



Current use of PREMs in oncology care in Europe and their actionability

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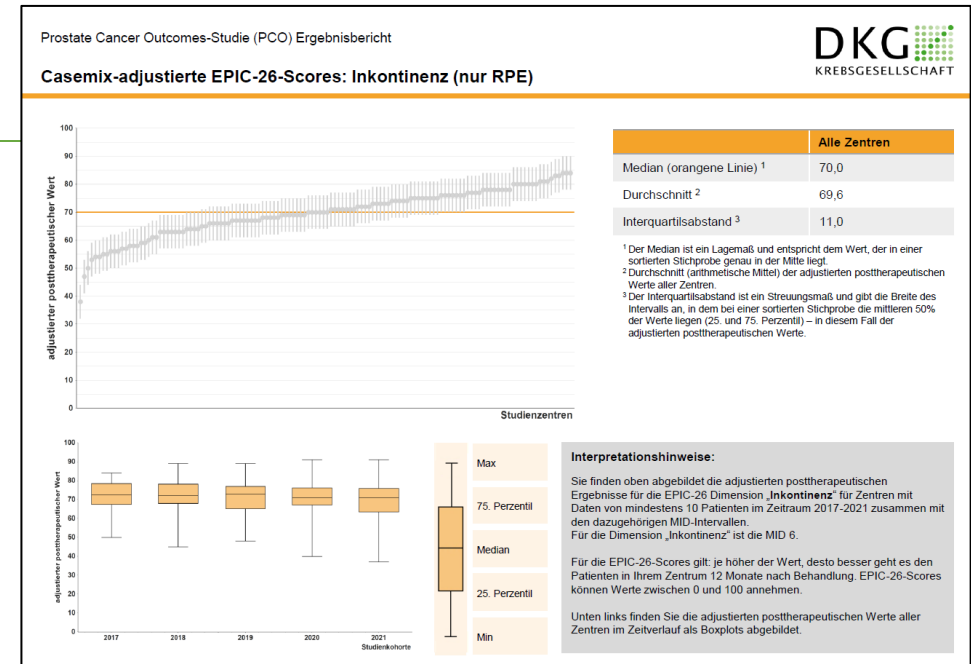
- Employee of the German Cancer Society
- Consultant (reimbursed) for IQTIG – German Institute for Quality and Transparency in Health Care
- No personal fees from industry

Agenda

- **Background**
German Cancer Society // Christoph Kowalski
- **PREMs**
Definition // What are they good for // PROMs
- **Examples from Europe**
NHS England // PaRIS // Breast Centers Northrhine-Westfalia // IQTIG
- **Actionability**
Requirements for actionability // Limitations // Evidence for improving care
- **Conclusion**
Are we there yet // Should we engage in PREM collection

Background: German Cancer Society

- Evidence-based Medicine – implement evidence into practice
- Guidelines
- QIs
- Certification
- Reporting
- PROs
- No PREMs (yet?) – should we?



Leitlinienprogramm
Onkologie

S3-Leitlinie Prävention, Diagnostik, Therapie und Nachsorge des Lungenkarzinoms

Version 3.0 – März 2024
AWMF-Registernummer: 020-0070L

> **Pneumologie.** 2024 Apr;78(4):250-261. doi: 10.1055/a-2204-4879. Epub 2023 Dec 11.

Development and Update of Guideline-based Quality Indicators in Lung Cancer

Martin Utzig ¹, Hans Hoffmann ², Niels Reinmuth ³, Wolfgang Schütte ⁴, Thomas Langer ⁵, Jessica Lobitz ⁶, Johannes Rückher ¹, Simone Wesselmann ¹

Affiliations + expand
PMID: 38081218 DOI: 10.1055/a-2204-4879

Abstract in English, German

Annual Report 2023
of the Certified Lung Cancer Centres

Audit year 2022 / Indicator year 2021

DKG
KREBSGESELLSCHAFT
Certification

Annual Report Lung 2023 (Audit year 2022 / Indicator year 2021)

19. Combination radio-chemotherapy in NSCLC stage IIIA/IIIB/IIIC (GL QI)

	Definition of indicator	All clinical sites 2021
Number	Primary cases of the denominator with combination radio-chemotherapy	12 ^a 0 - 73 100 ^b
Denominator	NSCLC primary cases stage IIIA/IIIB/IIIC with ECOG 0-1	24 ^a 0 - 203 200 ^b
Rate	Target value ≥ 25%	50.00% 21.74% - 100%

DKG
KREBSGESELLSCHAFT
Certification

Background: Christoph Kowalski

- Small but growing Health Services Research unit at DKG
- More into PROs: <https://www.pco-study.com/login>; <https://www.edium-studie.de/login>; prostate and colorectal cancer
- But: in the past in charge of surveying breast cancer patients in one state of Germany (3,000-5,000 patients per year)

Patient Education and Counseling 77 (2018) 146–158

Contents lists available at ScienceDirect

Journal of Home Page: www.elsevier.com/locate/yepc

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Breast cancer patients' trust in physicians: The impact of patients' perception of physicians' communication behaviors and hospital organizational climate

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ARTICLE INFO

Article history:
 Received 16 September 2016
 Received in revised form 20 August 2017
 Accepted 4 November 2017

Keywords:
 Hospital organizational climate
 Trust in physicians
 Breast cancer
 Physician communication behaviors

1. Introduction

Recently, research has repeatedly focused on patients' trust in their physicians. Trust has been used both as an outcome variable (e.g., for example, defining well-functioning physician-patient relationships) and as a determinant of patient satisfaction and treatment success. In general, trust is seen as a necessary basis for any sort of satisfactory physician-patient relationship [1,2]. For patients, it is the reciprocal interaction of physicians with their patients that forms a constitutive element of their trust in their physician [3]. A lack of trust on the part of patients can mean a decrease in compliance [4], whereas a trusting physician-

patient relationship leads to an increase in the patients' willingness to follow the recommendations of their physicians [5,6], promotes patient satisfaction [7–9], and improves health outcomes [10,12].

It is important for physicians to know how to establish an atmosphere that leads to a trusting relationship with their patients. It is well known that involvement in the treatment process is associated with patients' trust in physicians [5]. Recently, there has been a study that showed a strong influence of physicians' communication on trust in the health care system [13]. However, causal statements can hardly be made as most of these studies are not [14].

So far, it is not known whether the association between physician communication behaviors and trust disappears once hospital organizational factors are introduced into the analysis. Problems in coordination of care and its impact on patient outcomes have been discussed in a number of publications recently [15]. In addition, there are several studies that have examined the association between hospital organizational characteristics and patient-physician interaction [16].

So far, it is not known whether the association between physician communication behaviors and trust disappears once hospital organizational factors are introduced into the analysis. Problems in coordination of care and its impact on patient outcomes have been discussed in a number of publications recently [15]. In addition, there are several studies that have examined the association between hospital organizational characteristics and patient-physician interaction [16].

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Original Article 132

The Patients' View On Accredited Breast Cancer Centers: Strengths and Potential for Improvement

Zertifizierte Brustkrebszentren aus Sicht der Patientinnen: Stärken und Verbesserungspotenziale

Autoren
 C. Kowalski^a, S. Wenzelmann^b, R. Kneiberg^c, H. Schürz^d, H. Pfaff^d

ABSTRACT

Background: Breast Cancer Centers that were accredited according to the German Cancer Society criteria were offered to participate in a standardized patient survey in 2010, which was conducted by the Institute for Medical Sociology, Health Services Research and Rehabilitation Science, Faculty of Human Science and Faculty of Medicine, University of Cologne. Patients were included consecutively between March and November 2010. The Cologne Patient Questionnaire Breast Cancer (CPQ-BC) was used, which assesses a number of aspects of hospital care as perceived by the patients, among them: provider-patient interaction, the disease-specific information provided, the quality of organization, and more. A total of 195 Breast Cancer Centers and 160 of 251 hospitals participated in the study. 8226 patients completed the survey. The questionnaire of 2501 patients could be included in the analyses (89.3%). The results showed that patients are satisfied with their hospital stay and that the accreditation criteria are implemented in a way that serves the patients. However, there is room for improvement for a number of issues, for example with regard to the provision of information and patient involvement in decision making. In addition, for a number of indicators substantial differences were found between the hospitals. The results of the survey provide information on the breast centers' development and can be used by the centers' management for benchmarking purposes, to identify strengths and weaknesses, and to take actions.

Introduction

In 2010, the breast cancer centers certified in accordance with the criteria of the German Cancer Society (Deutsche Krebsgesellschaft e.V., DKG) were offered the opportunity to participate in a survey of patient satisfaction in a standardized manner. This survey was conducted by the Institute for Medical Sociology, Health Services Research, and Rehabilitation Science (IMSR) of the Faculty

Schlüsselwörter
 Breast cancer
 Accredited
 Patient survey
 Satisfaction
 Hospital organizational climate

1. Introduction

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Research Article

Meeting patients' health information needs in breast cancer center hospitals – a multilevel analysis

Christoph Kowalski^{a,*}, Shou-Whi D'Lee^b, Lena Ansmann^c, Simone Wesselmann^d and Holger Pfaff^d

Abstract

Background: Breast cancer patients are confronted with a serious diagnosis that requires them to make important decisions throughout the journey of the disease. For these decisions to be made it is critical that the patients be well informed. Previous studies have been consistent in their findings that breast cancer patients have a high need for information on a wide range of topics. This paper investigates (1) how many patients feel they have unmet information needs after initial surgery, (2) whether the proportion of patients with unmet information needs varies between hospitals where they were treated and (3) whether differences between the hospitals account for some of this variation.

Methods: Data from 5,024 newly-diagnosed breast cancer patients treated in 111 breast center hospitals in Germany were analyzed and combined with data on hospital characteristics. Multilevel linear regression models were calculated taking into account hospital characteristics and adjusting for patient case mix.

Results: Younger patients, those receiving mastectomy, having statutory health insurance, not living with a partner and having a foreign native language report higher unmet information needs. The data demonstrate small between-hospital variation in unmet information needs. In hospitals that provide patient-specific information material and that offer health fairs as well as those that are not teaching or have lower patient-volume, patients are less likely to report unmet information needs.

Conclusion: We found differences in proportions of patients with unmet information needs between hospitals and that hospital structure and process-related attributes of the hospitals were associated with these differences to some extent. Hospitals may contribute to reducing the patients' information needs by means that are not necessarily resource-intensive.

Keywords: Information needs; Breast cancer; Multilevel modeling; Hospital characteristics

Background

Breast cancer patients are confronted with a serious diagnosis that requires them to make important decisions throughout the journey of the disease. For these decisions to be made it is critical that the patients be well informed. Previous studies have been consistent in their findings that breast cancer patients have a high need for information, especially concerning the severity of their condition and their treatment options [2]. Halseth et al. found that breast cancer patients have a consistently high need for information, which does not significantly decrease over the course of treatment [3]. Mistry et al. came to the same conclusion in a heterogeneous sample of cancer patients [4].

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FEATURES

Associations between hospital structures, processes and patient experiences of preparation for discharge in breast cancer centers: A multilevel analysis

Nowak, Marina; Swora, Michael; Karbach, Ute; Pfaff, Holger; Ansmann, Lena

Author information

Health Care Management Review 46(2):p 98-110, 4/6 2021. | DOI: 10.1097/HMR.0000000000000237

BUY | SDC

Metrics

Abstract

Background

Discharge management is a central task in hospital management. Mitchell's quality health outcomes model offers a contextual framework to derive expectations about the relationship between indicators of hospital structures and processes with patient experiences of preparation for discharge.

Purpose

The aim is to analyze the association between hospital structures and processes with patient experiences of preparation for discharge in breast cancer centers.

Methodology

The data were collected between February 1 and July 31, 2014–2016, with annual cross-sectional postal surveys on patient experiences of preparation for discharge in breast cancer center hospitals in Germany. These data were combined with secondary data on hospital structures, obtained from structured quality reports 2014 and the accreditation institution certifying breast cancer centers, constituting a hierarchical data structure. A total of 10,750 newly diagnosed breast cancer patients from 67 hospitals were analyzed. Following listwise deletion, 9,762 patients could be included in linear hierarchical regression analyses.

PREMs (a systematic)

- **Definition**

Kingsley/Patel 2017: "PREMs gather information on patients' views of their experience whilst receiving care. They are an indicator of the quality of patient care, although do not measure it directly. PREMs are most commonly in the form of questionnaires."

- **What are they good for**

- Benchmarking (provider comparison)
- Changes over time
- Health system performance assessment



- **PROMs**

PREMs are not PROMs. Kingsley/Patel 2017: "In contrast to PROMs, PREMs do not look at the outcomes of care but the impact of the process of the care on the patient's experience e.g. communication and timeliness of assistance."

PREMs (a systematic)

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- Changes over time
- Health system performance assessment

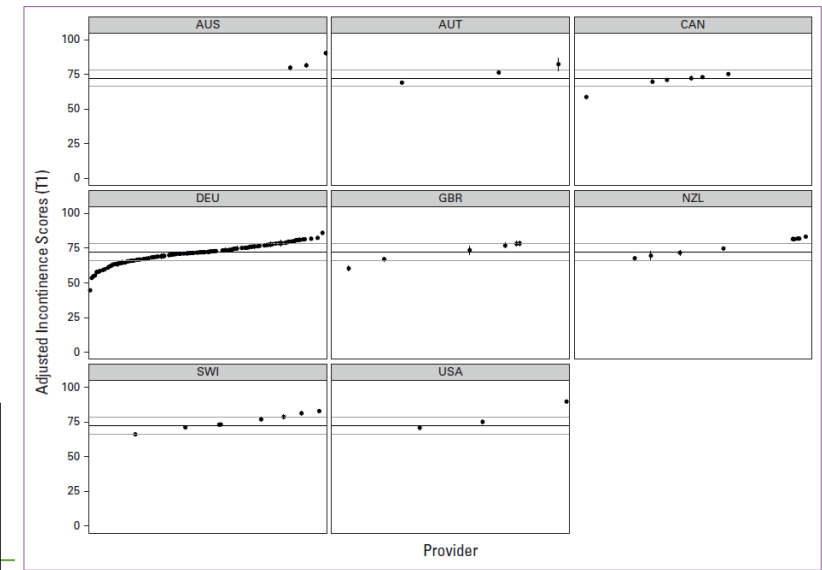
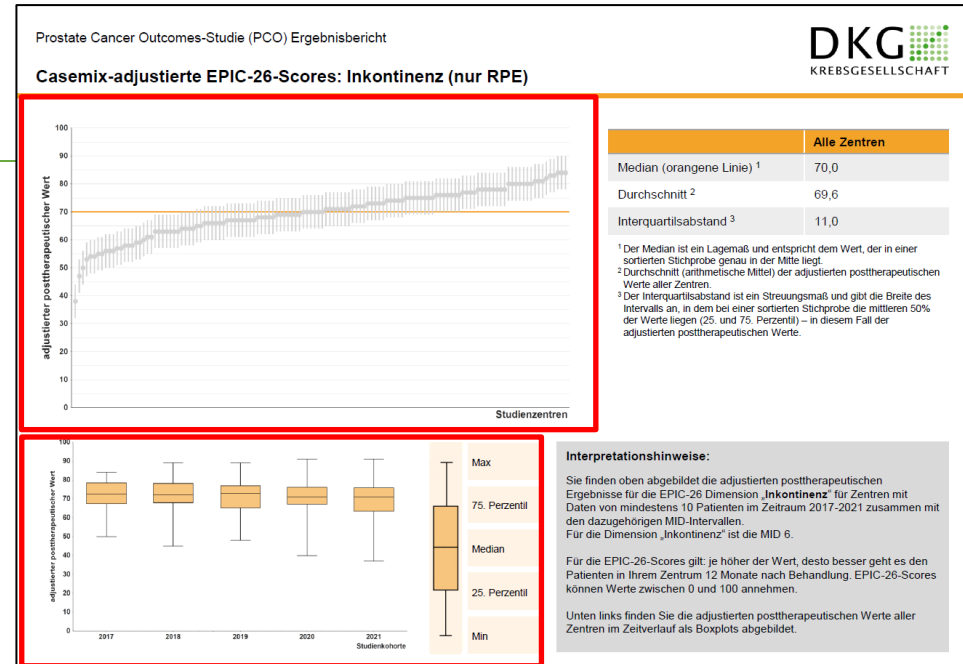


FIG 3. Adjusted incontinence scores of providers stratified by country 1 year after RP: median indicated as horizontal line, MID ranges around median (± 6) indicated as light gray horizontal lines. AUS, Australia; AUT, Austria; CAN, Canada; DEU, Germany; GBR, Great Britain; MID, minimally important difference; NZL, New Zealand; RP, radical prostatectomy; SWI, Switzerland; USA, United States of America.

Original Reports | Health Services Research

International Variations in Surgical Quality of Care in Men With Prostate Cancer: Results From the TrueNTH Global Registry

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DOI: <https://doi.org/10.1093/aje/kwz213.0445>

ABSTRACT

PURPOSE: Functional problems such as incontinence and sexual dysfunction after radical prostatectomy (RP) are important outcomes to evaluate surgical quality in prostate cancer (PC) care. Differences in survival after RP between providers are known, but differences in functional outcomes after RP between providers from different countries are not well described.

METHODS: Data from a multinational database of patients with PC (nonmetastatic, treated by RP) who answered the EPIC-26 questionnaire at baseline (before RP, T0) and 1 year after RP (T1) were used. Linking survey data to clinical information, Casemix-adjusted incontinence and sexual function scores (TI) were calculated.

Accepted March 28, 2024
 Published May 28, 2024

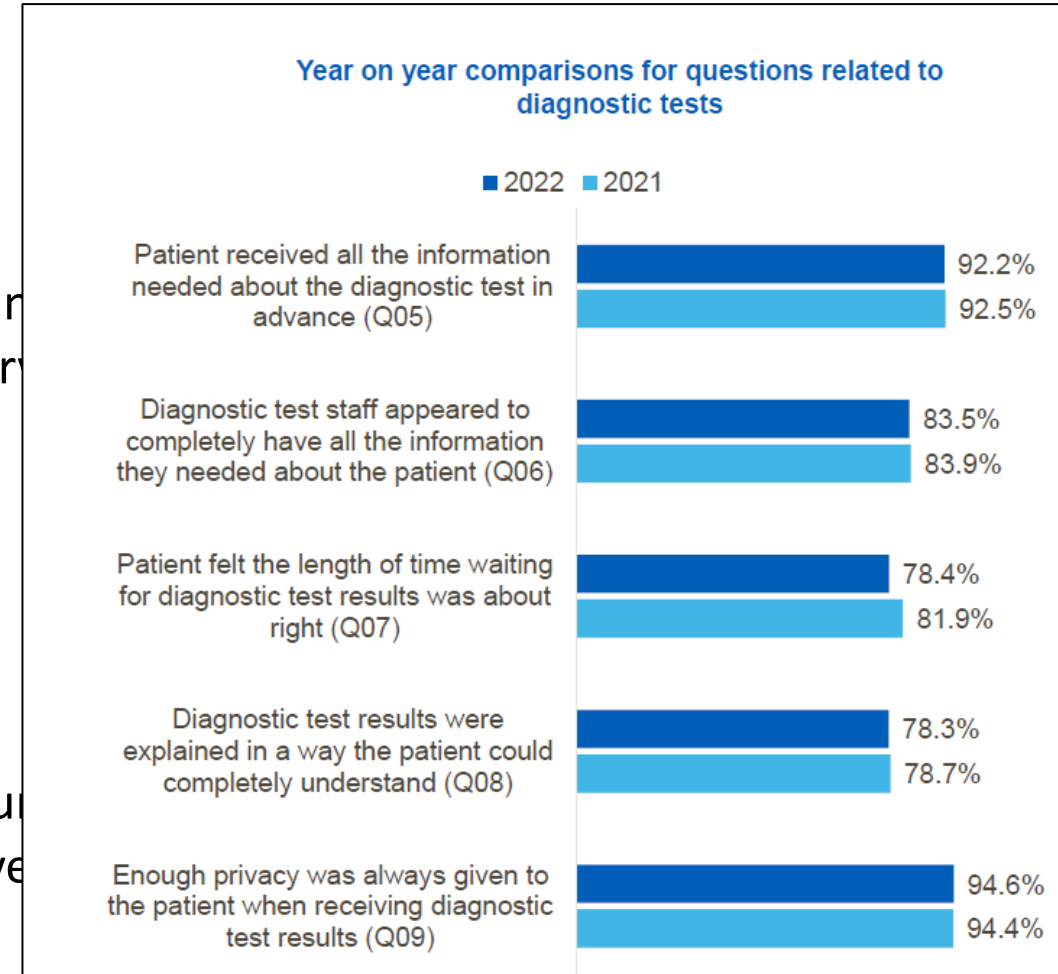
JGIM (Serial Online First) 2024;39(5):e1-10
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Examples from Europe

- **NHS England**
- **PaRIS**
- **Breast Centers Northrhine-Westfalia**
- **IQTIG (Institute for Quality and Transparency in Health Care, Germany, Prostate Cancer)**

NHS England: National Cancer Patient Experience Survey 2022, Picker

- **Purpose**
“monitor national progress on experience of cancer care”
- **Patients**
adult cancer population discharged from NHS trust April-June 2022
Out of 115,662 people, 61,268 people responded to the survey
- **Since when**
2010, annually
- **Differences between hospitals:** depictable, adjusted
- **Changes over time:** depictable
- **Sample item**
Were the results of the tests explained in a way you could understand to a certain extent; no, I didn't understand the explanation; I didn't have

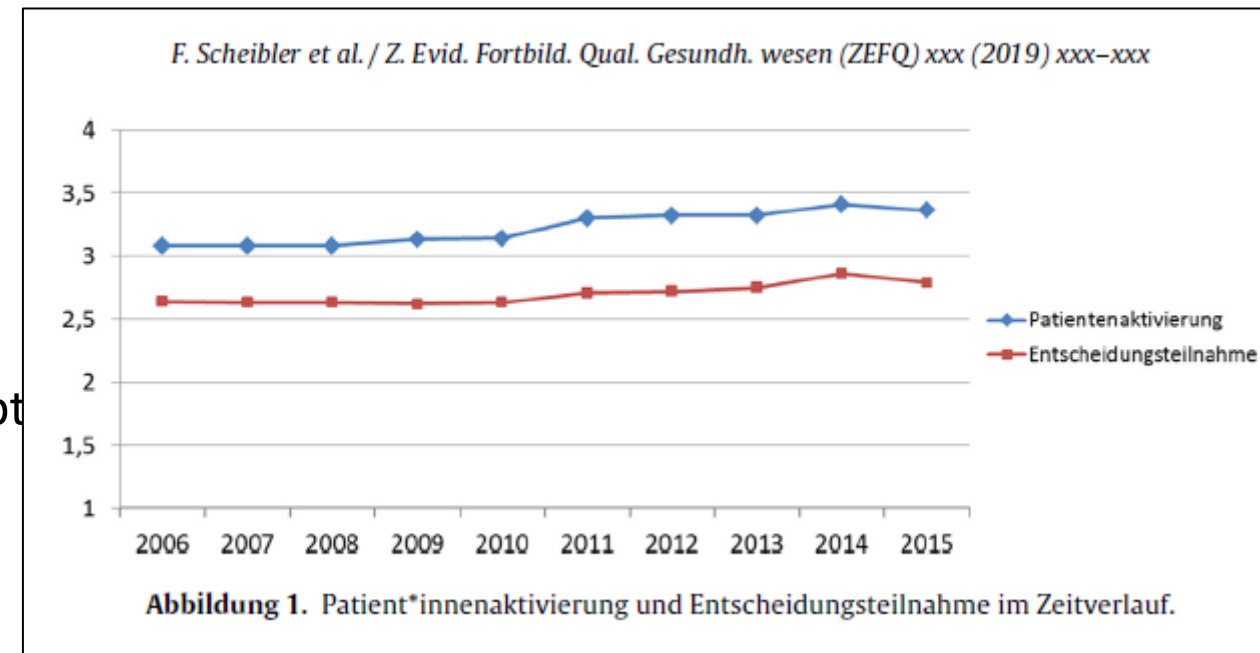


PaRIS: Patient-Reported Indicator Surveys, chronic conditions, OECD

- **Purpose**
“...Patient-Reported Experience Measures (PREMS), which measure how patients experience health care and refers to practical aspects of care, such as care co-ordination, waiting times and provider-patient communication...”
- **Patients**
“People aged 45 and older who have visited primary/ ambulatory health care at least once in the six months preceding the survey. To identify patients with **chronic conditions**, a validated list of the most common conditions will be used.”
- **Since when**
2023, main survey in 20 countries [Kendir et al. 2023]
- **Differences between providers:** between countries and providers
- **Changes over time:** not yet
- **Sample item**
Is your health care organised in a way that works for you? (yes, definitely; yes, to some extent; no, not really; no, definitely not; not sure)

Northrhine-Westfalian Breast Cancer Centers, Germany

- **Purpose**
“accompanying health services research” – part of certification / quality assurance, benchmarking
- **Patients**
adult breast cancer patients surveyed after discharge from 50 ~centres February-July; 4.000-5.000 patients annually
- **Since when**
2006
- **Differences between hospitals:** depictable
- **Changes over time:** depictable
- **Sample item**
The doctors gave me a full explanation of my symptoms completely)



IQTIG (Institute for Quality and Transparency in Health Care, Germany, Prostate Cancer)

It's in the law: §630 II Law for the Improvement of patients' rights: (2) The practitioner is obliged to inform the patient in an understandable manner at the beginning of the treatment and, if necessary, in the course of the treatment about circumstances essential for the treatment, in particular the diagnosis, the expected development of the patient's health, the therapy and the measures to be taken during and after treatment.

annually

● **Since when**

10.2	Evidenzbasierte Empfehlung	geprüft 2018
Empfehlungsgrad A	During the medical consultation, the patient should be informed about all relevant treatment options described in this guideline, their prospects of success and their possible effects. In particular, the effects on his physical appearance, his sex life (impotence), his urinary and faecal control (incontinence) and aspects of his male self-image (self-image) should be discussed.	
Level of Evidence 4	[133] , [1563] , [1567] , [1568] , [1569] , [1535]	
	Starker Konsens	

Did a doctor talk to you before the operation about the following side effects that may occur as a result of the operation?

Please tick one box in each line!

Uncontrolled loss of urine (incontinence)

yes

no

don't remember

Impotence (erectile dysfunction)

yes

no

don't remember

Shortening of the penis

yes

no

don't remember

Difficulty or pain when urinating

yes

no

don't remember

Actionability

- **Requirements for Actionabilities**

“An indicator is actionable if progress toward the target is reflected in the indicator and if policymakers and stakeholders use the indicator to monitor progress toward the target (suggesting a positive feedback loop).” [German Federal Ministry for Economic Cooperation and Development 2015, The Indicators We Want]
> reacts to changes in practice, requires follow-up measurement

- **Limitations**

- Are the right persons addressed, do we follow-up (really), do we take it seriously, are sanctions in place?
- Interacts with SMART criteria, of course: specific, measurable, achievable, relevant, and time-bound

- **Evidence for improving care**

Difficult...; costly, long-term studies

Conclusion (my opinion)

- **Are we there yet**
 - No
 - Few good practices
 - Often not totally clear what the rationale is, if it can be achieved with what is done, if it is sustainable
- **Should we engage in PREM collection**
 - We = European oncology community (including DKG)
 - Only if we look at experiences that reflect guideline recommendations / legal requirements / “high level” expert consensus (including patients) and that are actionable
 - And it needs to be methodologically sound
 - NB: Do not use PREMs as substitute for QIs you really want to measure
 - If not, there are better ways to spend money

Thank you for your attention!

