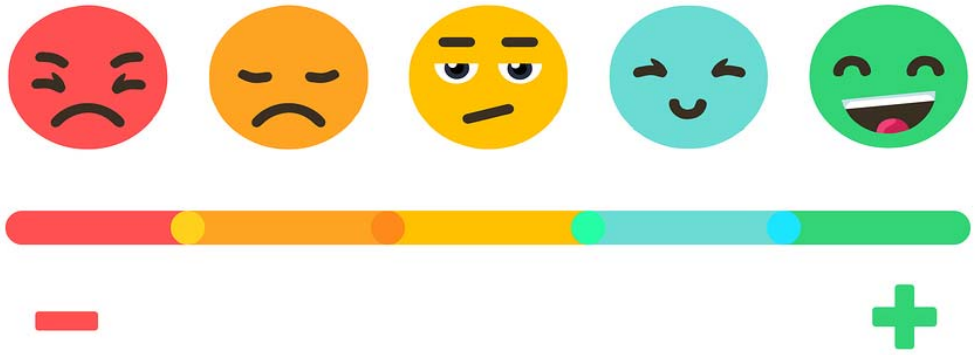
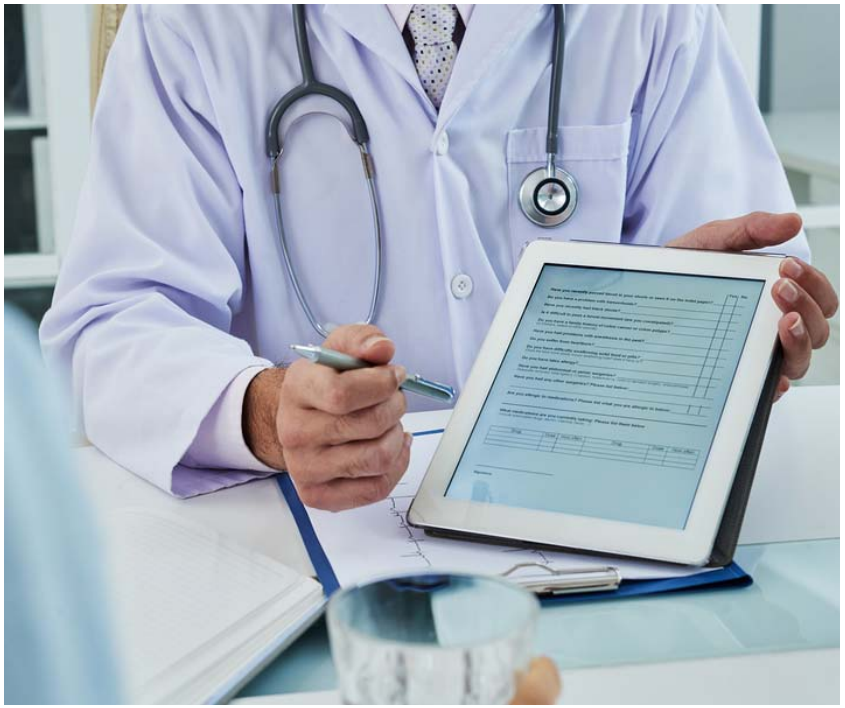
KCE REPORT 303Cs

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

SHORT REPORT

USE OF PATIENT-REPORTED OUTCOME AND EXPERIENCE MEASURES IN PATIENT CARE AND POLICY





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HEALTH SERVICES RESEARCH

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USE OF PATIENT-REPORTED OUTCOME AND EXPERIENCE MEASURES IN PATIENT CARE AND POLICY

ANJA DESOMER, KOEN VAN DEN HEEDE, MATTANJA TRIEMSTRA, JOHN PAGET, DOLF DE BOER, LAURENCE KOHN, IRINA CLEEMPUT

FOREWORD

‘Give us your opinion and you could win smartphone’. ‘Your opinion is important to us. All it takes is two clicks’... We are used to these pushy messages now. They pop up here, there and everywhere and can sometimes even be annoying. Our opinion does have value these days - market value. It provides free advertising, even though this advertising can sometimes be negative. Companies play opinions off against one another and even the most well-known review websites have the greatest difficulty distinguishing between real and false opinions and preventing fraud. And the health sector does not escape this widespread phenomenon, either...

But rest assured. Measuring health outcomes and experiences, as seen by patients, serves a noble purpose: to improve quality of care and place patients’ needs at the centre. In fact, it has now been proved that collecting these ‘PROMs’ and ‘PREMs’ has a positive effect on the doctor-patient relationship... at least if a culture of patient-oriented care is already in place. We are convinced that this culture is part and parcel of those who have opted for a career in health care. But the performative nature of these measurements can only have an additional positive effect: drawing up questionnaires, discussing them with colleagues and testing them among staff and patients helps improve the existing situation. The more we focus on ways of placing the patient centre stage, the more this becomes unavoidable and indispensable. The process has started and can no longer be stopped. Things can only get better.

Without wishing to be killjoys, however, we would like to draw attention to at least two possible pitfalls: an exaggerated focus on indicators on the one hand and competitiveness on the other. The existing and future indicators represent only a limited number of aspects of the care relationship. So we must not fall into precisely the trap we are trying to avoid. Care providers must not become so obsessed by the scores achieved for certain indicators that they lose sight of non-quantifiable or non-objectifiable elements. What’s more, in a society and an economy steeped in competition and competitiveness, a number of conditions need to be fulfilled when comparing care institutions and providers with one another. The data used must be accurate and they must represent concepts and values that are relevant for the patient. In addition, account must be taken of the patient’s ability to understand and answer the questions. So let us go forward, but with the necessary caution.

Marijke EYSSEN
Deputy general director a.i.

Christian LÉONARD
General director a.i.

SYNTHESIS

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1. INTRODUCTION

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) can be used in healthcare for different specific purposes, but essentially they are used to improve the quality of healthcare services, be it at the national level, the institutional level or the individual patient level.

PROMs and PREMs are meant for the measurement of outcomes for which it is likely that patients are the best judges. They are used complementary to other outcome measures, such as mortality, progression-free survival, and healthcare process measures, such as waiting lists, compliance with clinical practice guidelines. They are usually applied in the context of a larger endeavour to improve patient participation, patient-centeredness and patient empowerment, alongside other instruments such as patient panels, qualitative interviews with patients, patient education and patient diaries. Patient empowerment is a broader concept than patient participation and patient-centredness[1], but all these concepts fit within the evolving thoughts about the role of patients in healthcare. Patients are increasingly regarded as the primary decision maker regarding their health and an equal partner in their healthcare choices. This viewpoint is linked to a modern vision of the individual's freedom and ability to choose and societal criticisms like the criticism of the bio-power by M. Foucault[2,3] and the criticism of the health system power by I. Illich[4]. It is generally agreed that patients should be supported to understand their therapeutic options. Information for but also from (about) patients, like PROMs and PREMs, could help to improve patients' autonomy, but at the same time one should remain cautious about social and health inequalities which might be induced by systems focusing on PROMs, PREMs and similar instruments to increase autonomy.

For example, it is well known that health literacy is characterized by a socioeconomic gradient and that the capacity to express emotions, opinions and facts is not equally distributed. It is important to be aware of these ethical consequences and the methodological challenges associated with measuring patient-reported outcomes and experiences (i.e. trying to objectify subjectivity in a systematic manner) in all population subgroups, especially for purposes that envisage increased individual (financial) responsibility.

In this report we explain what PROMs and PREMs are and explore how and why they could be relevant to patients, clinicians and policy makers. The study was commissioned by the federal public service for health, food safety and environment (FOD – SPF Public Health), which considers this study as a component of its empowerment policy. The FOD – SPF requested to evaluate the use, benefits, barriers and facilitators of PROMs and PREMs in daily clinical practice, in quality assurance and in policy (e.g. reimbursement decisions, payment models, etc.). To respond to these questions we analysed the international initiatives (section 0 of the scientific report), conducted a review of the peer-reviewed literature (section 0 of the scientific report) and made a critical analysis of current Belgian initiatives (section 0 of the scientific report). The use of PROMs in trials is considered out of scope. Also an overview of existing instruments to measure patient-reported outcomes or experiences is out of scope, as these are numerous, variable in quality in terms of their reliability and validity, and depending very much on the purpose of the PROMs and PREMs registration. Finally, calculating the costs related to the implementation of PROMs and PREMs at the micro- meso- or macro-level was also out-of-scope of the current study.

1.1. Key concepts

1.1.1. Patient-reported outcome measures

A patient-reported outcome (PRO) is any report of the status of a patient's health condition (e.g. quality of life, symptoms, treatment effects, functioning) elicited directly from the patient, without interpretation of the patient's response by a clinician or anyone else. Tools used to capture information about PRO's, mostly questionnaires and survey's, are **called patient reported outcome measures or PROMs**. A distinction can be made between generic and condition-specific PROMS.

Generic PROMs are not specific to any particular disease or condition and are intended to make comparisons between and within interventions as well as across different diseases and sectors of care. These instruments often focus on the impact of a person's health state, on his 'health-related quality of life (HRQoL)' or 'Quality of Life (QoL)' in general, but they can also focus on specific dimensions of HRQoL, such as physical functioning. Generic PROMs are less sensitive to small, yet clinically significant, changes in patient-relevant outcomes of specific patient populations. An example of a generic HRQoL measure is the EQ-5D-5L, a five-dimensional instrument, asking patients to rate their mobility, self-care, usual activities, pain/discomfort and anxiety/depression on a five-level scale.

Condition-specific PROMs have the benefit of being more sensitive, but do not easily allow comparisons with outcomes in other disease areas or other populations. Condition-specific PROMs measure PROs in a way that is specific to a particular disease (e.g. diabetes), set of conditions (e.g. cancer), a domain (e.g. pain), an intervention (e.g. knee arthroplasty), population (e.g. children) or part of the body (e.g. eyes). The level of specificity of the condition-specific PROMS can differ. For example, the European Organisation for Research and Treatment of Cancer (EORTC) developed a quite general PROM for cancer patients' (EORTC QLQ-C30), and added specific modules for tumour sites (e.g. lung, brain), treatment modalities (e.g. breast reconstruction), or QOL dimensions (e.g. cancer related fatigue).

There is no 'gold standard' for measuring PROs. Very often, several disease-specific PROMs exist for the same condition. Existing instruments moreover differ on several aspects such as scoring, aggregation and purpose. Generic and condition specific PROMs should be regarded as complementary to each other. Condition-specific PROMs include more clinical detail, which makes them more suitable for clinical applications than generic measures (e.g. for shared decision making), whereas generic PROMs are more suitable for policy purposes, often requiring comparability of outcome measures across conditions (e.g. performance measurement, value for money).

1.1.2. Patient-reported experience measures

Patient reported experience measures (PREMs) measure patients' perceptions of their experience of the process -rather than outcome- of care. Patient-reported experiences (PREs) encompass satisfaction (e.g. with information given by nurses and doctors), subjective experiences (e.g. control of pain), objective experiences (e.g. waiting time before first appointment) and observations of healthcare providers' behaviour (e.g. whether or not a patient was given discharge information). The main limitation of PREMs is that they are influenced by patients' expectations, which in turn depend on their preferences, personality and previous experiences. This is especially the case with satisfaction measures, which should therefore be considered as a subgroup of PREMs.

1.2. Why measuring patient-reported outcomes and experiences?

PROMs and PREMs complement traditional outcome measures and enable a more comprehensive understanding of the outcomes and effectiveness of healthcare. They may have value to health systems at different levels:

- On the **micro or individual patient level**, PROMs can be used to support *shared decision making*[a] between the patient and healthcare provider, and to support *patient-centred care*[b]. Patients are increasingly considered active partners in the medical decision-making process with self-management responsibilities. Individual PROMs data can result in information that is, for instance used to change the treatment plan or to undertake self-care activities. Individual PROMs data can also be used as part of routine patient assessment and management. PROMs used for this purpose can either be standardised validated instruments or individualised questions. Standardised PROMs might be particularly useful to screen for common health problems and symptoms that are often overlooked, increase diagnostic accuracy, monitor disease progression or regression, monitor the effects of treatment and facilitate the communication within the multidisciplinary team and between patients and providers by triggering the patient to talk about issues that otherwise might not have been raised. Individualised questions could focus on the particular issues raised by patients during previous contacts. Although the individualised questions are not useful for aggregated analyses, they might be appropriate for the purpose of improving the quality of individual patient care. Aggregated PROMs data can be used in the clinician-patient interaction to inform patients about the consequences of their condition or treatment for their quality of life and functioning, given their age, sex, existing conditions, and severity of their condition. This can help patients to decide on the best treatment for them.
- On the **meso or institutional level**, aggregated PROMs and PREMs data can be used to drive *healthcare quality improvement* initiatives. Data are used to assess and compare the performance of providers (benchmarking and feedback), to identify which quality issues remain insufficiently addressed in current practice and to inform the general public to enable informed patient choice (public reporting). PROMs and PREMs feedback, benchmarking and reporting are to be considered as only one element in a chain of actions that should be undertaken to achieve quality improvement, besides, for instance, creating a culture of quality improvement, increased patient engagement and leadership support. In current practice, PREMs data are still more often used than PROMs data for quality improvement purposes at the meso-level.
- On the **macro level**, PROMs can be used for *population health monitoring* and *reimbursement decision-making* and PREMs can be used for *macro-level healthcare performance measurement*. Many countries added PROMs and PREMs to population health surveys to generate information at the population level that can help to prioritise, design and assess public health activities such as disease prevention, health promotion, measurement of health disparities, and evaluation of interventions. The value of these measures at the population level will increase when these data are linked to other surveillance data, such as clinical registries, billing and hospital discharge data. Inclusion of PROMs in health technology assessments (HTA) provide a more complete picture of the impact of health interventions on outcomes that matter to patients, which helps decision makers to make better-

[a] Shared decision making refers to "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences".(Elwyn G, Coulter A, Laitner S, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. BMJ. 2010;341:c5146. doi: 10.1136/bmj.c5146.)

[b] Patient-centred care refers to an approach where the patient's specific health needs and desired health outcomes are the driving force behind the health care decisions and quality measurements.

informed decisions. PROMs and PREMs can also be used on the macro level for contracting healthcare services, macro-levels healthcare performance measurement and in specific payment models, such as pay for quality models.

Table 1 summarizes the different purposes PROMs and PREMs can serve at different levels, with for each purpose the typical data collection methods applied, sample, types of measures, frequency, and use.

Table 1 – Purposes and characteristics of PROMs and PREMs

Level	Purpose	Data collection method	Sample	Type of measure	Frequency	Use	Remarks
Micro-level	Shared decision making and care in partnership with patients	Individual or aggregated patient data (e.g. checklists, web-portal, surveys integrated in medical records, patient diaries …)	All patients from the target group	Condition-specific PROMs	Longitudinal (chronic care) Pre-post intervention (elective surgery)	Screening Diagnosis Monitoring of disease progression Support of treatment decisions Communication (patient-provider; provider-provider)	Aggregated data will require that impact of risk-factors (e.g. age, co-morbidities, socio-economic characteristics) is taken into account
Meso-level	Information to drive quality improvement initiatives	Mostly paper or electronic patient surveys that are aggregated at the level of the provider or organisation (for benchmarking and public reporting) or at the patient group level (for adverse events monitoring)	All patients receiving a particular service (if providers are being compared) or a sample	PREMs Condition-specific PROMs	Cross-sectional Longitudinal	Identify areas for quality improvement Public reporting to allow informed provider choice Monitoring patient-reported adverse events Comparing providers and organisations or benchmarking them to identify poor performers and learn from good performers	Risk-adjustment required
Macro-level	Population health monitoring	National health surveys (mostly telephonic or face-to-	Representative population sample	PREMs Generic PROMs (Health-related quality of life)	Recurrent cross-sectional measurements	Supportive information for public health activities: • Prioritization of patient groups, conditions, etc	Value of these data increase when they can be linked to other

Level	Purpose	Data collection method	Sample	Type of measure	Frequency	Use	Remarks
		face household interviews)				• Designing public health initiatives • Monitoring of effects of policy initiatives	data sources (e.g. clinical registries)
	Re-imbursement decisions	Part of HTA (data are study based) or real-world evaluation of health interventions (clinical registries)	Patients getting standard intervention as well as patients getting new intervention	Generic and/or condition-specific PROMs	Pre-post intervention + (possibly) longitudinal (duration depending on the condition)	Assess relative effectiveness of treatments and services Assess patient issues associated with condition and treatment	Once positive reimbursement decision is taken, unbiased comparison of intervention and standard of care becomes difficult.
	Contracting services and payment models	Patient surveys (PREMs) Clinical registries (PROMs)	All patients from the target group or a representative sample	Generic PREMs (Pay for performance) or (condition specific-) PROMs (meeting minimum thresholds of outcomes)	Cross-sectional (PREMs) Pre-post (elective surgery PROMs) Longitudinal (chronic care PROMs)	Pay-for-performance Contracting decisions	Risk-adjustment to avoid unintended effects (e.g. patient selection)

2. EVIDENCE ABOUT THE IMPACT OF PROMS AND PREMS

Although PROMs and PREMs can be used for multiple purposes, most research focuses on the use of PROMs in clinical care as a tool to support clinical management and improvement of quality of care. Oncology seems to be the most frequently studied domain.

Based on a review of 15 reviews there seems to be an impact of PROMs on healthcare processes. PROMS help to improve the communication between patients and clinicians and within the multidisciplinary team. The use of PROMs is found to help to discuss symptoms and outcomes that are otherwise not discussed. PROMs can act as a reminder to clinicians to address particular areas or as early symptom alerts, notifying clinicians if a patient's symptoms either cross a threshold of severity or worsen significantly. The level of "actionability" is important to have impact. Actionability means that the results of the measurements allow to identify concrete areas for improvement where specific actions can be taken. Especially in specific patient populations with a large number of problems (e.g. chronic conditions) or severely ill patients for whom there is much room for improvement, the effect can be significant.

However, the evidence about the impact of PROMs on the disease management (e.g. symptom control) and patient outcomes (quality of life, pain, patient satisfaction) is mixed. Patient satisfaction seems to increase when PROMs are used for clinical purposes; for health outcomes, it is difficult to demonstrate an isolated impact because there are multiple determinants of health outcomes. Nevertheless, no studies showed statistically significant negative results: results were either non-significant or significantly positive. The evidence about the use of PROMs as a screening tool is also ambiguous, especially for more complicated problems such as depression. Effects on action undertaken by clinicians (e.g. referrals, medication prescriptions) were favourable in some but not in all studies. Overall, however, the balance seems to be in favour of a positive impact, especially on improving patient-provider communication, identifying unrecognised problems and treatment response monitoring.

As for the impact of PROMs and PREMs on the macro level (payment models), no conclusion can be drawn based on the literature due to lack of primary studies.

3. INTERNATIONAL INITIATIVES

There is a plethora of PROM- and PREM initiatives which result in fragmentation of efforts and hampers comparisons between countries, between providers, between treatments and in time. Some countries supported the development and implementation of PROMs or PREMs as part of a national policy initiative. There is, however a growing awareness that cross-country collaboration could enhance this domain. Commonly cited 'generic' cross-country initiatives include ICHOM, OECD – PaRIS, The Commonwealth Fund, PROMIS and the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID). Also collaborations on specific domains exist, e.g. on pathology-specific disease registries, but these are beyond the scope of the current report. Two large initiatives are ICHOM and the initiatives taken by the OECD.

The **International Consortium for Health Outcomes Measurement (ICHOM[c])** aims to develop standardised sets of condition-specific patient-centred outcome measures to support cross-country comparisons and knowledge gathering. Patient-centred outcomes are outcomes that matter to patients. They include clinical outcomes as was as PROs. The main objective of ICHOM is to develop patient-centred outcome measures for use in clinical practice and studies. ICHOM brings together working groups (patients, health professionals, researchers, outcome measurement experts and policy makers), organised around a particular medical condition. They use a structured consensus-driven approach underpinned by an initial literature review. The working groups: 1) prioritize and select outcome domains (e.g. symptom burden, health-related quality of life, functional status); 2) select outcome measures based on criteria such as psychometric properties, feasibility, ability to interpret scores and actionability; 3) prioritize case-mix domains; and 4) select case-mix definitions. Belgian experts participate in several of these working groups.

Patients are systematically involved in the development of ICHOM standard sets. In addition, patient advisory groups comprising 6 to 10 patients support the working groups, for instance to identify outcome domains of interest and to check if the final recommendations correspond with patients' values patient.

ICHOM is a non-profit organization forming networks of hospitals, government agencies, professional organisation, industry, etc. around the world. These organisations act as sponsors and they work together to start to measure, benchmark and use patient-centred outcomes that represent true success in managing the specified medical condition. The sponsors receive, depending on their membership type ('bronze'; 'silver'; 'gold'), feedback reports (with international benchmarks) and a voice in which 'standard sets' should receive priority. The end product (set of outcome measures) are published on the ICHOM-website and publicly available.

ICHOM standard sets are condition-specific but ICHOM is also developing a core set of outcomes measures that would cut across conditions and form the basis of all adult health Standard Sets. ICHOM has now produced 21 standard sets of outcomes, while 10 other standard sets are under development for diverse conditions.

The **OECD** takes several initiatives on PROMs and PREMs. It monitors PREMS in ambulatory care in 19 countries. PREMs are also part of the Health at a Glance reports. These reports are published bi-annually by the OECD and includes key performance measures with benchmarks for OECD member states. Besides these initiatives the OECD recently launched the PaRIS-initiative[d] (Patient-Reported Indicators Survey), following the recommendation of the OECD Health Ministers to develop internationally comparable PROMs and PREMs. The PaRIS-initiative ('Patient-Reported Indicators Survey') has two main objectives:

c www.ichom.org

d www.oecd.org/health/paris.htm

- To accelerate and standardise international monitoring, in population groups where patient-reported indicators are already used starting with breast cancer and hip and knee problems. There will be no new instruments developed but panels of experts will convene to agree on which existing instruments are most appropriate to be used in the PaRIS-initiative. Piloting the data collection is foreseen in a selection of countries from May 2018 onwards. Mental health has been pointed out as the next domain for which indicators will be developed.
- To develop new patient-reported indicators in critical areas of healthcare, where none currently exist (complex, long-term conditions), and to publish international benchmarks of health system performance for these healthcare areas. This activity of the PaRIS-initiative is still in its early stages.

Within PaRIS, collaborations are sought with other international partners, such as ICHOM and the Commonwealth Fund[e].

The OECD developed a set of principles for establishing national systems of PREMs, based on lessons learnt from members states about what works and what does not (see Text box 1).

Text box 1 – Principles for establishing national systems of patients experience measurement as proposed by OECD, HCQI Project[f]

- Patient measurement should be patient based (e.g. input from patients via focus groups or interviews to make sure that the questions concern topics that are important to patients).
- The goals of patient measurement should be clear (e.g. external [accountability to general public] versus internal goals [e.g. quality improvement by providers]). Although some measures can serve several goals, determining the goal before measurement is essential. When the goal is quality improvement the instrument should deal with actionable elements of the care process. When the goal is to facilitate choice, the measures should be able to show meaningful differences between providers.
- Patient measurement tools should undergo cognitive testing and the psychometric properties should be known. It is also important that changes to questionnaires are documented and when necessary re-tested.
- The actual measurement and analyses of the patient experiences should be standardised. Countries can, for instance, introduce accreditation procedures for the various agencies/vendors who conduct surveys.
- The reporting method of findings of patient experiences measurement should be chosen with care.
- International comparability of measurement of patient experiences should be enhanced.

e www.commonwealthfund.org

f www.oecd.org/els/health-systems/health-care-quality-indicators.htm

- National systems for the measurement of patient experiences should be sustainable which requires long-term health system commitment and resourcing:
  - A clear governance structure including organizational and research and development infrastructure. This could either be within a newly established institute or within an existing institute (e.g. the Ministry of Health or the Central Bureau of Statistics). According to the OECD the creation of a new institute more often results in robust results. Dividing responsibilities over different organisations, as is done in some countries, entails a challenge (or threat) for the development of robust strategies in measuring and reporting PREMs.
  - Funding and resourcing commitment. Political commitment and stable budgets are required to make the collection and reporting of PREMs part of routine activities of a health system. Nevertheless, the financial sustainability of PREMs seems to be vulnerable, as demonstrated by the diminishing willingness to pay in countries because of general budget cuts in healthcare.

Source: adapted from OECD 2017[5]

4. NATIONAL INITIATIVES IN FRANCE, THE NETHERLANDS AND THE UK

We examined the implementation and use of PROMs and PREMs for the improvement of patient care and policy purposes in the UK, the Netherlands and France.[g]

4.1. Different systems and stages of implementation

Although all studied countries have a legal basis for measuring patient experiences they are at different stages in the implementation and use of PROMs and PREMs. They all started with PREMs and subsequently implemented PROMs. UK was an early adopter, while France is still in the early stages of performance measurement.

[g] The UK was selected because they have world-famous programmes for PROMs and PREMs, the Netherlands because of their substantial experience with the implementation of PROMs and PREMs and the personal network of the researchers who performed this study within the Netherlands and France because much of the grey literature is in French, which made it more feasible to include this country than other language countries.

Table 2 – PROMs and PREMS in France, the Netherlands and the UK

	France	The Netherlands	United Kingdom
Sectors in which PROMs/PREMs are used	Hospital care (PREMs)	Various (Hospital care, primary care, mental healthcare, long-term care) See for PREMs (CQI-questionnaires): https://www.zorginzicht.nl/bibliotheek/cqi-overzicht/Paginas/Home.aspx	Various (GP services, Hospital care, Accident & Emergency care, Mental healthcare, Maternity care, Social care, Cancer care)
Intended aims (alphabetical order)	• Pay for performance • Public reporting / Transparency • Quality improvement	• Accountability / Governance • Benchmarking / Monitoring • Clinical practice • Patient choice / Empowerment • Pay for performance (P4P) • Public reporting / Transparency • Quality improvement	• Accountability / Governance • Benchmarking / Monitoring • Clinical practice • Commissioning, Contracting, P4P • Patient choice / Empowerment • Public reporting / Transparency • Quality improvement
Financing	Ministry of Health	• Ministry of Health • Health insurance companies • Funds and foundations • Providers	• Department of Health • National Health Service Trusts • Care Quality Commission • Clinical Commissioning Groups • Providers • Innovation funds / Prizes

4.2. Comparable aims

France, the UK and the Netherlands have formulated comparable aims when starting to implement PROMs and PREMs. PROMs/PREMs were intended for:

a) Policy reasons such as governance, regulation, commissioning/ reimbursement and transparency – aimed to monitor performance across professionals, specialties or divisions, organizations, regions or whole health systems; and

b) Clinical practice: for screening/diagnosis, health needs assessment, patient monitoring, shared decision-making etc. – aimed to improve the clinical management and individual patient care.

The extent to which the intended goals have had an impact is difficult to assess. On the one hand, there appear to be promising examples for each of the intended goals, while on the other hand many initiatives failed to reach the intended goals, were restructured, aborted, or followed up by other types of initiatives. Moreover, even promising initiatives that appear to reach goals, or are expected to reach goals, were often terminated or restructured. The most pronounced example is the world-leading the PROMs programme in the UK; this programme effectively stalled in 2012 due to a lack of funding. However, while achieving the aims as intended might be difficult and pre-existing expectations might not be reached for diverse reasons, there appears to be a persistent faith in the potential of PROMs and PREMs that drives continuing efforts for implementation and optimization.

4.3. Different implementation strategies

There are different approaches for implementing PROMs/PREMs that lie on a continuum between two extremes. One extreme is where the government or management of a healthcare institution drives the implementation process, defines the rules, performs the assessments and takes action based on the results. This could be considered as a strict top-down approach. Another extreme is where the entire initiative is driven from the field, with healthcare providers setting up a data collection system, assessing and using the data in their daily practice or for defining quality improvement strategies. In-between these two extremes, intermediate approaches exist.

Also the emphasis on either of these approaches may shift over time. Although many initiatives state that they have multiple aims, top-down approaches tend to focus more on external accountability and control, while bottom-up approaches tend to focus more on quality improvement and clinical management.

In France there has been a top-down approach, with the Ministry of Health establishing a strong legal framework for PREMs (and other quality indicators) and the Haute Autorité de Santé (HAS[h]) coordinating data collection, analysis and presentation[i] of the results. In the Netherlands the nationwide implementation of PREMs was instigated by a top-down approach, because of a reform of the health system in 2006 and the introduction of regulated market competition, but bottom-up initiatives of healthcare providers, patient organizations and health insurance companies quickly followed and the government reduced their own involvement from 2012 onwards. Similarly, in the UK, there was initially a strong top-down approach, reinforced by governmental and regulating bodies and supported by white papers, legislation and reimbursement schemes. The aim was to monitor accountability and reimbursement of healthcare performance, but slowly – and more recently – the approach is shifting towards bottom-up for use in clinical practice.

h See www.has-sante.fr/portail/jcms/c_1661702/fr/le-patient-traceur-en-etablissement-de-sante and www.has-sante.fr/portail/jcms/c_2614161/fr/le-patient-traceur-en-ville

i www.scopesante.fr

4.4. Various instruments and survey methods

Whereas France uses a single PREM questionnaire to evaluate hospital care, the UK and the Netherlands use a wide range of both generic and disease-specific PROMs and PREMs. The generic PROM used by both countries is the EQ-5D[j]. For PREMs and disease-specific PROMs, the questionnaires vary by condition, service or treatment. For the collection of data, both postal and electronic questionnaires are used.

In general, PREM data are collected retrospectively and PROMs are measured pre- and post-treatment. The response rates in the Netherlands and the UK generally ranged from 70-90% for PROMs and 30-50% for PREMs (no data for France). Response rates are generally lower in disabled, elderly patients, ethnic minorities. There also seems to be an overall decrease in response rates over time which may suggest survey / questionnaire 'fatigue'.

As for the presentation of PROMs and PREMs analyses, several guides, handbooks and quality standards have been published in all three countries. All three countries stimulate transparency and have public websites for reporting patient experiences.

4.5. Scarce evidence on the use and effects of PROMs/PREMs

Despite ample reporting on the use of PROMs/PREMs in France, the Netherlands and the UK, there is very little evidence on actual quality improvements. For example in the UK, where PROMs were introduced to improve the equity and appropriateness of care, recent studies still show significant health disparities, practice variation and regional differences (such as the persisting 'London effect', showing lower quality scores in the region of London as compared to the rest of England). Few longitudinal studies show a modest overall improvement in patient experiences in the UK, mostly following a national focus or target, supported by extra funding or commissioning (e.g. improved access to primary care or cleanliness in hospitals).

j euroqol.org

5. PROMS AND PREMS IN BELGIUM

We performed an online survey to get a rough idea of the current use of PROMs and PREMs in Belgium. Based on this survey 10 cases were selected for a more in-depth analysis. In the selection of the cases the following variables were balanced: small and large initiatives, initiatives that implemented PROMs, PREMs or both, French-speaking and Dutch-speaking organisations, micro-, meso- and macro-level initiatives. This selection is by no means intended as a representative sample of all initiatives in Belgium. The main objective was to get a general idea of the status of PROMs and PREMs in Belgium and the experiences so far. For each case, a site visit was scheduled to conduct semi-structured interviews with key-informants (e.g. clinicians and management). One researcher attended all site-visits and was accompanied by one of two other researchers (alternating each visit). During the interviews we focused in general on the 'steps in the process of setting up a PROM or PREM initiative' as well as on the 'main facilitators and barriers'. Each interview was audio-recorded. Together with field notes the researchers made a transversal analysis based on these audio-recordings. This transversal analysis was first made by one researcher and next challenged by the two other researchers.

5.1. General observations

A first general observation that, independent of the purpose of the PROMs or PREMs initiative, there is a large variability in (1) the extent of the initiative, (2) the standardisation of instruments, and (3) the embeddedness in the decision making processes. In several cases, PROMs are currently still only measured in a pilot project or study context.

Secondly, all initiatives seem to struggle with the resource requirements for their initiatives.

Thirdly, most initiatives in hospitals depend on the enthusiasm of some people within the organisation. While these individuals have a strong drive to improve practices, their dynamic attitude is not necessarily shared within the entire organisation. This might be explained by the fact that PROMs and PREMs are only at the early phases of development in Belgium and it will take time but also support (financial and managerial) to create a PROMs/PREMs culture within the healthcare system in general and the healthcare organisations in particular.

5.2. Purpose of PROM and PREM data collection

In several hospitals PROMs are measured with a purpose of quality improvement of clinical care at service or hospital level (meso level) and individual patient care or shared decision making (micro level).

Given the trend of increased home care for patients with chronic diseases such as cancer (e.g. chemotherapy at home), systematically measuring PROMs from a distance can help to improve the clinical follow-up of these patients and avoid potential risks associated with health interventions provided at home (e.g. serious side-effects of medication).

Both PROMs and PREMs are used for benchmarking and quality improvement. Umbrella organisations, such as Santhea[k] and the *Vlaams Patiëntenplatform*[l], and independent research associations or service providers such as BSM[m] and PAQS[n] support hospitals in their PROMs and/or PREMs initiatives, but do not interfere with internal procedures, feedback and process changes. They help, for instance, with the choice of instruments, coordinate collaboration between members, provide scientific support (e.g. statistical analysis, overview of the evidence-base for specific PROMs or PREMs) and perform benchmarking. However, the limited standardisation of PROMs and PREMs used across hospitals hampers real benchmarking.

Two large initiatives, one in the Flemish-speaking region and one in the French-speaking region, are supporting hospitals in using standardized

k www.santhea.be

l www.vlaamspatientenplatform.be

m www.bsm-management.be

n www.paqs.be

PREMs: the *Vlaamse Patiëntenpeiling*[o] *(VPP)* and the project *ASPE (Attentes et Satisfaction des Patients et de leur Entourage*[p]*),* respectively. A description of the VPP and project ASPE is provided in Text box 2. Nevertheless, besides the questionnaires of the VPP, ASPE, several other PREMs are being used by the responding organisations, sometimes validated existing measures, but often also self-developed questionnaires or questionnaires of unknown origin.

Text box 2 – Largest PREMs initiatives in hospitals in the Flemish and French-speaking communities in Belgium

Project ASPE: Attentes et Satisfaction des Patients et de leur Entourage (French-speaking community)

The project ASPE is a project set up by the independent private consultancy company BSM for the French-speaking part of Belgium. It originated from a PhD project of the director of BSM, followed by a project supported by the Walloon Ministry of Health until 2004, which was then moved to BSM from 2005 onwards to guarantee continuity.

The project ASPE aims to

- provide methodological support to the quality-improvement initiatives of participating hospitals, both scientifically (content based on literature) and statistically standardise measurements of patient-reported experiences and satisfaction in order to allow benchmarking between participating hospitals,
- provide comparative analytical data of key variables about patient satisfaction and experiences,
- identify 'best practices' and priority areas for action to improve patients' and their family's satisfaction and experiences,
- exchange experiences of successful cases and organise site visits, including concrete advice from colleagues.

Participation by hospitals is voluntary. Although the project is coordinated by BSM and all scientific analytic work is performed by collaborators of BSM, the project is governed by 9 representatives of the participating hospitals. Currently, 17 hospitals participate in the project, representing 40 sites. Besides the governing body (comité de pilotage), responsible for the strategic decisions and priorities, a coordinating committee (comité des coordinateurs) exists with members of all participating hospitals. The coordinating committee has a very important role. It is responsible for the administration, communication and follow-up of concrete initiatives in collaboration with the quality coordinators of the participating hospitals.

The project governing committee decides on the activities performed during the project. Several domains are worked on. The participants are free to choose to which activity they participate and to which activity they do not participate. However, once engaging in an activity, the participating hospital is committed to adhere to the terms of the chosen framework (duration, instrument, mode of distribution, …) in order to ensure valid and comparable data.

Both generic and domain-specific PREMs are used. The generic PREM relates to the classic hospitalisation as well as to the one-day clinic. Domain-specific activities currently included encompass maternity care, paediatrics, day hospitalisation and surgery, emergency department, medical imaging, revalidation, hotel function, social service, consultations, geriatric care, intensive care (visitors' experiences), nuclear medicine, high-risk pregnancy, dialysis, medically assisted pregnancy, chronic psychiatry, acute psychiatry, treating physician, retirement home, satisfaction of staff.

o vlaamspatientenplatform.be/themas/kwaliteit-van-zorg#Kwaliteitsindicatoren%20AZ

p patientfriendlyhospital.be/aspe

For some of these domains, an annual benchmarking is performed, for others every two or three years and some upon request. Each year, 7 to 8 benchmarks are performed. Data of about 50.000 questionnaires are analysed each year for these purposes. For each benchmarking exercise, a detailed presentation as well as an executive summary is provided. The results are sent to the general directors and quality coordinators of the participating hospitals.

The questionnaires are developed with the partners in consultation with patients and healthcare professionals. They are based on literature, the methodology for analysing the data on patient experiences and the multi-attribute model applied to analyse the service quality dimensions from the patient's point of view. The questionnaires are systematically pre-tested in other patient populations, in different contexts and hospitals.

The hospitals are free to use their own results of the benchmarking studies for marketing purposes, however, always without making reference to any of the other hospitals participating in the project by name.

Hospitals who wish to participate in a benchmarking exercise for one or more of the domains are required to follow the instructions regarding the timing and the protocol of the study. The questionnaires include questions about the patients' profile, reason for choosing the hospital, quality indicators based on patients' experiences, PREMs, global performance indicators (quality, satisfaction, trust, empowerment, recommendation, etc) and an open question regarding suggestions. For example, for the classic hospitalisation the questionnaire for 2018 encompasses 30 questions on the patient profile, 12 PREMs, 70 quality indicators covering 9 generic themes, and 6 general satisfaction questions and one open question.

Besides benchmarking, other services are provided: scientific and practical support to partners, exchange of experiences between partners, an online closed "patient-friendly hospital"-platform on which partners can discuss experiences and scientific evidence is posted, board tables, and updates regarding e.g. e-health and scientific advances in the field of patient satisfaction and experiences.

The Vlaamse Patiëntenpeiling (VPP) (Flemish community)

The Flemish Indicator Initiative 'VIP²'q aims to improve the quality of patient care by means of clinical process and outcome indicators. The initiative was initiated by the two hospital umbrella organisations, the Flemish government and the association of chief physicians. All relevant stakeholders are involved, (i.e. besides the initiators also the Flemish umbrella patient organisation, the scientific community, and the data registry owners (Sciensano, the Cancer Registry and the Intermutualistic Agency). It collects indicators for acute hospitals on the following domains: mother and childcare, orthopaedics, cardiology, breast cancer, stroke, patient experiences and hospital-wide quality; as well as for mental healthcare and assisted-living centres. Besides the provision of feedback and benchmarking reports to organizations and healthcare providers, for a selection of indicators the results are made public in an aggregated manner on the website www.zorgkwaliteit.be. The public reporting is organised on a voluntary basis and the website only allows to generate the results from three hospitals per report. On a monthly basis on average about 3000 unique visitors are counted but it has not been appraised who visits this web site and how they use the data from this website.

q www.zorg-en-gezondheid.be/kwaliteitsindicatoren-voor-algemene-ziekenhuizen

One of the domains included in the VIP² indicator set for which results are publicly available are PREMs. The PREMs were introduced under the leadership of the 'Flemish Patient Platform (VPP – Vlaamse Patiëntenplatform)'. The VPP developed, together with an academic centre, questionnaires to survey experiences of hospitalised patients in acute hospitals and of both hospitalised and ambulatory patients in mental health services. Both instruments were rigorously developed with much attention to the psychometric properties of the instrument as to the preferences of patients and healthcare providers. The instrument development process included: a scoping literature search to identify topics and instruments, focus groups with patients and experts to identify priorities, preliminary field test followed by extensive region wide testing to test psychometric properties and fine-tune the wording and response categories.

The instrument for acute hospitals, is largely based on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), and includes questions about: 'preparing for hospital stay', 'information and communication', 'coordination', 'respect', 'privacy', 'safe care', pain management', and 'participation'. There are also two general questions: one asks to rate the hospital from 0 to 10 (worst to best possible hospital) and one that asks if patients would recommend the hospital to friends and family. At the end of the questionnaire some demographic variables are questioned to allow for case-mix adjustments in the data analysis.

Acute hospitals participate on a voluntarily basis (but nearly all hospitals do so: in 2016: 48 out of 55 hospitals) with two measurement periods (March/April and September/October). There are clear instructions to collect the data (e.g. data collection should involve the entire instrument, patients with a sufficient knowledge of Dutch at surgical, medical, geriatric, maternity, and specialized unit) but also a degree of flexibility (e.g. hospitals can add questions at the end of the questionnaire, data collection at the end of discharge versus after discharge).

Hospitals are required to recruit a minimum of 150 adult patients per period and are asked to submit data within two months to the Flemish Agency for Care and Health (Flemish public administration). In 2016, the data from 31 892 patients collected by 48 different hospitals showed that 54.9% of patients rate their hospital 9 or 10 (min: 39.0%–max: 69.3%), which is far below US standards. In addition, large variability between Flemish hospitals exist.[6]

The main limitations reported are: the lack of response rates reporting; absence of case-mix adjustment and the absence of a mechanism to assess whether all completed questionnaires are transferred to the Flemish Agency for Care and Health. Case-mix adjustment, also retrospectively to allow assessment of evolutions over time, is being worked on and will still be solved in 2018. Another limitation in light of national policy initiatives (such as pay-for-performance) is that the questionnaire is not used in French speaking hospitals. Another limitation is that only top box ratings on the general question (respondents giving the hospital a score of 9 or 10 on a scale from 0 to 10) were publicly reported. Although in general all items of HCAPHS were strongly positively associated with the global rating, recent research suggest that the widely used cut-off point of 9 may not be the most optimal reflection of positive patient experiences with care. What's more, individuals across populations appear to use the hospital rating scale differently which limits the use of these cut-off points (especially when comparing populations). The Agency is working on this issue and will report the scores on individual items from 2018 onwards.

The first version of the Flemish Patient Survey of Mental Healthcare, which followed a similar development process, includes 8 demographic items, 2 items reflecting global rating, and 35 core questions hypothesized to measure nine domains: information about mental health problems and treatment, participation, therapeutic relationship, personalized care, organization of care and collaboration between professionals, safe care, patient rights, result and evaluation of care, and discharge management and aftercare.

Patients can only complete the questionnaire after at least 4 days of admission (psychiatric hospital, general hospital psychiatric ward, psychosocial rehabilitation, and psychiatric nursing home) or after at least four sessions or contacts (sheltered housing, ambulatory public funded mental health services, and mobile community teams). A process evaluation showed that the clear communication about the objectives and contents of the questionnaire, the clear inclusion and exclusion criteria, and questionnaire length were appreciated. Nevertheless, the informed consent procedures were viewed as too complex and the availability of a Dutch version of the questionnaire only was considered as too restrictive. In the meantime, a French version exists. Moreover, the manual input was too time-consuming. This related to the main negative point, mentioned by a number of organizations, which was the short time span in which the data collection and uploading needed to be completed. Whereas several organizations indicated that they would prefer continuous measurement of each discharged patient, a large majority (n = 35, 64%) indicated that it would not be possible to do two rounds a year. This would be too expensive and time-consuming.

Also for assisted-living centres, a survey was performed. All residents were asked to complete the questionnaire, but only about 40% were capable to do so. The survey ran for 3 years and was then abandoned for reasons of lack of feasibility (low response rates).

PREMs are also used by hospitals for marketing purposes but at the same time they increase the average quality of care in the Belgian hospital sector, which will benefit public health.

The *Vlaams Patiëntenplatform* emphasizes that the *Vlaamse Patiëntenpeiling* should be considered as a barometer for the hospital, to identify the areas in which quality improvement is possible. It might be that further questioning of patients is needed to identify exactly how quality could be improved in these areas. The "*Projet ASPE*", however, aims to support hospitals directly in their quality improvement initiatives. The richness of the data collected (>25 000 questionnaires) allows statistical analysis that permit to identify procedural aspects that determine the satisfaction of patients (through factor analysis), which is relevant overall, not for one specific hospital. The initiative demonstrates that these data can be used to improve quality of care overall, if the individual hospitals are prepared to (invest in the) use the outcomes for their quality improvement actions.

On the macro level, PROMs and PREMs are included in the Health Information Survey (HIS), organised and coordinated by the Scientific Institute of Public Health (WIV/ISP, recently reformed into Sciensano[r]). These PROMs and PREMs allow monitoring of patient health and experiences with healthcare. PREMs items included are those proposed by the OECD and relate to patient experiences with GP consultations, specialist consultations (at the outpatient department of a hospital, at an ambulatory practice or by telephone) and with healthcare in general. The PREM questions are standardised across countries and used by the OECD for cross-country comparisons (published in the "Health at a Glance" reports). For PROMs, a generic questionnaire is used, the EQ-5D-5L, allowing monitoring on five general domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The PREMs included in the HIS allow a general assessment of patient issues and organisational issues associated with health conditions and treatments.

[r] www.sciensano.be

At the level of the RIZIV – INAMI reimbursement commission, PROMs could play an important role in reimbursement decisions according to the representative interviewed, not only for individual reimbursement decisions such as in the context of the Special Solidarity Fund, but also for other types of decisions taken at the RIZIV – INAMI. The unmet needs commission (CATT – CAIT) has to judge the level of unmet need in a particular disease in order to evaluate whether a promising new drug is eligible for coverage through the unmet medical needs programme. However, up to now little or no initiatives have been taken to systematically collect PROMs for this purpose, hence only PROMs used in the context of studies can now be taken into account in the appraisal processes.

The use of PREMs in the context of pay-for-performance is foreseen for the near future in Belgium. Part of the performance points used for this purpose will be based on PREMs. An issue with this is that currently different regions are working with different PREMs. Lack of coordination between the initiatives, leading to a lack of harmonization in data collection methodology and data analyses, might hamper the implementation of PREMs for the pay-for-performance objective in Belgium.

5.3. Stakeholder involvement

Success stories mainly come from organisations where the initiative was taken by the healthcare professionals involved in clinical care. This confirms the finding in the other countries that a bottom-up approach seems to work better than a top-down approach. Also a multidisciplinary approach was mentioned by several interviewees as an important success factor. The advantage of a multidisciplinary working group is that different visions are present and a broader perspective can be taken (e.g. anaesthesiologists can have a different perspective than nurses). Nurses often take care of the data collection, and sometimes provide support in the data analysis phase. IT support is often needed to ensure accessibility of the data, and clear reporting of results. Finally, juridical support is also crucial for a legally correct implementation of a PROMs and PREMs initiative.

The engagement of clinicians is also very important for the participation of the patients. If clinicians use the input provided by patients through the PROMs and PREMs in their clinical practice, patients are more likely to engage in the data collection initiative. When patients were also involved in the development of the PROMs or PREMs initiative, this likelihood may increase further. Patients can also help to assess the user-friendliness of the feedback regarding e.g. the benchmarking on the web-sites of hospitals. However, involvement of patients was not seen systematically in all initiatives. Those who do involve patients state that patient information and education is essential to ensure patient engagement.

Although a bottom-up approach seems to work better than a top-down approach in hospitals, involvement of the management (including quality coordinators) is of crucial importance, especially to streamline the approaches across departments. Management obviously also plays a role in financing decisions.

Hospitals find it difficult to involve the general practitioners in their initiatives. Nevertheless, involvement of the primary care sector is important because not all patients will have to return to the specialist after intervention.

5.4. Digitalization of data registration and clinical registries

Hospitals using electronic surveys to collect data are positive about them. Electronic systems allow colour coding, ensuring that severe complications do not get unnoticed (e.g. by assigning them a red colour). The colour can be linked to alert systems, e.g. when a red coded complication is reported, the patient is prompted to contact the hospital immediately. Electronic systems also allow to include reminders to complete the PROM instrument, graphical presentation of the results and, in principle, direct integration in other databases, such as clinical registries or other centralised databases. Clinical registries play an important role in obtaining ‘real world’ data to generate evidence about the impact of treatment and service delivery models on health outcomes in real life. The integration of PROMs in clinical registries is on the rise in Belgium, but integration of PROMs in registries is not systematic yet. Technical and operational aspects and aspects of privacy still need to be sorted out for many PROMs. It was outside the scope of this study to examine in-depth the ways privacy issues can be tackled, but clearly the protection of the privacy of citizens is a high priority topic for many institutions and governmental agencies. It is crucial to consider standardisation of data collection and instruments to make these data registries useful for meso- and macro-level purposes.

Sporadically also phone-calls are used to collect PROMs data. This is an intensive and expensive approach, but effective for initial non-responders and identifying patients with significant medical problems that would have gone unnoticed otherwise.

5.5. Integration of data in electronic patient records and registries

Integrating results directly into the electronic health record can help to ensure that clinicians get this information at the right time. While all hospitals included in our sample expressed an interest in integrating PROMs in the electronic health record of the patient, only one performed such integration for one of its PROM initiatives for one specific service, in the context of a pilot study.

5.6. Measurement frequency

In the context of a pilot project, one of the initiatives measures PROMs longitudinally and prospectively in one chronic patient population. Despite the recognized advantages of longitudinal PROM data, many hospitals ask patients to complete the PROM only once, e.g. after surgery, or at discharge. This is considered sub-optimal because it gives no idea about the evolution in the outcomes over time (e.g. after surgery, several days of measurement is considered essential), but often related to time and budget constraints.

For PREMs, cross sectional data collection is more frequent. There is quite a large variability in timing and frequency of registration amongst institutions. Some hospitals administer the PREMs the day before discharge from hospital, others ask patients to complete the questionnaires after discharge (in particular when electronic means are used but also phone calls are made for specific groups).

In the context of the HIS, recurrent cross-sectional measurements are performed. Because the sample of the general population varies across years, longitudinal data analyses cannot be performed.

5.7. Population

On the micro level, PROMs or PREMs could be administered to specific patients or all patients from the target group (e.g. lung cancer) or all patients of a specific department (e.g. stroke unit). Currently, each institution decides by itself to whom to distribute the PROMs and/or PREMs. It depends on the availability of resources and the purpose of the measurements.

Differences in implementation strategies between hospitals (not all hospitals asking all patients to complete the PREMs for instance) hamper comparisons between institutions, because it is impossible to judge to what extent the data provided emerge from a representative population sample of the hospital.

5.8. Instruments

The most commonly used instruments to collect PROMS and PREMs are surveys. For micro level purposes, usually condition-specific PROMs are preferred. There is a huge variety in instruments used in Belgium to measure PROs and PREs. The choice of the instrument is often determined by its practicality.

The standard sets of ICHOM are perceived as valuable, but some questionnaires are also perceived as being too long and burdensome for patients. Therefore, one hospital now works at shortening on of the standard questionnaires in a scientifically valid manner, with the help of an academic team. On the one hand, this may hamper the comparability between hospitals, but on the other hand the hospital considered it valuable to do the effort because others probably have the same concerns and are therefore reluctant to start using the ICHOM standard sets. Another hospital made the same comment and decided to implement only part of the standard set in a specific patient population, to allow for a quicker and more feasible implementation. Yet another hospital mentioned issues with language versions. Questionnaires not available in French or Dutch need to be translated and validated in these languages. This is a lengthy process.

Considerations that determine hospitals' choice of PROMs are

- the length of the questionnaire,
- the use in clinical studies or by respected international organisations,
- the possible integration in the electronic patient record,
- the financial aspects related to the purchase of the questionnaire,
- the scientific validity and usefulness for scientific research, and
- the generic (chosen by the hospital management) or condition-specific nature (chosen by clinicians).

For PREMs, regional differences are observed. The Flemish region mainly uses the *Vlaamse Patiëntenpeiling.* Some concerns were raised about the generic nature of the PREMs included in the VPP, and the absence of aspects that are relevant according to the hospital management (e.g. food, comfort of the room, cleanness of the room, reception). In French-speaking Belgium, patient satisfaction questionnaires as proposed by (the working group of) Santhea or the patient satisfaction questionnaires and PREMs as proposed by BSM for the ASPE project are used. There is overlap between the questionnaires used in both regions, but no standardisation across initiatives. Within ASPE the questionnaires for each domain considered (surgery, maternity, emergency services, …) are standardized, but between the PREMs used by ASPE and by Santhea, there are still important differences, also due to the liberty of the Santhea members to use part of the questionnaires or the full versions.

5.9. Operational aspects

A comment given by several interviewees was that informing the patient about the purpose of the data collection is a very important operational aspect. This is independent of the level on which the data will be used (micro, meso or macro). With better information, the participation increases. In addition, the number of questions and frequency of measurements should not be too high.

Also *vis à vis* the clinicians, good and convincing information is required to motivate engagement in PROMs or PREMs initiatives. One interviewee mentioned that clinicians always have reasons not to participate: lack of time, "patients do not want to fill out these questionnaires", "no need for these data to improve my practice because I have sufficient experience to know what I must do". By showing the data, and involving patients in the development process of the PROMs/PREMs initiative, the beliefs of the clinicians might change.

For the collection of PROMs and PREMs data, supporting staff is required. Also for the follow-up PROMs measurements, a dedicated person is needed, in order to avoid reduced participation of patients who are symptom free (knowing that patients are symptom free is also important from a clinical point of view).

At the hospital level, several ad hoc initiatives are taken in the context of scientific projects on PROMs or PREMs (e.g. PhD projects or other academic studies). This has several advantages. It builds a solid scientific foundation for the initiative. If financed through a research grant, less resources are moreover required from the hospital. However, project-based initiatives are often limited in time and heavily depend on the interest of researchers to develop further projects in this field. Their sustainability is hence not guaranteed.

A few interviewees referred to the usefulness of defining SMART objectives when developing an implementation plan. SMART stands for "Specific, Measurable, Attainable, Relevant and Timely". Defining the SMART objectives ensures focus, usability and applicability of the measurements.

On the meso and macro level the most important operational aspect is standardisation in the collection of data across institutions. If this is lacking, the usefulness of the data for assessing the quality of care and for benchmarking or for pay for performance is seriously reduced.

5.10. Data analysis and feedback

On the clinical care level, the main focus is on the identification of symptoms and problems and the evolution of PROMs over time and communication with the patient about observations on the PROMs. Information from PROMs is also used for multidisciplinary consultations.

Only few hospitals analyse PROMs and PREMs on a central level and use the results in feedback reports to the clinicians. Hospitals found that the actual use of the feedback reports as well as the implementation of actions distilled from it heavily depends on the culture at the hospital unit. Critical success factors for translation of results to actions are engagement of the nurses and doctors, and support and motivation from the quality coordinator and management.

Hospitals mentioned that the lack of integration of the PROMs and PREMs data in the electronic patient record hampers analyses on a transversal level, as corrections for patient characteristics are not possible.

The analyses of the VPP data are performed by a thrusted third party and are coordinated by the *Vlaams Agentschap Zorg en Gezondheid*. Hospitals do not have access to the individual data of other hospitals, only to aggregated benchmark data. Demographic data was up until now not used in the analysis, but would become more important for case-mix adjustment if pay-for-performance approaches would be considered.

The VPP publishes the results of the analysis of two generic questions from the PREM per hospital online on zorgkwaliteit.be. Hospitals are free to decide whether they want their results to be published, but almost all hospitals decide positively. On the web-site people can compare every hospital to two other hospitals of their choice. Hospitals in addition receive more detailed results for each question, where the other hospitals' names are concealed. According to the *Vlaams Patiëntenplatform*, it is the role of the hospital umbrella organisations to inform the hospitals on the good practices, with the *Vlaamse Patiëntenpeiling* as a barometer. The advantage of making all results publicly available is full transparency. However, the disadvantage is that the data provided might become biased, because hospitals do not want to appear on the website with bad results. As a consequence, the data become less useable for the purpose it tries to serve. Hospitals included in our sample expressed their doubts about the reliability of the results of the data analyses performed in the context of benchmarking activities, because of the differences in measurement frequency, data collection procedures etc. The Vlaams Patiëntenplatform organises regular feedback moments with hospitals, where hospitals can indicate, through a participative methodology, any problem with the questionnaires, test protocols etc.

The initiatives in the French-speaking region do not publish any results, but make the anonymised aggregated results available to all participating hospitals. Besides the aggregated results, each individual hospital also receives its own detailed results.

6. BARRIERS AND FACILITATORS FOR PROMS / PREMS INITIATIVES

Several **facilitators and barriers** for the implementation and use of PROMs and PREMs were identified from the literature, the international comparison and the Belgian case studies (Table 3).

Table 3 – Barriers and facilitators regarding the implementation of PROMs and PREMS

	Facilitators	Barriers
General conditions and contextual factors	• Leadership, vision, clear objectives, drive and persistence • Central coordination of initiatives[1] • Political and economic drivers • Legal basis • Organizational culture oriented towards what matters to patients • Trust and confidence amongst stakeholders in the appropriate collection, storage and use of data • Financial and human resources • Gradual implementation • Transparent and sufficient communication • Multidisciplinarity of the initiative • Peer-pressure to engage and participate • Education of centres, health professionals and patients • Support from e-Health	• Conflicting or competing priorities (nationally, regionally or within organizations) • Pressure on financial and operational resources • Lack of interoperability between systems (electronic patient record, PROMs database, clinical register) • Privacy legislation • Lack of knowledge about PROMs and PREMs • Lack of knowledge about international initiatives (like ICHOM)
Selection of PROMs/PREMs	• National framework (definitions, measures, indicators) • Use of standard sets from cross-national initiatives, like ICHOM and OECD • Involvement of patients in development and choice of PROMs/PREMs • Support from external experts (e.g. scientific expertise)	• Conflicting visions between clinicians regarding the features of the PROMs to be implemented • Confusion in the definitions of PROs, PREs and patient satisfaction • Limited flexibility in existing PROMs and PREMs to address local priorities
Data collection	• Availability of an infrastructure for data collection and storage, e.g. integrated in the electronic patient records • Clear instructions for data collection (timing, patients, alerts, reminders …)	• Lack of standardisation in instruments used, data collection methods and timing, and reporting • Administrative burden

	Facilitators	Barriers
	• Engaged and motivated patients and families • Use of digital technology • Involvement of patients in defining the data collection approach	• Response and selection bias[2] • Technical problems with digital surveys • Lengthy questionnaires • Lack of transfer of information on PROMs in primary care to secondary and tertiary care and vice versa
Analysis and presentation of data	• Accessible data infrastructure, providing interactive tools for analyses and presentation • Support from a central data analysis unit • Risk- and case-mix-adjustment[3] • Standards for analyses and publication • Easy to read reports, linked to concrete actions needed for change in clinical practice	• Outdated results due to time-consuming heavy data logistics at meso level • Limited data standardisation hampers comparisons between services • Concerns about accuracy of data (biases, confounding factors and chance) • Statistical and technical data issues (e.g. risk- and case mix adjustment, skewed data, ceiling-effect, small samples) • Absence of baseline data • Compliance with privacy protection rules
Usefulness for decision makers to pursue their objectives with PROMs/PREMs	• Coordination between initiatives and exchange of experiences and best practices, both between and within organisations and decision levels[4] • Transparency: availability of user-friendly, comparable, reliable and understandable public information in a central place • Staff engagement, training and support, and ownership of knowledge obtained from measurements • Timely feedback towards healthcare providers • Use of performance data for commissioning, clinical auditing and accreditation • Financial incentives (pay-for-performance schemes, rewards) • Positive attention to centres who collect PROMs / PREMs data in a standardised manner and use the results to improve the quality of care • Non-blaming tone in feedback reports: objective presentation of results of the analyses • Rigorous performance monitoring and evaluation system	• Small differences between providers do not help patient choice or pay for performance • Difficulties in demonstrating the impact of PREM/PROM-measurements on quality of care • Delay in publication of results or feedback reports • Insufficient collaboration between primary, secondary and tertiary care, making the interpretation of PROMs results difficult or impossible • Difficulty to implement changes after feedback reports; lack of actionability of feedback (e.g. unclear from feedback what actions need to be taken to improve) • Lack of time between feedback reports and next surveys to implement improvement work

[1] *Central co-ordination of initiatives encompasses guidance on which questionnaires to use, timing of data collection, which inclusion and exclusion criteria to apply to ensure representativeness of patient samples, what to do in case of missing data.*

[2] *Response bias encompasses:*

- *lower response rates among certain vulnerable populations (e.g. elderly, refugees, emergency care patients, disabled)*

- *exclusion of patients speaking other languages than French or Dutch due to unavailability of other language versions of the questionnaires*
- *nonresponse due to resistance from patients, either towards the data collection approach (e.g. digital surveys), towards the use of their data (distrust in respect for privacy) or towards the content of the questionnaires (cultural issues)*
- *selection of 'good' patients if data are used for financing purposes*

[3] Risk- and case-mix-adjustment in the analysis of the data is done to take the impact of risk-factors (e.g. age, socio-economic status, ethnicity) and case-mix (co-morbitities, severity of disease) on outcomes into account. Risk- and case-mix-adjustment is important when data are used for benchmarking, to avoid incentives to select 'good' respondents only.

[4] E.g. between Vlaamse Patiëntenpeiling and Project ASPE, and between hospitals contributing to VPP and project ASPE.

In general, the existence of a patient-centred healthcare **culture**, **supported** by management and politics, **awareness** of the potential value of PROMs and PREMs from the providers and sufficient **resources** seem to be the major requirements for successful PROMs and PREMs implementation. With these requirements in place, healthcare providers will not consider PROMs and PREMs as an additional administrative burden, for which they '"have no time", which they "do not need because they have always done without" and that "patients don't want". The fact that currently the same data have to be registered into different databases (e.g. the electronic patient file and a clinical registry), combined with a lack of knowledge about the value of PROMs and PREMs possibly contributed to this perception of administrative burden.

Availability and cost of human resources to collect PROMs and PREMs data is obviously a very important consideration when thinking about the implementation of PROMs and/or PREMs in an organisation. On the output level, it should also be taken into account that data collection generates big data sets within hospitals that need to be managed. An adequate IT infrastructure is needed, as well as people who manage and analyse these data. On the input level, staff is needed to collect the data. While currently nurses are often engaged in data collection processes, it might be envisaged to create a different profile for this task (e.g. medical secretaries or medical management assistants).

One barrier that is difficult to resolve in the short term is the risk of selection bias in respondents related to operational barriers for patients, such as cultural or language barriers. The development of a new instrument or the translation of an existing instrument takes time. If such barriers are experienced, the scientific community, i.e. academic research groups, should be involved to develop and test new PROMs or PREMs.

7. DISCUSSION

Based on our findings from the literature review, the international comparison of three countries and the experiences in Belgium, we can conclude that the application of PROMs and PREMs in real life is still a field in development. In Belgium, as in the Netherlands, France and the UK, several small and a few large initiatives are taken to measure patient-reported outcomes and experiences for different purposes.

The largest experience is built up with PROMs for micro-level purposes (individual patient care). Evidence shows that this use improves the patient-centeredness of care, by improving the communication between the patient and the provider, monitoring disease progression and regression, and monitoring the effects of treatment. The evidence on the impact of PROMs on patient outcomes and satisfaction is mixed between 'no impact' and 'positive impact'. Often, no impact could be found due to ceiling effects. Especially in severely ill patient populations in whom there is much room for improvement, the evidence tends to be positive.

For the purpose of defining quality improvement initiatives on the meso and macro level, mainly PREMs are used, although PROMs also play a role. The extent to which the intended macro-level goals are achieved is difficult to assess because many initiatives are modified, restructured or replaced after implementation. It has been highlighted that there is a risk in using PROMs and PREMs for benchmarking purposes, especially when the results are made public. Hospitals or providers might have an incentive to select the best patients, either for completing the questionnaires or- in the worst case- for providing care. Whilst the relationship between PROMs / PREMs and quality improvement is hardly demonstrated, there appears to be a persistent faith in the potential of PROMs and PREMs that drives continuing efforts for implementation and optimization. Sharing of results within and between institutions is considered crucial for achieving quality improvement.

Risk- and case-mix adjustments of PROMs and PREMs are highlighted as being very important when PROMs and PREMs data are aggregated (e.g. for benchmarking purposes, for evaluation of health interventions, etc). Indeed, variation in these measures is influenced by many patient-level variables (e.g. age; sex; socio-economic status; ethnicity; healthier or sicker population; health behaviours such as compliance; life events; new healthcare episodes) that are beyond the control of the provider. The longer the time between the care episode and the outcome assessment, the higher the impact of these factors. Not all of the relevant confounding factors are included in the electronic patient record. Therefore, it might be challenging to perform adequate risk-adjustments in the analyses of the data. However, risk-adjustment is considered a prerequisite when PROMs and PREMs are compared between providers. Further empirical research will be required to identify which provider characteristics (e.g. workload, volume of patients, hospital type) influence variations in PROMs.

An additional challenge is rapid feedback, which is considered essential to define actions for quality improvement. However, rapid feedback is not always possible for PROMs as PROMs are often measured several months after treatment (e.g. full effect of knee surgery is believed to be reached after 6 months only). Moreover, the longer the time window, the more difficult it becomes to attribute outcomes to healthcare practice. The timing issue is also important for PREMs. To attribute PREM results to a provider, patients should be questioned about a specific care episode.

The experience with PROMs and PREMs for payment purposes is limited. The international examples show that PREMs initiatives are often started top-down, defining pay-for-performance as one of the aims, whilst at the same time many bottom-up initiatives are taken in clinical practice. This seems to indicate that health professionals consider PROMs and PREMs useful for quality improvement in clinical practice, irrespective of the initial objective of the PROMs and PREMs systems put in place by a government or regulating body. Despite the fact that initiatives at the macro level (for pay-for-performance, performance measurement, determining value for money) are often modified and changed or sometimes even abandoned, there appears to be a persistent faith in the potential of PROMs and PREMs that drives continuing efforts for implementation and optimization, especially at the micro level. This is also where the evidence on impact is strongest. The evidence of the impact of on PROM and PREM based pay-for-performance programs on patient outcomes is limited. Yet, when PROMs and PREMs are used for pay-for-performance the general considerations for pay-for-performance programs, as described in KCE reports 118 and 229,

apply (kce.fgov.be/publication/report/advantages-disadvantages-and-feasibility-of-the-introduction-of-%E2%80%98pay-for-quality%E2%80%99; kce.fgov.be/en/conceptual-framework-for-the-reform-of-the-belgian-hospital-payment-system).

The use of PROMs for reimbursement decision making is well-established, although PROM data used for this purpose mainly come from clinical studies. For re-assessment of already reimbursed interventions, PROMs should be collected routinely in real life. Despite a few exceptions, this has not systematically been established yet. For example TARDIS is a registry for rheumatoid arthritis, which contains clinical and PROMs information. Reimbursement of specific pharmaceutical products is conditional upon the registration of these data in the registry. Linking reimbursement to data input helps routine PROM registration, and can at the same time benefit the advisory committees at the RIZIV – INAMI who have to evaluate and re-evaluate the therapeutic value of pharmaceutical products or other healthcare interventions. Especially in the case of rare diseases, decision makers would benefit from a centralised database collecting the PROMs of all patients with the same rare disease. Also in the context of the managed entry agreements (art 81 conventions[s]), the systematic collection of PROMs in patients receiving the products under convention, would provide very important information for the re-assessment after the contractual period. However, these applications are very much top-down. They risk to be considered by healthcare providers as burdensome and imposing additional administrative obligations, for which they do not have time, and from which they do not see an immediate benefit for their clinical practice. Efforts should therefore be made to choose instrument in such a way that they are valuable for different decision making processes.

The variety of existing, validated PROMs and PREMs and differences in data collection approaches jeopardize comparisons between initiatives. Cross-country initiatives like ICHOM and PaRIS are developed to help to increase the standardization of PROMs and PREMs used in different countries and ensure scientific validity of measures used. A clear recommendation with respect to the implementation of PREMs for benchmarking purposes from the OECD is that political commitment and a stable budget is required to set up a governance structure to ensure robust strategies and results for PREMs.

On the national or regional level, alignment of data collection strategies (population, timing, instruments, …) is desirable to increase the data analysis possibilities. Inter-organisational comparisons can only be made when the approaches are similar in the different organizations. However, for clinical purposes, different organizations might want to make different choices. It has been highlighted by the international comparison and the Belgian case studies that **top-down guided bottom-up initiatives are the most successful in terms of changing practices**. Therefore, differences in choices should be respected and will probably lead to better results than determining the approach top-down, create resistance from the stakeholders implying the non-use or suboptimal use of the results.

[s] Art 81 conventions are managed entry agreements (MEA) for expensive pharmaceutical products or products for which the (cost-)effectiveness is still unknown or highly uncertain. They are used to grant early access to these products while controlling the budget impact, allowing additional data collection for the assessment of the (cost-)effectiveness, monitoring the (rational) use in clinical practice and generating real life data (e.g. on effectiveness and use). Often art 81 conventions are used to negotiate a lower price for very expensive pharmaceutical products. The agreements are confidential between the company and the public health authority.

8. CONCLUSION

The study showed that PROMs and PREMs are valuable in the endeavor to improve the quality of patient care. Especially on the clinical care level, PROMs have shown to improve the communication between patients and healthcare providers and thereby improve the experience of patients. Through PROMs, healthcare providers get a better idea of the impact of a disease and treatment on outcomes that matter to patients. PROMs and PREMs are complementary to traditional clinical process and outcome measures. They support, together with other initiatives (e.g. patient panels), the shift towards patient-centred care and to enable a more comprehensive understanding of outcomes and effectiveness of health interventions.

The evidence about the impact of PROMs and PREMs on meso-level processes and outcomes is still premature. No scientific evidence exists on the impact of PROMs and PREMs for macro-level purposes. More research, evaluation and close monitoring of nationwide initiatives is needed to establish the effects of PROMs and PREMs on health system performance and improvements in clinical practice. A stepwise introduction of PROMs and PREMs is recommended, preferably coordinated by a central coordination team to avoid huge variations in the choice of instruments, the data collection methods and the application. Although a calculation of the implementation costs was not performed in the current study, it is clear that sufficient resources are needed to implement PROMs and PREMs, both in terms of people and in terms of financial resources. Evaluation and optimization of measurement instruments and methods is needed to optimize and assure the quality and usability of data.

Several barriers and facilitators for PROMs and PREMs initiatives emerged from our study. Using a ‘bottom-up’ (clinically driven) approach in combination with top-down guidance (policy driven) seems to be the best approach to improve healthcare performance and clinical practice in an efficient manner. Guidance should consider the relevance of each measure for the purposes they mean to serve, in order to avoid patients’ survey fatigue. International initiatives such as ICHOM and the OECD initiatives can help Belgian decision makers to set up harmonized PROMs and PREMs initiatives in Belgium.

In the next section, recommendations are formulated both for the federal and regional governments and for the healthcare institutions and providers aiming at the introduction of PROMs and PREMs.

9. EXPLANATION OF THE RECOMMENDATIONS

The current study described why decision makers at different levels are potentially interested in PROMs and PREMs. The barriers and facilitators described in Table 3, can be translated in possible action points at different decision levels for the different objectives. Table 4 summarizes the different decision levels and their possible objectives with PROMs or PREMs.

Table 4 – Possible objectives of PROMs / PREMs initiatives at different decision levels

Objective	Decision level*			
	Individual healthcare provider	Institution	Regions	Country
Pay for quality			(x)	x
Public reporting			x	x
Benchmarking		x	x	x
Quality and outcome improvement	x	x	x	x
Improvement of individual patient care	x			

**The decision level is arbitrary divided in 4 broad categories. Categories in between exist (e.g. initiatives of different hospitals to collaborate more formally). They are situated between the institutional level and the regional level and can use of PROMs/PREMs for quality improvement, benchmarking and public reporting.*

Barriers and facilitators for PROMs and PREMs initiatives often relate to: the (lack of) knowledge about PROMs and PREMs, governance, resources, technical and operational aspects, data handling and trust. We can distill a number of general and specific recommendations for setting up an efficient system of PROMs and PREMs in Belgium, at different levels and for different purposes. First, we discuss the general recommendations that apply to all decision levels and are independent of the purpose of the PROMs/PREMs initiative. Second, we discuss the recommendations towards actors (governments, institutions, individual healthcare providers) and for different purposes (pay for quality, public reporting, benchmarking, quality and outcome improvement and improvement of individual patient care-.

9.1. General requirements independent of the aims or decision level

Central **governance** of any initiative, showing **leadership,** is relevant for decisions on all levels, be it for macro-level decisions regarding pay for quality, meso-level decisions regarding quality assessment or benchmarking or micro-level decisions regarding individual patient care. Closely related is the requirement of coordination between several initiatives. **Coordination** is needed to ensure efficient data collection, use of data and avoidance of survey fatigue in patients (and healthcare professionals). Wherever possible, alignment of PROMs and PREMs surveys for different purposes should be pursued. This requires discussion and deliberation between the different decision levels. Not only the choice of the instrument should be aligned where possible but also, for instance, the timing of data collection. For PROMs, it is important to have **baseline data** from patients as well as data at selected **follow-up** times if the data are to be used for assessment of outcome improvement due to quality improvement actions (macro and meso level), or for the assessment of the effectiveness of health interventions (micro and macro level). **Avoiding missing data and drop-out** is also relevant for these purposes. Patients who are doing well after treatment might lose interest and ignore invitations to complete their PROMs. Approaches to avoid missing data and drop-outs should be developed, and could include monitoring of compliance on-the-spot or sending automated digital reminders.

Patient involvement in the prioritization, design and implementation of a PROMs or PREMs initiative is essential. Instruments used should have been developed with patients to ensure relevance, data collection methods should be discussed with patients to ensure feasibility. PROMs or PREMs should be user-friendly and secured.

Every initiative should start with a **clear definition of the objectives** of the data registration: all data collected have a purpose and actually serve this purpose. It should be recognized and explained that PROMs and PREMs are complementing other instruments used to reach the objectives. For example, for complex problems (e.g. screening for depression), PROMs should be complemented by other decision-making aids, such as disease management plans and clinical pathways. The objectives should be clearly **communicated** to the relevant stakeholders.

Any well-developed PROMs or PREMs initiative requires additional **resources** on top of existing resources. There are costs associated with the selection, purchase or development of measures (scientific validation, translation, testing), the measurements (e.g. staff time, IT support, electronic devices), the data analysis, the reporting, the use (e.g. education of self-management skills; quality improvement initiatives) and the evaluation of the initiative.

The introduction of PROMs and PREMs, on each level, requires a **considerate approach**. *Zorginstituut Nederland* developed a toolbox for PROMs (selection and application) to be used in clinical practice and for internal and external quality assurance purposes (www.zorginzicht.nl/kennisbank/Paginas/prom-toolbox.aspx). It can also be used for PREMS and it takes several identified facilitators and barriers into account. The toolbox consists of 4 phases (purpose definition; selection; testing; implementation) and 8 steps (Table 5).

It is recommended to implement PROMs and PREMs **gradually**. This also applies to all decision levels. For national or regional initiatives, it is important to give healthcare institutions and providers the time to build up knowledge, experience and trust and allow them to express potential concerns. National and regional governments could start with improving existing initiatives (e.g. using more specific PREMs for some services, or producing timely feedback reports) or setting up new modest initiatives where none exist yet (e.g. measuring PROMs in patient populations where variation in clinical outcomes is found to be large between institutions, or adding PROMs to routinely collected clinical data included in a clinical registry, such as Orthopride or Tardis). For initiatives at the institutional level, gradual implementation could mean implementation of PROMs first in services treating mainly severely ill patient populations, with a lot of room for improvement. Also important for the institutional level, but equally important for the individual patient care level, is that the clinicians are motivated to measure PROMs. They can become an example for other services or providers when the initiative is extended.

Information and education of healthcare providers is a necessary first step to increase awareness about the potential value of PROMs and PREMs amongst healthcare providers and resolve knowledge gaps. A conference explaining how PROMs and PREMs can improve quality of care, for which other purposes they can and cannot be used, international initiatives such as ICHOM and the OECD initiatives could be organized, either at the national level or at the regional level.

Compliance with the **privacy protection regulation** is obviously necessary on all decision levels. The national and regional governments might consider providing support to the institutions from legal experts.

Table 5 – Toolbox for setting up a PROMs or PREMs initiative (Zorginstituut Nederland)

PROM / PREM-toolbox	
First phase: purpose definition	
I. Define the purpose (clinical practice; internal/external quality improvement)	**General principles:** limit registration burden by selecting PROMs for multiple purposes. This is challenging since every purpose might have its own prerequisites. Therefore purposes, target population and setting should be prioritized with the relevant stakeholders. These choices determine the next steps. Before starting new initiatives the current PROMs and PREMs initiatives in the target group should be listed by asking patient and professional organisations.
Second phase: selection	
II. Select PRO	**2a) Chose aspects to be measured** (e.g. symptoms, functional status, perceived health status, quality of life) based on patient involvement and, depending on the purpose, stakeholders such as healthcare professionals [benchmarking] and policy makers [e.g. public reporting]). **2b) Identify target group, purpose and context** by a literature review, potentially supplemented by expert consultation. **3c) Prioritize and select** in consensus between patients and healthcare professionals (and policy makers in case of external quality assurance purposes) and ensure the PROs fit the purpose: clinical practice (e.g. PRO can be influenced by the treatment); internal and external quality (e.g. PRO can be influenced by the way the care process is undertaken).
III. Select PROM (list current instruments and their validity, reliability and practicality, opt for PROMs that are informative for as much as disciplines as possible)	**3a) Set criteria:** generic versus condition-specific; measurement method: paper, telephone, app; psychometric properties; practicality and acceptability. This is done by the project team (and potentially the relevant stakeholders). **3b) List existing PROMs**: literature review and expert consultation. **3 c) Pre-select based** on the content or face validity. **3d) Identify published psychometric properties** (validity; reliability) or test (in next phase) when unavailable or untested. **3e) Test ease of use for patients and healthcare professionals**: acceptability and interpretability (meaning of scores is clear as well as the need to undertake action). **3f) select PROM** based on the previous steps and after consulting the relevant stakeholders. When no single PROM fulfils all the criteria, the criteria that are most dominant for the purpose, target group and context are used for the selection. Potential actions: 1) test a PROM without changes; 2) further develop (depending on budget and timing) existing PROM: not all relevant PROs are measured, untested in target population, not available in the required language; 3) develop PROM de novo when nothing exists with input from scientific expertise.
Third phase: testing	
IV. Test PROM	Dependent on the purpose: e.g. benchmarking quality should make differences between providers visible. Check if the reported results of validity, reliability and applicability also apply in practice.
V. Define indicators to make PROM meaningful	**5a) Specify exact calculation method** within the target population (e. g. mean pain score on a scale of 0 to 10 across low back pain patients). **5b) Ensure comparability** by standardizing data collection, sampling and risk-adjustment; ensure comparable response rates. **5c) Define the indicator concept** including a standard norm (e.g. based on scientific literature; expert opinion; a statistical criterion such as the mean); the way results are calculated (e.g. a percentage) and the level on which it is calculated (e.g. clinician, institution, region). Consult indicator experts and methodological experts when necessary.

VI. Test indicator	**Start small before expanding** (e.g. 30 patients per institution and 30 institutions), test statically and clinical significance. When needed: redefine the indicator (step V), or select or develop a different PROM (step III)
Fourth phase: implementation	
VII. Prepare implementation and use in practice	Factors contributing to successful implementation are stakeholders support, limiting registration burden, integration of PROMs and PREMs in existing processes. In case of external quality improvement purposes a register is indicated. PROMs eligible for a register should meet the following criteria: 1) relevant stakeholders were involved during the development phase; 2) the relevant stakeholders make a common proposal; 3) the relevant stakeholders agree about the measurement method and instructions; 4) the information is valid and reliable.
VII. Maintain & evaluate recurrently	Evaluate the following: are the chosen PROs still relevant? Does the PROM measure the desired outcome? Is the measurement sufficient and accurate? Does the measurement still meets the criteria of comparability? If the evaluation is negative then previous steps can be repeated.

9.2. Governmental initiatives

Evidence about the unique impact of PROMs and PREMs in meso- and macro-level applications is lacking, because PROMs and PREMs are only one element in these applications amongst many others. Some general guidelines for these specific applications (e.g. pay for performance, public reporting) should be taken into account. In general, any quality improvement initiative taken by the government requires trust, education and training of providers and adequate feedback to be successful. For PROMs and PREMs initiatives in particular, we recommend to take into account the following general principles:

- Inform, sensibilize, and create a culture supportive of PROMs/PREMs
- Align and make use of what already exists (avoid duplication)
- Implement stepwise and follow the logical steps of the implementation tool developed by *Zorginstituut Nederland*
- Create a governance structure with sufficient resources and expertise to guide bottom-up initiatives from the top.

When PROMs and PREMs are used for political decision making, at national or on regional level, PROMs / PREMs initiatives should be granted **political support**. This means that governments should give a clear signal to the healthcare providers that they consider quality of care and public information about quality of care as a priority. Collaborations between primary, secondary and tertiary care for sharing PROMs data should be stimulated and if possible facilitated, e.g. by bringing them together in a conference to present the benefits of PROMs for patient care by showcasing a few examples, proposing measures that would be valuable and feasible to apply in the three care levels and discussing with professional umbrella organisations how the implementation and sharing of data could be organised. **Integrating PROMs and PREMs in the electronic patient record** would be an important step in this direction, as this would facilitate data sharing, as well as aggregation of data and analyses that take case-mix and baseline risks into account.

E-Health could be a valuable instrument to increase the value of PROMs and PREMs on all decision levels. It can help to develop an integrated data system, linking electronic patient records, to PROMs and PREMs databases, clinical registries and reimbursement data. Interoperability between databases would avoid duplication of data input. Having to register the same data in different databases is inefficient and might be a hurdle to the implementation of PROMs and PREMs in institutions or by healthcare providers. **Data linkage** offers opportunities for more comprehensive analyses and comparisons of health services (benchmarking), allowing risk-

and case mix adjustment in the analyses. Moreover, when linked to the electronic patient record, the effectiveness of treatments can be assessed better, which can be valuable for individual treatment decisions but also, when aggregated and corrected for baseline risks, for reimbursement decisions or health technology assessments.

9.2.1. Governments aiming at using PROMs and PREMs for pay-for-performance purposes

If PROMs and PREMs are to be used for pay for quality purposes, it is essential to collect data on the same measures across the country. **Mutual agreement on data collection methods and instruments** across regions is thus required. When analysing the data, **case-mix and risk-adjustments** should be made to ensure comparability of the results.

In the context of the reform of the Belgian hospital payment system a 'Pay-for-performance (P4P)' programme will be introduced in the Belgian Hospital Budget (BFM/BMF) from 1st of July 2018 onwards. Six million Euro will be distributed across the Belgian hospitals that decide to participate in this P4P-programme. The available budget is divided into a fixed part (20%: each hospital that participates receives a lump sum) and a variable part (80%). The variable part is distributed across hospitals based on a point-system (weighted for the 'justified hospital activities'). The 2018 P4P-programme includes a set of 4 hospital-wide (3 structure and 1 process- and outcome-indicator) and 12 pathology specific process indicators.

A total of 80 points per hospital can be obtained of which 55 are based on hospital-wide indicators. Fifteen of these are based on PREMS. The PREMS-indicator includes a process-indicator (10 points can be earned when at least 300 completed questionnairest are collected on surgical and internal medicine wards in the period 01/01/2017-15/05/2018) and an outcome indicator. The results on two items ("How do patients rate the hospital?" and "Would patients recommend the hospital to friends and family?") are taken into account for the outcome indicator. A maximum of 5 points can be obtained when the percentage of patients giving a positive rating is high enough. In calculating the percentage of patients that give a positive rating the different scoring systems are taken into account. A score is considered positive when: a score of 3 or 4 is given on a 4-point Likert Scale; a score of 4 or 5 is given on a 5-point Likert Scale; a score of 7-10 is given on a 11-point Likert Scale. A maximum of 5 points is obtained when on both items at least 60% of the respondents give a positive rating. The goal is to evolve towards an indicator that is entirely outcome-based, also include other wards than surgery and internal medicine and besides PREMs also include PROMs. In addition, also the fact that PREMs are used in quality improvement initiatives could be taken into account in the future.[u]

[t] Although hospitals are encouraged to participate in cross-hospital initiatives such as the Vlaamse Patiëntenpeiling, BSM or Santhea, also PREMs collected autonomously by the hospital are taken into account for the year 2018. .

[u] www.health.belgium.be/sites/default/files/uploads/fields/fps_health_theme_file/begeleidende_nota_p4p_24_april_2018.pdf

9.2.2. Governments aiming at benchmarking healthcare institutions and stimulating in this way quality improvement initiatives at institutional level

Benchmarking can only be done reliably when there is **trust** from the healthcare institutions and providers that the results will be used in an appropriate way. Trust can be built by ensuring appropriate data analysis, e.g. applying **case-mix and risk adjustments** when analysing PROMs and PREMs data, and by using a **non-blaming tone** when reporting and/or sharing results.

Education of centres and health professionals (doctors, nurses, allied health workers) about the purposes of the data and their use is necessary to ensure engagement and unbiased data collection. **Results** of benchmarking exercises should be **specific** enough to allow identification of concrete improvement options. This presumes the use of questionnaires that are considered relevant and sufficiently specific by the providers and managers at healthcare institutions. Moreover, the results should be presented **timely** and **regularly** to allow institutions to relate the results to the actual situation.

Feedback reports should have a standardised format, allowing managers and providers to find the information they need quickly. Graphical presentations of centres' longitudinal results might help the interpretation.

Governments should organise meetings between centres to **share experiences and best practices** in order to increase the impact of the PROMs / PREMs initiatives. They should organise **trainings** on how to collect the data and how to use the feedback reports for quality improvement.

Governments could support healthcare centres in their local PROMs/PREMs initiatives, e.g. by creating a web-site with an overview of validated PROMs and PREMs in French and Dutch (for Belgium).

9.2.3. Governments aiming at public reporting of institutional quality of care

Patients might need **training** for the interpretation and use of the results of benchmarking exercises. This could be through existing channels of e.g. sickness funds and patient organisations. Developing the quality indicators and templates for the feedback reports in collaboration with patients might also help the interpretability of the results for the general public.

Results used for public reporting require **standardisation in data collection methods** across institutions.

It should be noted that the above recommendations regarding benchmarking and public reporting also apply to collaboration initiatives between different organisations (e.g. a network of hospitals, an umbrella organisation) that are set up without the support or involvement of public authorities.

9.3. Institutions aiming at quality and outcome improvement

Support from the **management** of the institution is crucial for the success of an institution-based PROMs / PREMs initiative, both in terms of logistics (IT infrastructure, IT support) and in terms of resources (time, people and money). Management can stimulate and encourage an organizational **quality-oriented culture** that puts patient-relevant outcomes at the centre. This requires **information** to and knowledge building of staff. The desired values and behaviours can only be embedded in the organizations if there is a general awareness and understanding of what matters most to patients and how this can improve the quality of care.

A PROMs or PREMs initiative is more likely to succeed if it is developed **multidisciplinary**, involving clinicians, nurses, patients, management, IT people, a statistician, data manager, administrative staff. Potential differences in visions with respect to what needs to be measured should be discussed.

To increase the impact of PROMs and PREMs on the quality of care and on patient outcomes, it is important to provide **regular timely feedback**. This requires support from a data analyst that can dedicate sufficient time to regular analyses. Results should be presented in a clear format, individualised, possibly supported by graphs, and a meaningful interpretation of the results should be provided. Health professionals might need training for the interpretation and use of the results. Possible action points identified from the feedback reports should be discussed within the team. This also applies to collaboration initiatives (e.g. locoregional hospital networks) between individual organisations. What is more, joining efforts is recommended to share expertise, best practices and overhead costs.

9.4. Clinicians aiming at improvement of clinical practice (patient-physician communication, shared decision making, follow-up)

Recommendations for clinicians apply to all levels of specialisation, be it primary care, secondary care or tertiary care, if the goal is to improve care for the individual patient (e.g. for shared decision making, better communication and identification of problems that would otherwise go unnoticed). Clinicians collecting PROMs for improving the individual patient care will have to **inform patients** about the objectives of the PROMs and their use in order to build trust and engagement in the patient. Patients should not be instrumentalised in any PROMs initiative, but should experience the impact of their participation in the measurements. Patients might have concerns about the confidentiality of their responses. Physicians, but also sickness funds could play a role in informing patients about the use and value of PROMs data in clinical care.

The use of **digital** tools (smartphones, tablets) to collect PROMs or PREMs data offer more flexibility to patients and the possibility of real-time feedback to clinicians. In the future, when interoperability between databases would be organised, electronic PROM/PREM data can be entered directly and automatically in clinical records. This would safe time to the clinician, who then gets all relevant information concerning the patient at one place.

For clinical practice, it is of utmost importance to use **disease-specific PROMs** in order to create a feeling of recognition in patients and caregivers. **Completion time** should be limited to maximum 30 minutes to minimize patient burden.

9.5. Possible action points at different decision levels

Table 6 contains a number of possible action points at different decision levels, related to 9 basic requirements for a successful PROMs / PREMs initiative.

Table 6 – Overview of possible action points for the different decision levels and different purposes

Requirement	Decision level*			
	Individual healthcare provider	**Healthcare institution**	**Regional government**	**Federal government**
Define objectives	Could be: Improving patient-physician communication Improving patient satisfaction Improving follow-up / earlier detection of problems	Could be: Defining areas for quality improvement Following-up outcomes of care	Could be: Pay-for-performance for regional matters (e.g. rehabilitation) Assessing quality of care in healthcare institutions Informing the public about quality in healthcare institutions through public reporting	Could be: Pay-for-performance Assessing quality of care in healthcare institutions Assessing relative effectiveness of health interventions for HTA and reimbursement decision making
Inform / educate stakeholders	Inform patients individually about the objectives of the data collection during a patient contact.	Organise an annual event to inform and educate stakeholders (clinicians, nurses, IT staff, data analysts) at the institution about the value of PROMs and PREMs and the requirements.	Organise meetings between centres to discuss experiences and best practices. Organise a seminar for all stakeholders to demonstrate how results of PROMs and PREMs are used. Involve sickness funds and patient organisations to transfer information to patients.	Bring together the relevant stakeholders for each of the defined objectives to explain why data are needed, how they will and will not be used and how they can be collected. This can be incorporated in the regional seminar on which all stakeholders are invited.
Create a climate of trust, openness and transparency	Focus on and prioritize key aspects of care that patients identify as being important during patient contacts.	Provide objective individualised feedback on PROMs/PREMs to providers or services and stimulate them to develop improvement actions (bottom-up). Provide support in implementing and testing these actions.	Set up limited initiatives if none exist or extend existing initiatives gradually, e.g. by adding a generic PROM to an existing PREMs initiative.	Allow for a gradual implementation of PROMs and PREMs for national level purposes: Start with using the data that are already collected (e.g. in the context of the HIS) to serve specific objectives (e.g. prioritizing

Requirement	Decision level*		
	Implement PROMs/PREMs gradually, starting with populations where large variation is observed in outcomes between providers or populations who are worse off.	Report PROM/PREM results objectively, timely and regularly. Individualise the reports to centres and make the results specific enough to allow identification of quality improvement initiatives. Use a fixed template, with recognizable sections and graphical presentations of longitudinal results.	domains for public health interventions based on EQ-5D data). Allow healthcare providers to get familiar with PROMs and PREMs and become convinced about their value. Search for PROMs/PREMs that are useful for both the provider and the national decision maker.
Create a governance structure	Create a central governance structure at management level, showing leadership, and support bottom-up initiatives with expertise and resources.	Create regional governance structures supporting and guiding healthcare institutions in the implementation of PROMs and PREMs measured for benchmarking or public reporting purposes. Do not impose and control, but develop a framework together with the institutions and subsequently guide bottom-up initiatives in order to make them useful for regional purposes.	Create a central governance structure to facilitate discussion and deliberation between regional initiatives with the aim to align questionnaires and data collection methods.
Coordinate initiatives	Make efficient use of resources by streamlining diverse initiatives at different services or departments within the institution: use a common core of instruments, apply the same data collection methods, share data collection staff.	Organise a workshop to discuss where alignment would be possible; involve all stakeholders. Draft a joint framework for PROMs / PREMs alignment and pilot test it. Evaluate the pilot test and jointly discuss necessary or preferable modifications.	Organise a joint meeting with all decision levels to present current initiatives Connect with international initiatives such as those of the OECD.
Provide resources	Make sufficient resources available for staff to collect the	Appoint dedicated staff for coordination of the initiatives:	

Requirement	Decision level*			
		data and monitor survey compliance, IT support, data management, electronic devices, (survey licenses), (scientific support)	Data managers Data analysts Communication specialists for (public) reporting	
Select or develop PROMs/PREMs	Follow the stepwise approach for PROMs/PREMs implementation as proposed by *Zorginstituut Nederland*, involving patients or patient organisations (Table 5).			
	Select disease-specific PROMs in collaboration with patient representatives	Use disease-specific PROMs already used for clinical purposes by individual providers, complemented with a generic PROM and a PREM to allow comparisons between services.	Select a generic PROM and PREM, as well as disease-specific PROMs for selected cases (high priorities). Define priorities in collaboration with stakeholders and based on existing data from e.g. the HIS and clinical registries.	Select a generic PROM for relative effectiveness assessment purposes. Create a web-site with an overview of tools to measure PROMs and PREMs in Belgium (validated French and Dutch language tools), references to standard sets of PROMs and PREMs and keep this website up-to-date.
Collect data	Create or use existing user-friendly, digital applications to complete PROMs and PREMs, with a secured log-in Comply with privacy protection rules Involve patients in defining the data collection approach Collect baseline data as well as follow-up data Take sufficient time for questionnaire administration Monitor survey compliance and completeness of data Set up a reminder system			
	Use data collection tools that provide on-the-spot information to the healthcare provider.	Create performant infrastructures for collecting and storing the data.	Align data collection methods (inclusion and exclusion criteria, digital tools) to ensure comparability of the data across institutions.	Use e-Health to integrate PROMs and PREMs in electronic patient records and clinical registries. Provide support to institutional initiatives from e-Health regarding privacy legislation
Analyse the data	Combine quantitative measurements with possible qualitative feedback provided by patients.	Apply risk- and case-mix adjustment in the data analysis to ensure validity and comparability of results between providers or services.	Apply risk- and case-mix adjustment in the data analysis to ensure validity and comparability of results between centres. This becomes easier when PROMs	Apply risk- and/or case-mix adjustment in the data analysis (for evaluation of relative effectiveness, only risk-adjustment is needed, as all data from all institutions will be pooled

Requirement		Decision level*		
			and PREMs are integrated in the electronic patient record.	and case-mix becomes irrelevant). This becomes easier better when PROMs and PREMs are integrated in the electronic patient record.
Develop actions	Discuss the outcomes reported by the patient with the patient and discuss how to deal with those that matter most to him or her.	Management and providers should identify areas of improvement and discuss together possible action points following the results of the analyses of the PROMs and PREMs data.	Embed the PROMs and PREMs in a global quality assurance policy. Communicate in a transparent manner about the results of PROMs and PREMs.	

**The decision level is arbitrary divided in 4 broad categories. Categories in between (e.g. collaboration initiative between different hospitals situated between the institutional level and the regional level: use of PROMs/PREMs for quality improvement, benchmarking and public reporting) exist.*

RECOMMENDATIONS[v]

General recommendations, applicable to all decision levels and objectives

- **PROMs and PREMs should be embedded in a global quality assurance policy.**
- **Clearly define the objectives of the PROMs or PREMs implementation.**
- **Inform, educate and sensibilize stakeholders and create a culture supportive of PROMs and PREMs. Education about PROMs and PREMs should be part of the basic education of healthcare providers.**
- **Implement PROMs and PREMs gradually and follow the logic steps of the implementation tool developed by *Zorginstituut Nederland*. Stakeholders should be involved in defining the priority areas for implementation. Patient involvement is crucial in the design of initiatives.**
- **Create a governance structure with sufficient resources and expertise to guide bottom-up initiatives.**
- **Ensure coordination of different initiatives at different levels, being sensitive to the response burden to patients and healthcare providers, the mutual benefits of PROMs and PREMs for decision makers at different levels (clinicans, institutions, regional and federal governments) and efficient use of resources.**
- **Ensure transparency towards patients about data collection, analysis and results.**
- **Define and plan clear improvement actions based on the PROMs and/or PREMs data, in a timely manner.**

Recommendations to both the regional and national healthcare governments

- **Create a culture of trust, openness and transparency, by adopting a no-blaming approach when presenting the results of benchmarking activities and allowing professionals to learn from PROMs / PREMs data for a few years before results are shared with other stakeholders and / or the general public.**

[v] The KCE has sole responsibility for the recommendations.

- **Align initiatives at different levels and make use of what already exists (avoid duplication).**
- **Link different databases that require the same data inputs (clinical registries, electronic patient records, PROMs/PREMs databases).**

Recommendations to the national government

- **Related to pay-for-performance**
  - **Use the same measures across the country.**
  - **Apply case-mix and risk adjustment in the data analysis.**
- **Related to the relative effectiveness assessment of interventions**
  - **Use a generic PROM.**
  - **Apply risk-adjustment in the data analysis.**

Recommendations to the regional healthcare governments

- **Related to benchmarking**
  - **Continue existing top-down facilitated bottom-up initiatives and ensure stepwise further development (including PROMs, risk- and case-mix-adjustment).**
  - **Enhance timely and regular feedback, and help to identify follow-up actions.**
  - **Set up an initiative in regions where PROMs and PREMs are not yet implemented. Collaborate with existing initiatives to align instruments and data collection methods.**
  - **Organise meetings between institutions to share experiences and best practices.**
- **Related to public reporting**
  - **Ensure standardisation in data collection methods across institutions.**
  - **Inform and train patients in interpreting the results of public reports.**

Recommendations to umbrella organisations of healthcare institutions

- **Support member organisations in implementing PROMs and PREMs, using knowledge from the approaches applied in regional initiatives.**

- **Connect organisations to share best practices.**

Recommendations to healthcare organisations

- **Involve people from different disciplines in the development of the initiative (clinicians, nurses, patients, IT staff, data analysts, scientific experts, management).**
- **Evaluate the initiative to ensure continuing motivation of stakeholders to participate. Modify initiatives that do not prove to be quality improving.**
- **Develop timely and actionable feedback reports to providers.**

Recommendations to clinicians

- **Use the most adequate type of PROM and PREM, depending on the purpose.**
- **Limit the completion time for the patient, by using digital tools where possible.**

Recommendations for future research

- **Explore the opportunities and requirements for implementing PROMs and PREMs in primary care.**

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COLOPHON

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