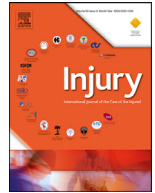




ELSEVIER

Contents lists available at ScienceDirect

Injury

journal homepage: www.elsevier.com/locate/injury

Real-world patient data: Can they support decision making and patient engagement?

Alexander Joeris^{a,*}, Tracy Y Zhu^a, Simon Lambert^b, Andrea Wood^c, Prakash Jayakumar^d

^a AO Innovation Translation Center, Clinical Science, AO Foundation, Davos, Switzerland

^b University College London Hospital, London, United Kingdom

^c Universal Research Solutions LLC, Columbia, MO, United States

^d Department of Surgery and Perioperative Care, Dell Medical School, The University of Texas at Austin, Austin, TX, United States

ARTICLE INFO

Article history:

Accepted 4 December 2021

Available online xxx

Keywords:

Patient-reported outcomes

Shared decision making

Patient engagement

Orthopedics

Care pathway

ABSTRACT

Patient-reported outcomes (PROs) capture data related to patients' perception of their health status and aspects of health care delivery. In parallel, digital innovations have advanced the administration, storage, processing, and accessibility of PROs, allowing these data to become actively incorporated in day-to-day clinical practice along the entire patient care pathway. Further, the emergence of shared decision making, where patients are engaged in informed treatment selection aligned with their preferences, values, and needs, can be realized by PROs and technology. This technology-enabled, data-driven approach provides insights which, when actioned, can enhance musculoskeletal care of patients and populations, while enriching the clinician-patient experience of decision making. In this review, we provide an overview of the opportunities enabled by PROs and technology for the cycle of orthopedic care.

© 2021 The Authors. Published by Elsevier Ltd.

This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Introduction

Stakeholders in health care delivery are recognizing the need to shift from a biomedical to biopsychosocial model of health that accounts for the physical as well as emotional and social aspects of health and wellbeing. Patient-reported outcomes (PROs) are currently central to this endeavor and increasingly being implemented by health systems, aspiring to provide a more patient-centered approach to delivering health. Driven by systemic factors (e.g., changes in health policies, legal frameworks [1,2], and payment reforms [3–5]), technological advances (e.g., growing computing power of digital technologies and wearable devices [6]), and the overarching goal of incorporating patients' voice in decision making [7], the stage is set for implementing PROs into clinical practice [8]. Tools to capture PROs range from patient-reported outcome measures (PROMs), patient-reported experience measures, patient engagement/activation measures, to measures assessing aspects of shared decision-making.

Digital innovations have facilitated administration, storage, processing, and access to PRO measures, allowing them to be actively

incorporated into day-to-day clinical practice. The drive to actively engage patients in care delivery and emergence of shared decision making (SDM) have sparked new opportunities for PRO measures to be utilized within the dynamic process of managing health [8–12]. SDM depends on an exchange of information and evidence-based best practices, combined with effective communication skills, trust, and relationship building, to arrive at an informed clinical decision that is aligned with the patients' preferences, values, and needs [13,14]. This approach represents an important shift from a paternalistic relationship to a partnership between clinicians and patients, where patients are empowered to actively engage in their health and health care ecosystem [15]. Improved patient engagement and effective SDM have shown to improve decision quality, patient experience, satisfaction with communications, patient compliance, and, ultimately, health outcomes [10,16].

The objective of this article is to provide an overview of the opportunities afforded by PROs and associated technologies within the complete pathway of orthopedic care. We explore benefits of PROs for the individual patient care and focus on evolving trends in PROs facilitated by technological advances.

* Corresponding author.

E-mail address: alexander.joeris@aofoundation.org (A. Joeris).

Patient care pathway

Initial assessment

Assessment of symptoms, limitations, and quality of life

Typically collected prior to or at the commencement of the first medical encounter, baseline PRO measurements provide an initial snapshot of a patient's health status in terms of symptomatic impact, limitations, emotional and social health, and quality of life, which complement—and might otherwise be missed within—clinical assessments. Baseline PRO scores can be associated with future health outcomes. For example, in patients undergoing total knee arthroplasty (TKA), preoperative Knee Injury and Osteoarthritis Outcome Score and Short Form-12 scores have been shown to predict the likelihood of clinically meaningful improvements in functional outcomes [17]. Collecting baseline PROs in orthopedic trauma can be challenging and should be as close as possible to the time of injury, allowing for clinical priorities [18], although patients may accurately recall their baseline PRO measurements several months after initial presentation [19,20]. Initial and longitudinal assessments should obtain PROs through a limited set of tools and a restricted, yet optimal, number of questions to avoid survey fatigue and overburdening patients. Patients should also be able to complete these tools with an adequate level of support and resources, e.g., clinic staff providing patients with a tablet device displaying surveys in a user-friendly format. Written and spoken narratives by the clinical team priming patients about the nature and importance of completing the surveys should be aligned.

Screening for psychological distress

Collecting PRO measures can increase awareness of patients' concerns, helping clinicians and patients more easily share their thoughts, including sensitive issues, during medical encounters [21,22]. PRO measures of mental health can help screen pain-related psychological distress [23] (e.g., depression and anxiety) and unhelpful thoughts or misconceptions about pain (e.g., pain catastrophization or kinesiophobia) [24]. This can impact apparently unrelated interventions. For example, poor surgical outcomes in patients undergoing spine surgery are linked to preoperative depression, which can be positively influenced by the implementation of preoperative mental health counseling [10].

Patient phenotyping for personalized care

Identifying patient phenotypes can help tailor care delivery and guide efforts and resources toward more vulnerable and high-need populations [25]. For example, Lentz et al. identified four psychological phenotypes among patients with knee or hip osteoarthritis (OA): high overall distress, low overall distress, low self-efficacy and acceptance, and negative pain coping [26]. Such phenotypes help navigate care for a heterogeneous patient group with different psychological traits toward tailored and coordinated care delivery pathways. However, phenotyping and statistical grouping of PRO scores should only serve as a guide for care delivery and an opportunity to enhance communication, rather than misuse and risk labeling and stigmatizing patients because the individual human experience lies within a societal continuum and is context-dependent.

Evaluating patient activation in health

Clinicians can gain a better understanding of a patient's knowledge, ability, and willingness to effectively manage, participate in, and engage in their health and healthcare system through instruments such as the Patient Activation Measure [27,28]. 'Activated' patients demonstrate an increased likelihood of commitment to

long-term health-improving lifestyle changes, greater medication adherence, improved health outcomes, and being more adept at navigating health care services [29,30]. Jayakumar et al. found that the combination of psychosocial factors and patient engagement accounted for 14–20% of the variation in physical limitations 6 to 9 months after upper limb fracture; moreover, more engaged patients showed fewer limitations and greater satisfaction during recovery [31]. The level of patient activation was also found to be independently associated with costs after adjusting for demographics, severity of the condition, and health risk scores [29], suggesting that even patients with severe illnesses can reduce their healthcare costs by making healthier choices and taking health-improving actions. Evaluating patient activation can also help clinicians identify patients who lack the knowledge, skills, and confidence to manage their own health so that interventions, e.g., tailored general and behavioral health coaching, education, and communication strategies, can be implemented [32].

Evaluating social determinants of health

The World Health Organization describes social determinants of health (SDOH) as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” [33]. SDOH are closely linked with health outcomes and contribute to chronic health conditions [34–36]. Bennett et al. examined over one million medical records and found that socioeconomic status had a significant effect on operative mortality, with patients of the lowest socioeconomic status having the greatest mortality, even after adjusting for other hospital- or patient-level factors [37]. Validated tools have been developed to evaluate patients' SDOH, such as the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences [38], and the Health-Related Social Needs Screening Tool [39]. Health providers can use these tools to identify patients who lack support systems and adequate access to health care and make referrals to community services to address these patients' needs, e.g., transportation and legal assistance [40].

Health literacy, digital literacy, and the user experience

Health literacy is the capacity to obtain, process, and understand basic health information and the services needed to make appropriate health decisions [41]. Poor health literacy is common [42–44] and a barrier to adequate disease knowledge [45,46], completing necessary screening tests [45,47,48], taking prescribed medications [46], adequate disease control [49], and making informed decisions [50].

Nonetheless, clinicians tend to misperceive patients' health literacy, and materials developed to convey health information and education often overestimate patients' health literacy [51]. This may contribute to health disparity and inequality in health care delivery [44,51], especially in the context of digital health. Digital literacy in health care shares the core aspects of health literacy but requires additional skills such as computer literacy and the ability to gain and appraise health information from different electronic sources [52]. With the utility of PROs increasingly dependent on patients' level of digital health literacy, standardized best practices to improve communication and participation for patients of all levels of health literacy become important [53]. Strategies include the alignment of content and mode of delivery of health materials and communications with different levels of health literacy, developing contents with alternative modes of delivery for patients who prefer not to interact with digital media, and increasing access to digital devices for those who cannot afford these tools [52].

Informed decision making

Goal setting and preference elicitation

It is critical to assess a patient's global goals of care in the context of their usual life and elicit their preferences, values, and needs regarding the intended treatment. In cancer care, patients' unmet needs and preferences can be successfully elicited using the Cancer Survivor Profile survey, which utilizes PROMIS item bank and provides a brief but comprehensive profile of problem areas experienced by breast cancer survivors [54]. Patient preference reports or platforms that facilitate clinicians' real-time access to patients' health, concerns, and preferences can help prioritize topics for discussion during medical encounters [55].

Realistic goal setting should be a shared process incorporating clinicians' expertise and patients' preferences and expectations. For example, up to one third of joint replacement surgeries in the US have been shown to be inappropriate based on appropriate use criteria [56]. Avoiding inappropriate interventions through comprehensive preoperative assessments of patients' health status and their expectations is desirable. Quantitative assessments of patients' expectations of function and their perception of decrement in function in relation to the general and matched populations facilitate an individualized roadmap to recovery, which can predict specific time-dependent areas of concern, answer patients' questions, and give a numerical value, or comparator, to their expectations.

While PRO scores can be discussed with patients by using thresholds, e.g., minimal clinically important difference, true goals elicitation and the extent to which goals are attained can be achieved using measures such as the Patient Specific Functional Scale (PSFS) [57]. When comparing the short-version Disabilities of the Arm, Shoulder, and Hand and the PSFS with regard to patient preference and measurements of goals and responsiveness after treatment, most patients found the PSFS more personalized and effective in capturing their goals [58]. When setting goals, clinicians and patients should recognize that the experience and perception of quality of health is on a sliding scale. Therefore, it is important to utilize systems based on continuous scoring rather than artificially defined dichotomies. An example of quantitative assessment of goal achievement is the Goal Attainment Scale [59]. This method encourages the patient to set three to five personally prioritized goals for an intervention or series of interventions. Each goal is measured on a five-point scale after a period agreed with the clinician. A derivative calculation shows how close the achievement at a point in time is to the desired attainment level, and the decrement, for each goal, indicates the preferred pathways for future interventions.

Facilitating and evaluating SDM

The Montreal Accord on Patient-Reported Outcomes summarizes how these tools positively impact communication, enable patients to be engaged in clinical decision making, facilitate patient management, augment self-management action plans, and impact health related outcomes [11]. PRO measures can assist surgeons in evaluating the likelihood of patients demonstrating meaningful improvement after surgery [60,61]. Advanced analytical tools using artificial intelligence (AI) can incorporate PRO measures, alongside a wide range of patient characteristics and preferences, to improve the quality of SDM, health outcomes, and patient satisfaction [62]. In a randomized controlled trial, Jayakumar et al. developed an AI-enabled patient decision aid incorporating PROMs, patient education, preference assessment, to deliver personalized estimates of future health outcomes for patients with knee OA considering TKR [55]. This patient decision aid was associated with

significant improvement in decision quality, level of SDM, patient satisfaction, and functional outcomes when compared with education and usual care alone.

Various instruments have also been developed to capture and evaluate the SDM process, including the understanding and attainment of knowledge, elicitation and consolidation of preferences, decision quality, decision conflict, and decision regret [63,64]. Examples are the Shared Decision Making Process scale [65], Knee Decision Quality Instrument [66], and CollaboRATE survey [67]. Evaluating SDM is important to understand how a high-quality decision can be achieved between clinicians and patients, which factors promote it, and how it can improve patient outcomes. Standardization of these tools are guided by professional guidelines such as the International Patient Decision Aid Standards [68]. Future studies are needed to consolidate the psychometric properties of these tools.

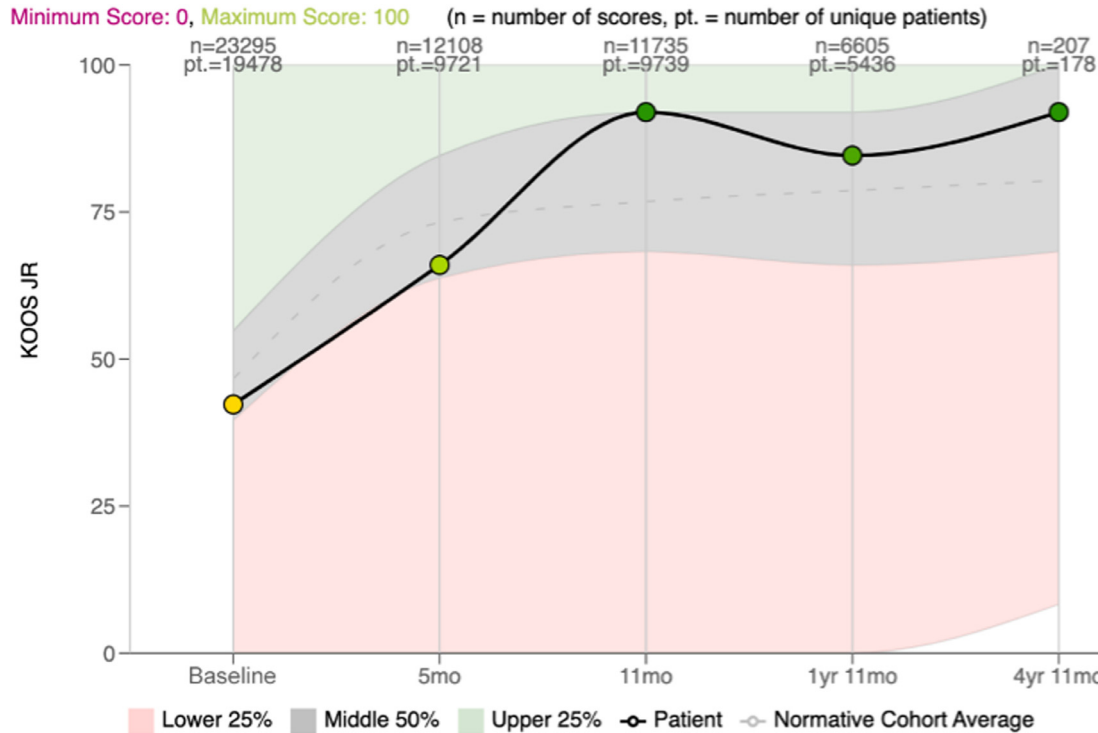
Monitoring recovery and evaluating treatment

Evaluating dynamic change in health and quality of life

PRO measures provide static snapshots across an individual's health trajectory—the dynamic change in health and quality of life over time [69]. Clinicians can use PRO measures to monitor patients' symptoms, limitations, and quality of life while driving decision-making in care delivery. To achieve this goal, platforms that enable a real-time review of the PRO measurements should be in place to provide visual and quantitative illustrations of where patients are along their health or recovery trajectory (Fig. 1). These illustrations are particularly valuable when they are in the context of patients' baseline scores and by comparisons with aggregated population level scores and means [12]. Defining patient outcomes and response phenotypes could help fine tune care delivery, trigger further investigations, and modify treatment plans. Axen et al. showed that patients lacking improvement at the early stage after initiating chiropractic treatment for low back pain are less likely to demonstrate improvement based on their PRO measures; therefore, these patients may warrant more active engagement by the health care team, re-evaluations of psychosocial and life stressors, and modified treatment plans [70]. Tracking or predicting patients with higher likelihood of performing very well within 3 months after TKA may channel these individuals toward remote surveillance and virtual consultations, potentially lowering overall health-care costs [60,71]. In an alternative scenario, unexpected decline in PRO scores after an orthopedic surgery may signal adverse postoperative events requiring prompt workup, e.g., assessments for hardware failure and infection.

Patient engagement in outcome measurement

A fundamental component of capturing PROs is the engagement of patients within the outcome measurement process. Patients completing PRO measures over the complete care pathway can help them track changes in symptoms, limitations, and quality of life. As such, improvements, even if not consciously appreciated, may become evident for positive feedback on performance. Supplying patients with PRO scores and visualizations of their metrics can help them gain an awareness of change and even trigger behavioral change. These insights can help patients, together with their clinical teams, decide whether the current treatment and progress align with expectations, and whether components of care should be modified [72]. This engagement process empowers patients to participate in their health management continuously and actively, while motivating them to remain adherent to treatment plans [73].

KOOS JR

Patient was measured with initial KOOS JR score of 42.281, placing them with surgical timing in the normative range of all patients categorized into . Knee Order Set.

Fig. 1. Sample real-time view showing the patient's dynamic change of patient-reported outcome score. Patients' scores are shown in context of their baseline score and their normative cohort based on demographics and treatment attributes.

Looking ahead*Exploring the mobile/wearable technologies*

Longitudinal capture of PRO measures remains challenging due to the burden placed on patients via excessive or complex surveying and on providers via the human and administrative resources required to deploy and maintain them. This can impact the ability to effectively map health trajectories over time and pose a critical barrier to progress in this field. Clinicians and patients may face critical information shortages as they try to align expectations and make shared informed treatment decisions [74]. Harnessing the increased prevalence and sophistication of smartphones and wearable sensors may help to address these challenges. These digital tools can be used to capture and analyze passive patient-generated health data (PGHD), i.e., data related to behavioral patterns, social interactions, physical mobility, mood, and cognitive functioning [75] (Fig. 2). PGHD has the potential to support personalized health care delivery. For example, using a consumer-level wearable sensor to monitor patients' activity level after total joint arthroplasty, Patterson et al. found that patients who were objectively more sedentary early in their recovery experienced less pain without compromising subjective health outcomes measured by PROMs [76]. Actively and passively captured 'digital biomarkers' quantify health status and enable digital phenotyping, defined as the "moment-by-moment quantification of individual human phenotypes in situ using data from personal digital devices, in particular smartphones" [77]. A recent review by Jayakumar et al. provided an overview of digital phenotyping and passive PGHD for outcome measurement

in surgical care [78]. How these data can be integrated into the health care infrastructure and existing care delivery pathway requires interdisciplinary collaborative efforts from shareholders in both health care and digital health [79].

Innovative platforms for patient data

A flexible and effective platform for collection, storage, analytics, and patient-provider dashboards is critical. Nowadays, a variety of tools that enable successful collection, application, and visualization of PROs are available. To maximize their utility, these tools should have interface design, automation, and customization features that meet the needs of individual patients and provide a robust back end for centralized global data sets, supporting machine learning projects, SDM tools, and benchmarking recovery. It is also important for patients to feel that their data are safe and secure in a digital world, and that they are willing to have their personal data shared and utilized for their care and, in anonymized form, potentially improving care for the wider population. Furthermore, understanding how platforms can be optimized via integration with electronic medical records (EMRs), given the resources, standards for EMR delivery, and clinical workflow, is a key consideration.

Conclusion

PROs place the patient's voice at the center stage of current health care delivery, capturing the individual's perspective on health and wellbeing as well as their preferences, values, and

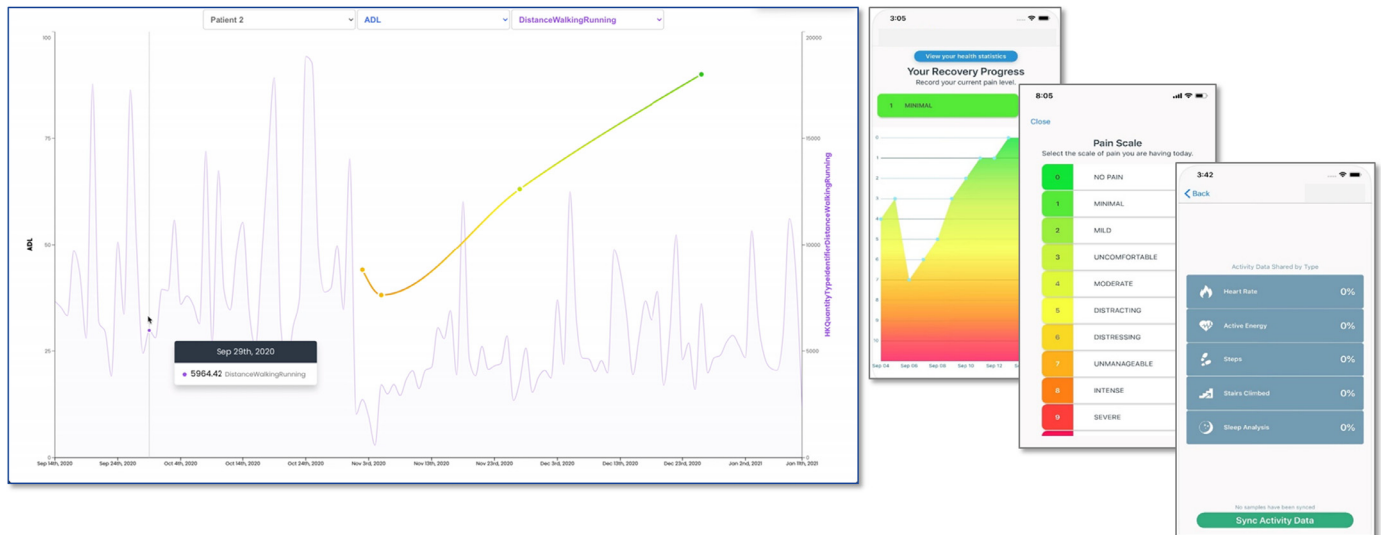


Fig. 2. An example of an active tracking wearable app. The wearable app captures various metrics, such as steps, heart rate, quality of sleep, and calories burned, for remote patient monitoring and tracking recovery trajectories.

needs. Integrating PROs into care delivery in a standardized manner can aid SDM and promote patient engagement. Information generated by PROs provides a holistic but nuanced view of patients that helps clinicians understand the patients' health journey and identify modifiable factors influencing health outcomes. PROs are valuable in supporting clinical decisions and play an important role as a facilitator of SDM. Through their ability to track and monitor health outcomes, PROs can empower patients to actively manage their health and improve their healthcare experiences.

Declaration of Competing Interest

Alexander Joeris and Tracy Y Zhu are employees of the AO Foundation, an independent medically guided not-for-profit organization. Andrea Wood is an employee of Universal Research Solutions LLC, Columbia, Missouri, USA. Universal Research Solutions LLC is the developer of Oberd™. Simon Lambert and Prakash Jayakumar declared that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgement

This work was partially supported by the AO Foundation.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.injury.2021.12.012](https://doi.org/10.1016/j.injury.2021.12.012).

References

- Chan SW, Tulloch E, Cooper ES, Smith A, Wojcik W, Norman JE. Montgomery and informed consent: where are we now? *BMJ* 2017;357:j2224.
- Institute of Medicine (US) Committee on quality of health care in america. crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press (US); 2001.
- Squitieri L, Bozic KJ, Pusic AL. The Role of Patient-Reported Outcome Measures in Value-Based Payment Reform. *Value Health* 2017;20:834–6.
- Porter ME. Value-based health care delivery. *Ann Surg* 2008;248:503–9.
- Porter ME. A strategy for health care reform—toward a value-based system. *N Engl J Med* 2009;361:109–12.
- Sharma A, Harrington RA, McClellan MB, Turakhia MP, Eapen ZJ, Steinhubl S, et al. Using Digital Health Technology to Better Generate Evidence and Deliver Evidence-Based Care. *J Am Coll Cardiol* 2018;71:2680–90.
- Gilmore KJ, Pennucci F, De Rosi S, Passino C. Value in Healthcare and the Role of the Patient Voice. *Healthc Pap* 2019;18:28–35.
- Lavallee DC, Chenok KE, Love RM, Petersen C, Holve E, Segal CD, et al. Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care. *Health Aff (Millwood)* 2016;35:575–82.
- Field J, Holmes MM, Newell D. PROMs data: can it be used to make decisions for individual patients? A narrative review. *Patient Relat Outcome Meas* 2019;10:233–41.
- Baumbauer JF. Patient-Reported Outcomes - Are They Living Up to Their Potential? *N Engl J Med* 2017;377:6–9.
- Noonan VK, Lyddiatt A, Ware P, Jaglal SB, Riopelle RJ, Bingham CO 3rd, et al. Montreal Accord on Patient-Reported Outcomes (PROs) use series - Paper 3: patient-reported outcomes can facilitate shared decision-making and guide self-management. *J Clin Epidemiol* 2017;89:125–35.
- Tew M, Dalziel K, Clarke P, Smith A, Choong PF, Dowsey M. Patient-reported outcome measures (PROMs): can they be used to guide patient-centered care and optimize outcomes in total knee replacement? *Qual Life Res* 2020;29:3273–83.
- Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27:1361–7.
- Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ* 2010;341:c5146.
- Murali NS, Deao CE. Patient Engagement. *Prim Care*. 2019;46:539–47.
- Wilson CD, Probe RA. Shared Decision-making in Orthopaedic Surgery. *J Am Acad Orthop Surg* 2020;28 e1032–e41.
- Berliner JL, Brodtko DJ, Chan V, SooHoo NF, Bozic KJ. Can Preoperative Patient-reported Outcome Measures Be Used to Predict Meaningful Improvement in Function After TKA? *Clin Orthop Relat Res* 2017;475:149–57.
- Grogan Moore ML, Jayakumar P, Laverty D, Hill AD, Koenig KM. Patient-Reported Outcome Measures and Patient Activation: What Are Their Roles in Orthopedic Trauma? *J Orthop Trauma* 2019;33:S38–42 Suppl 7.
- Condon DM, Chapman R, Shaunfield S, Kallen MA, Beaumont JL, Eek D, et al. Does recall period matter? Comparing PROMIS(R) physical function with no recall, 24-hr recall, and 7-day recall. *Qual Life Res* 2020;29:745–53.
- Stepan JG, London DA, Boyer MI, Calfee RP. Accuracy of patient recall of hand and elbow disability on the QuickDASH questionnaire over a two-year period. *J Bone Joint Surg Am* 2013;95:e176.
- Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. *J Eval Clin Pract* 2006;12:559–68.
- Yang LY, Manhas DS, Howard AF, Olson RA. Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication. *Support Care Cancer* 2018;26:41–60.
- Espallargues M, Valderas JM, Alonso J. Provision of feedback on perceived health status to health care professionals: a systematic review of its impact. *Med Care* 2000;38:175–86.
- Hampton SN, Nakonezny PA, Richard HM, Wells JE. Pain catastrophizing, anxiety, and depression in hip pathology. *Bone Joint J* 2019;101-B:800–7.
- Edwards RR, Dworkin RH, Turk DC, Angst MS, Dionne R, Freeman R, et al. Patient phenotyping in clinical trials of chronic pain treatments: IMMPACT recommendations. *Pain* 2016;157:1851–71.
- Lentz TA, George SZ, Manickas-Hill O, Malay MR, O'Donnell J, Jayakumar P, et al. What General and Pain-associated Psychological Distress Phenotypes Exist Among Patients with Hip and Knee Osteoarthritis? *Clin Orthop Relat Res* 2020;478:2768–83.

- [27] Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res* 2005;40:1918–30.
- [28] Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39:1005–26.
- [29] Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. *Health Aff (Millwood)* 2013;32:216–22.
- [30] Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* 2012;27:520–6.
- [31] Jayakumar P, Teunis T, Vranceanu AM, Williams M, Lamb S, Ring D, et al. The impact of a patient's engagement in their health on the magnitude of limitations and experience following upper limb fractures. *Bone Joint J* 2020;102-B:42–7.
- [32] Blash L, Dower C, Chapman S. Center for the Health Professions. PeaceHealth Team Fillingame: update 2014. UCSF Center for the Health Professions 2014 September.
- [33] WHO Commission on social determinants of health WHO. closing the gap in a generation: health equity through action on the social determinants of health: commission on social determinants of health final report. Geneva, Switzerland: World Health Organization; 2008.
- [34] Shen JJ, Wan TT, Perlin JB. An exploration of the complex relationship of socioecologic factors in the treatment and outcomes of acute myocardial infarction in disadvantaged populations. *Health Serv Res* 2001;36:711–32.
- [35] Rao SV, Schulman KA, Curtis LH, Gersh BJ, Jollis JG. Socioeconomic status and outcome following acute myocardial infarction in elderly patients. *Arch Intern Med* 2004;164:1128–33.
- [36] Volaco A, Cavalcanti AM, Filho RP, Precoma DB. Socioeconomic Status: The Missing Link Between Obesity and Diabetes Mellitus? *Curr Diabetes Rev* 2018;14:321–6.
- [37] Bennett KM, Scarborough JE, Pappas TN, Kepler TB. Patient socioeconomic status is an independent predictor of operative mortality. *Ann Surg* 2010;252:552–7.
- [38] National Association of Community Health Centers (NACHC) Association of Asian Pacific community health organizations (AAPCHO), Oregon primary care association (OPCA). the protocol for responding to and assessing patient assets, risks, and experiences (PRAPARE), Bethesda, MD: NACHC; 2019. <http://www.nachc.org>.
- [39] Billioux A, Verlander K, Anthony S, Alley D. Standardized Screening for Health-Related Social Needs in Clinical Settings: The Accountable Health Communities Screening Tool. *NAM Perspectives 2017 Discussion Paper*, National Academy of Medicine, Washington, DC. doi:10.31478/201705b.
- [40] Spruce L. Back to Basics: Social Determinants of Health. *AORN J* 2019;110:60–9.
- [41] McCaffery KJ, Holmes-Rovner M, Smith SK, Rovner D, Nutbeam D, Clayman ML, et al. Addressing health literacy in patient decision aids. *BMC Med Inform Decis Mak* 2013;13:S10 Suppl 2.
- [42] Herndon JB, Chaney M, Carden D. Health literacy and emergency department outcomes: a systematic review. *Ann Emerg Med* 2011;57:334–45.
- [43] Menendez ME, Mudgal CS, Jupiter JB, Ring D. Health Literacy in Hand Surgery Patients: A Cross-Sectional Survey. *J Hand Surg [Am]* 2015;40:798–804.
- [44] Sudore RL, Mehta KM, Simonsick EM, Harris TB, Newman AB, Satterfield S, et al. Limited literacy in older people and disparities in health and healthcare access. *J Am Geriatr Soc* 2006;54:770–6.
- [45] Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *Am J Obstet Gynecol* 2002;186:938–43.
- [46] Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med* 1998;158:166–72.
- [47] Peterson NB, Dwyer KA, Mulvaney SA, Dietrich MS, Rothman RL. The influence of health literacy on colorectal cancer screening knowledge, beliefs and behavior. *J Natl Med Assoc* 2007;99:1105–12.
- [48] Oldach BR, Katz ML. Health literacy and cancer screening: a systematic review. *Patient Educ Couns* 2014;94:149–57.
- [49] Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, et al. Association of health literacy with diabetes outcomes. *JAMA* 2002;288:475–82.
- [50] Muscat DM, Shepherd HL, Nutbeam D, Trevena L, McCaffery KJ. Health Literacy and Shared Decision-making: Exploring the Relationship to Enable Meaningful Patient Engagement in Healthcare. *J Gen Intern Med* 2021;36:521–4.
- [51] Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health care disparities. *Patient Educ Couns* 2007;66:119–22.
- [52] Smith B, Magnani JW. New technologies, new disparities: The intersection of electronic health and digital health literacy. *Int J Cardiol* 2019;292:280–2.
- [53] Muscat DM, Smith J, Mac O, Cadet T, Giguere A, Houston AJ, et al. Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Med Decis Making* 2021 272989X211011101.
- [54] Todd BL, Feuerstein M, Gehrke A, Hydeman J, Beuplin L. Identifying the unmet needs of breast cancer patients post-primary treatment: the Cancer Survivor Profile (CSPro). *J Cancer Survivor* 2015;9:137–60.
- [55] Jayakumar P, Moore MG, Furlough KA, Uhler LM, Andrawis JP, Koenig KM, et al. Comparison of an Artificial Intelligence-Enabled Patient Decision Aid vs Educational Material on Decision Quality, Shared Decision-Making, Patient Experience, and Functional Outcomes in Adults With Knee Osteoarthritis: A Randomized Clinical Trial. *JAMA Netw Open* 2021;4:e2037107.
- [56] Riddle DL, Jiranek WA, Hayes CW. Use of a validated algorithm to judge the appropriateness of total knee arthroplasty in the United States: a multicenter longitudinal cohort study. *Arthritis Rheumatol* 2014;66:2134–43.
- [57] Eppler SL, Kakar S, Sheikholeslami N, Sun B, Pennell H, Kamal RN. Defining Quality in Hand Surgery From the Patient's Perspective: A Qualitative Analysis. *J Hand Surg Am* 2019;44:311–20.
- [58] Shapiro LM, Eppler SL, Roe AK, Morris A, Kamal RN. The Patient Perspective on Patient-Reported Outcome Measures Following Elective Hand Surgery: A Converged Mixed-Methods Analysis. *J Hand Surg Am* 2021;46 153 e1–e11.
- [59] Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. *Clin Rehabil* 2009;23:362–70.
- [60] Makhni EC. Meaningful Clinical Applications of Patient-Reported Outcome Measures in Orthopaedics. *J Bone Joint Surg Am* 2021;103:84–91.
- [61] McCormick JD, Werner BC, Shimer AL. Patient-reported outcome measures in spine surgery. *J Am Acad Orthop Surg* 2013;21:99–107.
- [62] Jayakumar P, Bozic KJ. Advanced decision-making using patient-reported outcome measures in total joint replacement. *J Orthop Res* 2020;38:1414–22.
- [63] Elwyn G, Edwards A, Mowle S, Wensing M, Wilkinson C, Kinnersley P, et al. Measuring the involvement of patients in shared decision-making: a systematic review of instruments. *Patient Educ Couns* 2001;43:5–22.
- [64] Dy SM. Instruments for evaluating shared medical decision making: a structured literature review. *Med Care Res Rev* 2007;64:623–49.
- [65] Valentine KD, Vo H, Fowler FJ Jr, Brodnev S, Barry MJ, Sepucha KR. Development and Evaluation of the Shared Decision Making Process Scale: A Short Patient-Reported Measure. *Med Decis Making* 2021;41:108–19.
- [66] Sepucha KR, Stacey D, Clay CF, Chang Y, Cosenza C, Dervin G, et al. Decision quality instrument for treatment of hip and knee osteoarthritis: a psychometric evaluation. *BMC Musculoskelet Disord* 2011;12:149.
- [67] Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. *Patient Educ Couns* 2013;93:102–7.
- [68] Holmes-Rovner M. International Patient Decision Aid Standards (IPDAS): beyond decision aids to usual design of patient education materials. *Health Expect* 2007;10:103–7.
- [69] Henly SJ, Wyman JF, Findorff MJ. Health and illness over time: the trajectory perspective in nursing science. *Nurs Res* 2011;60:55–14.
- [70] Axen I, Jones JJ, Rosenbaum A, Lovgren PW, Halasz L, Larsen K, et al. The Nordic Back Pain Subpopulation Program: validation and improvement of a predictive model for treatment outcome in patients with low back pain receiving chiropractic treatment. *J Manipulative Physiol Ther* 2005;28:381–5.
- [71] Kagan R, Anderson MB, Christensen JC, Peters CL, Gilliland JM, Pelt CE. The Recovery Curve for the Patient-Reported Outcomes Measurement Information System Patient-Reported Physical Function and Pain Interference Computerized Adaptive Tests After Primary Total Knee Arthroplasty. *J Arthroplasty* 2018;33:2471–4.
- [72] Wright JG. Evaluating the outcome of treatment. Shouldn't We be asking patients if they are better? *J Clin Epidemiol* 2000;53:549–53.
- [73] Bernstein DN, Fear K, Mesfin A, Hammert WC, Mitten DJ, Rubery PT, et al. Patient-reported outcomes use during orthopaedic surgery clinic visits improves the patient experience. *Musculoskeletal Care* 2019;17:120–5.
- [74] Jayakumar P, Bozic KJ, Lee TH. Information Asymmetry: The Untapped Value of the Patient. *NEJM Catalyst Innovations in Care Delivery*. 2019; October 15.
- [75] Hull S. Patient-generated health data foundation for personalized collaborative care. *Comput Inform Nurs* 2015;33:177–80.
- [76] Patterson JT, Wu HH, Chung CC, Bendich I, Barry JJ, Bini SA. Wearable activity sensors and early pain after total joint arthroplasty. *Arthroplast Today* 2020;6:68–70.
- [77] Onnela JP, Rauch SL. Harnessing Smartphone-Based Digital Phenotyping to Enhance Behavioral and Mental Health. *Neuropsychopharmacology* 2016;41:1691–6.
- [78] Jayakumar P, Lin E, Galea V, Mathew AJ, Panda N, Vetter I, et al. Digital Phenotyping and Patient-Generated Health Data for Outcome Measurement in Surgical Care: A Scoping Review. *J Pers Med* 2020;10:282.
- [79] Tiase VL, Hull W, McFarland MM, Sward KA, Del Fiol G, Staes C, et al. Patient-generated health data and electronic health record integration: a scoping review. *JAMIA Open* 2020;3:619–27.