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The influence of patient-reported outcome measures on healthcare delivery: A review of methodologies and applications

Ehizogie Paul Adeghe [1, *], Chioma Anthonia Okolo [2] and Olumuyiwa Tolulope Ojeyinka [3]

[1] Pediatric Clinic, William. D Kelley School Dental Clinic, Kornberg School of Dentistry, Temple University, US.
[2] Federal Medical Centre, Asaba, Delta State, Nigeria.
[3] Houston Community College, Houston Texas.

Abstract

Patient-Reported Outcome Measures (PROMs) have emerged as integral tools in assessing healthcare outcomes from the patient's perspective. This comprehensive review explores the methodologies employed in the development, administration, and validation of PROMs, shedding light on their applications and influence on healthcare delivery. It examines the various modes of PROMs administration, including the burgeoning role of technology through electronic platforms and mobile applications. Challenges related to patient adherence, engagement, and disparities in technological access are discussed, offering insights into potential barriers. It meticulously outlines the multifaceted applications of PROMs in healthcare. From influencing clinical decision-making and quality of care assessments to fostering patient-centered care and contributing to health policy initiatives, PROMs have permeated diverse aspects of healthcare delivery. The review also explores the role of PROMs in shaping research endeavors, serving as essential components in health policy initiatives and advancing the understanding of patient outcomes and experiences. While emphasizing the positive impact of PROMs, the paper addresses challenges and considerations associated with their use, including standardization issues, interpretation challenges, and technology-related barriers. The future directions and opportunities section examines potential advancements in personalized medicine, the integration of technology, and the empowerment of patients through increased involvement in their healthcare journey. Ethical considerations surrounding privacy, confidentiality, and informed consent in PROMs implementation are also scrutinized. This review consolidates current knowledge on PROMs methodologies and applications, offering a comprehensive understanding of their influence on healthcare delivery. The paper emphasizes the need for ongoing research, standardization efforts, and the ethical use of PROMs as they continue to shape a patient-centric and personalized approach to healthcare.

Keywords: Patient; Healthcare delivery; Applications; PROMs; Integral tools

1. Introduction

Patient-Reported Outcome Measures (PROMs) have become pivotal instruments in contemporary healthcare, providing a unique avenue to capture the subjective experiences and perspectives of individuals undergoing medical treatments (Black, 2013). A brief overview of PROMs is essential to comprehend their relevance. PROMs encompass a diverse array of tools, surveys, and questionnaires designed to gather data directly from patients regarding their health conditions, symptoms, and overall well-being (Valderas et al., 2008). Unlike traditional clinical metrics, PROMs delve into the lived experiences of patients, acknowledging their role as active contributors to their healthcare journey. The importance of PROMs in healthcare lies in their ability to enrich the understanding of treatment outcomes from the patient's viewpoint (Greenhalgh et al., 2018). Traditional clinical assessments often fall short in capturing the nuanced aspects of an individual's health status. PROMs bridge this gap by allowing patients to articulate their feelings, functional abilities, and the impact of treatments on their quality of life (Basch et al., 2011). The incorporation of patient-reported outcomes into healthcare practices acknowledges the patient's voice as a vital and distinct source of information. The primary

* Corresponding author: Ehizogie Paul Adeghe

purpose of this paper is to underscore the significance of comprehending the profound influence that PROMs wield on healthcare delivery. Beyond being mere tools for data collection, PROMs shape clinical decisions, refine quality assessments, and contribute to patient-centered care. Understanding their methodologies and applications becomes imperative for healthcare practitioners, researchers, and policymakers alike. This paper aims to delve into the methodologies employed in the development, validation, and administration of PROMs. By elucidating the intricate processes involved in creating these measures, healthcare professionals can gain insights into their reliability and applicability (Calvert et al., 2013). Simultaneously, the focus extends to the applications of PROMs, exploring their impact on clinical decision-making, quality assessments, patient-centered care, and their contribution to health policy and research endeavors (Greenhalgh et al., 2016). In light of the multifaceted nature of PROMs, the thesis of this paper is unequivocal: The integration of Patient-Reported Outcome Measures (PROMs) into healthcare practices is a transformative force, influencing not only the methodologies employed in their development and administration but also redefining the landscape of healthcare delivery. By comprehensively exploring the intricate processes involved in creating and applying PROMs, this paper aims to shed light on their profound influence, emphasizing their pivotal role in shaping patient-centered care, clinical decision-making, and broader healthcare policies. As healthcare increasingly recognizes the value of patient perspectives, understanding and harnessing the power of PROMs emerge as essential components of delivering effective and patient-centric healthcare.

1.1. Methodologies in patient-reported outcome measures

Patient-Reported Outcome Measures (PROMs) undergo a meticulous development process to ensure their validity and reliability (Uimonen et al., 2023). Initially, a conceptual framework is established, identifying the key domains and constructs relevant to the targeted health condition or treatment. This phase often involves collaboration between clinicians, researchers, and, notably, patients, ensuring that the PROMs truly capture the aspects of health that matter most to those experiencing the condition (Snyder et al., 2019). Subsequently, item generation takes place, involving the creation of specific questions or statements that reflect the identified domains (Haladyna and Rodriguez, 2013). These items are then refined through qualitative methods such as interviews or focus groups with the target population. The goal is to ensure that the items are clear, relevant, and comprehensive in capturing the intended patient experiences (Black, 2013). Rigorous psychometric testing follows, assessing the internal consistency, reliability, and validity of the PROM. This involves statistical analyses to ensure that the measure consistently captures the intended construct and produces reliable results across diverse populations (Basch et al., 2011). An increasingly recognized and crucial aspect of PROMs development is the active involvement of patients throughout the process (Greenhalgh et al., 2018). Patient engagement contributes to the content validity of PROMs, ensuring that the measures align with the experiences and priorities of those living with the condition. Patients can provide unique insights into the language, nuances, and relevance of the items, ultimately enhancing the authenticity and comprehensibility of the PROM (Greenhalgh et al., 2016). PROMs can be broadly categorized into generic and disease-specific measures. Generic PROMs are designed to assess general aspects of health-related quality of life and are applicable across various health conditions. Disease-specific PROMs, on the other hand, target specific conditions and delve into aspects more relevant to those particular patient populations. The choice between generic and disease-specific measures depends on the research or clinical objectives, balancing the need for a comprehensive overview with the specificity required for certain conditions (Basch et al., 2011). The psychometric properties of PROMs are essential to ensure their reliability and validity. Psychometric testing involves assessing key properties such as reliability (consistency of measurement), validity (the extent to which the PROM measures what it intends to measure), and responsiveness (sensitivity to changes over time) (Calvert et al., 2013). Rigorous validation processes are conducted to confirm that the PROM accurately captures the targeted constructs and produces consistent and meaningful results. PROMs can be administered through various modes, including traditional paper-based surveys, electronic platforms, and mobile applications. The choice of administration mode depends on factors such as patient preferences, technological accessibility, and the study's objectives. Electronic and mobile-based administration methods offer advantages in terms of efficiency, real-time data collection, and potential cost-effectiveness, but considerations for diverse patient populations and data security are crucial (Valderas et al., 2008). Determining the optimal timing and frequency of PROMs administration is essential to capture relevant information without imposing undue burden on patients. The timing may vary based on the specific research or clinical context. Some PROMs are designed for regular use in clinical practice to monitor ongoing symptoms, while others may be more suitable for specific time points, such as before and after a treatment intervention. Striking a balance between collecting comprehensive data and minimizing patient burden is a key consideration in determining the timing and frequency of PROMs collection (Snyder et al., 2019).

Challenges in Implementing PROMs Methodologies, Achieving high levels of patient adherence and engagement in completing PROMs is a common challenge. Factors such as the length and complexity of the measures, as well as the mode of administration, can influence patient participation (Longtin et al., 2010). Strategies to enhance adherence may include clear communication about the purpose of PROMs, incorporating patient feedback in the development process,

and exploring user-friendly administration methods (Greenhalgh et al., 2016). The increasing use of electronic and mobile-based PROMs introduces challenges related to technological accessibility and health literacy. Not all patients may have access to or be comfortable using digital devices, potentially introducing biases in data collection (Demanuele et al., 2022). Addressing these barriers involves considering alternative administration methods for diverse populations, providing adequate support and instructions, and ensuring that technological solutions do not exacerbate existing health disparities (Valderas et al., 2008). The considerations for patient involvement, choice between generic and disease-specific measures, and challenges in implementation set the stage for a nuanced understanding of how PROMs contribute to enhancing patient-centered care and shaping healthcare outcomes.

1.2. Applications of patient-reported outcome measures (proms)

PROMs play a pivotal role in enhancing clinical decision-making by providing a holistic view of the patient's health status directly from their perspective (Greenhalgh et al., 2018). Integrated into routine clinical assessments, PROMs offer valuable insights into symptoms, functioning, and overall well-being that may not be captured by traditional clinical measures alone (Basch et al., 2011). This integration allows healthcare providers to tailor treatment plans based on a more comprehensive understanding of the patient's experience. The use of PROMs in clinical decision-making extends beyond initial assessments to guide ongoing treatment planning and adjustments (Holmes et al., 2017). Regular monitoring through PROMs enables healthcare providers to track changes in symptoms or health-related quality of life over time. This real-time feedback empowers clinicians to make timely and informed decisions, adjusting interventions to better align with the patient's evolving needs and preferences (Snyder et al., 2019). PROMs serve as valuable tools in the assessment of healthcare quality by providing a direct measure of patient-reported outcomes. Healthcare institutions and providers can utilize PROMs data to evaluate the effectiveness of interventions, patient satisfaction, and adherence to quality standards (Calvert et al., 2013). This patient-centric approach contributes to a more comprehensive understanding of the impact of healthcare services on individuals. The systematic collection and analysis of PROMs data enable comparisons and benchmarks for healthcare providers (Al Sayah et al., 2021). By aggregating and anonymizing data across different providers or institutions, it becomes possible to identify variations in patient-reported outcomes. This not only facilitates quality improvement initiatives but also empowers patients to make informed choices about their healthcare providers based on outcomes that matter most to them (Black, 2013). PROMs facilitate shared decision-making between patients and healthcare providers by incorporating the patient's perspective into the dialogue. Shared decision-making involves collaborative discussions about treatment options, considering the patient's values, preferences, and goals. PROMs contribute valuable information to these conversations, allowing healthcare providers and patients to jointly determine the most suitable course of action (Greenhalgh et al., 2016). The routine use of PROMs enhances communication by providing a structured and standardized approach to discussing patient experiences. PROMs data serve as conversation starters during clinical encounters, prompting discussions about symptoms, treatment impacts, and aspects of daily life affected by the health condition. This improved communication fosters a deeper understanding of the patient's needs and enhances the therapeutic alliance between patients and healthcare providers (Basch et al., 2011). PROMs have gained recognition as valuable tools in shaping health policy initiatives. Policymakers use PROMs data to inform decisions about resource allocation, quality improvement goals, and the development of patient-centered healthcare policies (Valderas et al., 2008). The inclusion of patient-reported outcomes in policy considerations reflects a commitment to aligning healthcare systems with the priorities and experiences of those they serve. PROMs contribute significantly to research endeavors by providing rich and nuanced data on patient outcomes and experiences (Roe et al., 2022). Researchers leverage PROMs to explore the effectiveness of treatments, understand the impact of health conditions on daily life, and investigate factors influencing patient-reported outcomes. The incorporation of PROMs in research studies enhances the evidence base for healthcare interventions and informs future developments in patient-centered care (Snyder et al., 2019). The diverse applications of PROMs in clinical decision-making, quality assessments, patient-centered care, and health policy underscore their transformative potential in shaping the healthcare landscape. By integrating patient-reported outcomes into these facets, healthcare providers, policymakers, and researchers can collectively work towards a more personalized, patient-centric, and effective healthcare system.

1.3. Challenges and considerations in the implementation of proms

One significant challenge in the implementation of PROMs is the lack of standardization in the selection of measures (Churruca et al., 2021). The vast array of available PROMs for different health conditions can lead to inconsistencies in the choice of tools across healthcare settings and research studies. Standardization efforts are essential to establish a common framework for PROMs selection, ensuring that the chosen measures are valid, reliable, and relevant to the specific context (Calvert et al., 2013). Interpreting PROMs outcomes can be complex due to variations in scoring systems and the context-specific nature of patient-reported data. Establishing standardized benchmarks or reference values for PROMs outcomes is challenging, as the interpretation often depends on factors such as the population studied and the clinical context (Churruca et al., 2021). Efforts to enhance standardization include the development of normative data

and guidelines for interpreting PROMs scores to facilitate meaningful comparisons (Basch et al., 2011). Distinguishing between clinical significance and statistical significance poses a significant challenge in PROMs interpretation. While statistical significance indicates a measurable change, clinical significance revolves around the meaningful impact of that change on the patient's daily life. Determining the minimal clinically important difference (MCID) for specific PROMs requires careful consideration of patient perspectives and meaningful thresholds, contributing to the overall challenge of translating statistical changes into clinically relevant outcomes (Snyder et al., 2019). The cultural and linguistic diversity among patients introduces challenges in the interpretation of PROMs. Language nuances, cultural perceptions of health, and variations in health literacy levels can impact the validity and reliability of patient-reported data (Perrin et al., 2021). Ensuring that PROMs are linguistically and culturally appropriate for diverse populations is crucial for minimizing biases and obtaining accurate representations of patient experiences (Valderas et al., 2008). The increasing use of electronic and mobile-based PROMs introduces challenges related to the digital divide. Not all patients have equal access to digital devices or the internet, potentially introducing disparities in data collection. Addressing this barrier involves considering alternative administration methods for diverse populations, ensuring equitable access to PROMs, and acknowledging potential biases in digitally collected data (Greenhalgh et al., 2016). The electronic administration of PROMs raises concerns about data security and privacy. Safeguarding patient-reported data is paramount to maintain trust in the healthcare system. Implementation strategies need to prioritize secure platforms, encryption methods, and adherence to privacy regulations. Clear communication with patients about data security measures is essential to mitigate concerns and ensure their willingness to engage in electronic PROMs collection (Black, 2013). Achieving high levels of patient adherence and engagement in completing PROMs is crucial for the success of their implementation. Factors influencing participation include the length and complexity of the measures, patient understanding of the purpose of PROMs, and the mode of administration (Long et al., 2021). Strategies to enhance adherence may involve patient education, providing clear instructions, and incorporating patient feedback in the PROMs development process (Greenhalgh et al., 2016). Patients may experience survey fatigue, particularly when asked to complete multiple PROMs over time. The cumulative burden of regular data collection can diminish patient enthusiasm and compromise the accuracy of responses. Implementing strategies to minimize survey fatigue, such as prioritizing key measures, optimizing the timing and frequency of administration, and employing user-friendly interfaces, is essential to maintain sustained patient engagement (Snyder et al., 2019). Ethical considerations in PROMs implementation include ensuring informed consent and respecting patient autonomy. Clear communication about the purpose, use, and potential implications of PROMs data is essential to obtain valid and voluntary participation (Ruseckaite et al., 2019). Respecting patient autonomy involves allowing individuals to choose their level of engagement with PROMs and being transparent about how their reported data will be utilized (Basch et al., 2011). Implementing PROMs ethically requires special attention to vulnerable populations, including those with cognitive impairments, language barriers, or limited health literacy. Strategies to protect vulnerable populations may involve additional support in the PROMs completion process, the use of validated measures for specific populations, and continuous efforts to address health disparities in data collection (Valderas et al., 2008). Navigating these challenges and considerations is crucial for the successful and ethical implementation of PROMs in healthcare settings. By addressing standardization issues, enhancing interpretation practices, overcoming technology-related barriers, promoting patient adherence, and prioritizing ethical considerations, healthcare providers and researchers can harness the full potential of PROMs to improve patient-centered care and healthcare outcomes.

1.4. Strategies for successful proms implementation

Successful implementation of PROMs involves seamlessly integrating them into routine clinical workflows (Driscoll et al., 2022). This requires collaboration between healthcare providers, administrators, and technology specialists to design efficient processes for PROMs administration, data collection, and interpretation. By incorporating PROMs seamlessly, clinicians can leverage patient-reported data to inform decision-making without disrupting the natural flow of patient care (Snyder et al., 2019). Electronic Health Records (EHRs) play a pivotal role in the integration of PROMs into clinical workflows. Linking PROMs data with EHRs allows for streamlined access to patient-reported information during clinical encounters (Wu et al., 2013). Additionally, electronic platforms enable automated scoring and interpretation of PROMs, providing clinicians with real-time insights that can inform discussions with patients and guide treatment decisions (Valderas et al., 2008). Successful PROMs implementation necessitates clear communication with patients about the purpose and benefits of completing these measures. Patients should understand how their reported data contribute to personalized care, treatment planning, and quality improvement initiatives (Lavallee et al., 2016). Educating patients about the impact of PROMs on their healthcare experience enhances their engagement and fosters a sense of partnership in their care (Greenhalgh et al., 2016). Establishing a feedback loop by sharing PROMs results with patients enhances their engagement and reinforces the value of their contributions. Clinicians can discuss changes in PROMs scores over time, link these changes to treatment outcomes, and collaboratively set goals for future interventions. This patient-centered approach not only empowers individuals in managing their health but also strengthens the provider-patient relationship (Calvert et al., 2013). Recognizing the diversity of patient populations,

healthcare settings should consider tailoring PROMs selection to specific conditions, demographics, and cultural backgrounds. Customizing PROMs ensures that the measures are relevant, sensitive, and meaningful to the individuals being assessed. This approach acknowledges the unique aspects of different health conditions and patient experiences (Basch et al., 2011). Offering flexibility in the modes of PROMs administration accommodates the preferences and needs of diverse patient populations. While electronic platforms provide efficiency and real-time data access, alternative methods such as paper-based surveys or telephone interviews may be necessary for individuals with limited digital access or comfort (Skelton et al., 2020). A flexible approach enhances inclusivity and minimizes barriers to participation (Snyder et al., 2019). Successful PROMs implementation requires training healthcare providers on the purpose, administration, and interpretation of PROMs. Providers should be equipped to integrate PROMs seamlessly into clinical discussions, interpret results within the broader context of patient care, and respond appropriately to changes in patient-reported data. Continuous education ensures that clinicians feel confident and competent in utilizing PROMs effectively (Valderas et al., 2008). Providing support for patients during the PROMs completion process is crucial for optimizing data quality and minimizing barriers. This support may include clear instructions, user-friendly interfaces, and assistance for individuals with varying levels of health literacy. Offering guidance ensures that patients feel comfortable and empowered to contribute accurate and meaningful data (Greenhalgh et al., 2016). Ongoing evaluation of PROMs implementation is essential to assess the impact on clinical workflows, patient outcomes, and overall healthcare quality. Implementation outcomes, including feasibility, acceptability, and sustainability, should be regularly monitored. Identifying challenges and successes allows healthcare organizations to refine their approaches and implement continuous quality improvement initiatives (Black, 2013). Establishing feedback loops for continuous quality improvement involves incorporating insights from PROMs data into healthcare practices. Regular review sessions, involving clinicians, administrators, and patients, can identify areas for improvement, refine PROMs selection or administration processes, and ensure that the implementation aligns with the evolving needs of both healthcare providers and patients (Calvert et al., 2013). Prioritizing informed consent and ethical use of PROMs data is fundamental to successful implementation. Patients should have a clear understanding of how their reported data will be used, stored, and protected (Courbier et al., 2019). Ethical considerations involve maintaining confidentiality, ensuring data security, and transparently communicating the intended purposes of PROMs in both clinical care and broader healthcare initiatives (Basch et al., 2011). A commitment to equity requires addressing health disparities in PROMs implementation. Healthcare organizations should actively work to minimize disparities related to access, language, and health literacy. Tailoring implementation strategies to the diverse needs of patient populations ensures that PROMs contribute to a more inclusive and patient-centered healthcare system (Valderas et al., 2008). The successful implementation of PROMs involves a multifaceted approach that encompasses the integration into clinical workflows, patient education, customization, continuous training and support, evaluation, and ethical considerations. By adopting these strategies, healthcare providers can harness the full potential of PROMs to enhance patient-centered care, improve outcomes, and drive quality improvement initiatives.

1.5. Future directions and innovations in proms implementation

The future of PROMs implementation involves the continued development of condition-specific measures that capture the unique aspects of various health conditions (Fleischmann and Vaughan, 2018). Advancements in measurement science will lead to more precise and sensitive PROMs, tailored to specific diseases or patient populations. This personalized approach ensures that PROMs remain relevant and impactful across diverse healthcare contexts (Basch et al., 2011). Combining patient-reported data with objective clinical measures, such as biomarkers or wearable device data, represents a promising direction. This integration enhances the comprehensive assessment of patient outcomes by providing a more holistic view of health. By leveraging both subjective and objective measures, healthcare providers can make more informed decisions about treatment effectiveness and patient well-being (Snyder et al., 2019). The integration of artificial intelligence (AI) into PROMs analysis holds significant potential for automating the interpretation of patient-reported data. AI algorithms can identify patterns, trends, and correlations within large datasets, aiding clinicians in extracting meaningful insights from PROMs outcomes. This technological innovation streamlines the analysis process and contributes to more efficient, data-driven healthcare decision-making (Black, 2013). The widespread adoption of mobile health (mHealth) platforms enables real-time monitoring of patient-reported outcomes. Patients can conveniently report their symptoms, well-being, or treatment adherence through mobile applications, providing continuous streams of data. This real-time feedback allows healthcare providers to promptly address emerging issues, adjust treatment plans, and enhance patient engagement in their care (Valderas et al., 2008). Beyond PROMs, the integration of Patient-Generated Health Data (PGHD) broadens the scope of patient-reported information (Bourke et al., 2020). PGHD includes data from wearables, home monitoring devices, and patient diaries. Incorporating PGHD alongside PROMs offers a more comprehensive understanding of patients' daily lives, activity levels, and health behaviors. This multimodal approach enriches the clinical picture and contributes to more personalized healthcare interventions (Calvert et al., 2013). The implementation of blockchain technology in PROMs and PGHD addresses concerns related to data security and patient control. Blockchain ensures the immutability and

transparency of data, enhancing trust in the integrity of patient-reported information. Moreover, patients can maintain control over who accesses their data and for what purposes, aligning with principles of privacy and patient autonomy (Greenhalgh et al., 2016). The future of PROMs involves a paradigm shift towards patient-centric clinical trials. Including patient-reported outcomes as primary endpoints in clinical trials ensures that the research aligns with the outcomes that matter most to individuals. This patient-centered approach enhances the relevance and applicability of trial results, providing a more accurate reflection of the impact of interventions on patients' lives (Basch et al., 2011). Longitudinal studies tracking PROMs trajectories over extended periods contribute to a deeper understanding of the natural course of diseases and the effects of interventions. Examining how patient-reported outcomes evolve over time provides valuable insights into the factors influencing health trajectories. This knowledge informs the development of targeted interventions and strategies for optimizing long-term patient outcomes (Snyder et al., 2019). Future directions in PROMs implementation emphasize empowering patients in the sharing and utilization of their data. Patient engagement strategies should involve transparent discussions about data sharing practices, allowing individuals to make informed decisions about the use of their information. This approach fosters a sense of ownership and control, aligning with principles of autonomy and respect for patients' preferences (Valderas et al., 2008). The future of PROMs implementation requires a concerted effort to address health inequities. Healthcare systems should prioritize inclusivity in PROMs implementation, considering the unique needs and challenges faced by diverse populations. This involves adapting strategies to overcome language barriers, enhancing access to technology, and tailoring PROMs to be culturally sensitive. By prioritizing inclusivity, healthcare providers can contribute to reducing disparities in patient outcomes (Greenhalgh et al., 2016). The evolving landscape of PROMs implementation is marked by advancements in measurement science, technological innovations, the integration of PGHD, patient-centric outcomes research, and a commitment to ethical considerations and patient empowerment. These future directions hold the promise of further enhancing the utility and impact of PROMs in healthcare, ultimately contributing to a more patient-centered and effective healthcare system.

1.6. Challenges and ethical considerations in the future of proms implementation

Despite the potential of technological innovations in PROMs implementation, challenges related to the digital divide persist (Kaufman et al., 2006). In the future, addressing access inequities will be crucial to ensure that all patient populations, regardless of socioeconomic status, have equal opportunities to engage in digital health initiatives. Strategies may involve targeted interventions, partnerships with community organizations, and policy advocacy to bridge the digital gap (Greenhalgh et al., 2016). As PROMs implementation increasingly relies on digital platforms, safeguarding data security and privacy becomes paramount. Future efforts should focus on developing robust cybersecurity measures, ensuring compliance with privacy regulations, and transparently communicating these measures to patients. Establishing trust in the security of patient-reported data is essential for sustaining patient engagement in digital health initiatives (Black, 2013). The integration of artificial intelligence (AI) in PROMs analysis raises ethical considerations related to algorithmic bias. Future endeavors should prioritize the development of unbiased algorithms to ensure fair and equitable analysis of patient-reported data. Ongoing scrutiny, transparency in algorithmic decision-making, and collaboration with diverse stakeholders are essential to address and mitigate potential biases in AI-driven PROMs analysis (Snyder et al., 2019). While blockchain technology enhances data security, ethical considerations related to data ownership emerge. The future of PROMs implementation should involve clear policies and mechanisms for defining patient ownership of their data within blockchain systems. Empowering patients to control access to their information and providing mechanisms for revoking consent are essential components of an ethical approach to data ownership in blockchain-integrated PROMs (Calvert et al., 2013). Ensuring cultural competence in PROMs development and implementation is crucial for capturing the diverse experiences of patient populations. Future initiatives should prioritize the inclusion of culturally relevant measures, considering language, cultural norms, and health beliefs (Napier et al., 2017). Collaborating with diverse communities in the development process enhances the validity and applicability of PROMs across various cultural contexts (Valderas et al., 2008). Vulnerable populations, such as those with limited health literacy or cognitive impairments, require special attention in future PROMs implementation. Tailoring strategies to address the unique needs of these populations involves employing validated measures, providing additional support, and ensuring that PROMs are accessible and comprehensible. Inclusivity in PROMs implementation contributes to a more equitable and patient-centered healthcare system (Basch et al., 2011). The ethical use of PROMs necessitates transparent communication with patients about how their data will be utilized (Rivera et al., 2022). Future implementations should prioritize clear and accessible information regarding the purposes of PROMs use, potential impacts on care, and any research or quality improvement initiatives involving patient-reported data. Open communication fosters trust, empowers patients, and aligns with principles of respect for autonomy (Greenhalgh et al., 2016). The future of PROMs implementation requires proactive measures to address conflicts of interest that may arise in the utilization of patient-reported data. Healthcare organizations should establish policies and guidelines to ensure that PROMs use remains patient-centric and free from undue influence. Maintaining transparency in the decision-making processes and involving patient advocates in governance structures contributes to ethical

PROMs implementation (Calvert et al., 2013). Empowering patients in the use of their data involves fostering collaborative relationships between patients and healthcare providers. Future initiatives should prioritize shared decision-making, where patients actively participate in discussions about their PROMs data, treatment options, and care plans. Recognizing patients as partners in their healthcare journey enhances autonomy, improves engagement, and contributes to patient-centered care (Snyder et al., 2019). Patient empowerment requires comprehensive education on the use and impact of PROMs data. Future strategies should involve educational initiatives that equip patients with the knowledge to make informed decisions about sharing their information (Coulter et al., 2008). Providing accessible resources, such as informational materials and digital tools, enhances patients' understanding of the role and implications of their data in healthcare decision-making (Valderas et al., 2008). The ethical implementation of PROMs involves continuous monitoring for unintended consequences. Future initiatives should establish mechanisms to identify and address any negative impacts on patients, healthcare providers, or the healthcare system. Regular evaluations, feedback loops, and responsiveness to emerging ethical considerations ensure that PROMs implementation evolves in alignment with the evolving landscape of healthcare (Black, 2013). Ethical considerations in PROMs implementation require ongoing governance involving diverse stakeholders (Hunter et al., 2015). Future efforts should include patients, healthcare providers, ethicists, policymakers, and community representatives in the development of guidelines, policies, and decision-making processes. An inclusive governance model ensures that ethical considerations remain at the forefront of PROMs implementation initiatives (Basch et al., 2011). Navigating the challenges and ethical considerations in the future of PROMs implementation requires a proactive and inclusive approach (Shapiro et al., 2022). By addressing disparities in access, integrating ethical considerations in technological advancements, ensuring inclusivity in PROMs development, promoting transparency, empowering patients, and establishing continuous evaluation mechanisms, healthcare systems can maximize the benefits of PROMs while upholding ethical standards.

2. Conclusion

The role of Patient-Reported Outcome Measures (PROMs) in healthcare is evolving rapidly, presenting exciting opportunities and ethical challenges. The implementation of PROMs promises a more patient-centered and personalized approach to healthcare delivery. However, this journey requires careful navigation to address technological disparities, ethical considerations in AI and blockchain integration, inclusivity in PROMs development, transparency, patient empowerment, and continuous evaluation. As healthcare systems advance in their use of PROMs, it is imperative to prioritize inclusivity and equity, ensuring that technological innovations benefit all patient populations. The integration of AI and blockchain technologies should be approached ethically, with a commitment to fairness, transparency, and patient data ownership. Culturally competent PROMs, tailored to diverse populations, will contribute to more meaningful and accurate insights into patient experiences Transparency in PROMs use and reporting is foundational to maintaining trust between patients, healthcare providers, and researchers. Open communication about the purpose and impact of PROMs ensures that patients are informed participants in their healthcare journey. Empowering patients through education and shared decision-making fosters a collaborative healthcare environment. Continuous evaluation and adaptation are essential as healthcare systems embark on this transformative journey. Monitoring for unintended consequences, engaging stakeholders in ethical governance, and proactively addressing challenges will contribute to the responsible and ethical implementation of PROMs. In embracing the future of PROMs, healthcare systems have the opportunity to revolutionize patient care, enhance outcomes, and contribute to a more patient-centric and equitable healthcare landscape.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

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