13th MVF Congress on 9 December 2024 in the Alliance room of the AOK Nordost in Berlin

# Patient-centred care with PROM and PREM

In Germany, the current status of the use of Patient-Reported Outcome Measures (PROM) and Patient-Reported Experience Measures (PREM) can be expanded. Currently, the use of these instruments in Germany is still rather fragmented and uncoordinated (1). The reason: there is a lack of comprehensive and systematic implementation that could contribute to a stronger focus on outcomes in the German healthcare system at the meta-level (2) or be able to generate more realistic and evidence-based endpoints at the system level, for example in 'special therapy situations'. The 13th specialist congress of 'Monitor Versorgungsforschung' is dedicated to this complex of topics under the title 'With PROM and PREM to patient-centred care': starting point for a possible rethink.

>> In contrast to our European neighbours, the situation regarding the use of PROM and PREM in Germany and Austria has so far been rather restrained. In countries such as Denmark, the Netherlands and Switzerland, the integration of Patient-Reported Outcomes (PRO) is already firmly anchored in health policy strategies (3).

The UK has been systematically collecting Patient-Reported Outcome Measures (PROMs) as quality indicators since 2009 (4). In Belgium, Patient-Reported Experience Measures (PREM) are integrated into the pay-for-performance programme for hospitals, while Sweden and the Netherlands have established national standards and registers for PROMs. And in Switzerland - explains Carolin Kamann, Strategic Business Development Raylytic and MVF congress speaker on 9 December in her presentation - there has been a dedicated committee since 2021, the Swiss Federal Quality Commission (EQK), which is dedicated to quality development in medical service provision. Between 2022 and 2024, the EQC has been tasked with evaluating the possibilities for analysing and using PROM and PREM in various settings and with regard to data protection issues, as well as evaluating the benefits for patients and the impact on quality development. Kamann: 'Since 2023, it has set itself the goal of obtaining standardised and (also internationally) comparable indicator sets. Various pilot projects for the implementation of Patient-Reported Outcome Measures in Switzerland serve this purpose.' For example, the ANQ (National Association for Quality Development in Hospitals and Clinics) has been commissioned to implement pilot projects such as the National Rehabilitation Measurement Plan or the ANQ quality measurements in acute hospitals.

In order to promote the development of outcome quality measurement in Switzerland, the EQC also decided to test the feasibility of various indicators and then make recommendations to the Swiss Federal Office of Public Health (FOPH). To this end, it invited tenders for a pilot project on Patient-Reported Outcome Measures to pilot the survey in terms of content, organisation and technology. Following the public tender, EQK 2023 awarded the pilot project for the cross-sector implementation of PROMs ('Open PROMs') to a consortium of Bern University of Applied Sciences, Brightfish B. V., MIDATA Cooperative and Insel Gruppe (5). Duration: 01.07.2023 to 31.07.2025. According to Kamann, various cantons have now implemented their own guidelines and programmes for collecting PROMs and PREMs, often in collaboration with academicinstitutions and healthcare facilities. In mid-2019, for example, the Zurich Health Directorate began a mandatory measurement

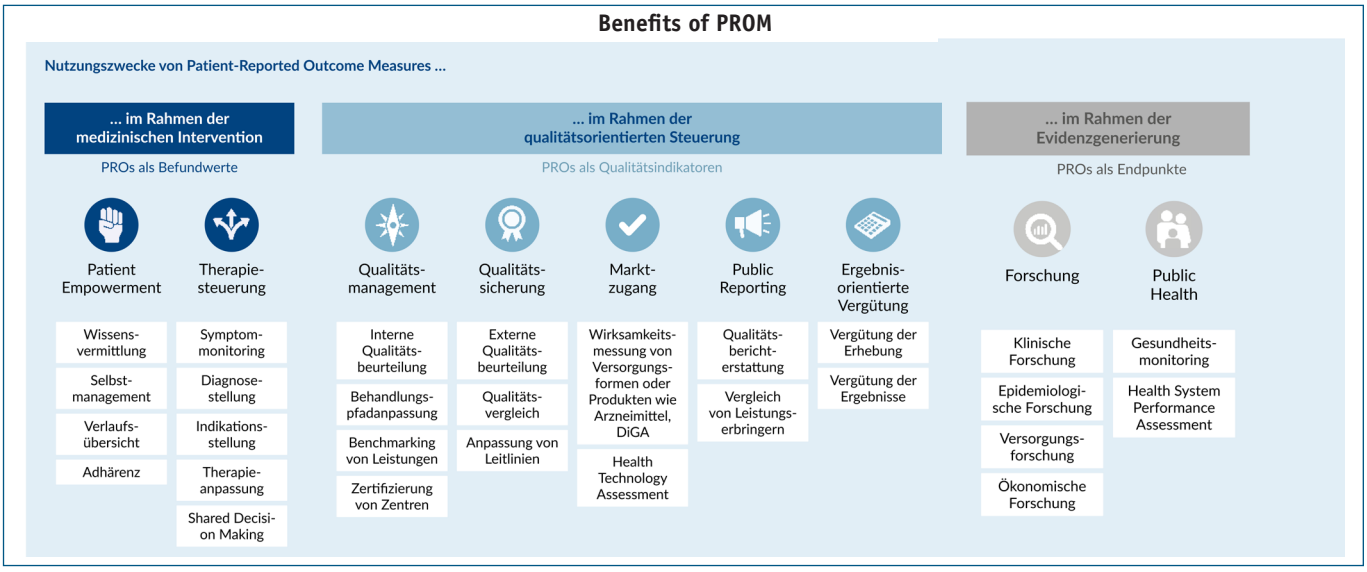



***Fig 1:*** *Purpose of PROM. Source: Spotlight Health 01/2023 Patient-Reported Outcomes, Bertelsmann Foundation.*

of the indication and outcome quality of patients undergoing hip and knee prosthesis surgery for the 21 listed hospitals in the canton of Zurich.

In the Netherlands, too, there is an increased focus on patient-centred and quality-oriented healthcare. This is described by Dr Valerie Kirchberger, who led the 'Feasibility study on cross-indication Patient-Reported Outcome Measurement - using digitalisation for patient-centred healthcare (DigiPROM)' in her final report (7). In 2017, the development of patient-centred healthcare indicators, quality-based reimbursement and shared decision-making were enshrined in the Dutch coalition agreement, following which the Ministry of Health, Welfare and Sport (Ministerie van Volksgezondheid, Welzijn en Sport) presented the concept 'Outcome based healthcare 2018-2022' for the gradual implementation of PROM. The declared goal: to collect PROs for all diseases that together account for at least 50% of the disease burden in curative healthcare by 2022. Funding has been approved and the National Institute of Health has been tasked with implementing the concept together with patient representatives, service providers, insurers and representatives from academia and international consortia. According to DigiPROM, four key points were defined:

1) Updating existing and developing new guidelines and measurement tools, as well as adapting international standards for the PRO survey.
2) The promotion of participatory/community decision-making between service providers and patients.
3) Healthcare contracting and the organisation of cross-sectoral healthcare should be based on PRO data.
4) The care-integrated use of PRO for patients and service providers, as well as the provision of aggregated data for insurance companies and science.

The implementation of the concept is also accompanied by an evaluation process, on the basis of which any adjustments can be decided at policy level in order to promote implementation in the best possible way.

The example of Denmark, which uses PROMs and PREMs to manage its healthcare system and thus plays a pioneering role, shows that the systematic use of both instruments has great potential to improve the quality of healthcare and place the patient perspective much more at the centre.

**Benefits of PROM in selected countries**

| | Level of implementation | Disease and treatment areas of focus | PRO-data use |
|---|---|---|---|
| Australia | » Mainly bottom up: Cross-clinical and pilot level, but also state-level initiative in NSW | » 25 diseases covered by NSW state program<br>» Focus: cancer, hip and knee replacement, rheumatology | » Research, service improvement, benchmarking, shared decision-making |
| Canada | » Mixture of top-down PROMs standards and bottom-up implementation; Province based implementation | » Focus on elective surgeries and chronic diseases<br>» National standard for hip and knee replacement | » Performance monitoring, research, shared decision-making |
| Denmark | » Top-down recommendations and infrastructure | » Chronic diseases, orthopedics, cancer, mental health, etc. | » P4P, outcome improvement, patient monitoring, reporting to registries |
| England | » Mainly top-down implementation but also bottom-up initiatives and registries | » Nationally, hip and knee replacement focus<br>» Pilot projects in additional areas, e. g. mental health | » Public reporting, research, quality improvement |
| Netherlands | » Bottom-up implementation and top-down financial support | » Speciality care – cancer, diabetes, heart diseases, hand and wrist care etc. | » Benchmarking, research, quality improvement, shared decision-making |
| Norway | » Bottom-up implementation and top-down support | » Mental health, orthopedics, NCDs (e. g. diabetes and heart diseases) | » Research, quality improvement, shared decision-making, benchmarking |
| Sweden | » National health data platform and bottom-up initiatives | » Chronic diseases, surgical/ orthopedics, cancer, mental health/neurology | » Quality improvement, research, benchmarking, public reporting, P4P |
| Switzerland | » Predominantly voluntary, bottom-up provider or regional projects<br>» First mandatory PROMs collection in the Cantons of Zurich and Basel-City | » Elective surgery (spine surgery, hip & knee replacement) and cancer care | » Patient monitoring, shared decision-making, public reporting, P4P, research |
| USA | » Voluntary, bottom-up provider / hospital networks and Medicare bundled payments | » Broad range of diseases and treatment areas: cancer care, orthopedics, primary care, variscose veins etc. | » Patient monitoring, shared decision-making, research and P4P |
| Germany | » Mainly voluntary, bottom-up provider level or cross-provider projects<br>» Planned selective introduction at national scale (DeQS-RL) in 2021 | » Elective surgery (mainly orthopedics) and cancer care, rehabilitation | » Research, patient monitoring, shared decision-making, (public reporting, P4P) |

***Fig. 2:*** *Benefits of PROMs in selected countries. Source: Patient-Reported Outcome Measures - an International Comparison, May 2021 Bertelsmann Stiftung.*

In his keynote speech at the MVF Congress, Olaf Mayer, Senior Advisor Health at the Royal Danish Embassy, will explain how PROM and PREM are used to manage healthcare in our northern neighbours for the benefit of all. Above all, this requires appropriate national legislation to promote and demand PROM/PREM. Danish health policy, for example, already did this in 2005 with the Danish Health Quality Programme (6). In the mid-2010s, Denmark's national health agenda built on this by prioritising PROMs: Several quality programmes and initiatives were introduced during this time to realise value-based healthcare (based on Michael E. Porter's 'Value-based Healthcare'), with the core aim of more clearly promoting patient-centredness and sustainable resource allocation in healthcare.

These EU countries are thus fully in line with the OECD, which had already postulated the following guideline in 2019: 'A people-centred health system needs to measure what matters to patients'(8). In other words: 'A patient-centred health system needs to measure what matters to patients.'

However, according to the OECD, few health systems assess their impact on health and well-being from the perspective of the people they are supposed to serve. Although the concept of health-related quality of life (QoL) has been around for almost three decades, the OECD says it is not systematically measured or reported. The 'Health at a Glance

2019' report cited above also states that performance indicators in the healthcare sector generally focus mainly on inputs and outputs. While outcomes such as life expectancy are important, they say nothing about a range of other things that can be reported by patients, including pain, functioning and quality of life, as well as the experience of care itself. This means that an essential part of the picture of healthcare and the performance of the healthcare system is missing. The OECD concludes: 'People-centred health systems remain an empty promise without more information about how healthcare and health policies actually impact the lives of individual patients.' To promote precisely this, the OECD has launched the 'Patient-Reported Indicator Surveys' initiative, PaRIS for short. It aims to promote the systematic use of key performance indicators in healthcare systems (9).

## Status quo in Germany

The question of why only sporadic projects and pilot applications exist in Germany in particular is complex and not easy to answer. The reasons are as varied as they are numerous. Without going into detail, six obstacles can be identified:

1) lack of political will and no national strategy for the introduction of these instruments
2) Structural challenges (fragmentation of the healthcare system, sector boundaries)
3) Financial and personnel hurdles (costs, personnel costs and shortage, lack of reimbursement)
4) Technical and infrastructural challenges (IT infrastructure not yet fully functional, data protection)
5) Standardisation and coordination (interoperable technical infrastructure for seamless integration)
6) Cultural and organisational factors (traditional views prevent the switch to a patient-centric perspective and the integration of PROM into existing processes and systems)

In order to achieve nationwide implementation in this country, above all - as has already happened in Denmark and Switzerland - considerable efforts and adjustments are required at various levels of the healthcare system. First and foremost, this requires the corresponding political will.

The Seventh Opinion and Recommendation of the Government Commission for Modern and Needs-based Hospital Care entitled 'Further Development of Quality Assurance, Quality and Clinical Risk Management (QA, QM and CRM)' (10) is clearly in favour of the concept of value-based health care. According to the 7th statement, this concept postulates a health competition in which service providers organise themselves in networks and are rewarded for achieving particularly good health outcomes for defined patient groups at the lowest possible cost (value = health outcomes in relation to the costs of achieving these outcomes). According to the government commission, competition for value has consequences for care structures and remuneration in particular. Certain patient groups should only be treated in departments that have the necessary infrastructure, staff and experience; and their remuneration should not be based solely on quantity, but should take quality aspects into account based on continuous measurement of results.

In this sense, the Commission sees the concept of service groups, their allocation to suitable hospital levels and remuneration based on quality and provision as important steps towards value-based healthcare.

The necessary patient-orientation as one of the dimensions in the WHO quality model for healthcare (11) requires not only adequate measures to ensure the appropriateness of healthcare in terms of high structural and process quality, including indication quality, but also and in particular the evaluation of the effects of healthcare on the basis of outcome indicators. According to the Government Commission, in addition to clinical indicators that can be mapped using healthcare-related data, 'the patient perspective should be mapped much more strongly than before by measuring the outcomes reported by patients (PROM) and their experiences with healthcare processes (PREM)'. And further: 'These measurements are a valuable source of information on the WHO quality dimensions of effective, safe, people-centred, timely, equitable and integrated healthcare.'

It is not the case that nothing positive is happening in Germany in terms of PROMs and PREMs. There are a whole series of innovation fund projects in the field of healthcare research that deal with PROM research, but these are mostly indication-based:

- Dent@Prevent - Implementation of routine data & PROM in evidence-informed intersectoral (dental) medical care
- E=MC² - Development of intersectoral medical care for patients with chronic critical illness (PROM should be used to ask patients about their current state of health)
- EPOS - Quality of outcome through Patient Reported Outcome Measures (PROM) for stroke patients in clinical routine
- PRO B - PROM in breast disease - new approaches in the care of metastatic breast cancer
- PROMchronic - Potential of PROM and PREM to improve the care of chronically ill patients
- PRO-P - Influence of electronic Patient Reported Outcomes (ePROMs) in surgical treatment of prostate cancer on the postoperative course

Notable exceptions are twoinnovation fund projects, both initiated by Prof Reinhard Busse, MD, from the Faculty of Business & Management, Department of Healthcare Management at the Technical University of Berlin:

- PROMchronic - Potential of PROM and PREM to improve the care of chronically ill patients (12)
- PROMoting Quality - Intersectoral use of Patient Reported Outcome Measures to improve patient-relevant outcome quality (13)

The PROMchronic project aims to improve the care of chronically ill patients with the help of the regular collection of digital Patient Reported Outcome Measures (PROM) and Patient Reported Experience Measures (PREM). According to the project description, this should help to identify gaps in care and enable non-medical patient expectations to be taken into account. Based on their analyses, the project participants will develop specific recommendations for the use of PROMs and PREMs. If successful, the project should help to improve the quality of healthcare and recognise care deficits at an early stage.

The project is being funded by the Innovation Fund for 48 months with a total of approx. 1.3 million euros. Consortium partners: aQua - Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen GmbH. BARMER, ONCARE GmbH. Duration: 07/2022 to 06/2025.

In the PROMoting Quality project, PROMs

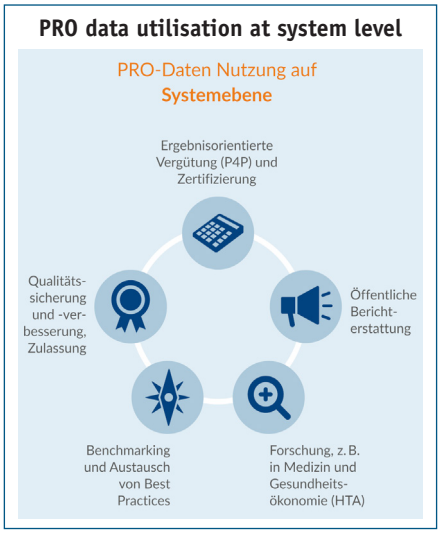



***Fig. 3:*** *PRO data utilisation at system level. Source: see Fig. 3.*

are used to evaluate the course of treatment when using hip or knee prostheses from the patient's perspective. According to the project description, the evaluation is intended to show whether the patients treated with the help of PROMs are better cared for and more satisfied at the end of the study than the patients in the control group. The analyses will also examine whether the intervention is more economical and assess the effects of a nationwide application of the new form of care. The project is being funded for four years with a total of around 3.5 million euros. Consortium partners: HRTBT Medical Solutions GmbH, BARMER, BKK Dachverband e. V., aQua - Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen GmbH. Duration: 04/2019 to 03/2023 Status: The final report is being prepared. <<

by: MVF editor-in-chief Peter Stegmaier

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**MVF-Kongress am 9.12.2024 bei der AOK Nordost in Berlin**

| von | bis | Thema | |
|---|---|---|---|
| | | **PROM/PREM: Chance für Versorgungssteuerung/-management** | |
| 09:00 | 09:10 | Begrüßung/Warm-Up | Prof. Dr. Reinhold Roski, Herausgeber MVF |
| 09:10 | 09:30 | Keynote 1: Mit PROM und PREM zur Patient Centered Care | Daniela Teichert, Vorstandsvorsitzende AOK Nordost |
| 09:30 | 09:50 | Keynote 2: Wie in Dänemark mit PROM/PREM die Versorgung zum Nutzen aller gesteuert wird | Olaf Mayer, Senior Advisor Health der Kgl. Dänischen Botschaft |
| 09:50 | 10:10 | Keynote: „Wie Versorgungssteuerung mit PROM und PREM aus Patientensicht Sinn stiften kann | Cordula Mühr MD MPH, ehrenamtliche Patientenvertreterin im G-BA |
| 10:10 | 10:30 | Was brauchen wir für ein lernendes Gesundheitssystem? | Prof. Dr. Bertram Häussler, Vorsitzender der Geschäftsführung IGES Institut |
| 10:30 | 10:50 | Wie aus PROM und PREM ein Patient-Centered-Care-Modell werden kann | Prof Dr. Volker Amelung, Medizinische Hochschule Hannover / Dr. Matthias Arnold, Mitglied der Geschäftsführung inav |
| 10:50 | 11:20 | Ein holistischer Bewertungsansatz zwischen Nutzen und Ökonomie | Melina Sophie Kurte, Senior Managerin VITIS Healthcare |
| 11:50 | 12:10 | Möglichkeiten und Grenzen des Einsatzes von PROMS/PREMS im Krankenversicherungsrecht | RA Dr. Dr. Thomas Ruppel, Kanzlei für Medizinrecht und Gesundheitsrecht |
| 12:10 | 13:00 | Podiumsdiskussion | Moderator: Prof.. Dr. Bertram Häussler, IGES |
| 13:00 | 14:00 | Mittagessen | |
| | | | |
| | | **PROM/PREM: Lotsen / AbD / besondere Therapiesituationen / Krankenhäuser** | |
| 14:00 | 14:30 | PROM/PREM – versorgungsnahe Daten aus Lotsenprojekten | Dr. Michael Brinkmeier, Vorstand Deutsche Schlaganfallhilfe |
| 14:30 | 15:00 | PRO Erhebungen im Rahmen von anwendungsbegleitenden Datenerhebungen (AbD) | Ulrike Seay, Ressort Arzneimittelbewertung, IQWiG |
| 15:00 | 15:30 | Kaffeepause | |
| 15:30 | 16:00 | Wie kommen wir zu einem situativ angepassten Umgang mit Endpunkten bei besonderen Therapiesituationen? | Dr. Andrej Rasch, Nutzenbewertung/ HTA-Koordination vfa |
| 16:00 | 16:30 | PROM/PREM: Erfahrungen aus der Schweiz – Praxisbeispiel aus dem Kantonsspital Winterthur | Carolin Kamann, Strategic Business Development Raylytic |
| 16:30 | 18:00 | Podiumsdiskussion: Folgen für die Politik | Moderator: Prof. Dr. Reinhold Roski, MVF |
| ab 18:00 | | Get-together | |