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White Paper

PATIENT-CENTRIC DECISION MAKING IN THE DIGITAL AGE

The importance of the patient's voice and approaches to incorporating it in healthcare decision making

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Introduction

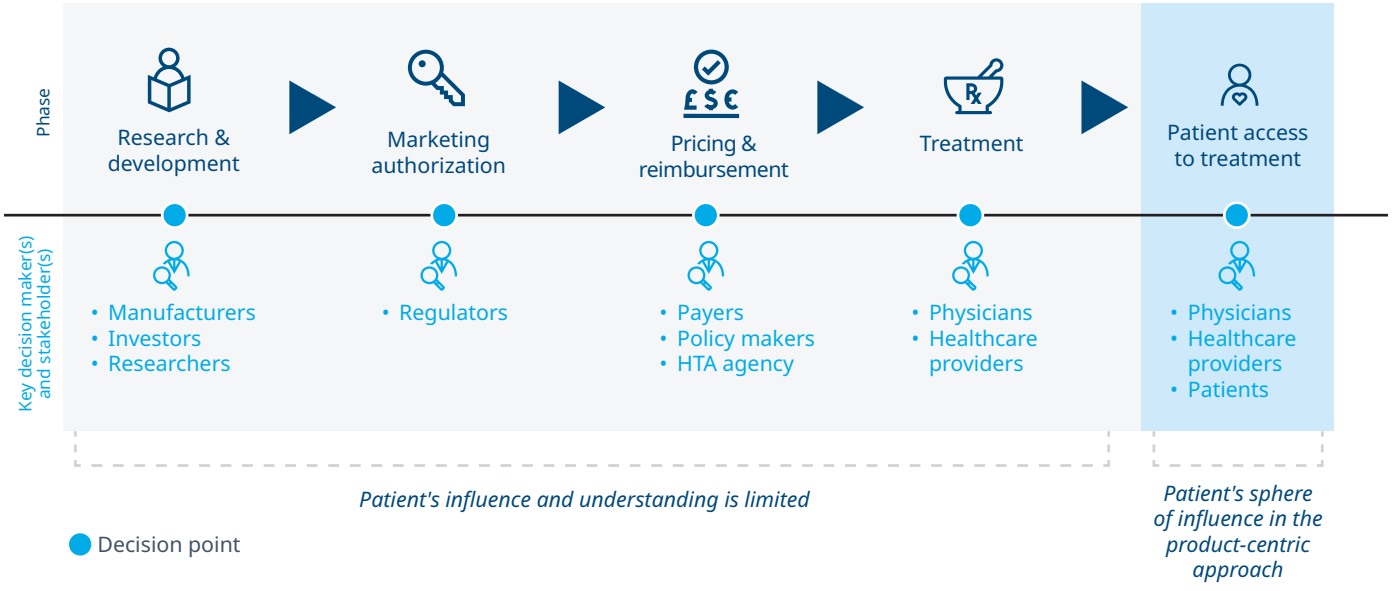
A patient's involvement in healthcare decision making is typically limited to the period between diagnosis and the initiation of the treatment pathway. The healthcare provider generally has direct control over the patient's clinical management, with payers and government agencies exerting some influence over the availability and accessibility of treatment options.

Medicine is a complex subject with multiple specialized domains of knowledge. Despite having access to a plethora of information online, there remains a gap between information that is available to healthcare professionals and patients. Furthermore, the healthcare industry is highly regulated to uphold safety standards. Consequently, regulators in most settings do not permit direct-to-patient promotional activities of any medical products. All information and activities involving patients are scrutinized and often require approval from health authorities. Policymakers and payers are also involved but play different roles in ensuring the provision of safe, effective, quality, affordable and value-for-money services through the healthcare delivery system. Decisions made in the deployment of an appropriate method of treatment often does not take into account the patient's perspective. The question then is, whether these decisions are truly representative of the patient voice and if patients should contribute more towards matters concerning their health and wellbeing.

Understanding the healthcare decision making journey

The healthcare system's traditional gatekeeping paradigm – experts should decide the best treatments for patients – has resulted in a largely product-centric approach to healthcare decision making, where each product or healthcare technology is assessed and discussed individually. A product is evaluated first by regulators for its safety, quality and efficacy before being granted marketing authorization. Thereafter, payers and policy makers assess the product's value for inclusion in their country's public health insurance benefit package. Finally, physicians discuss this 'available' treatment option with their patients *(Figure 1)*.

Figure 1: Product-centric approach: The traditional healthcare decision making journey



Importance of involving the patient in decision making

Digital is driving change across industries and the healthcare industry is no exception. The availability of information and the accessibility to digital technologies have given rise to the 'connected patient' who now takes charge of his or her own well-being, enabled via online tools, the internet, peer-to-peer sharing, consumer health devices, and mobile apps. The rise of digital has empowered patients to take charge of their own health, granting them greater confidence and autonomy over decisions relating to their health.

Some other advancements include the availability of telemedicine, home care and concierge care. These care delivery models offer attributes such as convenience, timeliness, value, communication and attention, which might be important to patients but sometimes overlooked by healthcare decision-makers. A growing educated and technology-savvy population has raised the awareness of treatment options and bridged the knowledge disparity between the patient and the physician. These new technology-enabled care delivery models enable the inclusion of the patient's voice in the treatment journey in ways which might not have been possible a decade ago.

The Institute of Medicine (IOM) defines patient-centered care as: "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions"[1]. Through digital technologies, patients now have a desire and ability to take a more active role in decisions related to their health. This alters the patient-physician relationship dynamic and enables conversations that facilitate a healthcare choice together. This is the Shared Decision Making approach. Studies have shown that patient involvement in decision making has a positive association with their health outcomes[2,3].

Given the complexities in health and healthcare, the other benefit of incorporating the patient voice is that it provides stakeholders and industry alike with an opportunity to re-evaluate what classifies as 'outcome' or 'quality-of-life' from the perspectives of the patient. This in turn can drive critical appreciation of existing health technology evaluation frameworks and drive the adoption of these technologies based on criteria beyond just its cost and efficacy alone, with the intention of benefitting the patient.

Therefore, insights generated through patient-centered approaches can help to shape research and policy priorities, guide the development of market access and pricing strategies of a treatment, and provide additional engagement opportunities among stakeholders.

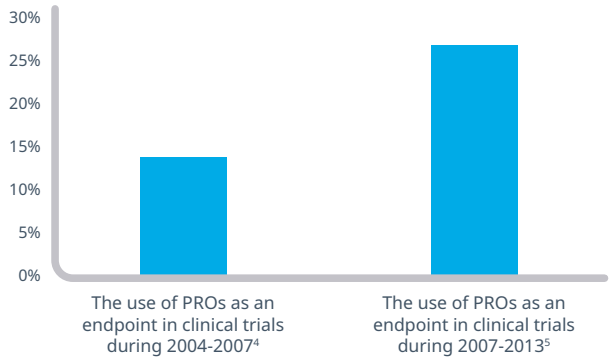
Manufacturers share in their role in realizing this goal but may also greatly benefit from patient insights to determine research priorities, understanding the pain-points and behavior patterns of the end-user, develop market access and pricing strategies, and engagement opportunities with gatekeepers.

Ways to involve the patient in decision making

Incorporating patient-reported outcome (PRO) data into marketing authorization decision

The importance of considering PROs alongside biomarkers of health improvement in clinical drug research has increased over the past two decades in parallel to advances in patient-centric healthcare, as evidenced by the increased use of PROs as clinical endpoints in clinical trials (*Figure 2)*.

Figure 2: Number of PROs used as an endpoint in clinical trials



PROs transform a qualitative endpoint into a quantifiable outcome and in the process, these add a patient's perspective on the impact of treatment on their health outcomes. In doing so, value created for the patients can be weighed against other traditional clinical outcomes. There are several available validated tools to measure a patient's health status. Health-Related Quality of Life (HRQoL) is the endpoint that assesses various dimensions such as the physical function, social function, pain severity, and mental status. HRQoL is recognized as one of key outcomes because it can measure the patients' health state and can also be translated into utility values and Quality Adjusted Life Year (QALY) which are commonly used as indicators for health care resource allocation as well as reimbursement decisions worldwide. The National Institute for Health and Care Excellence (NICE), for example, recommends the use of QALYs as a measure of health benefit for their 'reference case', to enable a standardized approach for comparing economic evaluations across different healthcare services and technologies[6]. Several countries in Asia such as Australia, South Korea, Singapore and Thailand follow the same recommendation. Hence, HRQoL has become a vital endpoint for most clinical trials.

PROs transform a qualitative endpoint into a quantifiable outcome

Integrating patient preference and involvement in the HTA process

The use of PROs alone is not enough to lead the paradigm shift towards patient-centered healthcare. Patient preferences should complement PROs and provide a more comprehensive understanding of the needs, values and priorities of patients for their treatment and care. Patient preference elicitation methods such as conjoint analysis, time trade-off and Willingness-To-Pay (WTP) have become popular methodologies for outcomes research as they allow flexibility in addressing various research questions. For example, it can determine the total cost and value of a health intervention, evaluate how patients value an existing treatment versus a simulated one before it is really implemented, and address issues related to treatment adherence or process. WTP studies are particularly insightful as more countries move towards universal health coverage and establish their Health Technology Assessment (HTA) processes[7]. WTP can guide the development of threshold ranges and justify cost-effectiveness and reimbursement decision for proposed new treatments. Countries

Case study - Listening to the patient's voice: The reimbursement of cochlear implants in Taiwan[9]

Patients, caregivers or patient groups are invited to submit their inputs on the National Health Insurance Administration (NHIA) website up to 14 days prior to a scheduled Pharmaceutical Benefit and Reimbursement Scheme (PBRS) meeting. These inputs are collected and summarized by the HTA division. Additionally, patient representatives could be invited to the PBRS Joint Meeting to represent the patient voice and express their opinions. Other than clinical and economic evidence, patients' inputs are also considered in the reimbursement decision making process. The involvement of patients led to the reimbursement of cochlear implants for hearing-impaired patients under 18 years old in Taiwan since July 2017. Undoubtedly, the involvement of patients in the HTA process are not without limitations and barriers. Continuous efforts are still needed to refine the input collection methodology and establish an efficient patient-HTA process. And the NHIA is committed to progress along this journey.

such as Thailand have developed their own threshold through WTP studies[8]. During the HTA process, the focus is often on the product's value as well as affordability due to limited government healthcare budgets. Unsurprisingly, clinical outcomes and costs often dominate these conversations but there have been encouraging developments where patients' perspectives have been given greater weightage. Australia has actively pursued mechanisms to do this and started the Patient Voice Initiative in 2015[10]. The initiative brings together professionals from industry and academia with patient presentative groups to discuss methods and approaches to incorporate patient perspectives on value assessments. Similarly, Taiwan has started involving patients in the HTA decision making process since 2015[9].

One framework that has been leveraged by several countries to integrate patients' perspective in reimbursement decisions is Multi-Criteria Decision Analysis (MCDA). MCDA is a structured technique that explicitly incorporates several criteria including patient perspectives into healthcare decision making. MCDA has been used for health resource allocation and policy prioritization in several European countries and has been explored in the region in countries such as Thailand and Taiwan.

Getting more 'value' out of the value proposition

A value dossier is one of the most important tools in market access. A compelling value proposition clearly demonstrates the evidence-based benefits a product has to offer as compared to its cost, and against its competitors. Essentially, people buy when they see value. Perception of value, however, is subjective. Traditionally, healthcare professionals and payers were the primary focus of product value messaging. This is due to the established healthcare paradigm, where manufacturers serve patients through these stakeholders with limited or no direct interaction with the patient. However, what matters to a healthcare professional or a payer might differ from what matters to a patient. This difference in value perception stems from the difference in needs and perspectives. By

incorporating evidence generated from patient's voice, a solid value proposition which is relevant across all stakeholders can be achieved.

Empowering patients through decision aids

Decision aids are tools which can help patients make informed decisions regarding their own health. These tools are helpful in the context of Shared Decision Making where physicians work together with patients to decide on interventions based on evidence as well as patient's preference. It has been shown that initiating treatments based on patients' preferences improves treatment adherence and satisfaction with care[11]. Leveraging the advancement in technology, a web-based decision aid can now be developed with minimal cost. Studies have shown that a web-based format performs similarly to conventional printed or video materials in terms of decision-quality outcomes[12]. The web-based approach increases patient access to decision aids as it is readily available and maintains the anonymity of patients. Web-based decision aids are increasingly used across different therapeutic areas such as oncology and immunology[13,14,15].

Future outlook

The evolution of digital health has transformed traditional healthcare. Tools can now readily be leveraged to connect the dots between patients and various other stakeholders, in order to support patient-centric healthcare decision making.

Gathering patient insights from AI and big data

Powered by technology, data related to patient preferences and treatment outcomes are increasingly becoming cheaper and faster to obtain. Technologies such as Artificial Intelligence (AI) have transformed patients' lives and healthcare experience. Wearables can be used to pick up events, outcomes and behaviors of interest. Patient preference could be elucidated from app usage, search histories, and medical records. AI may in future be able to infer hidden priorities and criteria that patients and clinicians themselves might have been unaware of. The possibilities are endless.

In China, tech giants are transforming the healthcare system with AI. AI is increasingly being used to support clinical management in many areas such as medical imaging and diagnosis. Faster and more effective options are available to cope with the increasing demand for healthcare services and providing accessibility to quality services in the remote rural areas. Insights generated from AI would also help in bringing the patient's perspective which truly reflects specific needs from patients and support a more patient-centric healthcare decision making.

Case study - Artificial-Intelligence (AI) at its best in China: The Ping An Good Doctor[16]

The Ping An Good Doctor portal provides a link between patients, healthcare providers and payers. It connects 265 million users with healthcare providers from thousands of clinics and pharmacy outlets across China. The app provides a one-stop solution to cater for all healthcare needs. Patients can utilize the app to access the healthcare system and request for online consultations. The artificial intelligence (AI) assisted online consultation collects relevant information from patients. A preliminary report will be generated and sent to a doctor for further consultation. The doctor's decisions are captured and entered into a machine learning system. This enables the AI model to continuously improve its diagnoses and predictions with the goal of being able to treat patients completely independently of human input. Patients can also fill their prescriptions and purchase drug through the app. The costs of treatment are borne by payers which are linked on the same portal.

Transforming PROs data collection with electronic platform

PRO methodologies have wholeheartedly embraced digital technologies to effortlessly collect information on patient's outcomes in a seamless workflow from recruitment to analysis. There are many standardized PROs that have been validated and integrated into electronic data collection templates. While this reduces the errors and manpower requirements inherent in any manual data entry and improve administrative and data management processes for researchers, the accuracy of self-reported data is still dependent on the patient and biases still remain. A technology-driven era of high connectivity has led to the high penetration of smart devices further encouraging and enabling the facilitation of PRO studies. The concept of Bring Your Own Device (BYOD) is taking root and is a viable alternative for PROs data collection. Patients or subjects can use their own devices, to complete the survey via a web-based portal or through a downloaded mobile app. BYOD allows patients to self-administer the questionnaire remotely and conveniently while at the same time, allowing the Principal Investigator access to a wider pool of patients or subjects. Although BYOD has clear advantages, some challenges in its execution remain to be addressed, especially in emerging markets in Asia, where literacy and penetration of smart devices may not be as high as the European counterparts.

Conclusion

Adoption of mechanisms that incorporate the patient's voice in healthcare decision making processes in Asia Pacific

With Australia and Taiwan taking steps towards incorporating patient perspectives in their healthcare decision making process, the trend is likely to continue to countries within the region regardless of the maturity of the healthcare system. In a heavily regulated industry such as healthcare, patient's voice provides a way to connect with the end-users of our industry and ensures that they are able to reap the benefits of healthcare innovations (*Table 1*).

Table 1: Some methods that add value to the decision making process through patient-centric approaches

METHODS	BENEFITS
Patient Reported Outcomes Multiple Criteria Decision Analysis Patient Preferences	• Better alignment of research efforts and resource allocation to the demands of the market • Richer data to showcase improvements in clinical outcome • Clear identification and prioritization of research gaps to complete the value story of products and services • Structured explicit approach to demonstrate value of products for appraisal committees, clinicians and private patients

Keeping the human touch at the core of digital health

While technology is used to expand the access to quality care, it should not come at the cost of humanity. The idea is to understand the patient in order to improve patient outcomes, while the challenge is to leverage the convenience which technology brings bearing in mind the 'human' at the center of care. With patients being the vulnerable consumers in healthcare, empathy is the key element to a good patient experience. After all, the goal of healthcare is to improve patients' health-related quality of life. And it is imperative to preserve the human touch in our efforts moving forward.

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