








Review Article:

Simplification of Patient-Reported Outcome Measures in Oncology: A Narrative Review

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Abstract

Background: Patient-reported outcomes (PROs) are reports provided by patients themselves detailing their medical health state or behavior related to an illness or medication use, without any interpretation by healthcare professionals. PROs are used to evaluate health status that cannot be quantified through tangible measures, for primary outcomes such as pain severity, and secondary outcomes such as quality of life. Patient-reported outcome measures (PROMs) are instruments or methods developed by professionals to assess data on PROs directly provided by patients during reporting procedures. In the oncology field, they are important to determine the impact of cancer and chemotherapy on patient's physical symptoms, mental well-being, and social functioning. The health system turned towards using PROMs as tools for remote monitoring, conducting visits when needed, and alerting stakeholders at the right time. **Aim:** To describe the uses and types of PROMs in use in clinical practice and the simplified PROMs that have been developed in oncology. **Conclusion:** PROMs are widely used in oncology for data collection. It became necessary to simplify measures by using patients' language, downsizing content, and promoting electronic PROMs through technological programs.

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1. Introduction

Patient-reported outcomes (PROs) are reports provided by patients themselves, detailing their medical health state or behavior related to an illness or medication use, without any interpretation by healthcare professionals (HCPs) (1 – 3). Throughout the treatment trajectory, patients can communicate their symptoms and any treatment-related side effects to their doctors. HCPs enter these data into the patient's medical record and interpret them immediately. However, these entries were not considered PROs (4).

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Patient-reported outcomes are used to evaluate health status that cannot be quantified through tangible measures, for primary outcomes such as pain severity, and secondary outcomes such as quality of life (QOL). Patient-reported outcomes are commonly used in drug manufacturing to assess medical effectiveness, patient adherence to treatment regimens, adverse drug reactions (ADRs), and the impact of drugs on patients' overall well-being (1, 5). Patient-reported outcomes can also capture many concepts, such as the severity of adverse drug reactions, the impact of treatment on health behavior and physical activity, patients' satisfaction with their treatment, and their overall opinion of their health condition (1, 3, 6).

Patient-reported outcomes assist in accurately collecting data related to narrative functions, symptoms, and ADRs. They also engage patients in decision-making, improve communication between HCPs and patients, boost patients' self-reliance, and enhance healthcare services (7). Additionally, they play a vital role in qualitative and quantitative clinical trials, making the results more credible

and acceptable (8). Patient-reported outcome measures (PROMs) are instruments or methods developed by professionals to assess data on PROs directly provided by patients during reporting procedures (3).

PROMs were first used in clinical trials before being developed for a variety of uses, including decision-making involvement, enhancing patient-HCP communication, improving patient care services (9), assessing symptoms and severity, health-related quality of life (HRQOL), physical functional status, psychological status, and patient satisfaction. PROMs can be used to estimate one or more of these concepts (1, 10). Several studies have been conducted focusing on PROMs' application in health systems and show a gradual increase in PROMs use in clinical trials, especially in the oncology field (11 – 13). This narrative aims to describe the uses and types of PROMs in use in clinical practice and the simplified PROMs that have been developed in oncology.

2. Patients Reported Outcome Measures (PROMs)

2.1. Uses of PROMs

PROMs could be used to illustrate various forms of self-assessment of health status and to describe several aspects including; symptoms and symptoms' burden, quality of life, functional status, mental status, and patient satisfaction. PROMs can be used for assessing one of the aforementioned concepts or more than one (1, 14).

2.2. Types of PROMs

PROMs serve various purposes and could be broadly categorized into generic and disease-specific PROMs. Generic PROMs are health conceptual measurements applicable to a broad spectrum of patient populations, allowing for comparisons and aggregation in a variety of contexts and scenarios. (1, 15 – 18). Generic PROMs can be used to assess many components of general health, including physical function, pain, adherence, vitality, and mental health (19, 20). Research showed that the most commonly used generic PROM in clinical trials is EuroQol-5 Dimension (EQ-5D) which collects accurate information about the patient's current health condition (21). It consists of questions related to the patient's level of mobility, ability to do self-care tasks, engagement in regular activities, experience of pain or discomfort, and presence of anxiety or despair. It also has a scale to determine the level of severity (non, little, or significant issue) (22). Other widely used generic PROMs are short-form (SF) 36-item questionnaire, and shorter versions; SF-20, and SF-12 (23 – 25).

On the other hand, specific PROMs target populations with specific characteristics and/or with specific diseases (22). Disease-specific PROMs are specifically created to detect particular symptoms and assess their effect on the functioning of those particular diseases like cancer, such as the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) (26),

which assesses the general QOL for cancer and can be subdivided into many specific questionnaires according to the type of tumor (27). Similarly, Functional Assessment of Cancer Therapy – General (FACT-G) PROM is specific to cancer and assesses four categories of well-being: social, emotional, physical, and functional (28, 29).

Furthermore, specific PROMs are used for special population or conditions like geriatric, children and adolescents, smokers, drinkers, pregnancy, or any other conditions (9, 30). For example, the Child Health and Illness Profile—Child Edition Child Report Form (CHIP-CE CRF) PROM is used to assess the general health of children (31), and the Adolescent-Quality of Life Questionnaire (32) to assess QOL and satisfaction of treatment in adolescents (33).

In most researches, clinical investigations used a blend of generic and disease-specific PROMs. For instance, a research study including individuals with asthma may incorporate a PROM specifically assessing 'asthma control', in addition to a generic PROM like the EQ-5D, to evaluate patients' quality of life (1). According to Churruca et al., (2021) study, there is an increasing trend towards the utilization of PROMs. The disease-specific PROM, with the highest average annual citation count, was the mental health PROM. Followed by generic PROM, blood and metabolic, cancer, respiratory, skin, kidney and urinary, musculoskeletal, neurological, reproductive and maternal, cardiovascular, hearing and vision, gastrointestinal, endocrine, infectious, injuries, and trauma (9). The highest utilization of mental health PROM may be attributed to its reliance on self-reporting as a primary method for diagnosing and monitoring these diseases, as they often lack identifiable biological indicators. Consequently, some mental health PROMs are employed for screening and diagnosing these conditions (34).

2.3. Advantages and disadvantages of PROMs

Generic PROMs have the advantage that they are intended to be used for a population that consists of persons who are in good health or individuals with several coexisting medical conditions (35). It can evaluate various aspects of overall functioning, well-being, or QOL (36), and is convenient to make comparisons between patients and populations (37). On the other hand, generic PROMs are less effective than specific measures in detecting specific changes in disease status, making them less responsive to targeted change (24). Furthermore, they might not be able to adequately address significant specific conditions and are less commonly used in clinical trials (38).

Disease-specific PROMs are just like generic PROMs, in which they have their advantages and disadvantages. Disease-specific PROMs have the advantage that they are used if the intended population is a subgroup of patients with a certain illness or undergoing a prevalent treatment (35). Furthermore, they are used to assess symptoms that are anticipated to be directly targeted by a condition-specific intervention, a particular symptom, or a combination of symptoms that are specific to the illness (36). They also enable the differentiation of groups at the same level of

specific symptoms or disease. Finally, they are more applicable in clinical settings and trials, sensitive, and have more clinical detail than generic PROMs (9). However, disease-specific PROMs have their own disadvantages that include, increased assessment burden, and the difficulty in the comparison between different conditions or diseases (37, 39). Moreover, they are inappropriate to be used for general or coexisting conditions since they were designed and validated primarily for specific diseases or used in research investigations (40).

3. PROMs in Oncology

Oncology practices are seriously seeking to monitor tumor growth and the effects of chemotherapy drugs. There is a lot of research and studies that have proven the importance of PROMs in the oncology field (40 – 43). Accordingly, the demand for incorporating PROMs into cancer care has consistently increased patient satisfaction and communication between HCPs and patients (44), more than data related to HRQOL (45). Many studies have shown the beneficial effects of PROMs on health outcomes and offered long-awaited confirmation that the regular utilization of PROMs in cancer clinical treatment might enhance health outcomes, such as HRQOL and even survival (16, 46 – 48).

In the oncology field, there are many PROMs used, which are classified into generic and specific PROMs (49). Generic forms like the European Quality of Life-5 Dimensions (EQ 5D) (50, 51), Short Form-36 (SF-36) (23), Short Form-12 (SF-12) (52), (EORTC QLQ-C30) (26), Functional Assessment of Cancer Therapy (FACT-G) (28), the MD Anderson Symptom Inventory (MDASI) (53), and the European Kid Screen-52 (KIDSCREEN-52) (54). Weingärtner et al., (2013) study showed that FACT, EORTC QLQ-C30, and EuroQoL 5D were the most popular PROMs used throughout the study's duration between 2010 and 2013 (55). The EORTC QLQ-30 questionnaire, which is considered the most popular PROM in the oncology field, is used to assess QOL in cancer and may be targeted for different diagnosed types of cancer (EORTC QLQ-LC13) for the Lung Cancer Module (9, 56).

Disease-specific PROMs are also used in the field of oncology, e.g., EORTC QLQ-HCC18 for liver cancer and EORTC QLQ-STO22 for gastric cancer (25). Preston et al., (2015) study has shown that QUEST GY is most commonly used for pelvic cancer, EORTC QLQ-OV28 for ovarian cancer, EORTC QLQ-CX24 for cervical cancer, EORTC QLQ-EN 24 for endometrial cancer, and FACT-V for vulval cancer (57). The Van Rooij et al., (2023) study showed that the Eating Assessment Tool-10 (EAT-10), and EORTC Head and Neck Cancer Quality of Life Questionnaire (EORTC H&N35) (58) were used to assess the HRQOL in patients with head and neck cancer (59).

3.1. Limitations of the available cancer-specific PROMs

Despite all the benefits of cancer-specific PROMs, studies have shown some limitations of PROMs in clinical trials;

- Culturally sensitive PROMs can contribute to increased attrition rates and elevated levels of missing data (60).
- The use of translated PROMs in multinational clinical studies that include the patient's health and cultural experiences is more responsive to environmental changes (61).
- The incorporation of translated as well as culturally validated PROMs into a more diverse pool of participants can lead to the absence of clear information, a decrease in the number of participants, and incomplete data (60).
- Insufficient transparency exists regarding the publication and reporting of data on some ethnic groups (5).
- The majority of PROMs were first designed and verified for application in collective settings for research purposes, thereby rendering them unsuitable for individual patient assessment (62 – 64).

3.2. PROMs simplification

Despite the positive impact of PROMs on patient monitoring and communication during cancer treatment, their recognition is not widespread (65). Among the downsides of currently in-use PROMs is the complexity of use since they use technical language that is hard to understand by lay person or needs assistance from healthcare professionals (66). Furthermore, they are time-consuming and tedious since they are long and many patients think that they are boring and may refuse to fill them (67). Moreover, long and demanding PROMs that depend on the patient's recalling, may lead to worsening fatigue and malaise in patients with cancer who already complain of these symptoms, therefore, they are less inclined to fill these PROMs (68).

The review of the literature revealed a paucity of research conducted to simplify PROMs, therefore, research are necessary to explore the simplification process of PROMs to improve care outcomes, and understand patients' experiences (69). Among the strategies that can be implemented to simplify and improve filling PROMs and overcome the barriers to their use, the following points have been suggested:

- The use of a common native language that facilitates detailed understanding and simplicity. This is crucial to overcome issues related to diverse linguistic backgrounds or non-native languages that can result in incomplete filling and data loss (70, 71).
- Content validity entails validating and condensing questions to match the target audience and research goal, in accordance with Food and Drug Administration (FDA) standards (72).
- Time for completing the questionnaire is crucial, as a lengthy one might be tedious and exhausting for people (73).
- Data gathering through the utilization of several methods of patient-reported data collection, such as the web (ePROMs), telephone, tablet, or paper (74).
- Implementing strategies to minimize missing data by training site staff, patients, and physicians and monitoring adherence in real time (75).
- Using specific PROMs since they are more accurate and focused on gathering the necessary information (76).

3.3. PROMs' applicability across the diverse patient population

To ensure that these tools are understood and achieve the desired benefit from their use around the world, PROMs should be translated into a language that is familiar to the target population (5). If the questionnaire is not clearly understood or filled out incorrectly by patients, it can result in inaccurate or incomplete reporting. This can compromise the validity and reliability of the collected data, as well as the quality of medical information needed for monitoring and health assessment (77). Utilizing translated and culturally adapted PROMs enables the incorporation of a more diverse group of participants. In contrast to culturally inappropriate PROMs, which can lead to a decrease in the number of participants and incomplete data (5), participants may not understand or find relevance in some items, which hinders the capacity to build a common understanding of the value of combining patient-centered data in clinical trial outcomes (78). Many guidelines emphasize that validation and translation procedures are meticulous and accurately represent the necessary cultural viewpoints. Nevertheless, it remains uncertain whether translated and culturally validated PROMs are being utilized in clinical trials that have PRO endpoints (61).

3.4. Examples of the widely used simplified PROMs in Oncology

3.4.1. EORTC QLQ-C30

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Group proposed the creation of a significant tool in 1986 that assesses HRQOL (79). The result was the EORTC Quality of Life Questionnaire-core module (EORTC QLQ-C30). This questionnaire is cancer-specific comprises 30 items, and is widely used in clinical practice (80). The main module is accompanied by subspecialty modules for certain diseases that provide in-depth information that is pertinent to assessing the HRQOL in particular patient groups, such as lung cancer (QLQ-LC13) (71), and breast cancer (QLQ-BR23) (81), evaluating symptoms associated with a particular tumor site, such as urinary, sexual, and bowel symptoms in prostate cancer (EORTC QLQ-PR25) (82). Complications that may arise in head and neck cancer patients, such as speech and feeding difficulties can also be measured (83, 84).

In 1987, researchers modified the initial version of the EORTC QLQ-30 (75) to make it more specialized to cancer, multifaceted in design, suitable for self-administration, can be used for different cultural groups, and can be applied for specialized modules related to types or treatments of cancer. (85). Later, the EORTC QLQ-30 was further modified based on the original fundamental concepts, to make it more concise and condensed (84, 86, 87). Due to its importance and usability, EORTC QLQ-30 was translated into more than sixty languages (73), including all the main Western languages, as well as numerous African and Asian languages (88). It only

requires 11 minutes on average to complete, without needing any help (75).

3.4.2. Functional Assessment of Cancer Therapy-General (FACT-G)

The FACT-G questionnaire form is a cancer-specific questionnaire; it is validated, reliable, and widely used in clinical trials and the oncology field (89). This PROM was created in 1987 with the invention of a generic CORE questionnaire and used to encompass various chronic illnesses and conditions (90). It consists of 27 general questions categorized into four domains related to quality of life (91): physical well-being, social/family support, emotional well-being, and functional well-being (92).

This PROM was simplified to the FACT-G7, which is a rapid 7-item version of the FACT-G (93), to assess the patient experiences within the past 7 days and requires less than 15 minutes to complete (94, 95). It is designed for self-administration, but it can also be completed through an interview. This PROM is suitable for patients with any type of cancer and has been tested and confirmed for use with other chronic conditions like HIV/AIDS and multiple sclerosis, as well as with the general population with some adjustments (96). It has been translated into more than 45 languages, including; Asian, European, and African languages (97).

3.4.3. Hospital Anxiety and Depression Scale (HADS)

Zigmond and Snaith introduced the HADS as a self-assessment tool in 1983 (98). It was validated and translated into more than 30 languages and it is considered as a brief measure that can be filled quickly, as it takes 2 to 5 minutes (99). It is considered the gold standard for mood scales in oncology and palliative care (100).

The HADS was initially developed to assess anxiety and depression in patients, even though it has been extensively used in screening and case-finding research. It can identify depression in patients with concurrent somatic illness, who have sleeping disturbances, lack of energy, or concentration difficulties due to their somatic illness (101). This PROM has also been modified, in which it had been separated into HADS-A for anxiety and HADS-D for depression, enabling separate measurements of these disorders (102).

3.4.4. The Short Form-36 (SF-36)

The SF-36 questionnaire is a generic, self-administered questionnaire with multiple dimensions (103). It is a validated and reliable PROM (104). HCPs widely use this PROM for burden diseases like cancer, especially for comparative purposes to assess health improvements (105, 106). It has been translated into more than 50 languages and it took approximately 7 minutes to fill (107). This tool assesses two main aspects of subjective well-being: physical and mental health, using 36 questions and 8 multi-item scales (108). The SF-36 was simplified to the SF-12, which is a condensed form of its previous version SF-36, that has been developed to reduce the load of responding and the burden on the respondent (109).

3.5. A comparative assessment between EORTC QLQ-C30, FACT-G, HADS, and SF-36

All of these PROMs are reliable, validated, and exhibit strong psychometric features. However, the selection of a certain PROM is dependent on the specific clinical inquiry and the intended purpose of its utilization (110). Since both EORTC-QLQ-30 and FACT-G are specific PROMs for cancer, they have a high level of patient compliance, are user-friendly, and pose no major challenges (111), with a minimum rate of error or missing data. Both are quick and take less than 15 minutes to fill (112).

Despite the great closeness between EORTC-QLQ-30 and FACT-G, studies have found some differences between them. Compared to FACT-G, the EORTC QLQ-C30 items often contain negative words, potentially leading to confusion among respondents and unsatisfactory item attributes, as they are harder to understand (113). King et al., (2014) study found that the total score of the FACT-G was more effective than the global scale of the EORTC QLQ-C30 in assessing the overall HRQOL (114). However, Iravani et al., (2018) study found that EORTC QLQ-C30 offers the benefit of generating symptom scores more specific than FACT-G (115).

Despite that HADS and SF-36, both are widely used in oncology, they are not specific to cancer. HADS is most suited for screening rather than case-finding (76). It is considered a distinctive measure that assesses only simple cases of anxiety and depression associated with cancer. On the other hand, the SF-36 has been proven to have content validity as a general assessment tool. However, it is acknowledged that it may not cover all the relevant content areas for specific populations. Additionally, the SF-36 has not been used in the context of palliative care, possibly because it does not address the specific concerns of patients with advanced disease (116).

3.6. Electronic PROMs (ePROMs)

To enhance the role of PROMs in the health system, in addition to conserving physician time since physicians' time is very tight (117), the health system shifted towards using PROMs as tools for remote monitoring, conducting visits when needed, and alerting stakeholders at the right time (46). By shifting from using old-fashioned PROMs that utilize pens and papers to the use of electronic PROMs (ePROMs). In which data are collected electronically through devices such as smartphones, tablets, or personal computers (118, 119). Moreover, ePROMs have the advantage of being completed either directly or through a telephone interview by the patients or their caregivers. The use of electronic devices has significantly reduced the time required to fill, collect, and organize information (117). Furthermore, the outcomes can be immediately shown at the location of treatment and examined on a visual representation (46).

Basch et al., (2016) study was conducted at Memorial Sloan Kettering Cancer Center, used ePROMs, and applied on patients with solid tumors who received chemotherapies distributed randomly into two groups. The first group,

known as the intervention arm, was required to electronically report 12 commonly experienced symptoms during chemotherapy. The second group, known as the control arm, received standard follow-up care as usual. After a 6-month follow-up, the study findings indicated a significant improvement in HRQOL among patients in the intervention group as compared to the control group. Furthermore, individuals in the intervention group experienced a decrease in emergency department visits and hospitalizations and also adhered to scheduled chemotherapy treatments for a longer duration (120). Furthermore, during long-term observation, the median overall survival rate was enhanced by 5 months when utilizing weekly ePROM monitoring as opposed to the standard periodic follow-up visits (121). Using ePROMs complying with local laws requires prioritizing data privacy and security (122). The use of ePROMs is also associated with some disadvantages:

- Cost: This is a significant obstacle to the implementation of ePROMs. Typically, ePROMs have a higher cost compared to conventional PROMs (123).
- Security: An additional significant disadvantage of ePROMs is their susceptibility to data breaches, which pose a risk to the confidentiality of sensitive information (124).
- Complicated programs: ePROMs necessitate computer programming, which might pose difficulties for inexperienced users and elderly patients, and may limit their utilization in some establishments (125). The McCleary et al., (2013) study showed that geriatric patients needed help to finish ePROMs due to computer illiteracy, while patients who could do the paper questionnaire needed less support (126). In another study, patients requiring assistance were notably older than 70 years old (127). In a different study, cancer patients who declined ePROM or preferred phone calls instead of ePROMs were around 10 years older. Elderly or technologically inexperienced patients encounter more obstacles with ePROMs and require training courses to become acquainted with the devices (128).
- Infrastructure requirement: Patients may vary in internet access, and compatible devices to run the ePROMs (129).

3.6.1. Examples of the widely used ePROMs in oncology

3.6.1.1. The McGill Pain Questionnaire (MPQ):

In cancer populations, the MPQ is a widely used, reliable, and validated ePROM used as a measure of pain. It quantifies the neurophysiological and psychological domains of pain, making it a valuable tool for cancer research. However, it is considered time-consuming, since it takes about 25–30 minutes to fill (130). Furthermore, the MPQ has further limitations as it has readability issues for some descriptors, and its three pain patterns are not adequate to account for changes in pain experienced by cancer participants (131).

To overcome these limitations, the MPQ was modified, simplified, and transformed into an electronic Short-Form McGill Pain Questionnaire (eSF-MPQ), which can be filled in 15 minutes (132). Cook et al., (2004) study compared the eSF-MPQ with the conventional (non-electronic) version of

the SF-MPQ and found that responses to both versions' testing modalities for the SF-MPQ showed strong agreement. Furthermore, patients suffering from chronic pain were widely embraced and often favored the electronic version (133).

3.6.1.2. Electronic New Patient Intake Questionnaire (e-NPIQ):

The electronic New Patient Intake Questionnaire (e-NPIQ) is a systematic electronic questionnaire used in clinical care for large-scale data collection and screening of patients for health and lifestyle factors affecting treatment. The e-NPIQ allows patients to fill out the online questionnaire from any personal device, phone, or tablet, and it has been recorded and saved in the electronic health system. The physicians would be notified when the data are collected and analyzed to implement the appropriate health interventions (134).

4. Conclusion

PROMs are used frequently in the oncology field and for research data collection. These measures were developed greatly by researchers and oncology organizations, to achieve the desired benefit, along with increasing the patient sample size in a short period and avoiding missing patients' data. It became necessary to simplify the available measures by; using patients' language, downsizing the content, easily completed by patients themselves, not time-consuming, in line with the level of society's culture, and using technological programs to encourage the using of ePROMs,

Conflict of Interest

The authors declare that there are no conflicts of interest regarding the publication of this manuscript.

5. References

1. Weldring T, Smith SM. Patient-reported outcomes (pros) and patient-reported outcome measures (PROMs). *Health services insights* 2013;6:HSI-S11093.
2. Nguyen H, Butow P, Dhillon H, Sundaresan P. A review of the barriers to using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine cancer care. *Journal of medical radiation sciences* 2021;68(2):186-95.
3. Snyder CF, Jensen RE, Segal JB, Wu AW. Patient-reported outcomes (PROs): putting the patient perspective in patient-centered outcomes research. *Medical care* 2013;1;51:S73-S79.
4. Ip EH. Editorial to the invited special section "advancing methods to assess patient-reported outcomes: Lessons learned from the patient-reported outcomes measurement information system®(PROMIS®) initiative". *Psychometrika* 2021;86(3):669-6670.
5. Slade AL, Retzer A, Ahmed K, Kyte D, Keeley T, Armes J, Brown JM, Calman L, Gavin A, Glaser AW, Greenfield DM. Systematic review of the use of translated patient-reported outcome measures in cancer trials. *Trials* 2021;22:1-6.
6. Shabila NP, Al-Tawil NG, Al-Hadithi T, Sondorp E. Assessment of the Iraqi primary care referral system: reporting a high self-requested referral rate. *Middle East J Fam Med* 2012;1;10(3):4-10.
7. Bevans M, Ross A, Cella D. Patient-Reported Outcomes Measurement Information System (PROMIS): efficient, standardized tools to measure self-reported health and quality of life. *Nursing outlook* 2014;1;62(5):339-45.
8. Kim A, Chung KC, Keir C, Patrick DL. Patient-reported outcomes associated with cancer screening: a systematic review. *BMC cancer* 2022;1;22(1):223.
9. Churruca K, Pomare C, Ellis LA, Long JC, Henderson SB, Murphy LE, Leahy CJ, Braithwaite J. Patient-reported outcome measures (PROMs): a review of generic and condition-specific measures and a discussion of trends and issues. *Health Expectations*. 2021;24(4):1015-24.
10. Müller-Bühl U, Engeser P, Klimm HD, Wiesemann A. Quality of life and objective disease criteria in patients with intermittent claudication in general practice. *Family practice*. 2003;1;20(1):36-40.
11. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. *Journal of clinical epidemiology* 2013;1;66(8):S12-20.
12. Vodicka E, Kim K, Devine EB, Gnanasakthy A, Scoggins JF, Patrick DL. Inclusion of patient-reported outcome measures in registered clinical trials: evidence from ClinicalTrials.gov (2007–2013). *Contemporary clinical trials* 2015;1;43:1-9.
13. Bottomley A, Jones D, Claassens L. Patient-reported outcomes: assessment and current perspectives of the guidelines of the Food and Drug Administration and the reflection paper of the European Medicines Agency. *European journal of cancer* 2009;1;45(3):347-53.
14. Cella D, Hahn EA, Jensen SE, Butt Z, Nowinski CJ, Rothrock N, Lohr KN. Patient-reported outcomes in performance measurement.USA;2015.
15. Lipscomb J, Gotay CC, Snyder CF. Patient-reported outcomes in cancer: a review of recent research and policy initiatives. *CA: A Cancer Journal for Clinicians*. 2007;57(5):278-300.
16. U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research, and U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health and Quality of Life Outcomes*. 2006;4:79.
17. Williams K, Sansoni J, Darcy M, Grootemaat P, Thompson C. Patient-reported outcome measures. Literature review. Sydney: Australian Commission on Safety and Quality in Health Care. 2016.
18. Oude Voshaar M, Terwee CB, Haverman L, van der Kolk B, Harkes M, van Woerden CS, van Breda F, Breukink S, de Hoop I, Vermeulen H, de Graaf E. Development of a standard set of PROs and generic PROMs for Dutch medical specialist care: Recommendations from the

- Outcome-Based Healthcare Program Working Group Generic PROMs. Quality of life research. 2023;32(6):1595-605.
19. Voon PJ, Cella D, Hansen AR. Health-related quality-of-life assessment of patients with solid tumors on immunotherapy. *Cancer* 2021;127(9):1360-8.
 20. Dincer AN, Brunckhorst O, Genel O, Dasgupta P, Muneer A, Ahmed K. Quality of life, anxiety and depression patient-reported outcome measures in testicular cancer: A systematic review. *Psycho-Oncology* 2021;30(9):1420-9.
 21. Rabin R, Charro FD. EQ-SD: a measure of health status from the EuroQol Group. *Annals of medicine* 2001;33(5):337-43.
 22. Black N. Patient reported outcome measures could help transform healthcare. *The British Medical Journal* 2013;346.
 23. Ware Jr JE, Sherbourne CD. The MOS 36-Item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical care* 1992;30(6):473-83.
 24. Stewart AL, Hays RD, Ware Jr JE. The MOS short-form general health survey: reliability and validity in a patient population. *Medical care* 1988;26(7):724-735.
 25. Winkelmann C, Mezentseva A, Vogt B, Neumann T. Patient-Reported Outcome Measures in Liver and Gastrointestinal Cancer Randomized Controlled Trials. *International Journal of Environmental Research and Public Health* 2023;20(13):6293.
 26. Boyes H, Barraclough J, Ratansi R, Rogers SN, Kanatas A. Structured review of the patient-reported outcome instruments used in clinical trials in head and neck surgery. *British Journal of Oral and Maxillofacial Surgery* 2018;56(3):161-7.
 27. Arraras JI, Arias F, Tejedor M, Pruja E, Marcos M, Martínez E, Valerdi J. The EORTC QLQ-C30 (version 3.0) quality of life questionnaire: validation study for Spain with head and neck cancer patients. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2002;11(3):249-56.
 28. Besson A, Deftereos I, Chan S, Faragher IG, Kinsella R, Yeung JM. Understanding patient-reported outcome measures in colorectal cancer. *Future Oncology* 2019;15(10):1135-46.
 29. Schurr T, Loth F, Lidington E, Piccinin C, Arraras JI, Groenvold M, Holzner B, van Leeuwen M, Petersen MA, Schmidt H, Young T. Patient-reported outcome measures for physical function in cancer patients: content comparison of the EORTC CAT Core, EORTC QLQ-C30, SF-36, FACT-G, and PROMIS measures using the International Classification of Functioning, Disability and Health. *BMC medical research methodology* 2023;21;23(1):21.
 30. Sansoni JE. Health outcomes: an overview from an Australian perspective. 2016.
 31. Mpundu-Kaambwa C, Bulamu NB, Lines L, Chen G, Whitehurst DG, Dalziel K, Devlin N, Ratcliffe J. Exploring the Use of Pictorial Approaches in the Development of Paediatric Patient-Reported Outcome Instruments: A Systematic Review. *PharmacoEconomics* 2024;1-29.
 32. Manificat S, Dazord A, Cochat P, Morin D, Plainguet F, Debray D. Quality of life of children and adolescents after kidney or liver transplantation: child, parents and caregiver's point of view. *Pediatric transplantation* 2003;7(3):228-35.
 33. Janssens A, Coon JT, Rogers M, Allen K, Green C, Jenkinson C, Tennant A, Logan S, Morris C. A systematic review of generic multidimensional patient-reported outcome measures for children, part I: descriptive characteristics. *Value in Health* 2015;18(2):315-33.
 34. Beck AT, Guth D, Steer RA, Ball R. Screening for major depression disorders in medical inpatients with the Beck Depression Inventory for Primary Care. *Behaviour research and therapy* 1997;35(8):785-91.
 35. Al Sayah F, Jin X, Johnson JA. Selection of patient-reported outcome measures (PROMs) for use in health systems. *Journal of patient-reported outcomes* 2021;5:1-5.
 36. Shearer D, Morshed S. Common generic measures of health related quality of life in injured patients. *Injury* 2011;42(3):241-7.
 37. Cella D, Nowinski CJ. Measuring quality of life in chronic illness: the functional assessment of chronic illness therapy measurement system. *Archives of physical medicine and rehabilitation* 2002;83:S10-7.
 38. Owolabi MO. Which is more valid for stroke patients: generic or stroke-specific quality of life measures?. *Neuroepidemiology* 2010;34(1):8-12.
 39. Comins JD, Brodersen J, Siersma V, Jensen J, Hansen CF, Krogsgaard MR. How to develop a condition-specific PROM. *Scandinavian Journal of Medicine & Science in Sports* 2021;31(6):1216-24.
 40. Graupner C, Kimman ML, Mul S, Slok AH, Claessens D, Kleijnen J, Dirksen CD, Breukink SO. Patient outcomes, patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care: a systematic review. *Supportive Care in Cancer* 2021;29:573-93.
 41. Graupner C, Breukink SO, Mul S, Claessens D, Slok AH, Kimman ML. Patient-reported outcome measures in oncology: a qualitative study of the healthcare professional's perspective. *Supportive Care in Cancer* 2021;29:5253-61.
 42. Boyes A, Newell S, Girgis A, McElduff P, Sanson-Fisher R. Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being?. *European journal of cancer care* 2006;15(2):163-71
 43. van Egdom LS, Oemrawsingh A, Verweij LM, Lingsma HF, Koppert LB, Verhoef C, Klazinga NS, Hazelzet JA. Implementing patient-reported outcome measures in clinical breast cancer care: a systematic review. *Value in Health* 2019;1;22(10):1197-226.
 44. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, MacGillivray S. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *Journal of clinical oncology* 2014;32(14):1480-510.

45. Howell D, Molloy S, Wilkinson K, Green E, Orchard K, Wang K, Liberty J. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Annals of Oncology* 2015;26(9):1846-58.
46. Govindaraj R, Agar M, Currow D, Luckett T. Assessing Patient-Reported Outcomes in Routine Cancer Clinical Care Using Electronic Administration and Telehealth Technologies: Realist Synthesis of Potential Mechanisms for Improving Health Outcomes. *Journal of medical Internet research* 2023;25:e48483.
47. Denis F, Lethrosne C, Pourel N, Molinier O, Pointreau Y, Domont J, Bourgeois H, Senellart H, Trémolières P, Lizée T, Bennouna J. Randomized trial comparing a web-mediated follow-up with routine surveillance in lung cancer patients. *JNCI: Journal of the National Cancer Institute* 2017;109(9):dxx029.
48. Basch E, Schrag D, Henson S, Jansen J, Ginos B, Stover AM, Carr P, Spears PA, Jonsson M, Deal AM, Bennett AV. Effect of electronic symptom monitoring on patient-reported outcomes among patients with metastatic cancer: a randomized clinical trial. *Jama* 2022;327(24):2413-22.
49. Murphy M, Hollinghurst S, Salisbury C. Identification, description and appraisal of generic PROMs for primary care: a systematic review. *BMC family practice* 2018;19:1-2
50. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, Bonsel G, Badia X. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of life research* 2011;20:1727-36.
51. Balestroni G, Bertolotti G. EuroQol-5D (EQ-5D): an instrument for measuring quality of life. *Monaldi Archives for Chest Disease* 2012;78(3).
52. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Medical care* 1996;34(3):220-33.
53. Cleeland CS, Mendoza TR, Wang XS, Chou C, Harle MT, Morrissey M, Engstrom MC. Assessing symptom distress in cancer patients: the MD Anderson Symptom Inventory. *Cancer: Interdisciplinary International Journal of the American Cancer Society* 2000;89(7):1634-46.
54. Ravens-Sieberer U, Gosch A, Rajmil L, Erhart M, Bruil J, Duer W, Auquier P, Power M, Abel T, Czemy L, Mazur J. KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert review of pharmacoeconomics & outcomes research*. 2005;5(3):353-64.
55. Weingärtner V, Dargatz N, Weber C, Mueller D, Stock S, Voltz R, Gaertner J. Patient reported outcomes in randomized controlled cancer trials in advanced disease: a structured literature review. *Expert review of clinical pharmacology* 2016;9(6):821-9.
56. Bergman B, Aaronson NK, Ahmedzai S, Kaasa S, Sullivan M. The EORTC QLQ-LC13: a modular supplement to the EORTC core quality of life questionnaire (QLQ-C30) for use in lung cancer clinical trials. *European journal of cancer* 1994;30(5):635-42.
57. Preston NJ, Wilson N, Wood NJ, Brine J, Ferreira J, Brearley SG. Patient-reported outcome measures for use in gynaecological oncology: A systematic review. *British Journal of Obstetrics and Gynaecology: An International Journal of Obstetrics & Gynaecology* 2015;122(5):615-22.
58. van Rooij JA, Roubos J, Vrancken Peeters NJ, Rijken BF, Corten EM, Mureau MA. Long-term patient-reported outcomes after reconstructive surgery for head and neck cancer: A systematic review. *Head & Neck* 2023;45(9):2469-77.
59. Singer S, Arraras JI, Chie WC, Fisher SE, Galalae R, Hammerlid E, Nicolatou-Galitis O, Schmalz C, Verdonck-de Leeuw I, Gamper E, Keszte J. Performance of the EORTC questionnaire for the assessment of quality of life in head and neck cancer patients EORTC QLQ-H&N35: a methodological review. *Quality of Life Research* 2013;22:1927-41.
60. Tennant A, Penta M, Tesio L, Grimby G, Thonnard JL, Slade A, Lawton G, Simone A, Carter J, Lundgren-Nilsson Å, Tripolski M. Assessing and adjusting for cross-cultural validity of impairment and activity limitation scales through differential item functioning within the framework of the Rasch model: the PRO-ESOR project. *Medical care* 2004;42(1):I-37.
61. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, Ring L. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO Good Research Practices Task Force report: part 2—assessing respondent understanding. *Value in Health* 2011;14(8):978-88.
62. Lord FM, Novick MR. *Statistical theories of mental test scores*. IAP; 2008.
63. Wright BD. *A history of social science measurement. Educational measurement: Issues and practice*. 1997;16(4):33-45.
64. Krogsgaard MR, Brodersen J, Christensen KB, Siersma V, Kreiner S, Jensen J, Hansen CF, Comins JD. What is a PROM and why do we need it?. *Scandinavian journal of medicine & science in sports* 2021;31(5):967-71.
65. Dobrozi, S., & Panepinto, J. (2015). Patient-reported outcomes in clinical practice. *Hematology* 2014, the American Society of Hematology Education Program Book, 2015(1), 501-506.
66. for Drug HS, for Biologics HS, for Devices HS, Health R. *Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance*. *Health and Quality of Life Outcomes* 2006;4:79.
67. Andersen Jr MJ, Yvellez OV, El Jurdi K, Lei D, Pearl TA, Zmeter N, Rubin DT. *Simplification of Validated Patient-Reported Outcome Instruments in Inflammatory Bowel Disease: 629. Official journal of the American College of Gastroenterology | ACG*. 2018 Oct 1;113:S357.
68. Nguyen H, Butow P, Dhillon H, Morris L, Brown A, West K, Sundaresan P. Using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine head and neck cancer care: What do health professionals perceive as barriers and facilitators?.

- Journal of Medical Imaging and Radiation Oncology 2020;64(5):704-10.
69. Bouazza YB, Chiari I, El Kharbouchi O, De Backer L, Vanhoutte G, Janssens A, Van Meerbeeck JP. Patient-reported outcome measures (PROMs) in the management of lung cancer: a systematic review. *Lung cancer* 2017;113:140-51.
 70. Kim AH, Roberts C, Feagan BG, Banerjee R, Bemelman W, Bodger K, Derieppe M, Dignass A, Driscoll R, Fitzpatrick R, Gaarentstroom-Lunt J. Developing a standard set of patient-centred outcomes for inflammatory bowel disease—an international, cross-disciplinary consensus. *Journal of Crohn's and Colitis* 2018;12(4):408-18.
 71. Velikova G, Coens C, Efficace F, Greimel E, Groenvold M, Johnson C, Singer S, Van De Poll-Franse L, Young T, Bottomley A, EORTC Quality of Life Group. Health-related quality of life in EORTC clinical trials—30 years of progress from methodological developments to making a real impact on oncology practice. *European journal of cancer supplements* 2012;10(1):141-9.
 72. de Jong MJ, Roosen D, Degens JH, van den Heuvel TR, Romberg-Camps M, Hameeteman W, Bodelier AG, Romanko I, Lukas M, Winkens B, Markus T. Development and validation of a patient-reported score to screen for mucosal inflammation in inflammatory bowel disease. *Journal of Crohn's and Colitis* 2019;13(5):555-63.
 73. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, Haes JC, Kaasa S. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *JNCI: Journal of the National Cancer Institute* 1993;85(5):365-76.
 74. Snyder CF, Aaronson NK. Use of patient-reported outcomes in clinical practice. *The Lancet* 2009;374(9687):369-70.
 75. Duncan EA, Murray J. The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC health services research* 2012;12:1-9.
 76. Mitchell AJ, Meader N, Symonds P. Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: a meta-analysis. *Journal of affective disorders* 2010;126(3):335-48.
 77. Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. *Health Expectations* 2017;20(1):11-23.
 78. Wild D, Eremenco S, Mear I, Martin M, Houchin C, Gawlicki M, Hareendran A, Wiklund I, Chong LY, Von Maltzahn R, Cohen L. Multinational trials—recommendations on the translations required, approaches to using the same language in different countries, and the approaches to support pooling the data: the ISPOR patient-reported outcomes translation and linguistic validation good research practices task force report. *Value in Health* 2009;12(4):430-40.
 79. Scott N, Fayers P, Aaronson N, Bottomley A, de Graeff A, Groenvold M, Gundy C, Koller M, Petersen MA, Sprangers MA. EORTC QLQ-C30. Reference values. Brussels: EORTC, 2008.
 80. Bottomley A, Efficace F, Thomas R, Vanvoorden V, Ahmedzai SH. Health-related quality of life in non-small-cell lung cancer: methodologic issues in randomized controlled trials. *Journal of Clinical Oncology*. 2003;21(15):2982-92.
 81. Tan ML, Idris DB, Teo LW, Loh SY, Seow GC, Chia YY, Tin AS. Validation of EORTC QLQ-C30 and QLQ-BR23 questionnaires in the measurement of quality of life of breast cancer patients in Singapore. *Asia-Pacific journal of oncology nursing* 2014;1(1):22-32.
 82. Van Andel G, Bottomley A, Fosså SD, Efficace F, Coens C, Guerif S, Kynaston H, Gontero P, Thalmann G, Akdas A, D'Haese S. An international field study of the EORTC QLQ-PR25: a questionnaire for assessing the health-related quality of life of patients with prostate cancer. *European journal of cancer* 2008;44(16):2418-24.
 83. López-Jornet P, Camacho-Alonso F, López-Tortosa J, Tovar TP, Rodríguez-Gonzales MA. Assessing quality of life in patients with head and neck cancer in Spain by means of EORTC QLQ-C30 and QLQ-H&N35. *Journal of Cranio-Maxillofacial Surgery* 2012;40(7):614-20.
 84. Singer S, Wollbrück D, Wolke C, Dietz A, Klemm E, Oeken J, Meister EF, Gudziol H, Bindewald J, Schwarz R. Validation of the EORTC QLQ-C30 and EORTC QLQ-H&N35 in patients with laryngeal cancer after surgery. *Head & Neck: Journal for the Sciences and Specialties of the Head and Neck* 2009;31(1):64-76.
 85. Aaronson NK, Cull A, Kaasa S, Sprangers MA. The European Organisation for Research and Treatment of Cancer (EORTC) modular approach to quality-of-life assessment in oncology: an update. In *Quality of Life and Pharmacoeconomics* 1996;179-189. Raven Press.
 86. Egan M, Burke E, Meskell P, MacNeela P, Dowling M. Quality of life and resilience related to chemotherapy-induced peripheral neuropathy in patients post treatment with platinum and taxanes. *Journal of Research in Nursing* 2015;20(5):385-98.
 87. van der Kloot WA, Kobayashi K, Yamaoka K, Inoue K, Nortier HW, Kaptein AA. Summarizing the fifteen scales of the EORTC QLQ-C30 questionnaire by five aggregate scales with two underlying dimensions: a literature review and an empirical study. *Journal of psychosocial oncology* 2014;32(4):413-30.
 88. Koller M, Aaronson NK, Blazeby J, Bottomley A, Dewolf L, Fayers P, Johnson C, Ramage J, Scott N, West K, EORTC Quality of Life Group. Translation procedures for standardised quality of life questionnaires: The European Organisation for Research and Treatment of Cancer (EORTC) approach. *European Journal of Cancer* 2007;43(12):1810-20.
 89. Yusuf M, Adeyemi O, Flannery M, Bouillon-Minois JB, Van Allen K, Cuthel AM, Goldfeld KS, Ouchi K, Grudzen CR, EMPAll Investigators. Psychometric Properties of the Functional Assessment of Cancer Therapy-General for Evaluating Quality of Life in Patients With Life-Limiting Illness in the Emergency Department. *Journal of Palliative Medicine* 2024;27(1):63-74.

90. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, Silberman M, Yellen SB, Winicour P, Brannon J, Eckberg K. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol* 1993;11(3):570-9.
91. Teckle P, Peacock S, McTaggart-Cowan H, van der Hoek K, Chia S, Melosky B, Gelmon K. The ability of cancer-specific and generic preference-based instruments to discriminate across clinical and self-reported measures of cancer severities. *Health and quality of life outcomes* 2011;9:1-0.
92. Cella D, Hernandez L, Bonomi AE, Corona M, Vaquero M, Shiomoto G, Baez L. Spanish language translation and initial validation of the functional assessment of cancer therapy quality-of-life instrument. *Medical care* 1998;36(9):1407-18.
93. Pearman T, Yanez B, Peipert J, Wortman K, Beaumont J, Cella D. Ambulatory cancer and US general population reference values and cutoff scores for the functional assessment of cancer therapy. *Cancer* 2014;120(18):2902-9.
94. Yanez B, Pearman T, Lis CG, Beaumont JL, Cella D. The FACT-G7: a rapid version of the functional assessment of cancer therapy-general (FACT-G) for monitoring symptoms and concerns in oncology practice and research. *Annals of oncology* 2013;24(4):1073-8.
95. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health and quality of life outcomes* 2003;1:1-7.
96. Sánchez R, Ballesteros M, Arnold BJ. Validation of the FACT-G scale for evaluating quality of life in cancer patients in Colombia. *Quality of life Research* 2011;20:19-29.
97. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health and quality of life outcomes* 2003;1:1-7.
98. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica scandinavica* 1983;67(6):361-70.
99. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale—a review of validation data and clinical results. *Journal of psychosomatic research* 1997;42(1):17-41.
100. Lawrie I, Lloyd-Williams M, Taylor F. How do palliative medicine physicians assess and manage depression. *Palliative Medicine* 2004;18(3):234-8.
101. Hansson M, Chotai J, Nordstöm A, Bodlund O. Comparison of two self-rating scales to detect depression: HADS and PHQ-9. *British Journal of General Practice* 2009;59(566):e283-8.
102. Snaith RP. The hospital anxiety and depression scale. *Health and quality of life outcomes* 2003;1:1-4.
103. Ware Jr JE. SF-36 health survey update. *Spine* 2000;25(24):3130-9.
104. Bunevicius A. Reliability and validity of the SF-36 Health Survey Questionnaire in patients with brain tumors: a cross-sectional study. *Health and quality of life outcomes* 2017;15:1-7.
105. Contopoulos-Ioannidis DG, Karvouni A, Kouri I, Ioannidis JP. Reporting and interpretation of SF-36 outcomes in randomised trials: systematic review. *British medical journal* 2009;12:338.
106. Fredheim OM, Borchgrevink PC, Saltnes T, Kaasa S. Validation and comparison of the health-related quality-of-life instruments EORTC QLQ-C30 and SF-36 in assessment of patients with chronic nonmalignant pain. *Journal of Pain and Symptom Management* 2007;34(6):657-65.
107. Patel AA, Donegan D, Albert T. The 36-item short form. *JAAOS—Journal of the American Academy of Orthopaedic Surgeons* 2007;15(2):126-34.
108. van der Meulen M, Zamanipour Najafabadi AH, Lobatto DJ, Andela CD, Vliet Vlieland TP, Pereira AM, van Furth WR, Biermasz NR. SF-12 or SF-36 in pituitary disease? Toward concise and comprehensive patient-reported outcomes measurements. *Endocrine* 2020;70(1):123-33.
109. Jenkinson C, Layte R. Development and testing of the UK SF-12. *Journal of health services research & policy* 1997;2(1):14-8.
110. Ģīga L, Pētersone A, Čakstiņa S, Bērziņa G. Comparison of content and psychometric properties for assessment tools used for brain tumor patients: a scoping review. *Health and Quality of Life Outcomes* 2021;19:1-8.
111. Davda J, Kibet H, Achieng E, Atundo L, Komen T. Assessing the acceptability, reliability, and validity of the EORTC Quality of Life Questionnaire (QLQ-C30) in Kenyan cancer patients: a cross-sectional study. *Journal of Patient-Reported Outcomes* 2021;5:1-8.
112. Weitzner MA, Meyers CA, Gelke CK, Byrne KS, Levin VA, Cella DF. The Functional Assessment of Cancer Therapy (FACT) scale. Development of a brain subscale and revalidation of the general version (FACT-G) in patients with primary brain tumors. *Cancer* 1995;1;75(5):1151-61.
113. Lee CT, Lin CY, Tsai MC, Strong C, Lin YC. Psychometric evaluation and wording effects on the Chinese version of the parent-proxy Kid-KINDL. *Health and Quality of Life Outcomes* 2016;14:1-0.
114. King MT, Bell ML, Costa D, Butow P, Oh B. The Quality of Life Questionnaire Core 30 (QLQ-C30) and Functional Assessment of Cancer-General (FACT-G) differ in responsiveness, relative efficiency, and therefore required sample size. *Journal of clinical epidemiology* 2014;1;67(1):100-7.
115. Iravani K, Jafari P, Akhlaghi A, Khademi B. Assessing whether EORTC QLQ-30 and FACT-G measure the same constructs of quality of life in patients with total laryngectomy. *Health and quality of life outcomes* 2018;16:1-8.
116. Erez G, Selman L, Murtagh FE. Measuring health-related quality of life in patients with conservatively managed stage 5 chronic kidney disease: limitations of the Medical Outcomes Study Short Form 36: SF-36. *Quality of Life Research* 2016;25:2799-809.
117. Narra LR, Verdini N, Lapen K, Nipp R, Gillespie EF. Patient-Reported Outcomes in Clinical Trials: From an

- Endpoint to an Intervention in Cancer Care. In *Seminars in Radiation Oncology* WB Saunders 2023;33(4):358-366 p.
118. Aiyegbusi OL, Nair D, Peipert JD, Schick-Makaroff K, Mucsi I. A narrative review of current evidence supporting the implementation of electronic patient-reported outcome measures in the management of chronic diseases. *Therapeutic advances in chronic disease* 2021;12:20406223211015958.
119. Sathe M, Moshiree B, Vu PT, Khan U, Heltshe SL, Romasco M, Freedman SD, Schwarzenberg SJ, Goss CH, Freeman AJ. Utilization of electronic patient-reported outcome measures in cystic fibrosis research: application to the GALAXY study. *Journal of Cystic Fibrosis* 2021;20(4):605-11.
120. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, Rogak L, Bennett AV, Dueck AC, Atkinson TM, Chou JF. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *Journal of Clinical Oncology* 2016;34(6):557.
121. Sandler KA, Mitchell SA, Basch E, Raldow AC, Steinberg ML, Sharif J, Cook RR, Kupelian PA, McCloskey SA. Content validity of anatomic site-specific patient-reported outcomes version of the common terminology criteria for adverse events (PRO-CTCAE) item sets for assessment of acute symptomatic toxicities in radiation oncology. *International Journal of Radiation Oncology* Biology* Physics* 2018;102(1):44-52.
122. García Abejas A, Serra Trullás A, Sobral MA, Canelas D, Leite Costa F, Salvador Verges À. Improving the Understanding and Managing of the Quality of Life of Patients With Lung Cancer With Electronic Patient-Reported Outcome Measures: Scoping Review. *Journal of Medical Internet Research* 2023;25:e46259.
123. Kitaura K, Hashimoto T, Wada Y, Sasaki Y, Shirakata S, Oga K, Oka T, Nakamura A, Nakaji S. A case of endocardial resection for the treatment of ventricular arrhythmia with left ventricular aneurysm. *Kyobu geka. The Japanese Journal of Thoracic Surgery* 1986;39(2):122-7.
124. Van Den Hurk CJ, Mols F, Eicher M, Chan RJ, Becker A, Geleijnse G, Walraven I, Coolbrandt A, Lustberg M, Velikova G, Charalambous A. A narrative review on the collection and use of electronic patient-reported outcomes in cancer survivorship care with emphasis on symptom monitoring. *Current Oncology* 2022;17;29(6):4370-85.
125. Longley D. KEEPROM. In computer security, an EPROM whose contents cannot be read unless a specific data value is given to it. See EEPROM. Kennedy. In *computer security, a virus*. London 1992;274-287.
126. McCleary NJ, Wigler D, Berry D, Sato K, Abrams T, Chan J, Enzinger P, Ng K, Wolpin B, Schrag D, Fuchs CS. Feasibility of computer-based self-administered cancer-specific geriatric assessment in older patients with gastrointestinal malignancy. *The oncologist* 2013;18(1):64-72.
127. Richter JG, Becker A, Koch T, Nixdorf M, Willers R, Monser R, Schacher B, Alten R, Specker C, Schneider M. Self-assessments of patients via Tablet PC in routine patient care: comparison with standardised paper questionnaires. *Annals of the rheumatic diseases* 2008;67(12):1739-41.
128. Meirte J, Hellemans N, Anthonissen M, Denteneer L, Maertens K, Moortgat P, Van Daele U. Benefits and disadvantages of electronic patient-reported outcome measures: systematic review. *Journal of Medical Internet Research perioperative medicine* 2020;3(1):e15588.
129. Wald T, Zebralla V, Boege M, Kunz V, Neumuth T, Dietz A, Wichmann G, Wiegand S. Web-Based Patient-Reported Outcomes for ENT Patients—Evaluation of the Status Quo, Patients' View, and Future Perspectives. *International Journal of Environmental Research and Public Health* 2022;19(18):11773.
130. Ngamkham S, Vincent C, Finnegan L, Holden JE, Wang ZJ, Wilkie DJ. The McGill Pain Questionnaire as a multidimensional measure in people with cancer: an integrative review. *Pain Management Nursin* 2012;1;13(1):27-51.
131. Graham C, Bond SS, Gerkovich MM, Cook MR. Use of the McGill Pain Questionnaire in the assessment of cancer pain: replicability and consistency. *Pain* 1980;8(3):377-387.
132. Wilkie DJ, Judge MK, Berry DL, Dell J, Zong S, Gillespie R. Usability of a computerized PAINReportIt in the general public with pain and people with cancer pain. *Journal of pain and symptom management* 2003;1;25(3):213-24.
133. Cook AJ, Roberts DA, Henderson MD, Van Winkle LC, Chastain DC, Hamill-Ruth RJ. Electronic pain questionnaires: a randomized, crossover comparison with paper questionnaires for chronic pain assessment. *Pain* 2004;1;110(1-2):310-7.
134. McCleary NJ, Haakenstad EK, Cleveland JL, Manni M, Hassett MJ, Schrag D. Framework for integrating electronic patient-reported data in routine cancer care: an Oncology Intake Questionnaire. *JAMIA open* 2022;1;5(3):ooac064.

تبسيط مقاييس نتائج المرضى المُبلغ عنها في الأورام: مقال مراجعة

الخلفية: النتائج التي أبلغ عنها المريض (PROs) هي التقارير المقدمة من المرضى أنفسهم والتي توضح بالتفصيل حالتهم الصحية الطبية أو سلوكهم المتعلق بمرض أو استخدام الدواء، دون أي تفسير من قبل متخصصي الرعاية الصحية. يتم استخدام PROs لتقييم الحالة الصحية التي لا يمكن قياسها من خلال تدابير مألوفة، للنتائج الأولية مثل شدة الألم، والنتائج الثانوية مثل نوعية الحياة. مقاييس النتائج التي أبلغ عنها المريض (PROMs) هي أدوات أو طرق تم تطويرها بواسطة متخصصين لتقييم البيانات الخاصة بمقاييس النتائج المقدمة مباشرة من قبل المرضى أثناء إجراءات الإبلاغ في مجال الأورام، من المهم تحديد تأثير السرطان والعلاج الكيميائي على الأعراض الجسدية للمريض، والصحة العقلية، والأداء الاجتماعي. تحول النظام الصحي نحو استخدام PROMs كأدوات للمراقبة عن بعد، وإجراء الزيارات عند الحاجة، وتنبيه أصحاب المصلحة في الوقت المناسب. **الهدف:** وصف استخدامات وأنواع PROMs المستخدمة في الممارسة السريرية والحالات الموسيقية المبسطة التي تم تطويرها في علم الأورام. **الخلاصة:** تستخدم PROMs على نطاق واسع في علم الأورام لجمع البيانات، وأصبح من الضروري تبسيط التدابير من خلال استخدام لغة المرضى، وتقليل حجم المحتوى، وتعزيز الحفلات الموسيقية الإلكترونية من خلال البرامج التكنولوجية.

الكلمات المفتاحية: رد فعل سلبي، علم الأورام، النتائج التي أبلغ عنها المريض