

What It Will Take to Achieve High-Value Patient-Centered Care Globally

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ABSTRACT

Healthcare systems worldwide have been facing a value crisis, with expenditure increasing at unsustainable rates and, in many cases, exceeding the real growth of GDP. Furthermore, this substantial increase in spending has not correlated with a significant improvement in health outcomes within many populations, and conventional outcomes have neglected patient needs. The ongoing COVID-19 pandemic has also exposed many shortcomings of the prevailing fee-for-service model of care delivery, including fragmentation in services, suboptimally-managed chronic diseases that have resulted in broader health impacts, and pervasive health disparities. This has highlighted the urgent need for a paradigm shift in the way care is delivered and reimbursed. In this paper, we outline the drivers of this value crisis in health care and offer approaches to addressing these, focusing on quality of care and highlighting the work of the International Consortium for Health Outcomes Measurement (ICHOM).

KEYWORDS

COVID-19, Expenditures, Fee-for-Free Service Model, Healthcare Systems, Position Paper, Unsustainable Rates, Worldwide Healthcare Systems

INTRODUCTION

Health care systems worldwide have been facing a value crisis, with expenditures increasing at unsustainable rates and, in many cases, exceeding the real growth of GDP (Papanicolas et al., 2018). Furthermore, this substantial increase in spending has not correlated with a significant improvement in health outcomes within many populations (Papanicolas et al., 2018), and conventional outcomes have neglected patient needs. The ongoing COVID-19 pandemic has also exposed many shortcomings of the prevailing fee-for-service model of care delivery, including fragmentation in services, suboptimally-managed chronic diseases that have resulted in broader health impacts, and pervasive health disparities (Lal et al., 2021; Sorenson et al., 2020). This has highlighted the urgent need for a paradigm shift in the way care is delivered and reimbursed (Nimako & Kruk, 2021).

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Value-Based Health Care

The global health care value crisis has been described as an unsustainable increase in spending and costs without an improvement in quality of care or patient outcomes (Fendrick et al., 2009). It is perhaps most visible in the United States, where per capita spending exceeded \$10,000 in 2020 and far exceeds that of other high-income countries, yet health outcomes are comparatively worse, services are fragmented, and both providers and patients are dissatisfied (Emanuel & Fuchs, 2008; Reinhardt et al., 2004). The prevailing fee-for-service model of care delivery was established with hopes that competition and market forces would drive fast improvements in quality and innovation. Rather than this being the case, competition has been placed at an inappropriate level, and improvement efforts have focused on cost reductions by the intermediaries, such as the health plan payers and employers, rather than on the overall ecosystem. The result has been that competition has incentivised quantity over quality of services and left costs rising (Gaynor et al., 2006; Porter, 2008).

In their 2006 book *Redefining Healthcare*, Professors Michael Porter and Elizabeth Teisberg argued for a complete rethink of the approach to health care (Porter & Teisberg, 2006). They introduced a new, value-based care model, proposing that a shift from the prevailing volume-based model to one that is quality-based and patient-centred would redirect competition in favour of care that promotes the best patient outcomes while driving down costs (Johansen & Saunders, 2017). In this model, payment schemes that are bundled yet require reporting of patient-centred outcomes can be a vehicle to increasing value—which is defined as these outcomes achieved per unit cost of achieving them (Porter & Teisberg, 2006).

The Role of Patient-Reported Outcomes

In value-based care, an important emphasis is put on the patient-centredness of the outcomes of interest, in other words capturing outcomes that matter to patients. Put simply, these outcomes should attend to the biggest concerns and questions patients tend to have following a medical diagnosis or event: “Will I survive this?” and “Will I be able to return to my normal life?” Patient-centred outcomes thus encompass aspects of cure and survival, as well as recovery and quality of life retained (Fendrick et al., 2009; Porter & Teisberg, 2006).

The 2013 Consolidated Standards of Reporting Trials (CONSORT) extension guidelines define a patient-report outcome (PRO) as “an outcome reported directly by patients themselves and not interpreted by an observer.” PROs provide the patient’s perspective on the impact of disease and its treatment and may identify areas of concern for patients that are all too often overlooked in typical practice—such as depression, incontinence following pregnancy, changes in sexual health as a side effect of chemotherapy and radiation. By some estimates, symptoms, subjective toxicities, and impaired functioning can go undetected by clinicians as much as 50% to 74% of the time (Warsame & D’Souza, 2019).

PROs can be used to help patients and clinicians choose between alternative treatment options, better quantify and monitor symptoms and illness impact on life, and identify toxicities related to treatment (Valderas et al., 2008). This information can, in turn, be used to adapt and personalise treatment so that it better responds to a patient’s individual treatment response and care preferences. PROs can also be used to monitor outcomes across patient groups and practices, as a means of evaluating quality of care and informing improvement efforts (Valderas et al., 2008). Studies have corroborated this, demonstrating that measurement of PROs can improve communication between patients and clinicians, patient adherence and satisfaction with care, utilisation of emergency services, and health-related quality of life (Snyder, Aaronson, et al., 2012; Valderas et al., 2008; Velikova et al., 2004). A recently published Cochrane review determined that there was evidence of moderate certainty that PROMs feedback (to patients or providers) improves quality of life, leads to an increase in patient-physician communication, diagnosis and notation and disease control (Gibbons et al., 2021). PROs have been associated with survival in observational studies (Norekvål et al., 2010; Quinten et al., 2011), and indeed measurement of some PROs has resulted in improvement in survival as evaluated

in randomised clinical trials (Basch et al., 2016). Given this backdrop, PROs have been widely used as primary or secondary endpoints in clinical trials and incorporated into registries (Warsame & D'Souza, 2019). More recently, some PROs have been incorporated into clinical guidelines (Cazzola et al., 2015; Snyder, Aaronson, et al., 2012), and there is increasing acceptance of their promise in transforming health care (Black, 2013; Phillips & Wong, 2020).

PROs as Part, But Not All, of Patient-Centred Outcomes

Well-intentioned discourse advocating for PROs can often eclipse the importance of other health outcomes that matter to patients but are not reported by patients. It is worth emphasising that PROs are part of what makes up patient-centred outcomes but are not the be-all and end-all. Measuring what matters most to patients means including the classical, typically clinician-reported, outcomes that speak to patients' concerns relating to survival and providing objective measures of health status. Clinician-reported outcomes and PROs indeed serve distinct yet complementary roles. Siloing PROs from other health outcomes removes the ability to see a complete picture of the physical, mental, and social impacts of illness. It also misses opportunities to leverage informative data that are already available in routine medical records and administrative systems and to raise the acceptability of PROs by coupling measurement of PROs with measurement of established performance evaluation metrics (Dressler et al., 2019).

Lack of Standardisation

In order for patient-centred outcomes to enable high-value care, they need to be measured at a large scale and in a standardised manner. While key measures of (clinician-reported) mortality and morbidity have been standardised for decades and widely recorded in routine care around the world, the same cannot be said for PROs. Despite the growing consensus on the utility of PROs in clinical care described above, PRO use has largely been relegated to research and select academic hospital initiatives (Snyder, Aaronson, et al., 2012). Many barriers to the broad uptake of PROs in routine clinical care have been cited. These include old habits and entrenched systems that were built based on classical clinical endpoints, a lack of standardisation of the way PROs are measured, the complexity of analysis and scoring of validated instruments that measure PROs, concerns about the burden of data collection on patients and clinical workflow, the prohibitive cost of commercial instruments, and limited technical know-how to integrate PROs into the existing electronic health information infrastructure (Fung & Hays, 2008; Nguyen et al., 2021; Qaseem et al., 2021). Among these, the lack of standardisation stands out and has been cited as a major barrier to fully integrating PROs into the workflow of routine clinical care (Basch, 2017).

Measurement of PROs has come a long way from the unstructured patient diaries to structured psychometrically sound questionnaires and instruments that are referred to as *patient-reported outcome measures* (PROMs). The development of PROMs has addressed issues related to the lack of standardisation to some extent, but not completely. There has been a dizzying proliferation of PROMs over the years, with a recent review finding 315 generic and condition-specific PROMs currently available (Churrua et al., 2021). This has further highlighted the need for standardisation and hindered the realisation of PRO utility in clinical settings (Warsame & D'Souza, 2019). Furthermore, even once an appropriate PROM has been identified, questions arise: How often should PROM-based data collection be done and when during the care cycle? How should PROM elements be consolidated for patients who have more than one medical condition? How should the case-mix of patients be adjusted in analysis when comparing patients cared for in different care settings? More standardised approaches—and responses to these questions—can help achieve a more uniform measurement of patient-centred outcomes. The standardised data generated can be used to support clinical management of individual patients, identify best practices, and contribute to research—all of which can feed into enabling high value, patient-centred care.

ICHOМ'S APPROACH

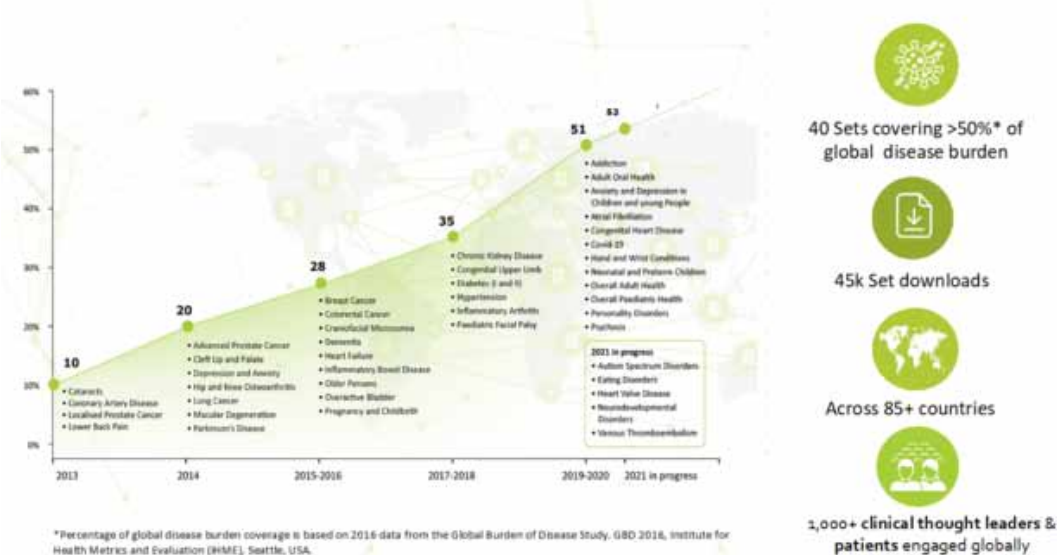
The International Consortium for Health Outcomes Measurement, ICHOM, is an international non-profit organisation that has been a champion in advancing value-based health care, specifically addressing the lack of standardised measurement of patient-centred outcomes. ICHOM's mission is to unlock the potential for value-based health care through defining globally applicable standard sets of patient-centred outcomes (*sets*) that evaluate care in a manner that is technically rigorous, holistic and puts the patient's perspective first. ICHOM drives global adoption of these sets through conferences, supporting implementation, analysis and benchmarking, and policy advocacy. Since its establishment in 2012, ICHOM has developed 40 sets (Figure 1) covering a variety of conditions that account for more than half of the global burden of disease. These sets are available for free (www.ichom.org), have been developed by engaging a network of over 1,000 experts, and are in use in health facilities in more than 85 countries. The process of developing the sets and their use in various care settings have been addressed in over 200 peer-reviewed scientific articles.

Standardised Holistic Sets of Patient-Centred Outcome Measures

ICHOM serves as a convenor, setting up an international multidisciplinary panel (*working group*) of 15–25 experts made up of patients, clinicians, researchers, and topic thought leaders. ICHOM's project team conduct relevant systematic literature reviews and host a series of video conferences through which the working group determines, in sequence, (a) relevant domains, (b) best instruments for measuring these, (c) the timing of measurement, and (d) the relevant risk adjustment (case-mix) variables. Instruments are appraised based on several criteria, including psychometric properties as exemplified in the COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) framework (Mokkink et al., 2010). This process, which is supported by a modified Delphi method for decision making, typically takes 9–12 months and concludes with the publication of the set in a peer-reviewed journal.

For each disease or condition amenable to medical treatment, ICHOM defines a standardised set of patient-centred outcomes and measures. These sets capture a range of both clinician-reported outcomes of survival and morbidity and patient-reported outcomes across physical, mental, and social

Figure 1. ICHOM's global standard sets of patient-centred outcomes and measures developed over the past decade



well-being domains. ICHOM Sets also define case-mix variables—sociodemographic characteristics, baseline medical status and treatment factors—that can be used to perform risk-adjusted analyses. By taking into account the mix of patients cared for in different care settings, risk-adjustment helps to make more sound comparisons between health care settings and can help to curb against penalisation of providers caring for sicker or more socially disadvantaged patients (Eijkenaar et al., 2013).

Incorporating pragmatic considerations related to care for patients with multiple morbidities and stakeholders assessing outcomes at the system level (meso- and macro-levels), ICHOM has also refined its standardisation approach by viewing Sets across diseases rather than simply within a single disease. A process of data harmonisation was undertaken to minimise redundancies where more than one set is applicable to one patient, improve internal consistency of data element definitions, and identify PROMs applicable to a large proportion of patient groups. A digital term bank of ICHOM's harmonised data elements has been developed that will enable consistent and efficient development of new Sets and assessment of outcomes for patients with multiple morbidities. Sets have been defined using Observational Medical Outcomes Partnership (OMOP) as the common data model, and concepts have also been mapped to SNOMED CT, LOINC, and ICD-10 (Blom et al., 2020). ICHOM has engaged with Fast Healthcare Interoperability Resources (FHIR) to configure the full term bank in line with FHIR HL7 requirements (Ingvar et al., 2021). Leveraging this term bank and experience with developing sets over the past decade, ICHOM is embarking on defining a blueprint of core domains that will include PROMs that, beyond having the desired psychometric properties in various patient populations, are general rather than disease-specific, parsimonious with respect to the number of items and complexity of scoring and are available in multiple languages. This blueprint can be applied to evaluate care across different diseases and patient populations and will provide a framework for accreditation.

Case Example of Quality Care: The Martini Klinik, Germany

An example of successful measurement and use of patient-centred outcomes to deliver value-based care is that of the Martini Klinik in Hamburg, Germany. This specialised centre for prostate cancer care was founded in 2005 by Professors Hartwig Huland and Markus Graefen as a subsidiary of the University Hospital Hamburg. From the beginning, the Klinik was set up as an integrated practice unit comprised of multidisciplinary teams focused on the individual patient's care cycle, making use of effective meetings and seminars, and committed to professional development and collaborative learning. There was also a commitment to measuring outcomes on every patient for the long term and utilising a variety of data sources, including electronic medical records, administrative records, and information received directly from patients. The data collected was then used to better understand best practices and drive continuous improvement in care. Regular quality review meetings were held in which staff across disciplines met and discussed analysis of outcomes from their patients and developed action plans for how to improve. One improvement effort resulting from these discussions was the introduction of a pre-operative patient education program. Another was the adoption of an innovative surgical technique that had been informed by a paper discussed in a literature review meeting; within 12 months, most surgeons at Martini had been trained and had switched to this procedure (full-length urethra preservation), and there were corresponding improved urinary continence rates (Porter et al., 2019).

In 2012, Professor Huland took the initiative at the international level by leading an ICHOM working group to develop a set for newly diagnosed localised prostate cancer (Martin et al., 2015). The working group was comprised of 28 renowned clinical experts and patient representatives, and the structured consensus-driven development process took seven months to complete. (Porter et al., 2019) The measures in the endorsed set capture survival and disease control, acute complications, and patient-reported health status domains (sexual dysfunction, urinary incontinence, urinary irritation, bowel irritation and hormonal symptoms). The set also contains case-mix variables characterising

patient sociodemographics, baseline comorbidities, tumour stage, and treatment factors (Figure 2; Martin et al., 2015).

Initially, data collection was paper-based, with data entered in an Excel spreadsheet and patients completing a 13-page questionnaire capturing health-related quality of life information. By 2014, an online patient survey was developed, and a health informatics team was established (an IT programmer, a biostatistician, and three documentation clerks) to process and analyse the data. By 2018, over 2,000 set-based surveys were being completed by patients every month, with a response rate (completing the survey) exceeding 85% (Porter et al., 2019).

By 2018, the Klinik had approximately 8,000 prostate cancer consultations and 2,500 radical prostatectomies performed annually (10% of Germany's total prostatectomy caseload; Michael Porter et al., 2019). Martini Klinik has consistently been a high performer in patient outcomes (Tilki et al., 2020; Würnschimmel et al., 2021). In addition to the lives saved and quality of life maintained for patients, Martini Klinik's impact can be felt in its contribution to science and national policies. In 2018 alone, 80 peer-reviewed articles were published by Martini Klinik faculty; the German Cancer Society has chosen to use the ICHOM Set in its certification procedures and, as of 2020, requires that all German prostate cancer treatment centres measure PROs in order to maintain certification.

FUTURE DIRECTIONS

Standardisation, while important, is the first of several hurdles to be overcome in enabling high value, patient-centred health systems globally. What is further needed is large scale measurement

Figure 2. ICHOM Set for localised prostate cancer (Source: Adapted from Porter et al. (2019) and Martin et al. (2015))

	Measure	Details	Measurement Timing	Data Source
Acute Complications (Within 6 months of Treatment)	Surgery Patients: Clavien Classification ^e	Presence or Absence of Grade 3 or Greater	6 Months After Treatment	Clinical or Patient Reported
	Radiation Patients: CTCAE Classification	Presence or Absence of Grade 3 or Greater Including Name of Event		
Survival & Disease Control	Overall Survival	Date of Death	Annually Until Death	Administrative Data
	Cause-Specific Survival	Was cause prostate Ca on Death Certificate?		
	Metastasis-Free Survival	Date of Metastatic Disease and How Diagnosed		Clinical or Patient Reported
	Biochemical Recurrence-Free Survival	Date of PSA Recurrence		
Patient Reported Health Status	Urinary Incontinence Scores	EPIC-26 ^g	At Baseline, 6 Months After Treatment and Then Annually for 10 Years	Patient Reported
	Urinary Irritative/Obstructive Scores	EPIC-26		
	Bowel Symptom Scores	EPIC-26		
	Sexual Symptom Scores	EPIC-26, EORTC QLQ-PR25		
	Hormone Symptom Scores (Pts on ADT)	EPIC-26		

Case mix variables: age, body mass index, date of diagnosis, comorbidities (Charlson score), baseline PSA, AJCC 7 clinical stage, AJCC 7 pathologic stage, number of biopsy cores, greatest % involvement of biopsy, cores, biopsy Gleason score, prostatectomy Gleason score, surgical margin status

Adapted from Harvard Business School Case Study and Martin et al, Eur Urol 2015(Martin et al., 2015)

aligned with these standards and the use of data collected so that it can be linked to reimbursement policies. Easing the burden of measurement can drive up the scale of measurement. In this regard, digital solutions are useful. Computer adaptive testing—as has been done for measures in the Patient-Reported Outcomes Measurement Information System (PROMIS; Wong & Meeker, 2022)—can be employed so that questionnaires are tailored in real time to responses, thus individualising responses and potentially reducing questionnaire length. Analytics can be simplified and automated (Kane et al., 2020; Snyder, Wu, et al., 2011). Digitised versions of measures can be developed to enhance interoperability with electronic health records systems in common use (such as FHIR resources; Ingvar et al., 2021) and with widespread mobile phone platforms (Bass, 2012). The latter is worth particularly highlighting as the collection of ultimate outcome data often has to be done a long time after the final hospital or clinical visit related to a health care episode.

Standardised technology-enabled tools need to be coupled with support on how to implement measurement and utilise findings in a particular care context. These implementation supports are likely to fail if they comprise of training alone or engage only a subset of the relevant stakeholders. Instead, support should be guided by theory-based frameworks such as those used in implementation science (van der Wees et al., 2019) and employ evidence-based change strategies such as continuous coaching, use of clinical champions, and stakeholder mapping (Franklin et al., 2017). It is important to emphasise that without effective implementation—where measurement is continuous and data analysis results are fed into improvement efforts—measurement will not result in local improvement in outcomes.

While implementation of standardised patient-centred outcomes measurement may arguably be most daunting in resource-limited settings, low-and middle-income countries (LMICs) should not be left behind in the efforts to achieve high-value health systems. For too long, health care performance evaluation in developing countries has largely focused on the volume-based access to care metrics and not sufficiently on examining the quality of care patients receive once they reach clinics and hospitals. Health indicators from the Millenium Development Goals era illustrate the unfortunate consequences of this narrow focus, which is that investments that were successful in improving access to care did not yield improvements in health outcomes. For example, in India shifting millions of births from home to hospitals through cash incentives did not result in reduced deaths of mothers and newborns (Kruk et al., 2016; Powell-Jackson et al., 2015). With already constrained resources, LMICs frankly cannot afford to not pay attention to quality of care. Care that provides better outcomes is not a luxury to be enjoyed by richer countries alone but a necessity for LMICs to more efficiently use their limited resources and is integral to achieving global health goals (Kruk et al., 2016). Kim, Farmer, and Porter (2013) and Nimako and Kruk (2021), among others, have proposed strategies for enabling transformation to “competent and caring” value-based health systems in LMICs. While these strategies are complex undertakings, there is reason to be optimistic, buoyed by technological and care delivery innovations enabled by the COVID-19 pandemic and leveraging the Universal Health Coverage global agenda (Nimako & Kruk, 2021).

Standardised measurements permit benchmarking, which provides a tremendous research and improvement opportunity where the variation of outcomes can yield insights on best practices in care and differences in patient sub-populations that can inform treatment stratification and drug discovery. With this opportunity in mind, ICHOM launched its global benchmarking platform in 2021. More sophisticated analytic methods need to be developed to refine risk adjustment across countries (Beane et al., 2021) and to provide insights on performance at the population level (Kindig, 2006). Furthermore, refinement of case-mix variables and more intentional application of an equity lens in analyses are needed so that incentivised efforts result in improved as well as equitable health outcomes.

The final hurdle is linking large scale standardised measurement and use of collected data with reimbursement policies. Collective multi-sectoral action at the local level is necessary in order to fully realise the concepts of value-based health care for the benefit of the patients and tax/insurance payers. Health care reform is a long-haul undertaking, requiring that efforts outlast political cycles.

For this reason, a strong local community of advocates beyond elected officials (such as technical experts, professional associations, consumer groups, and civil society organisations) is essential (Nimako & Kruk, 2021). Finally, more local and international platforms are needed that foster joint research, implementation and advocacy work between experts operating on the two sides of the value coin—those who are outcomes-focused and those who are cost-focused.

CONCLUSION

Value-based care promotes patient outcomes and supports the reformation of reimbursement systems from a focus on volume to a focus on quality. Large scale standardised measurement of patient-centred outcomes is the cornerstone of achieving value-based care globally and can be enabled through standardisation, technological innovations that ease data collection and use, and supports for implementation in all settings, including LMICs. Translating large scale measurement to changes in reimbursement policies will require collective, multi-sectoral action at the local and international levels.

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