

Involvement and support of healthcare professionals is an important prerequisite for the use of PROMs. A practical precondition for successful implementation is the integration of PROM measurements and reporting in the electronic patient record. For patients, the actual use of PROMs in the consulting room is important as far as support for completing the questionnaires is concerned.

### **Integration of purposes is desirable, but the feasibility of this is not yet clear**

In the Netherlands, the policy is strongly aimed at integrating goals: use in the consulting room for individual care and at group level for quality improvement and transparency.

At the same time, it is known that this integration of goals creates tension because of the different interests of stakeholders. This raises the question of whether a choice should be made for a primary goal, to which the other goals are subordinated. For example, if the primary goal is to apply a PROM in individual care, it should be accepted that the reliability and validity of the use for external transparency is (at present) not optimal because standardisation is difficult. In addition, there may be different interests for different stakeholders (patients, practitioners and health insurers) that may hinder the integration of goals.

### **Policy initiatives are developing faster than knowledge about the use of PROMs**

Finally, policy initiatives in this field seem to be developing faster than knowledge from scientific research. Almost everyone agrees that PROMs have great potential as an instrument for use in clinical practice and for quality improvement. However, at the same time it appears that it is very difficult to select a good PROM, and to use it sensibly in the complex real-world situation. In literature, there is much talk of rhetoric in which authors welcome the added value of using PROMs for quality improvement and transparency without underlying evidence.



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## Literature review on the use of PROMs



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### Appendix 1 Literature review search strategies

#### Search strategy 1 - based on OECD report (2017)

This is an update (previous one was performed on 31 July 2016). We conducted the following broad search strategy in Pubmed on 12 September 2017: (("patient" AND "reported" AND "outcomes") AND ("feedback" OR "quality improvement" OR "performance measurement")) AND Review[ptyp]

This resulted in 260 titles, 53 more than in 2016. After screening the titles and abstracts of these 53 titles, we first selected 15 titles and eventually added 8 titles to the literature review.

#### Search strategy 2 - based on Greenhalgh et al. (2017):

This is an update (previous one was carried out in April 2014). We conducted a search strategy in Ovid Medline on 13 September 2017 (see table below) and selected titles from April 2014. After screening the titles and abstracts, we first selected 29 titles and eventually added 4 titles to the literature review.

1. ("patient report\*" adj3 (outcome\* or data)).tw.
2. proms.tw.
3. ("public\* report\*" adj3 (outcome\* or data or information or care)).tw.
4. exp \*Health Status Indicators/ and (\*patient satisfaction/ or \*patient preference/ or \*Patient- Centered Care/)
5. \*"Outcome Assessment (Health Care)"/ and (\*patient satisfaction/ or \*patient preference/ or \*Patient- Centered Care/ or \*Professional-Patient Relations/)
6. \*Self Report/ and \*Quality of Life/
7. \*"Quality of Life"/ and Health Status/ and patient satisfaction/ and ("Outcome Assessment (Health Care)"/ or Questionnaires/)
8. ("public report\*" adj3 hospital\*).tw.
9. (star adj2 rating\*).ti.
10. or/1-9
11. exp Decision Making/
12. quality indicators, health care/
13. exp treatment outcome/
14. exp Feedback/
15. ((PROM or PROMs or PRO) adj3 acceptab\*).tw.
16. (improve\* or feedback).ti.
17. or/11-16
18. 10 and 17
19. limit 18 to "reviews (maximizes specificity)"
20. (Review\* adj5 outcome\*).ab.
21. (Review\* adj7 outcome\*).ti.
22. (Review\* adj2 (PRO or PROM or PROMs)).tw.
23. (review\* adj3 data).tw.
24. or/20-23
25. 18 and 24
26. 19 or 25
27. limit 26 to yr="2014 -Current"

#### Search strategy 3 – based on expertise

After implementing the above search strategies, we reviewed additional reference lists of the included studies and supplemented them on the basis of our own knowledge and expertise. In this step, we added n=4 studies to the literature review.

