ONLINE FIRST PUBLICATION

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Patient-reported outcome measures and value-based medicine in paediatrics: a timely review

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Singapore Med J 2021, 1–29

<https://doi.org/10.11622/smedj.2021102>

Published ahead of print: 21 September 2021

Online version can be found at
<http://www.smj.org.sg/online-first>

ABSTRACT

Healthcare delivery is moving towards a more personalised and patient-centric approach. There is now an appropriate emphasis on providing value in our healthcare system. Patient-reported outcome measures (PROMs) assess our patients' perceptions of the status of their health and quality of life, measured over a period of time. PROM is an integral component of a value-driven and value-based healthcare system and is key if we want to practise value-based medicine. In paediatrics and child health, PROMs, if implemented well with appropriate measurement tools that are regularly updated and validated in a self-learning healthcare ecosystem, will help to enhance personalised healthcare delivery and collectively improve the health of the community at large. This review covers the role of PROMs in paediatrics, as well as their role in value-based medicine.

Keywords: paediatrics and child health, patient-reported outcome measures, value-based medicine and care

INTRODUCTION

Timely, appropriate, evidence-based and cost-effective delivery of medical care for patients is the primary goal of healthcare providers. With advances in scientific research, medical knowledge has improved in leaps and bounds, further fuelled by technology, in a vastly interconnected medical milieu.

In recent years, there is an increasing focus on integration of care – providing care closer to patients' homes, as well as providing adequate support within communities. Healthcare providers need to go beyond the boundaries of traditional healthcare facilities and work with community partners. Many medical providers do not fully appreciate the impact that medical illnesses and treatment plans can have on their patients' day-to-day functioning and lives.⁽¹⁾

Often, quality in healthcare is measured by looking at easily quantifiable outcomes from the direct and immediate medical care that has been delivered. However, quality in healthcare should be measured not only by routine and well-established clinical outcomes such as survival rates, length of stay and complications such as healthcare-associated infections, but also take into account patients' perspectives, experiences and other quality-of-life (QoL) parameters that are related to both healthcare and health. In other words, outcome measures in health and healthcare can be divided into three components: clinical outcome measures, patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

The paediatric service has traditionally incorporated many patient-reported outcomes and experiences to improve the medical care rendered. However, there is a lack of systematic collection of patient-reported outcomes and experiences, as well as application of such data in quality improvement programmes. With increasing global awareness of the benefits of patient and public engagement in the design and delivery of healthcare services, this article discusses why PROMs

matter, how PROMs can be applied, and what value-based medicine (VBM) means in paediatric clinical care today.

PATIENT-REPORTED OUTCOME MEASURES

Health is ‘*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*’.⁽²⁾ Huber posits that ‘*health is the ability to adapt and to self-manage, in the face of social, physical and emotional challenges*’.⁽³⁾ Multiple factors affect health-related QoL (Fig. 1).^(4,5) As clinicians, we often lack awareness about the consequences of a disease and treatment on our patients’ daily lives.⁽⁶⁾ We may take a comprehensive history, do a laudable physical examination and communicate effectively with our patients, but the extent to which we register and embed the effects of disease and care on the health of our patients is debatable. We should therefore not neglect the great significance of patient and public involvement in the remodelling of healthcare services.

PROMs are used to objectively assess our patients’ perceptions of the status of their health and QoL, measured over a period of time. They are ‘*directly reported by the patient without interpretation of the patient’s response by a clinician or anyone else and pertain to the patient’s health, QoL, or functional status associated with healthcare or treatment*’.^(7,8) Validated measurement tools and questionnaires are used in PROMs to qualify and quantify these patient-reported outcomes.

PROMs provide information that only patients themselves can provide to healthcare providers (Box 1). They are relevant and crucial to allow healthcare providers to arrive at sound medical decisions with patients through better and effective conversations. PROMs help to bridge the gap by representing patients’ voices and views regarding their individual health. They help

physicians to improve patient satisfaction with medical care. Box 2 lists several pertinent reasons for why patients' views matter.

Box 1. Information unique to a patient (experience and perspective):⁽⁸⁾

- Non-obvious symptoms
  - Symptoms, e.g. headache and tiredness, sleep problems not obvious to observer
  - Psychological symptoms, e.g. stress, depression
- Frequency of symptoms
- Severity of symptoms
- Nature of symptoms
- Impact of disease on daily living and life
- Perception or feeling about disease and treatment rendered

Box 2. Why consider patients' views?⁽⁹⁾

- Most healthcare treatments aim to reduce symptoms, minimise disability and improve quality of life – aspects that only patients can assess
- As patients welcome being involved, having their views considered may have health benefits in itself
- Patients' response rates are invariably better than clinicians' (a patient only has to complete one questionnaire, whereas a clinician has to do it for every patient)
- This measure avoids observer bias (there is obvious bias if clinicians are to do a self-assessment of the care they deliver)
- Considering patients' views increases public accountability of health services and healthcare professionals

PROMs are not outcome measures per se but measurements of patients' health journey at different time points in their life course.⁽⁹⁾ The choice of adopting PROMs at different time points is important to reduce subjectivity and recall bias in the patients involved. In general, PROMs can be any method in which patients' input is obtained without interpretation by medical providers or anyone else – including from diaries and event logs using free-text input, to one-item or multi-item multi-domain scales. Data collection, analysis and interpretation are standardised and well documented to accurately represent the target patient population.

Outcomes do not always need to be patient reported, but could also be observer or proxy reported. An observer-reported outcome is one where an observer (anyone other than the patient) is compiling the outcome from a patient, such as a doctor seeking a specific outcome from the patient. A proxy-reported outcome is one where someone other than the patient is reporting the outcome as if he/she is the patient, such as a parent reporting a specific outcome on behalf of a young child.^(7,8) This becomes especially relevant in the development of paediatric PROMs and is elaborated on later in this article.

In comparison, PREMs assess the experiences patients go through and address ‘the humanity of care’. PREMs can be relational as well as functional. Relational PREMs measure patients’ perception of their healthcare journey from a relational perspective (e.g. did the patients feel that they were treated with respect?), while functional PREMs measure more operational issues, such as the facilities where the care was rendered.⁽¹⁰⁾ PROMs and PREMs can enhance the efficacy of the medical care given to patients because they enable more patient-centric care to be delivered, with treatment and care tailored to their specific and individual needs.^(11,12)

Types of patient-reported outcome measures

PROMs must be contextualised and determined by the specific patient needs and requirements of healthcare providers and their patients. They can be domain-specific, disease-specific, generic and preference-based (Table I). Commonly assessed areas in PROMs include:⁽¹³⁾

- Overall and health-related QoL
- General perception and outlook on health
- Satisfaction with healthcare
- Physical functioning

- Mental well-being
- Psychosocial function and well-being
- Others: including symptoms and impairments (e.g. pain, sleep), cognitive well-being and role activities (e.g. employment, financial well-being)

Table I. Types of patient-reported outcome measures (PROMs).

Types	Description
Domain-specific PROMs	• Allow high precision in targeted assessment • Examples of commonly evaluated domains of health include physical function, symptoms, psychological well-being, social well-being, cognitive functioning, role activities, personal constructs and satisfaction with care
Disease-specific PROMs	• Clinically relevant and highly acceptable • Limited usefulness, as there is no direct comparison to general population • Restricted focus may lead to failure to detect unforeseen effects of treatment • An example is the Mini-Asthma Quality of Life Questionnaire⁽¹⁴⁾
Generic PROMs	• Comprise items relevant to the widest range of patient conditions and general population • Allow effective comparison across broad range of health conditions and treatments between different patient groups • Helpful in assessing new treatments when therapeutic effects are uncertain • Less responsive to clinically important changes • Sensitive to measurement bias • An example of a generic PROM is the PROMIS Global-10 short form⁽¹⁵⁾
Preference-based PROMs	• Broad in content • ‘Weigh’ and adjust outcomes reported by patients according to the preferences for health outcomes of a group of individuals such as the general public or of patient groups in the computation of quality-adjusted life-years • Provide utility and values regarding health for use in, e.g. cost-utility analyses of interventions⁽¹³⁾ • Examples include the EuroQol 5D (five-dimension) instrument and Health Utilities Index^(16,17)

PROMIS: Patient-Reported Outcomes Measurement Information System

PATIENT-REPORTED OUTCOME MEASURES IN CLINICAL PRACTICE

PROMs were originally developed for research and have been well established in clinical trials and pharmacological research for many years. Recently, regulatory bodies use PROMs to standardise interpretation in clinical trials.^(7,18) In health services research, PROMs facilitate swift and cost-effective evaluation of policies and services. The EuroQol 5D (five-dimension) instrument, for example, has been used for cost-effective evaluation in various programmes. The evolution of the applicability of PROMs in clinical practice demonstrates their critical role in the modern world. There is an unmet need to establish and maintain collaborative framework for validation of PROMs.

Core outcome sets

Core outcome sets (COS) are an accepted, consensus-based, standardised and minimum set of outcomes for a specific disease or trial population within a specified setting.^(19,20)

Development of COS is a multi-step process to achieve consensus that includes a literature review of the evidence, followed by a series of Delphi questionnaires and rounds of discussion among a panel of experts. Delphi surveys aim to achieve consensus from among healthcare providers as well as the respective community on what outcomes to address. The expert panel deliberates and, once these core outcomes are agreed upon, determines the specific measurement domains and measurement instruments to use. The COS forms the basis upon which further domains and dimensions can be measured and subsequently developed.⁽²¹⁾ The Outcome Measures in Rheumatology (OMERACT) initiative, for instance, frames four key ‘impact of health’ aspects: survival, life impact, economic impact/resource use and pathophysiological manifestations.^(22,23)

Applying to clinical practice

Healthcare is strengthened by PROMs as they enable medical providers to deliver improved care that is patient-centric, and to evaluate and benchmark the quality of care by collecting information for assessing current practices and policies, providing the means to enhance healthcare productivity and quality of care.⁽⁹⁾ They can be translated into clinical practice in the monitoring and surveillance of an individual's health and healthcare needs, and used in quality improvement and safety initiatives.⁽⁷⁾ Although some medical providers were initially skeptical about the usage of PROMs,⁽⁹⁾ most, if not all, will acknowledge the benefits of taking patients' views in clinical practice.

Selection of the relevant PROMs is crucial⁽⁴⁾ and will impact what the output is and how this eventually translates into care for the patients specifically and is scaled to the population at large. It is a multi-step process involving clear elucidation and comprehensive planning.

The objectives and the population or patient group must first be clearly defined. A panel of experts must review the current evidence and literature, seeking feedback not only from healthcare practitioners but also patients, patient advocacy groups and the general population. The core outcomes to be measured and other important outcome parameters must be decided on, followed by choosing appropriate measurement instruments and tools. As there are many validated and well established outcome measurement tools, the challenge is to choose the most appropriate basket of measurement tools for the specific and required objectives.

General considerations in choosing measurement tools

There are some key principles when choosing patient-centred measurements. The choice of a PROM is dependent on various factors including ability to detect change, validity, reliability,

acceptability and feasibility.⁽¹³⁾ The principles of patient-centred measurement state that measurements are: (a) patient-driven, with patients' goals, preferences and priorities driving the metrics and assessment; (b) holistic, factoring aspects of the patient within and outside of the healthcare system; (c) transparent and accessible to all stakeholders; (d) timely and comprehensible; and (e) co-created with patients as equal partners in the enterprise.⁽²⁴⁾

Firstly, the PROM tools must have been robustly validated and evaluated. They must also measure what they have been designed to assess. Other important considerations are compliance, preferences, implementation time and costs. Patients should be involved in its development. The PROM needs to be able to identify changes over time. The PROM must be clear and appropriately formatted so that there is patient participation and compliance. It must be consistent, reliable and reproducible. Finally, the PROM needs to be feasible to implement so that it is widely adopted and used by medical providers and administrators (Box 3).

Box 3. Summary of various aspects to consider when choosing patient-reported outcome measures:^(8,13)

- **Ability to detect change**
- **Validity**
  - Content validity
  - Construct validity
  - Criterion validity
- **Reliability**
  - Test-retest or intra-interviewer reliability
  - Internal consistency
  - Inter-interviewer variability
- **Acceptability**
- **Feasibility**

Barriers, challenges and caveats in implementation

There are many technical, logistical, social, cultural and legal barriers to translating PROMs into clinical practice in a sustainable manner.⁽⁶⁾ Varying definitions and terminologies currently exist

in this field of practice. OMERACT, for instance, uses ‘core domain sets’, whereas the HOME (Harmonising Outcome Measures for Eczema) initiative⁽²⁵⁾ describes ‘core outcome domains’. COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments), COMET (Core Outcome Measures in Effectiveness Trials) and COMIS (Core Outcome Measurement Instrument Selection) are all initiatives that aim to set guidelines and consensus in a standardised way. In addition, there are also varied approaches in PROM methodologies.

In order to strengthen and not compromise the validity of the PROMs collected, regulatory bodies ensure standardised and robust translation of the PROMs by qualified linguists. This should reflect the best practice to minimise inter-racial variability among various languages when collecting data.⁽²⁶⁾

Other challenges and caveats in implementing PROMs include the following.⁽²⁷⁾ (a) There must be high rates of patient participation. (b) The three dimensions of quality (safety, effectiveness and experience) must be incorporated. (c) The costs and time of data collection, analysis, interpretation and presentation must be manageable and sustainable. (d) Timely administration can avoid various confounding bias, including attribution bias and recall bias after specific events (for measurements such as emergency care) due to time lag with meaningful comparisons when attributing outcomes to quality of care. (e) PROMs should add value to patient care and not be used erroneously to simply ration medical care.

To ensure the sustainability of PROMs in the clinical system, their incorporation should be embedded into existing clinical frameworks and workflows. They cannot exist as a standalone vicarious entity. Otherwise, the uptake by clinicians will be poor. PROMs should be seamlessly integrated into existing clinical notes and into patients’ electronic health records.

PROMs take time out of clinical encounters, as they are usually administered during clinic visits and may pose delays and challenges for clinicians. Technology can help to reduce logistical barriers to PROM assessment with the use of Internet-based data collection platforms, thereby allowing completion of PROMs outside of clinical appointments and minimising administrative burdens.

Experiences from centres that have integrated PROMs into clinical practice show that they can contribute to better care delivery by facilitating remote monitoring of progress by healthcare providers and the minimising of visits or rescheduling of earlier visits when indicated. PROMs enable better communication between healthcare provider and patient, enhance physicians' awareness of patients' problems, and allow for more consistent and real-time adjustments to healthcare.

Patient-Reported Outcomes Measurement Information System

Various centres have started using PROMs in clinical practice. The practice is growing in the United States and even more so in Europe, including efforts by the United Kingdom National Health Service. The Patient-Reported Outcomes Measurement Information System (PROMIS), from the National Institutes of Health in the United States, is a collection of person-centred measures that are accessible through the internet, assessing and monitoring “*physical, mental and social health in both adults and children*”. PROMIS aims to standardise and facilitate “*a common measurement system for patient-reported outcomes across clinical research*”.^(7,28)

PROMIS uses cognitive and psychometric theories and tools, utilises ‘think-aloud’ and ‘respondent debriefing’ cognitive interviewing methods,⁽²⁹⁾ and item response theory. Item response theory is also known as latent trait theory, strong true score theory or modern mental test

theory, and is a paradigm for the design, analysis and scoring of various measurement variables. Computerised adaptive testing, also known as tailored testing in PROMIS,⁽³⁰⁾ adapts to the respondent's ability level (Box 4).

Box 4. Patient-Reported Outcomes Measurement Information System:

Adult self-reported health

- Global health
- Physical health
- Mental health
- Social health

Paediatric and parent-proxy reported health

- Physical health
  - Physical function
  - Pain
  - Fatigue
  - Asthma impact
- Mental health
  - Anger
  - Anxiety
  - Depression
- Social health
  - Peer relationship

International Consortium for Health Outcomes Measurement

The International Consortium for Health Outcomes Measurement (ICHOM)⁽³¹⁾ is a non-profit institution that plans to promote “*the potential of value-based healthcare by determining global standard sets of outcomes measures that are crucial to patients of various medical conditions*”, through facilitating endorsement and reporting of these measures worldwide to enable learning, choice and competition on value. To date, ICHOM has produced 28 standard sets covering various medical conditions and specific patient groups (Box 5).

**Box 5. International Consortium for Health Outcomes
Measurement standard sets:**

Paediatric focused

- Pregnancy and childbirth
- Cleft lip and palate
- Craniofacial microsomia
- Paediatric facial palsy
- Congenital upper limb anomalies

In progress

- Paediatric overall health
- Personality disorders
- Psychotic disorders
- Depression and anxiety for children and young people
- Hand and wrist conditions
- Adult overall health
- Oral health
- Disorders related to substance abuse or addictive behaviours
- Congenital heart disease

Non-paediatric focused

- Inflammatory arthritis
- Hypertension in low- and middle-income countries
- Chronic kidney disease
- Atrial fibrillation
- Inflammatory bowel disease
- Overactive bladder
- Diabetes mellitus
- Colorectal cancer
- Breast cancer
- Heart failure
- Older person
- Dementia
- Coronary artery disease
- Localised prostate cancer
- Low back pain
- Cataracts
- Parkinson's disease
- Depression and anxiety
- Advanced prostate cancer
- Lung cancer
- Hip and knee osteoarthritis
- Stroke
- Macular degeneration

Standard sets are derived through Delphi surveys and consensus in international expert panels. Case-mix factors and variables including demographic data (e.g. age and gender) as well as socioeconomic factors (e.g. employment and educational levels) are identified. Case-mix variables are important to provide clearer context and allow statistical adjustments for subsequent comparison and benchmarking between different cohorts to provide better and more accurate analysis.

PATIENT-REPORTED OUTCOME MEASURES IN PAEDIATRICS

Many PROMs exist in paediatrics and across its various subdisciplines, capturing a range of health outcomes including QoL and symptom severity in paediatrics and child health. They include generic as well as disease-specific instruments (Box 6).

Box 6. Examples of patient-reported outcome measures (PROMs) in paediatrics:

Generic PROMs

- Child Health Questionnaire⁽³²⁾
- KIDSCREEN⁽³³⁾
- Paediatric Quality of Life Inventory (PedsQL)⁽³⁴⁾
- Students' Life Satisfaction Scale/Multidimensional Students' Life Satisfaction Scale⁽³⁵⁾

Chronic-generic PROMs

- DISABKIDS⁽³⁶⁾

Disease-specific PROMs

- Airway-Dyspnoea-Voice-Swallow scale and PROM in paediatric laryngotracheal stenosis, which provides a shared language for outcomes communication and benchmarking for this complex condition⁽³⁷⁾
- Child Amblyopia Treatment Questionnaire and PedsQL instruments in measuring quality of life in amblyopia treatment⁽³⁸⁾
- PedsQL and Pediatric Asthma Quality of Life Questionnaire for asthma⁽³⁹⁾

Challenges in development and conduct

Development of paediatric PROMs has peculiar considerations. Paediatric PROMs need to be tailored to varying developmental abilities of patients, even within the same age group. Not all children of varying ages are necessarily able to complete the PROMs reliably. As such, the age range of each PROM must be determined and evaluated within the intended target population prior to implementation.

In the design of paediatric PROMs, due consideration should be given to making these paediatric PROMS relevant for the intended target group. There should be avoidance of medical

jargon and use of words that are beyond the developmental reading ability of the child. Age-appropriate response options should be used with suitable recall periods, and PROM questionnaires should be of appropriate lengths. Use of illustrations and attention to the format of PROMs will affect the clarity and validity of the intended PROMs. The approach to PROM administration and data collection, including the use of electronic devices, should also be considered.

The content of paediatric PROMs should be validated by involving children in the early qualitative research stages, so that the target group can understand the contents. This can be done via interviews with the children and their parents. Paediatric PROMs should be completed by the child as much as possible to avoid bias. Proxy reports should only be considered if the children cannot complete them due to young age or cognitive delays; when there are proxy reports, they should be analysed separately from self-reports. Patients and their caregivers (e.g. adolescents and their parents) may have different views about the content assessed in PROMs, and thus their reported outcomes should not be weighed equally. Lastly, paediatric PROMs may not be applicable if they are in a different culture or language and thus will need to be reviewed and calibrated accordingly.^(40,41)

While many paediatric PROMs are available and in existence, there is limited data about their efficacy in clinical care. Studies have suggested that these PROMs need further validation even for research purposes. Inconsistencies in developing and validating PROMs have limited their use by the paediatric community,⁽⁴²⁾ such as in the use of PROMs for genodermatosis. In addition, some PROMs that were developed for research may not have the ability to detect a difference in an individual's QoL over time clinically, thus limiting their use in routine clinical settings. Gaps of knowledge on which PROMs to use and how to use them in clinical practice pose

major obstacles to their systematic integration into routine clinical care. However, continued research is under way to determine how PROMs can affect health-related QoL, use of healthcare resources, patient outcomes and care quality in children with chronic diseases.⁽⁴³⁾

Applying to clinical practice

PROMIS is used by the Pediatric Patient Reported Outcomes in Chronic Diseases (PEPR) Consortium. The long-term goal of the PEPR Consortium is to conduct validation studies of PROMs in research and clinical care settings, and to determine “*the impact of environmental stressors (including socioeconomic aspects) on children’s symptoms and QoL in a variety of chronic diseases or conditions*”.^(41,44)

Another example is KLIK, a web application used⁽⁴⁵⁾ in Amsterdam. KLIK auto-generates an email to invite children and/or parents to complete electronic patient-reported outcomes that evaluate different aspects of health-related QoL. The responses generate information for medical providers to explore regarding QoL issues and allow monitoring of these outcomes over time. Use of KLIK in the juvenile idiopathic arthritis cohort has enabled physicians to better examine the emotional health and social functioning of their patients. The Web-based method not only improves patient outcomes but also gives physicians greater job satisfaction, particularly in their ability to provide emotional support.^(46,47) In addition to disease-specific standard sets, ICHOM recently established an Overall Paediatric Health Standard Set in February 2020.⁽⁴⁸⁾

In summary, the role of PROMs in paediatrics and child health is to improve healthcare quality at the point of care and to serve as performance indicators for overall child health and paediatric care.^(33,49-51) Continued education of parents and children about the purpose of PROMs

and how they contribute to their care, together with physician buy-in and training on PROMs, would help in their successful integration into clinical practice.

VALUE-BASED MEDICINE AND PATIENT-REPORTED OUTCOME MEASURES

Value is the translatable quality or practical quality physicians can provide to patients and populations, framed by costs to ensure it is sustainable in the long run. Value “*represents healthcare that has positive results (improved patient outcomes, safety and satisfaction) at a total cost that is reasonable and affordable*”.⁽⁵²⁾ The value equation can be stated as:

$$\text{Value} = \frac{\text{Quality (outcomes [outcome sets: clinical, PROM, PREM and case mix] + patient experience)}}{\text{Cost (monetary and energy [teamwork, clinical path, integrated care])}}$$

In recent years, there has been much talk about creating and developing value in healthcare, beyond just quality. Value in healthcare goes beyond quality or evidence-based practice, and incorporates both patients’ perceptions of the healthcare delivered and the resources utilised.

VBM has five pillars (Box 7) and is defined as “*the practice of medicine incorporating the highest level of evidence-based data with the patient-perceived value conferred by healthcare interventions for the resources expended*”.⁽⁵²⁻⁵⁶⁾ Evidence-based data, patient perception, and resource utilisation are interconnected components of VBM. With this definition, VBM has three main stakeholders: the patients, the healthcare providers and the funding agency.

Box 7. Pillars of value-based medicine.⁽⁵³⁾

- All patients deserve medical care that results in the greatest value to the patient.
- Patient value is always key and is above financial value.
- Financial value is evaluated only when the patient value conferred by one or more medical care is not dissimilar.
- One should not base therapeutic decisions on cost-effectiveness alone.
- Value-based medicine information systems should be user-friendly and transparent with standardisation and patient preferences factored in critically.

Healthcare providers, by means of various diagnostic and therapeutic modalities based on the latest evidence, aim to produce a positive impact on patient outcomes. No one disputes the importance and relevance of evidence-based medicine (EBM) in delivering care to patients. However, in the pursuit of EBM, the importance of individualism and the needs of individual patients might arguably have been forgotten or misplaced.⁽⁵⁷⁾ Quality in healthcare has been erroneously construed to mean compliance with EBM guidelines rather than a focus on outcomes and improvement in care for our patients.⁽⁵⁸⁾

The consequent expanded volume of diagnostic and therapeutic interventions has generated an increase in healthcare expenditure, which does not support the perceived value in healthcare. With the final expenditure borne by the funding agency, there has been a paradigm shift in emphasis from the traditional volume-based funding to value-based funding in recent years. With rising costs in various healthcare systems, VBM can help to lower overall healthcare expenditure or optimise the appropriate use of limited resources in different countries.

In our opinion, value should always be centred around the patient⁽⁵⁹⁾ and “*since value depends on results, not inputs, value in healthcare is measured by the outcomes achieved, not the volume of services delivered, and shifting focus from volume to value is a central challenge*”. In other words, value to the patient is what matters, not the volume contributed to the system. Every patient can provide an input that can generate an improvement in the healthcare system. To practise and deliver patient-centric care, we need to focus on patients’ needs and what matters to them. The care we deliver must make sense to patients, and they must perceive the care rendered to be of value. This emerging concept of using PROMs as a tool to assess patient-reported outcomes in addition to clinical outcomes is appropriate and ultimately beneficial.

Focusing on value in healthcare is therefore not just a method to contain costs in the system, regardless of the needs of the patient. Rather, it involves calibrating healthcare to the needs of the patient and ensuring the sustainability of the healthcare system as a whole in the long run, benefiting the whole community.⁽⁵⁹⁻⁶¹⁾ Value-driven care, value-driven healthcare and value-driven outcomes are initiatives to focus health and healthcare back onto the healthcare and health needs of our patients. Value-driven care refers to a healthcare system that is driven by patients' health and healthcare outcomes with the utility of PROMs.⁽⁶²⁾

In paediatrics and child health, PROMs, if implemented well with appropriate measurement tools that are regularly updated and validated in a self-learning healthcare ecosystem, would help to enhance personalised healthcare delivery (Fig. 2). Use of PROMs would complement practice of true VBM, thereby improving the health of the community at large.

CONCLUSION

PROMs are key to delivering patient-centred and patient-centric care to meet the health and healthcare needs of our paediatric patients in the 21st century. As healthcare providers, we need to understand the holistic needs of our patients and calibrate care accordingly. Development and implementation of PROMs pose major challenges, particularly in paediatrics. Although considerable progress has been made, much remains to be done to facilitate integration of appropriate PROMs into routine paediatric clinical practice.

Effective PROMs enable us as healthcare providers to meaningfully meld 'hard' medical science with soft, 'heart' aspects to ensure optimal health for our patients. The practice of medicine in the final analysis is both a science as well as an art. As Paracelsus said, "*Medicine is not only a*

science; it is also an art. It does not consist of compounding pills and plasters; it deals with the very processes of life, which must be understood before they may be guided.”

ACKNOWLEDGEMENT

Dr Ng Kee Chong is a member of the ICHOM Overall Paediatric Health Workgroup 2018–2020.

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FIGURES

Fig. 1 Chart shows factors that affect health-related quality of life.⁽⁴⁾

Fig. 2 Flowchart shows how PROMS are leveraged to create a learning child health ecosystem with value-based medicine. AI: artificial intelligence