

Data, analysis, perspectives | No. 1, 2023

Patient-Reported Outcomes

Using patient-reported data to improve quality of care

- **Promote patient-centered care:** Patient-reported data complement purely clinical perspectives on care processes and outcomes
- **Focus on outcomes:** Patient-reported outcomes (PROs) allow patients to provide information regarding the medium- and long-term effects of medical treatments
- **Enable targeted treatment management:** Digitally transmitted PROs make it possible to monitor symptoms better and adjust treatments more quickly
- **Harness advances in digital technology:** Leveraging the potential of patient-reported data requires systemic digitalization
- **Learn from international champions:** Health policy strategies in Denmark, the Netherlands and Switzerland draw on PROs

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The principle of “putting patients first” – often emblazoned across banners hanging in the entryways of countless hospitals – is fast becoming a mantra in health policy debates. However, the extent to which patient-centered care is, in fact, practiced is sometimes difficult to assess. This is because the quality of health-care is measured by various instruments and data that are collected at different points along the course of treatment. There is, however, one important but underutilized source of data in efforts to assess quality: the perspective of those affected by treatments – the patients.

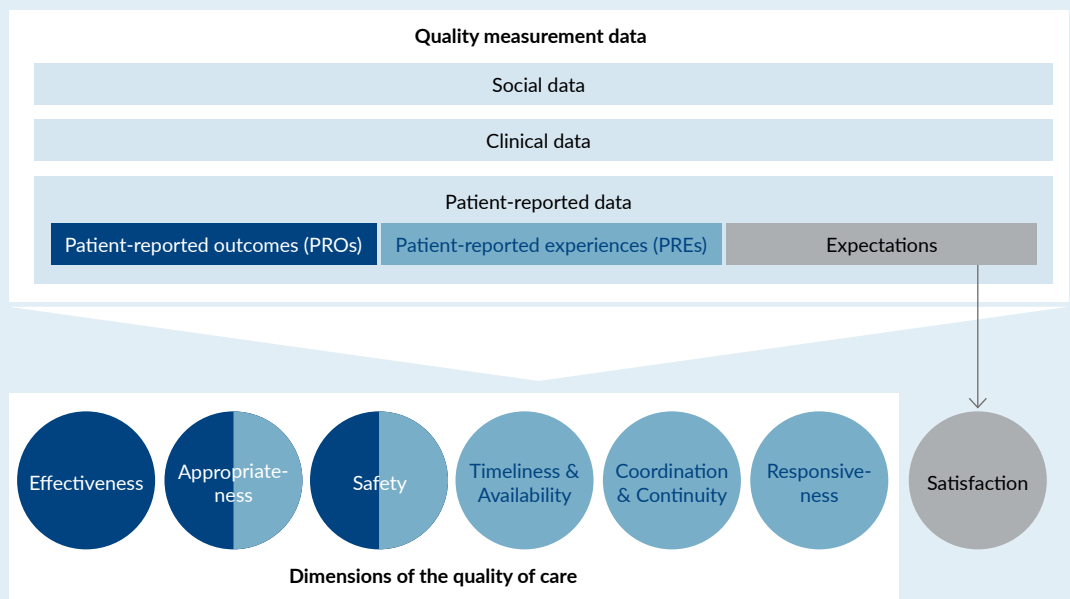
For example, from a purely medical perspective, an assessment of the care received by a recently discharged 76-year-old may be positive in nature, as there were no medical complications with the hip replacement surgery. There may have been nothing remarkable about the patient’s

“A patient-centered health system needs to measure what matters most to patients.”

OECD 2019

preoperative and postoperative length of stay, and mobility at the time of discharge and in rehab may have been satisfactory. But just how well did the surgical procedure go – from the patient’s perspective? Has it become easier for her to carry out her day-to-day tasks, can she climb stairs again, go shopping, or even ride her bike? Does she still experience pain and, if so, how much does it limit her activity? Only the patient can answer such questions. However, patients are not usually asked about such things in a standardized manner.

Contribution of PROs and PREs to quality-of-care measurement



■ Patient-Reported Outcomes (PROs) ■ Patient-Reported Experiences (PREs)

Figure 1 | Source: Authors’ elaboration, based on IOM 2001 and IQTIG 2022.

Clinical perspectives alone are not enough

The effectiveness, safety and appropriateness of treatment are considered to be basic dimensions of quality of care in medicine. They essentially show whether and to what extent a medical treatment was adequate and is leading (or has led) to the intended goals of treatment. But what about the perspective of those affected by the treatment? Have, in their eyes, the treatment objectives been achieved? And how did they experience the care provided? Clinical data alone are not enough when it comes to measuring the quality of care across all dimensions. The perceptions of those who receive care shed light on key aspects of quality that cannot be otherwise determined. Thus, obtaining a comprehensive image of the structural, procedural and outcome quality of healthcare involves incorporating patient-reported data into the assessment (see Figure 1).

The problem is that many countries, including Germany, do not systematically collect and evaluate this kind of data. However, some countries have recognized the relevance of patient-reported data and are using it to improve their healthcare. Which countries are leading the way when it comes to informing practice with the patient's perspective? And what can Germany learn from these countries?

To answer these questions, the Bertelsmann Stiftung and the Weisse Liste commissioned the Technical University of Berlin to conduct two analyses, each of which have been published as reports: 1) a cross-national comparison of PROM implementation and 2) the development and evaluation of an online survey of PROM use in German-speaking countries (see page 5).

PROs and PROMs – an overview

Both analyses focus on patient-reported outcomes and thus present individuals' perceived health and treatment outcomes and, as such, are distinct from patient-reported experiences (PREs), which refer to patients' experiences with the care process. When patient-reported outcomes or experiences (i.e., PROs and PREs) are ascertained through the use of questionnaires, they are referred to as "measures" (or "instruments"), that is, patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) (see Info box).

PROs and PROMs, PREs and PREMs – an overview

- › PROs and PREs are distinguished by the fact that they reflect information provided exclusively by patients and are not a product of medical interpretation
- › High-quality PRO or PRE instruments are scientifically sound, that is, they are valid, reliable and responsive

How am I doing?

PROs

Patient-reported outcomes

- › PROs pertain to a patient's perceived health in terms of symptoms, functional limitations, and their quality of life
- › PROs help improve how a disease is understood
 - Greater emphasis on symptoms and limitations
 - Comparison of physicians' and patients' perceptions regarding a patient's disease burden
 - Basis for dialogue on treatment goals and shared decision-making
- › PROs document health conditions over time
 - Effects of an intervention (physiotherapy, surgery, medication, etc.)
 - Health status throughout the course of a chronic condition or malignant disease

PROMs

Patient-reported outcome measures

- › PROMs are instruments (questionnaires) used to capture PROs
- › Generic PROMs
 - Measure general aspects of health, such as pain, fatigue, shortness of breath, etc.
 - Can be used for several illnesses
 - Are suitable for mapping a patient's health condition and quality of life
- › Specific PROMs
 - Measure aspects of health related to a specific illness or treatment.
 - Do a better job of mapping clinically relevant changes
- › PROMs can be used for medical interventions, quality improvement, and evidence generation

What have I experienced?

PREs

Patient-reported experiences

- › PREs provide information regarding what patients have experienced in their care with respect to:
 - Responsiveness: Clarification, shared decision-making, respectful interaction
 - Coordination and continuity: The exchange of information between service providers, transitions between sectors
 - Safety: Data protection, hygiene measures
- › PREs document ex post a patient's experience with a practitioner or hospital stay

PREMs

Patient-reported experience measures

- › PREMs are instruments (questionnaires) used to capture PREs
- › There are generic and specific PREMs
- › Some PREMs capture aspects such as level of satisfaction or recommendations; these are based not on facts but on expectations and needs
- › PREMs are used primarily for quality management and assurance, and for public reporting purposes

PROMs – the countries leading the way

In a study commissioned by the Bertelsmann Stiftung, “Patient-Reported Outcome Measures: an International Comparison,” the TU Berlin examined the introduction of PROMs in 10 countries. In addition to identifying the trends observed in each country with regard to the introduction of PROMs and the extent to which these trends overlap, the study sought to determine the challenges to implementation and the factors contributing to success in each. The research team thus conducted qualitative interviews with 28 international experts from the clinical and health policy fields in the following countries: Australia, Canada, Denmark, England, Netherlands, Norway, Sweden, Switzerland, the United States and Germany. The key findings are as follows:

- › Pilot and research projects demonstrating that the use of PROMs provides real benefit and value to individual patient care and quality improvement facilitate the use of PROMs in other medical areas, settings, regions, and the entire country.

- › PROMs are used most often in oncology, orthopedics, as well as for psychological conditions and chronic diseases such as diabetes and rheumatism. PRO data in these areas are used primarily for quality management and benchmarking practices, quality assurance and clinical research. At the same time, many countries are increasingly using PROMs for individual monitoring and treatment decisions (see Figure 2).
- › Challenges to the use of PROMs include the lack of cross-questionnaire comparability, inadequate funding as well as the lack of IT interfaces between PRO data collection and data analysis systems on the one hand and information systems in hospitals or medical practices on the other.

Denmark – remote patient monitoring

Denmark’s heavily digitalized healthcare system makes good use of PROMs to improve care for cancer patients or others with chronic conditions after they have left the hospital. Patients in Denmark use telemedicine tools to provide informa-

Applications of patient-reported outcome measures (PROMs) ...

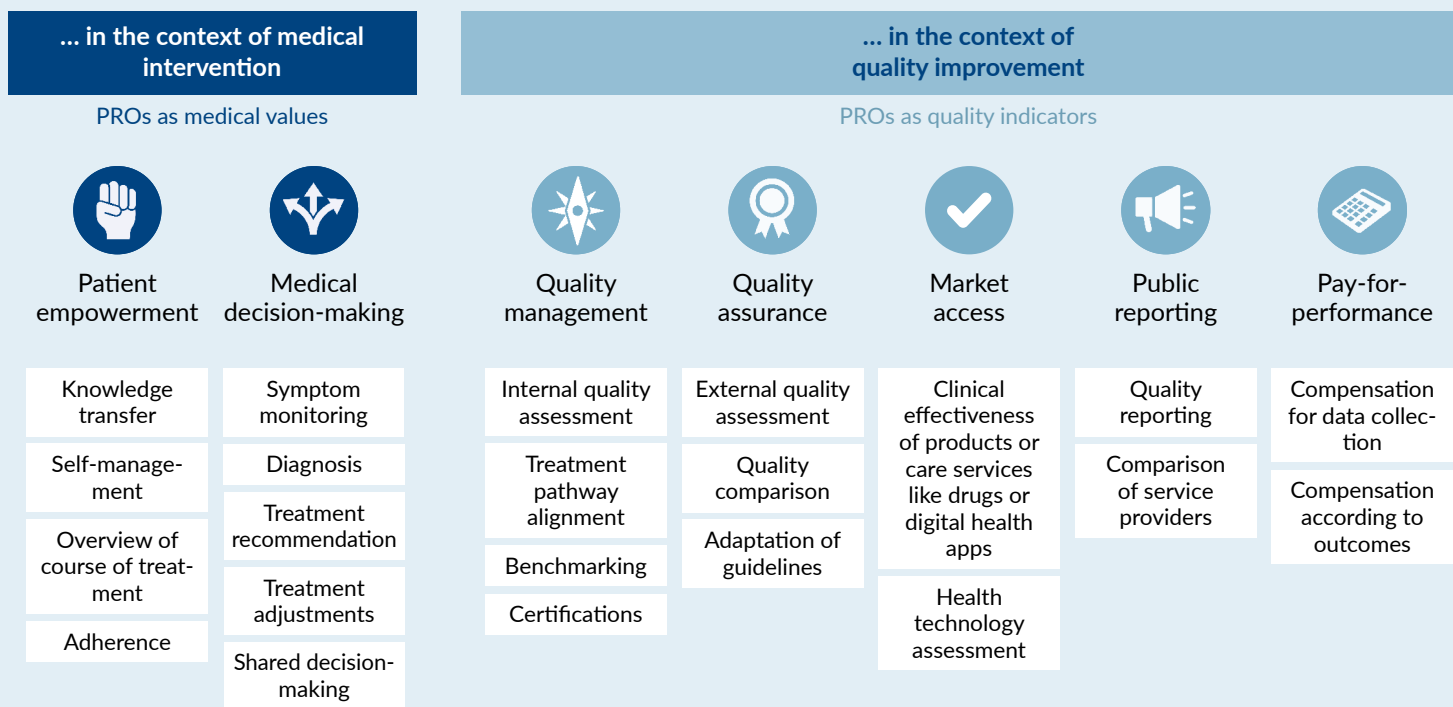


Figure 2 | Source: Authors' elaboration.

13,655

publications were published on patient-reported outcomes in 2021 compared to 2,883 publications in 2006

19

German Innovation Fund projects use PROs as medical values or quality indicators

In only

38%

of cases do patients and physicians agree exactly on assessments of the patient's health status

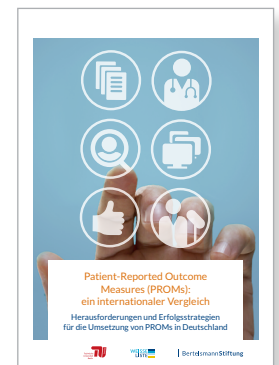
tion about the state of their health, such as pain levels or their physical and mental well-being. Medical professionals use these PROs to determine whether a patient should be re-admitted into the hospital. In addition, some Danish registries of quality in healthcare evaluate patient-reported data for quality management purposes and external quality assurance of healthcare providers. And in two Danish regions, questionnaires are accessed through electronic patient records.

The Netherlands: PROMs integrated into up-to-date clinical dashboards

In the Netherlands, where hospitals and other providers, as well as health policymakers, heavily advocate the use of PRO data, the country's PROM rollout is part of a national strategy. Many stakeholders use PROMs for the purpose of quality management and benchmarking, as well as for pay-for-performance models: The nonprofit Dutch Institute for Clinical Auditing (DICA), which was established by a physician initiative for greater quality assurance, collects PROs in addition to clinical data in 10 of its 22 quality registries for surgical procedures. Service providers in particular benefit from this approach, as a dashboard allows participating hospitals to view their quality data on a daily basis. The Dutch Heart Registry, which includes PROs in its hospital benchmarking practices, functions in a similar manner. Some hospitals and hospital groups also use PROMs as part of their medical interventions for people with cancer or diabetes, for example. The gains made by these initiatives ultimately resulted in the Dutch government launching in 2018 a healthcare program which, thanks to PROs, focuses more heavily on patient-centered care and outcomes.

Switzerland – national rollout for PROMs to improve quality of care

In Switzerland, initiatives at individual clinics have become the driving force behind efforts in specific cantons to introduce regulations designed to facilitate the increased use of PROMs. In the canton of Zurich, clinics have been required to implement PROM systems for knee and hip joint replacement procedures since 2019. A similar



Both publications are available for download at: <https://www.bertelsmannstiftung.de/en/our-projects/quality-based-health-care>



... in the context of evidence generation

PROMs as endpoints



Research



Public health

Medical research

Health monitoring

Epidemiological research

Health system performance assessment

Health services research

Economic research

requirement was instituted in the canton of Basel–City in 2021. Since then, clinics there have been able to determine themselves in which areas of their healthcare provision they will apply PROMs and which questionnaire is to be used in each case. In March 2022, the Swiss Federal Council adopted plans for a national PROMs roll-out. One of the eleven annual goals issued by Switzerland’s independent expert commission on quality issues, the EQK, recommends instituting the obligatory use of PROMs as an instrument for improving quality. The plan is to gather PRO data on an ongoing basis through a digital infrastructure that operates across sectors and can communicate with patients in real time.

PROMs in Germany – a patchwork of bottom-up initiatives

As the Bertelsmann Stiftung’s report on the use of PROMs in German-speaking countries (see page 5) shows, there appears to be some momentum in Germany among motivated stakeholders to introduce and use PROMs. Clinics such as the Martini-Klinik in Hamburg or the Schoen Clinic Group already use patient-reported data for the purposes of quality management, benchmarking and public reporting. German-based networks such as the IQM or the 4QD-Qualitätskliniken.de also collect PRO data for these purposes. In addition, health insurers, with an eye to the use of PROMs, are increasingly negotiating quality contracts in accordance with Section 110a of the German Social Code, Book V.

The Federal Joint Committee (G-BA), through its Innovation Fund, also finances several research

and healthcare projects that address the use of PROMs. It also commissioned the Institute for Quality Assurance and Transparency in Healthcare (IQTIG) to conduct a PRO and PRE survey for patients undergoing cardiac catheterization, specifying, however, that this should be done for quality assurance purposes alone. Finally, some hospitals are also collecting PREs and PROs through their new patient portals. Despite these positive developments, Germany continues to grapple with a patchwork of initiatives, questionnaires and IT solutions, the number of which only seem to be growing. To date, Germany has no stringent PROM strategies in place similar to those observed in Denmark, the Netherlands and Switzerland.

PROs as an element of patient-centered care

In addition to being used for the purposes of evidence generation and quality improvement, PROMs are also particularly useful in efforts to improve the quality of care for individual patients. When it comes to treating cancer or chronic conditions, PROMs offer a direct benefit when digitally acquired patient-reported data is integrated as a health parameter – in ways similar to lab results – into decisions regarding future steps to be taken. These benefits are demonstrated not only by the examples featured in the international comparison study but, above all, by scientific-review studies (see Figure 3).

This benefit of digitally collected PROMs is also the focus of the PRO B study funded by the Innovation Fund and led by the Charité – Universitätsmedizin Berlin in which patients with metastatic breast cancer at participating breast cancer cen-

Proven benefits of PROMs in medical interventions



Improves communication

- More structured, efficient conversations that save time
- Increases focus on symptoms and functional limitations
- Easier to discuss sensitive subjects
- Improves clinical decision-making processes
- Improves patient experience and increases satisfaction levels



Eases demand on healthcare system

- Activates patients to self-manage better
- Stronger adherence
- Fewer treatment complications
- Fewer emergency admissions
- Fewer hospitalizations



Better outcomes

- Less symptom burden
- Better physical functionality
- Lower levels of distress/suffering
- Less disability
- Higher quality of life
- Higher survival rates

“Patient-reported data provide scientifically sound answers to the question: ‘How are you?’”

Prof. Dr. Matthias Rose, Charité – Universitätsmedizin Berlin

ters nationwide are surveyed about their symptoms and quality of life throughout the course of their treatment. With the help of a smartphone app, patients submit regular updates on their condition, generally on a weekly basis. Any deterioration in health status reported in this way triggers an alarm, allowing the team of treatment providers to make decisions – together with the patient – about whether and how to adjust the therapy so as to alleviate the patient’s symptom burden and thus improve their quality of life.

The benefits of PROMs in a wide variety of applications were also confirmed by the Bertelsmann Stiftung’s online survey of experts from clinics, physician’s practices and academia. The survey’s respondents indicated that patient-reported data leads to knowledge gains in efforts to measure quality, adjust treatment pathways, and manage patient-reported symptoms. By way of free-text comments, the survey respondents also emphasized that looking at patient-reported data changes physicians’ attitudes toward patients, their symptoms and their complaints. This, in turn, improves the nature of doctor-patient communication. It also helps medical and nursing staff engage in more patient-centric practices and work more closely together.

Financial, IT and methodological support is needed

The experience of PROM users in Germany nonetheless shows that there are a number of challenges to transforming the country’s currently scattered application of PROMs into more targeted, routinized use. Fragmented interoperability in the country has made it more or less impossible to share patient-reported data across different facilities and for different purposes. In addition, those who use PROMs are not compensated for the additional work involved with collecting and using the data. Finally, there is a lack of standards: In order to ensure the comparability of aggregate PRO data, Germany needs to establish a consensus on the questionnaires used and their response scales, as well as on the types

PROMs used in Germany (selection)

Generic: PROMIS-29, PROMIS-GH, PROMIS-10, EQ-5D-5L, QLQ30, SF12, VR-12

Cardiology: Heart failure KCCQ-12 | Coronary artery disease SAQ-7

Neurology: Stroke Impact Scale (SIS)

Oncology: Colorectal cancer QLQ-CR29 | Breast cancer QLQ-BR23 | Prostate cancer EPIC-26

Orthopedics: Hip Surgery HOOS, Oxford Hip Score, Harris Hip Score | Knee surgery KOOS, IKDC | mobility ankle CAIT, AOFAS, COMT

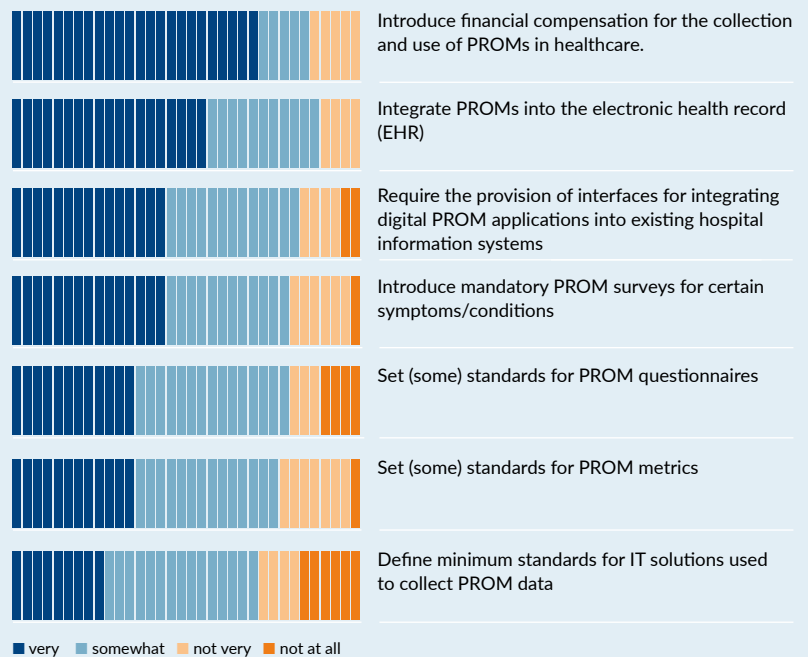
Pneumology: Dyspnea Rose Dysnea Scale COPD_CAT

Psychology: Anxiety disorder GAD-7 | Depression PHQ-9, PHQ-2

Urology: Erectile dysfunction IIEF-5

Assessment of policies and structural requirements needed to foster PROM implementation in Germany

Assessment of significance by respondents



n = 34 | Source: Online survey "PROMs in German-speaking countries," survey period July – Dec 2021

Figure 4 | Source: Authors' elaboration.



of surveys used and their processes. As Figure 4 illustrates, the evaluation of corresponding measures is apparent.

However, in addition to political stakeholders, everyone involved in providing healthcare, including regulatory authorities and researchers, are called upon to ensure the structured collection and analysis of patient-reported data and its use towards truly patient-centered healthcare.

Recommended actions

Improve quality of care with patient-reported data

Healthcare systems are created to serve patients. But how patients assess their own health, the impact of their medical treatment and what they have experienced in the course of such treatment – these things have yet to be systematically surveyed in Germany. Instead, the country runs the risk of fueling inefficiencies as a growing number of different questionnaires are used without coordination, duplicate and multiple surveys are applied and PRO data is increasingly collected by private players. These issues serve as barriers to the full potential of patient-reported data being realized in the country. Successful PROM implementation thus requires that the following steps be taken:

- **Patient focus:** Patients should be able to benefit from the information they disclose about themselves in the context of their care. They should be able to view their own PRO data and share it with the teams treating them.
- **Champions:** National and international examples of the successful use of PROMs in clinical practice should be used as models for use in routine care. Current PROM users who already experience benefits can advocate for the systematic implementation of PROMs in settings involving professional medical societies and associations.
- **Standardization:** Institutions such as medical professional societies, patient organizations, the IQWiG or the IQTIG should coordinate the development, selection, collection and purposeful evaluation of PROMs on the basis of specific indications as well as across different indications. These institutions also need to agree on a uniform set of standards.
- **Digitalization:** An interoperable IT infrastructure is needed to enable the reliable and efficient collection and analysis of digital PRO data in the individual treatment context and for the purpose of healthcare quality, management and research.
- **Incentives:** Legislation and the German health system's self-governing bodies should provide targeted monetary and non-monetary incentives for providers to collect, analyze and use PRO data.
- **Political will:** Health policy should target support for PROM implementation in those disease and treatment areas where use of PRO data will most improve the quality of care.

SPOTLIGHT HEALTHCARE is an initiative of the Bertelsmann Stiftung's Health program. Published periodically throughout the year, SPOTLIGHT HEALTHCARE addresses topical issues and challenges in healthcare.

The Bertelsmann Stiftung is committed to promoting a citizen-centric healthcare system. Our studies and projects highlight ways to strengthen health literacy, align healthcare with needs, and ensure the system's financial viability.



For more information:

<https://www.bertelsmann-stiftung.de/en/our-projects/quality-based-health-care> and <https://www.bertelsmann-stiftung.de/en/home>

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