Measuring Meaningful Patient Outcomes

Designing the Kingdom of Saudi Arabia's National Patient

Reported Outcome Measures (PROMs) Strategy

Foreword

Value in health is achieved with better health and better care at lower cost, with a focus on the individual and the whole population and what truly matters to them.

The National Patient Reported Outcome Measures Strategy embodies these objectives, while emphasising the specific priorities of the Saudi population.

The thorough groundwork described in this report is just the beginning of a powerfully transformative initiative – one that builds on international best practices and lessons learned from around the world. It attempts to make the patient voice louder and more influential within the health system.

Feeding the empowered patient voice directly into value-based care will be a game-changer for the Saudi healthcare sector, and I am enormously proud to be involved in such a trailblazing project, progressing at an impressive pace. Nothing has been left to chance, and no part of the ecosystem has been absent from the table as we have formulated ideas and developed the strategy and the implementation roadmap.

Innovation is at the heart of everything we do at the Center for Improving Value in Health, and the National PROMs strategy is a perfect opportunity to showcase how care must be accessed and delivered.

Dr. Reem Bunyan, CEO, Center for Improving Value in Health

Executive Summary

In the region, significant population growth rates and a high prevalence of chronic non-communicable diseases are driving the need to shift to more integrated care delivery models to improve coordination of care, reduce cost and improve outcomes. The practice of recording and responding to patient-reported outcome measures (PROMs) is being formalised as healthcare ecosystem stakeholders look for more meaningful ways to determine success from medical intervention. The Kingdom of Saudi Arabia has incorporated this perspective into its Vision 2030 programme, as it aims to provide better health, better care, and better value to its people.

Recording and measuring outcomes that resonate with patients aligns with a wider shift towards Value-Based Health Care (VBHC). It looks to prioritise the allocation of resources, to ensure long-term healthcare sustainability as demand on services grows.

With support from PwC Middle East and The Clinician from New Zealand, the Council of Health Insurance (CHI) has collaborated with the Center for Improving Value in Health and stakeholders from across the wider Saudi healthcare ecosystem, to develop a National PROMs Strategy. This will serve the entire health sector and pave the way for Value-Based Payment (VBP) in certain segments of the market.

The strategy builds on leading practices and lessons learned from across the world. It looks to standardise practices, measures and systems to optimise the opportunity for PROMs-based care decisions and continuous healthcare improvements and efficiencies.
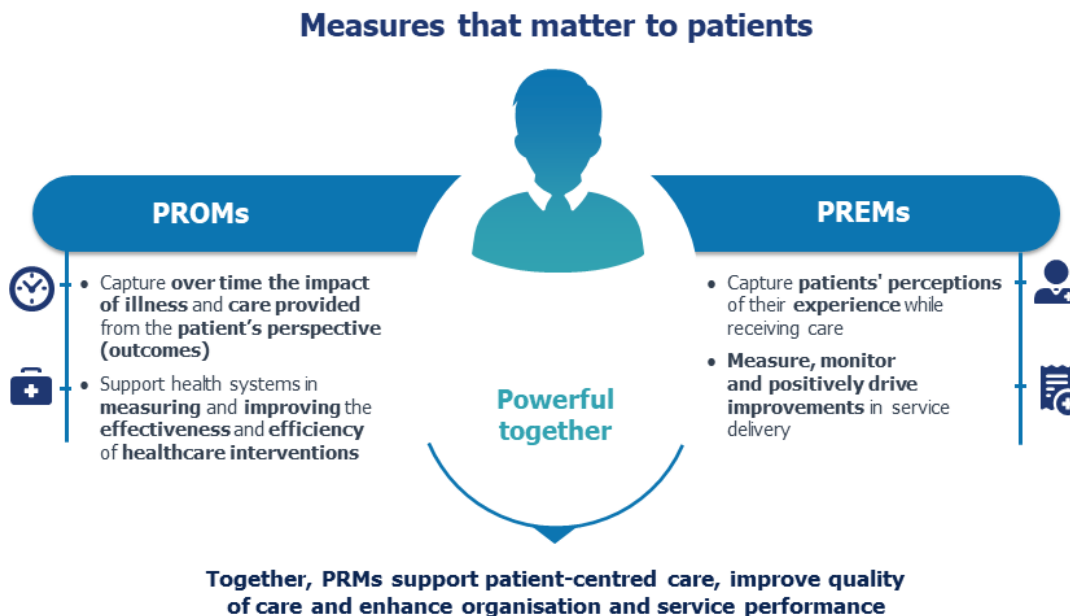
This paper details our strategy and progress to date, and the key success factors we have identified. These include a phased approach to delivery, and steps to establish and accelerate the rollout of an appropriate technology infrastructure and data collection capabilities, plus plans to digitally enable the workforce.

Introduction

Across the developed and developing world, attitudes to healthcare outcomes and associated performance measures are changing. Historically, health system measurement has focused on clinical and health service utilisation assessment, above what is important to the patient, including quality of life following medical intervention. Taking the example of a hip replacement, success until now has been measured based on whether there is an infection afterwards, rather than whether the patient can walk or ride a bike without pain.

Now, progressive healthcare systems are placing increasing importance on measuring patient-reported outcomes – defined as their own interpretation of their resulting health status. The practice of recording PROMs is now being formalised in developed health systems around the world, as the various decision-makers and stakeholders look for more meaningful ways to objectively determine a successful healthcare system *(see Figure 1).*

Figure 1: Patient Reported Measures are at the heart of value-based healthcare

Measures that matter to patients

PROMs
- Capture **over time the impact of illness** and **care provided** from the **patient's perspective (outcomes)**
- Support health systems in **measuring** and **improving** the **effectiveness** and **efficiency** of healthcare interventions

PREMs
- Capture **patients' perceptions** of their **experience** while receiving care
- **Measure, monitor and positively drive improvements** in service delivery

Powerful together

Together, PRMs support patient-centred care, improve quality of care and enhance organisation and service performance

Saudi Arabia has incorporated this perspective into its Vision 2030 strategic direction for the Kingdom. A framework provided by the Institute for Healthcare Improvement[1] is now widely accepted to guide the health system, and the Quadruple Aim sets out four priorities:

1. To improve the health of the population, by preventing and better managing prevalent, costly and chronic diseases
2. To improve efficiency and reduce the cost of providing care
3. To enhance the patient experience, by motivating and engaging patients to play an active role in their own care

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[1] Nundy S, Cooper LA, Mate KS. The quintuple aim for health care improvement: A new imperative to advance health equity. JAMA. Published online January 21, 2022.

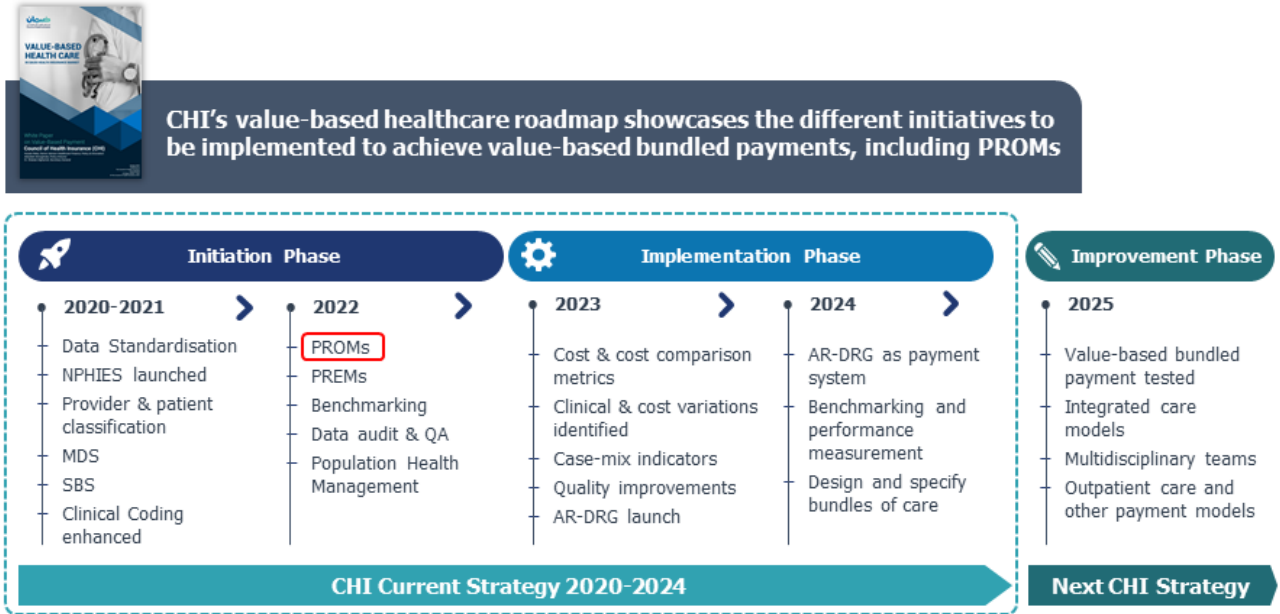4. To improve provider satisfaction through access to tools and resources that address burdens and burnout

Recording and measuring outcomes in terms that are more meaningful to patients is one direct way that KSA is improving the quality, efficiency and sustainability of its health system. This aligns with a wider shift taking place globally, towards VBHC that looks to weigh the improvement in a patient's health outcomes against the cost of achieving the improvement. VBHC favours the use of a range of different measures, including patient-reported outcomes *(see Figure 2)*.

Figure 2: Outcomes measurement is a foundational principle of value-based healthcare
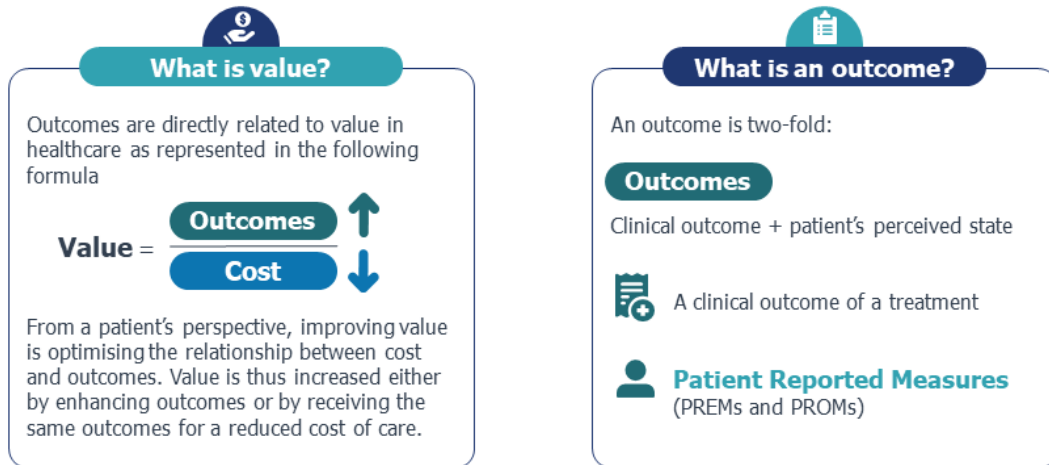
All of this will allow Saudi Arabia to prioritise the allocation of resources, to ensure long-term healthcare sustainability as demand on services grows. Associated developments to date include the establishment of the Center for Improving Value in Health and the Council of Health Insurance (CHI)'s VBHC strategy *(see Figure 3)*.

Figure 3: PROMs are one of the key projects supporting CHI's VBHC agenda, towards value-based payments

CHI's value-based healthcare roadmap showcases the different initiatives to be implemented to achieve value-based bundled payments, including PROMs

Initiation Phase		Implementation Phase		Improvement Phase
2020-2021	**2022**	**2023**	**2024**	**2025**
Data Standardisation	PROMs	Cost & cost comparison metrics	AR-DRG as payment system	Value-based bundled payment tested
NPHIES launched	PREMs	Clinical & cost variations identified	Benchmarking and performance measurement	Integrated care models
Provider & patient classification	Benchmarking	Case-mix indicators	Design and specify bundles of care	Multidisciplinary teams
MDS	Data audit & QA	Quality improvements		Outpatient care and other payment models
SBS	Population Health Management	AR-DRG launch		
Clinical Coding enhanced				

CHI Current Strategy 2020-2024   Next CHI Strategy

Source: Council Health Insurance Strategy document

With support from PwC Middle East and The Clinician in New Zealand, CHI has collaborated with the Center for Improving Value in Health and stakeholders from across the wider healthcare ecosystem, to develop a National PROMs Strategy. This will serve as a starting point for the entire health sector. The aim is to link financing to a more comprehensive and inclusive assessment of outcomes, that is standardised as far as possible across Saudi Arabia.

Over the following pages we chart our progress to date - from how we developed and refined the National Strategy, to the approach and methodology we have adopted, the instruments we are using and the roadmap we are following with energy and pace. We also explore the adaptations we have been making along the way and the next milestones we are working towards.

Defining a National PROMs Strategy

The National PROMs Strategy has been informed and agreed by a range of leaders across the healthcare system – from government bodies, private health insurers and payers, to clinicians and patients. This dynamic top-down and bottom-up approach paves the way for healthcare providers to accelerate positive change through more informed decision-making, drive rapid progress and deliver better patient outcomes consistently across the Kingdom *(see Figure 4)*.

Figure 4: PROMs provide a patient-centric measurement approach across the stages of the patient care journey
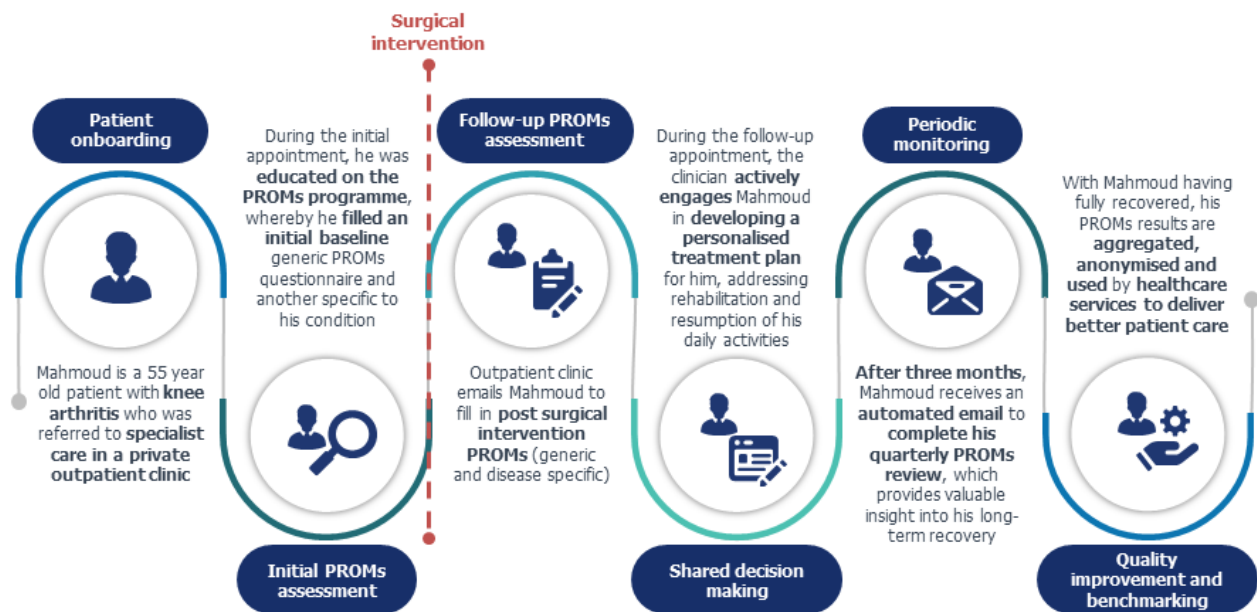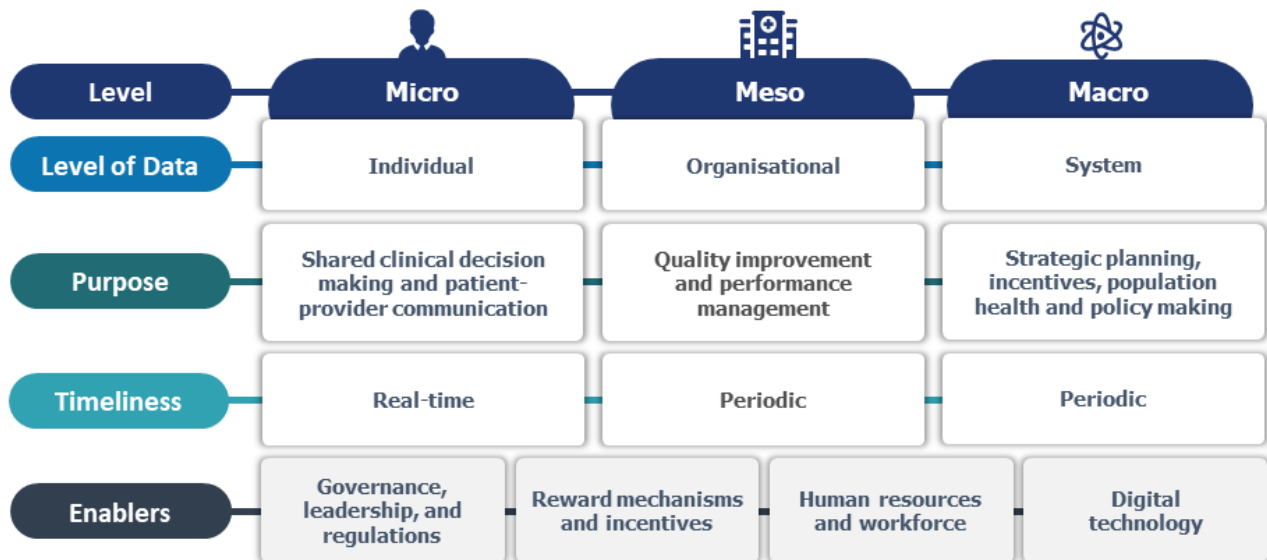

With the evolution of PROMs already underway in numerous developed markets, ranging from the UK to Singapore, we have drawn on those experiences to create an optimum strategy locally. Taking a national approach will help drive necessary disruption in conventional healthcare, incubate new ideas and kickstart improved standardisation. With a commitment to act purposefully on patient-reported outcome data, we are keen to ensure that parameters, standards

and governance, as well as the supporting IT infrastructure, are consistent and interoperable across the Kingdom.

This uniformity will pave the way for reliable data exchange, comparison, combination and decision-supporting insights, with maximum potential for innovative onward use cases. It will also be more efficient to support and manage than a more piecemeal approach nationally. This approach also allows scaling to the entire health sector.

At every stage of strategy development, planning and delivery, we have considered the views and needs of each stakeholder and user group, providing a micro-, meso- and macro-level steer to every decision and plan *(see Figure 5).*

Figure 5: PROMs are used at micro, meso and macro levels to drive performance and quality improvement, empowered by a number of key enablers

Level	Micro	Meso	Macro
Level of Data	Individual	Organisational	System
Purpose	Shared clinical decision making and patient-provider communication	Quality improvement and performance management	Strategic planning, incentives, population health and policy making
Timeliness	Real-time	Periodic	Periodic
Enablers	Governance, leadership, and regulations	Reward mechanisms and incentives · Human resources and workforce	Digital technology

We recognise that we can't cater for all possible combinations of patient-reported outcome measures from day one. Rather, we needed to identify a logical, coherent and meaningful way of realising our initial ambitions while still delivering value to all stakeholders (from government bodies and health insurance providers to clinicians and patients).

A further goal has been to ensure that whatever best practices are distilled from the approaches of other nations and healthcare systems, ours will be tailored to the priorities of the Saudi population.

With these perspectives in mind, we set about developing a National Strategy. We began with a collaborative workshop with key relevant stakeholders to envision the desired future state. This session included the patient's voice.

This informative, engaging session allowed us to gain valuable insights from various stakeholder groups in a Saudi-specific context. More than 35 participants took part in a five-hour interaction session which incorporated real-life stories and experiences from the two patients, to help frame the opportunity we had and set a springboard for the Strategy formulation.

All stakeholders were actively engaged in formulating the vision, mission and objectives of the Strategy, giving representatives for each group a sense of inclusion, control and buy-in from the outset, while ensuring that no potentially significant considerations would be overlooked *(see Figure 6).*
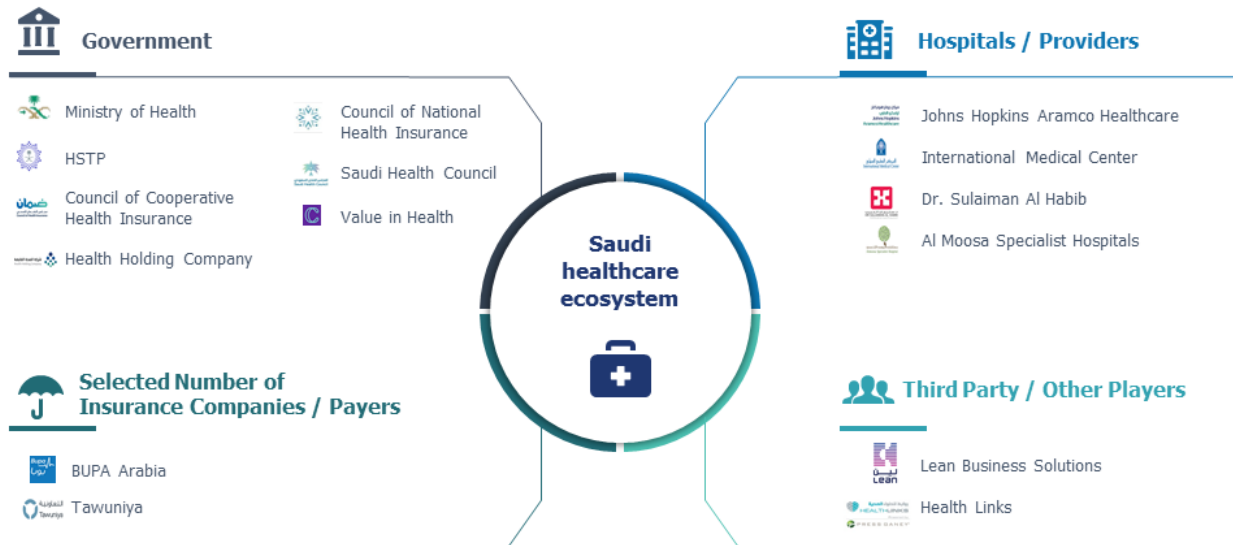
Vision, Mission & Objectives

As with any effective strategy, we are guided by a strong, clear and energising Vision and Mission. The National PROMs Strategy is aligned with Saudi Arabia's wider Health Sector Transformation Program (one of the Vision 2030 Vision Realisation Programs). Its **Vision** is to "*establish an exemplary National PROMs programme for the Saudi health system which promotes patient-centricity and long-term healthcare sustainability, as the population grows, ages and develops more complex and costly health condition*s."

To achieve this Vision, the **Mission** is to "*empower patients, providers, payers and policymakers to support Value-Based Healthcare (VBHC), through meaningful and actionable PROMs insights*."

Supporting all of this are four core guiding principles:

1. Patient centricity: placing patients, citizens and residents at the forefront to ensure they receive a superior healthcare experience
2. Value-based healthcare sustainability: to serve the population affordably well into the future
3. Instilling a PROMs culture across the health ecosystem: supporting PROMs across the Kingdom, while promoting a culture of accountability and commitment
4. Maintaining a state of agility: to enable continuous improvement over time.

Based on the co-designed vision and mission, we were able to detail a coherent series of strategic initiatives which, once executed, would get us to where we had envisaged.

Our three Strategic Objectives were to:

1. Design and integrate PROMs into care delivery
2. Develop PROMs data collection infrastructure and capabilities
3. Harness PROMs insights to empower patients, enable organisational performance benchmarking and support value-based healthcare incentives

For each, we defined strategic outcomes; key performance indicators (KPIs) with which to measure success, and specific initiatives that would take us towards those goals. We were then able to confidently develop a detailed roadmap and plan of action.

Implementation and execution: how we did it

To determine KSA's best route forward, we needed to establish our starting point, and then perform some international benchmarking *(see Figure 7)*.

Figure 7: CHI's PROMs requirements

| Collect and analyse data	Interview stakeholders	Benchmark PROMs programmes	Assess maturity	Identify key opportunities
Existing client and health ecosystem documentation and data were collected and analysed to understand the current state of PROMs in KSA	Key stakeholders across the KSA health ecosystem were interviewed to validate documentation and data, and to understand existing challenges and opportunities	A rigorous process to identify and benchmark PROMs programmes was conducted, based on a set of prioritisation criteria and the PROMs assessment framework	PROMs maturity in KSA was assessed using a qualitative comprehensive maturity scale to evaluate the current state of PROMs	Key PROMs opportunities in KSA were ultimately formulated to guide the subsequent development of the PROMs strategic direction and initiatives

We performed a 'current state' assessment, by consulting the existing health ecosystem and strategies, along with other relevant documents and data, to understand the current state of PROMs in KSA.

Among the Key findings:

- The existence of some patient outcome recording, but only in selected areas (see Figure 8)
- A lack of a national strategy towards PROMs
- The absence of a standardised approach to prioritising or deciding on where PROMs would be used, as well as a lack of consistent means of collecting and reporting patient-reported outcomes

Figure 8: Currently, CHI has four disease registries that could potentially be leveraged for PROMs data collection.
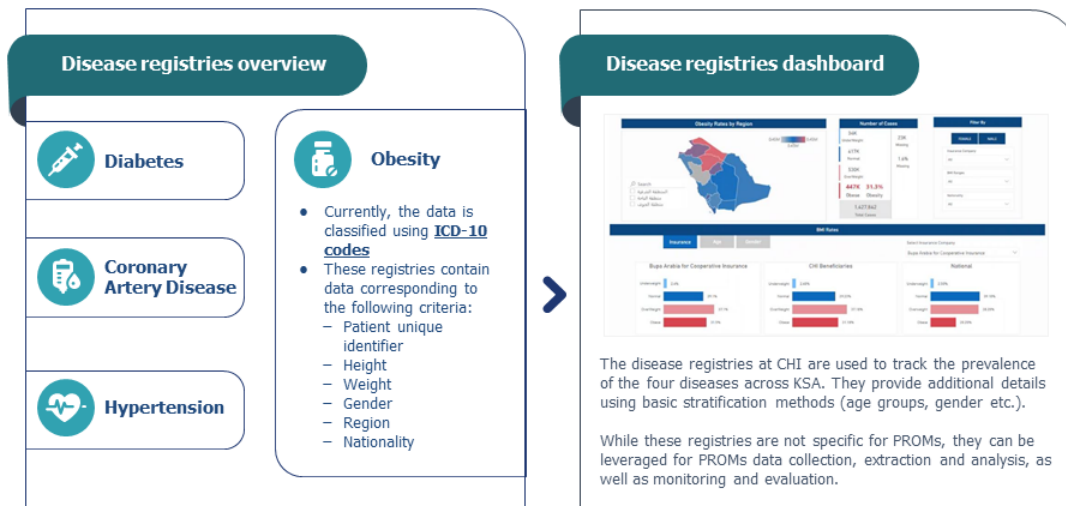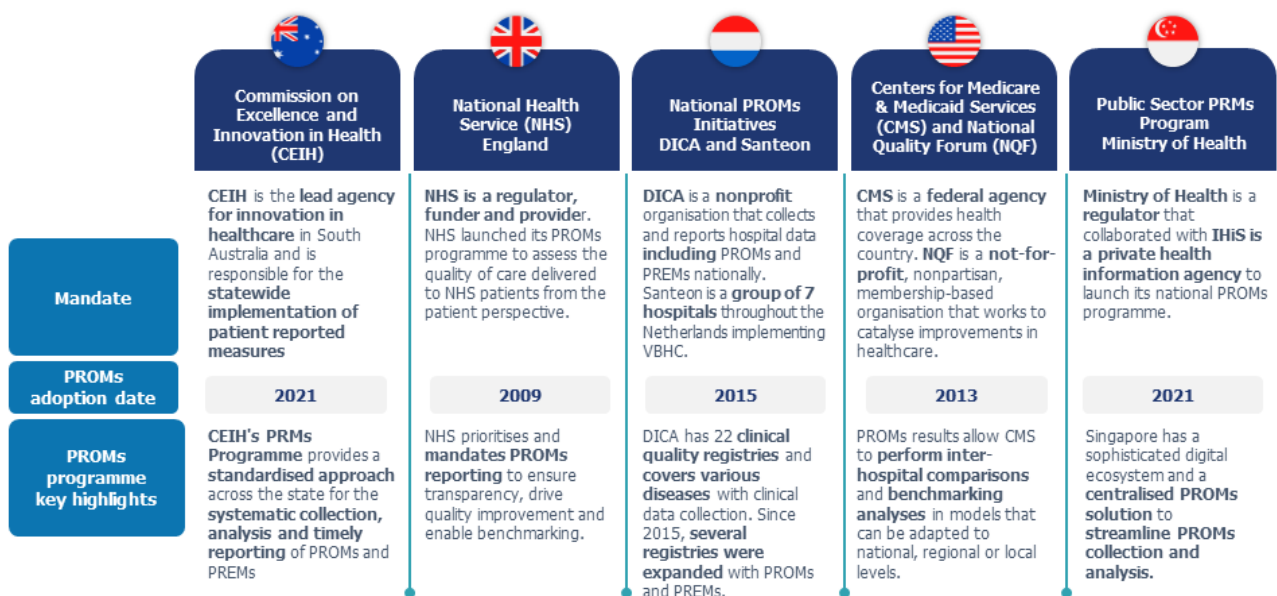

Source: Team Analysis, Stakeholder interviews

We also found that some value-based payment initiatives already exist under KSA's Payment Model Innovation (for cataract, hip and knees, bariatric, and cardiovascular and diabetes-related treatments) and that the kingdom's digital infrastructure will also help accelerate PROMs implementation and scalability.

To determine what other nations worldwide had done to enable PROMs and how well these initiatives were going, we then undertook a global benchmarking exercise spanning the US, UK, the Netherlands, Singapore and South Australia *(see Figure 9).*

Figure 9: Five leading entities were benchmarked to derive best practices for PROMs across a wide range of geographies, mandates and experiences

	Commission on Excellence and Innovation in Health (CEIH)	National Health Service (NHS) England	National PROMs Initiatives DICA and Santeon	Centers for Medicare & Medicaid Services (CMS) and National Quality Forum (NQF)	Public Sector PRMs Program Ministry of Health
Mandate	CEIH is the **lead agency for innovation in healthcare** in South Australia and is responsible for the **statewide implementation of patient reported measures**	NHS is a **regulator, funder and provider.** NHS launched its PROMs programme to assess the quality of care delivered to NHS patients from the patient perspective.	DICA is a **nonprofit** organisation that collects and reports hospital data including PROMs and PREMs nationally. Santeon is a **group of 7 hospitals** throughout the Netherlands implementing VBHC.	CMS is a **federal agency** that provides health coverage across the country. **NQF** is a **not-for-profit**, nonpartisan, membership-based organisation that works to catalyse improvements in healthcare.	Ministry of Health is a **regulator** that collaborated with **IHiS is a private health information agency** to launch its national PROMs programme.
PROMs adoption date	2021	2009	2015	2013	2021
PROMs programme key highlights	CEIH's PRMs **Programme** provides a **standardised approach** across the state for the **systematic collection, analysis and timely reporting** of PROMs and PREMs	NHS prioritises and **mandates PROMs reporting** to ensure transparency, drive quality improvement and enable benchmarking.	DICA has 22 **clinical quality registries** and **covers various diseases** with clinical data collection. Since 2015, **several registries were expanded** with PROMs and PREMs.	PROMs results allow CMS to **perform inter-hospital comparisons** and **benchmarking analyses** in models that can be adapted to national, regional or local levels.	Singapore has a sophisticated digital ecosystem and a **centralised PROMs solution** to **streamline PROMs collection and analysis.**

This additional groundwork provided a series of useful takeaways which we fed into KSA's National PROMs Strategy. These included:

Leadership

The importance of understanding the purpose of using PROMs (clinical decision making, patient empowerment, payment models) and how it drives the choice of the priority areas to cover first, with consistent patient representation and influence throughout implementation. Through this work we established a formal advisory committee to provide guidance and ensure stakeholder buy-in.

Culture

Patients and clinicians should be engaged in the design of PROMs programmes to help foster a continuous improvement culture, while all stakeholder engagement efforts should focus on education, alignment and collaboration to promote a common understanding of PROMs, along with buy-in and trust.

Infrastructure and measures

Existing infrastructure should be harnessed through the adoption of a specialised, fully integrated PROMs solution to streamline data collection, sharing and analysis, and measures should be standardised using validated PROMs instruments, translated and localised to a KSA context.

Reporting

There should be clearly established and standardised PROMs collection schedules that integrate into existing clinical workflows.

Performance management and improvement

Linking payments to PROMS achievement and costs. One example could be integration with the financing of diagnosis-related groups (DRGs).

Developing priority initiatives

For each of our three agreed strategic objectives, we defined the following strategic outcomes, key performance indicators (KPIs) with which to measure success, and specific initiatives that would take us towards those goals.

1. **Integrating PROMs into care delivery**

The goal here is to establish a PROMs framework and ensure it is progressively integrated into care delivery. Success measures include:

- The percentage of established PROMs priority areas, frameworks and instruments
- The percentage of digital PROMs integrated into patient journeys

The strategic initiatives to get us there are:

- To identify priority areas that are relevant in a Saudi context
- To review and select PROMs frameworks, identifying best practice and standardised PROMs for the priority areas
- To design and integrate digital PROMs administration into existing clinical and administrative pathways and workflows.

More details on these initiatives can be found in the appendix.

2. **Developing PROMs data collection capabilities**

Appropriate technology infrastructure and data collection capabilities are essential to operationalise PROMs. Interoperability is crucial to enable reliable data exchange and to maximise buy-in and adoption. The workforce must also be digitally enabled.

Success will be measured in terms of the percentage of electronic transactions exchanged for patients enrolled in PROMs programmes and the percentage of staff trained on the target 'ePRO' digital solution.

Specific initiatives towards these goals will be:

- Assessing current digital readiness
- Assessing whole system interoperability
- Defining the technology requirements for digital PROMs
- Establishing privacy, security and data governance (given the sensitivity of patient reporting)
- Allocating the required resources (in terms of funding, workforce,
- process and technology)
- Driving stakeholder engagement and clinical change management (with a clear plan, as well as guidelines and educational content and support, clinician champions and early adopters)

3. Making positive, proactive use of PROMs insights

The most critical strategic objective of all is ensuring that PROMS insights go on to empower patients, to enable organisational performance benchmarking and to support value-based healthcare incentives.

KPIs to measure success here will include:

- The patient PROMs response/engagement rate
- The proportion of administrators/providers accessing the PROMs portal to check their patients' results
- The percentage of value-based payment contracts using PROMs

Associated strategic initiatives, which are detailed in full in the Appendix, include:

- Empowering patients and clinicians
- Informing clinical quality improvement and performance benchmarking at a community/organisational level and creating a learning health system (for example, via a feedback loop)
- Developing outcome measures incentives and driving value-based healthcare at a macro level (moving away from current volume-based funding towards quality- and performance-based models)

Establishing strong governance

To keep everything aligned and on track, we put in place strong governance in the form of a steering committee that included representatives from all stakeholder groups. This will also ensure a continuous alignment with Saudi Arabia's Vision 2030 and the National Health Sector Transformation Program in particular.

This will ensure that the below established PROMs priority areas, identified through a prioritisation assessment process and validation with stakeholders from across the KSA healthcare ecosystem, are aligned with the prevalence of the selected medical interventions among the Saudi Arabian population:

- Cataract surgery
- Bariatric surgery
- Pregnancy & childbirth
- Diabetes

A staged implementation

To keep the task manageable, a staged implementation allows the scope to build momentum and capabilities and gather and build on the lessons learned, along the road to successfully scaling PROMs at the national level for the private health sector.

Ultimately, the plan is that other ecosystem partners take the National PROMs Strategy and adapt it to their needs, building on the experiences of the current CHI PROMs programme.

- **Stage 1:** The pilot implementation of PROMs in the priority areas, within a year
- **Stage 2:** The progressive implementation of PROMs by additional private providers, over a period of 18 months
- **Stage 3:** The national roll-out of PROMs across the private sector will overlap with the above, taking up to two years

There is a requirement for agility across the ecosystem, too. Continuous monitoring, evaluation and consolidation of lessons learned will inform and drive the next stages of implementation. At the end of each wave of activity, a new bespoke timeline will be designed based on the lessons learned from the implementation of each wave.

As the initial CHI pilot broadens out into a more national initiative, with CHI serving as a PROMs incubator and testing the PROMs proof-of-concept, lessons learned will be turned into guidance to support the expansion of consistent patient-reported outcome measures across the private sector. At this point the initial steering committee will evolve to become a national governing body, with updated terms of reference in support of a broader implementation across Saudi Arabia.

Conclusion and next steps

The National PROMs Strategy for Saudi Arabia provides a powerful example of what is possible, with a coordinated, standardised approach to patient-reported outcome measures. KSA's National Strategy has harnessed leading practice right from its initial design, based on the best PROMs approaches observed to date internationally.

At a practical level, we have deliberately specified a consistent e-PROMs approach and solution to capture and exchange patient-recorded outcome data.

Identifying priority clinical areas has been another recommended practice, to maintain focus and accelerate progress. Proactive stakeholder engagement and active use of the findings to guide service quality improvements and drive value-based healthcare and payment, are further drivers of buy-in and ongoing success.

The plans are in place for a substantial, game-changing transition in KSA's healthcare planning and delivery. They will ensure that the very best care will be available to all citizens well into the future, as the population grows and as requirements evolve. The Strategy will help place the patient at the heart of all critical decisions, ultimately supporting Saudi Arabia's shift towards value-based payments and value-based healthcare.

From this point onwards, seeing through the strategic initiatives during the pilot phase will be crucial to furthering an exemplary programme that can be rolled out nationally across KSA. Generating actionable insights will be essential to inform micro-, meso- and macro-level decision-making. The staged implementation, meanwhile, will help build momentum and capabilities and allow lessons to be learned and fed into the subsequent phases along the way.

Appendix

Detailed breakdown of National PROMs programme initiatives:

1 Strategic Objective	Initiative	Description
Design and integrate PROMs into care delivery	**1.1** Identify priority areas	Develop selection criteria to identify priority areas relevant to the Saudi context.
	1.2 Review and select PROMs frameworks and instruments	Identify best practice and standardised PROMs frameworks for selected priority areas for the Saudi context.
	1.3 Design and integrate digital PROMs administration into existing clinical and administrative pathways and workflows	Map PROMs patient journeys defined by selected frameworks into existing clinical and administrative pathways and workflows to create end-to-end digital care pathways (DCPs). These DCPs will drive the electronic administration of PROMs using digital ePRO solutions

Source: Team analysis, PROMs strategy workshop

2 Strategic Objective | **Initiative** | **Description**

Develop PROMs data collection infrastructure and capabilities

Initiative	Description
2.1 Assess digital readiness	Identify relevant information systems, enabling IT services and existing data holdings in order to build a successful PROMs programme to drive VBHC agenda. These may include Nphies, Sehhati, LEAN registry for personal, provider and facility identifiers, clinical registries and datasets such as claims, prescriptions, DRGs etc.
2.2 Ensure whole system interoperability	Investigate data formats, standards, and coding and classification systems used in relevant information systems and data holdings. Design and implement a fit-for-purpose, flexible and future-proof information architecture for PROMs
2.3 Define technology requirements for digital PROMs	Define functional and non-functional requirements for a digital PROMs system to engage with patients, administer surveys, collect and store responses, analyse and present results, both at individual and population levels via charts, dashboards and reports.

Source: Team analysis, PROMs strategy workshop

2 Strategic Objective | **Initiative** | **Description**

Develop PROMs data collection infrastructure and capabilities

Initiative	Description
2.4 Establish privacy and security and data governance	Identify relevant regulations, standards and best practices in KSA for managing identifiable patient information outside provider boundaries (e.g. cloud) and decide on data hosting options (e.g. public cloud vs private cloud vs dedicated data centres).
2.5 Allocate required resources (funding, workforce, process and technology)	Identify all types of resources in order to implement a PROMs programme with clear ownership from relevant stakeholders and create an initial resourcing plan, including workforce capacity building
2.6 Drive stakeholder engagement and clinical change management	Create a stakeholder engagement and change management plan along with guidelines and educational content and support clinician champions and early adopters

Source: Team analysis, PROMs strategy workshop

3 **Strategic Objective**

Initiative

Description

Utilise PROMs insights to empower patients, enable organisational performance benchmarking and support value-based healthcare incentives

3.1 Empower patients and clinicians at micro level

Ensure PROMs programme can facilitate patient-provider communication, enable patients to take an active role in care planning and delivery, support routine clinical care at the micro level, and define measurable value propositions

3.2 Inform clinical quality improvement, performance benchmarking at meso level and create a learning health system

Ensure collected PROMs data can be utilised at clinic / provider level to inform clinical quality improvement initiatives, performance benchmarking, and establish a feedback loop to make sure learning can be applied at the meso level

3.3 Develop outcomes measurement incentives and drive VBHC at macro level

Define appropriate and effective financial and non-financial incentives to move away from current volume-based funding towards VBHC quality and performance-based funding models at macro level

Source: Team analysis, PROMs strategy workshop

The staged implementation timeline:
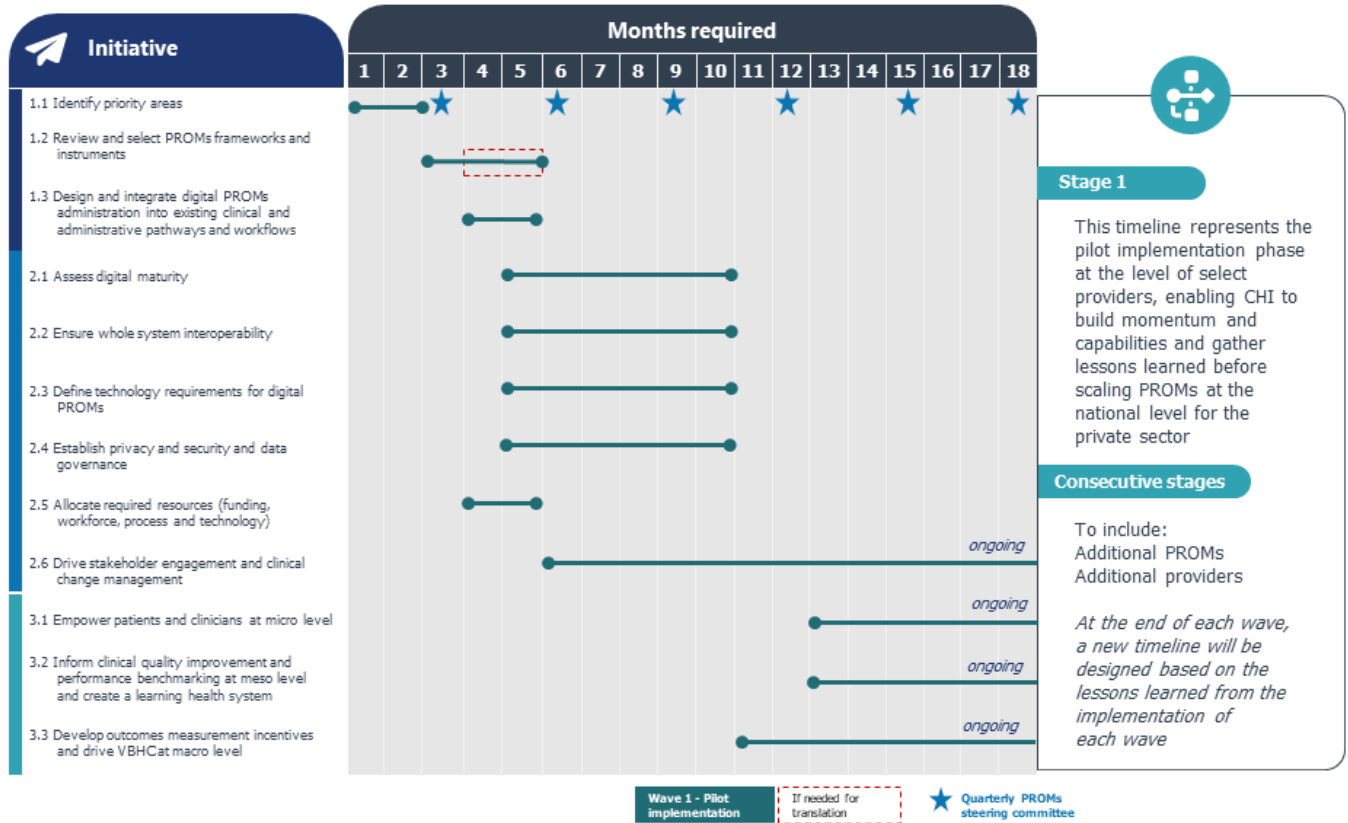
Selecting priority areas

To identify the PROMs priority areas, we followed an evidence-based approach. First, we compiled a longlist of potential measures to be addressed, based on the findings of a literature review as well as the International Consortium for Health Outcomes Measures (ICHOM) outcome measure sets, while also taking into consideration the aspirations of Saudia Arabia's healthcare ecosystem leaders:
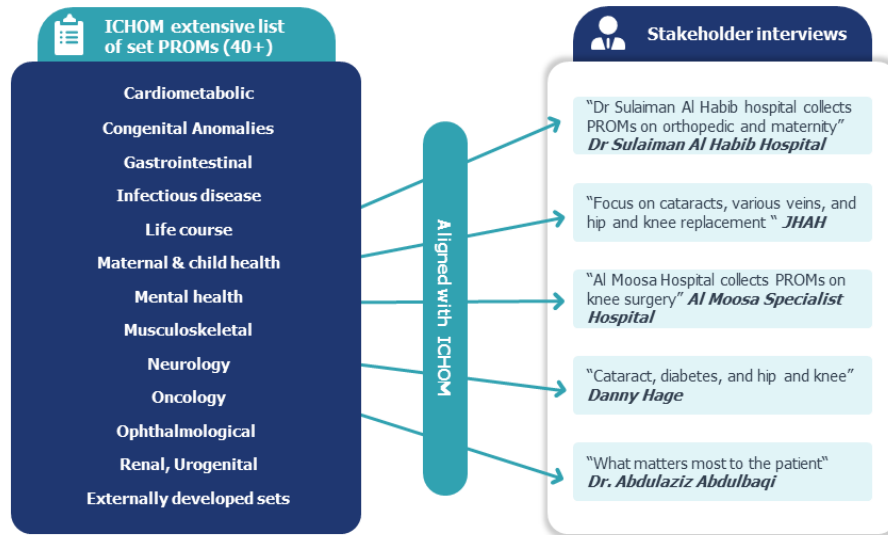
We then established a list of guiding principles and filter criteria, again drawing on our review of the literature as well as emerging international best practices, in consultation with PROMs experts:

The selection of PROMs priority areas will be:

Guiding principles to our PROMs priority area selection

1 Driven by viability of implementation and data collection
PROMs priority areas are set up to ensure success and gather lessons learned to guide subsequent expansion of more complex PROMs programmes. PROMs priority areas should act as PROMs implementation "use cases"

2 Focused on discrete episodes of care
PROMs priority areas need to focus on discrete interventions/surgeries to enable clear linkage between intervention and outcomes. More complex PROMs programmes will be considered once PROMs implementation and collection maturity is achieved

3 Guided by the international best practices
PROMs priority areas should have ample evidence of successful large scale implementation across health systems internationally

4 Adapted to the KSA context
PROMs priority areas need to have an an Arabic (culturally-adapted) and validated PROMs survey to ensure its psychometric properties are retained, when possible

Inputs

- International best practices
- Literature review
- Subject matter expert input

Output

4 selection criteria

- High patient/ procedure volume
- Existing clinical and stakeholder engagement
- Demonstrable impact on outcomes (quality of life, symptom burden, physical function, emotional wellbeing)
- Clear ability to measure outcomes and link to impact of care and funding

Finally, to confirm that the proposed priorities aligned with the prevalence of the selected medical interventions among the Saudi Arabian population, we undertook a prioritisation assessment process, validating this with stakeholders from across the KSA healthcare ecosystem.

As noted above, we agreed the following four PROMs priority areas:

- Cataract surgery
- Bariatric surgery
- Pregnancy & childbirth
- Diabetes

Diabetes did not fit the criterion of a clear episode of care but was identified as a good starting point from which learnings can be applied to other chronic diseases in future stages.

Ecosystem stakeholders validated the following PROMs priority areas through Steering Committee meetings and a workshop:
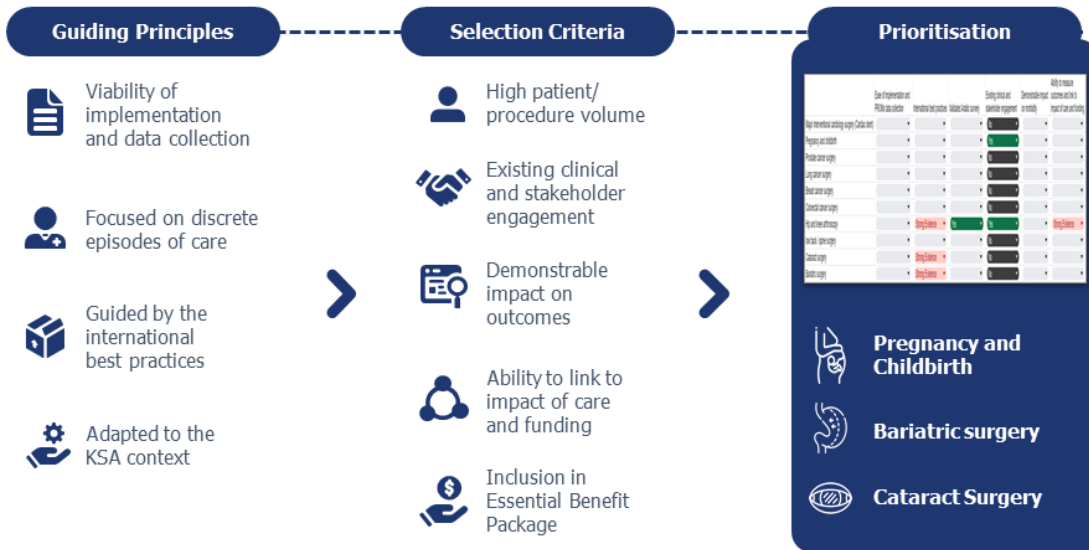
They also highlighted the need to set the stage for the next phase of PROMs adoption for long term conditions:

Following consultation with the ecosystem leaders, we arrived at a single, standardised, generic set of PROMs across all priority areas, supplemented by appropriate, condition-specific instruments to measure outcomes linked to health domains specific to the given clinical area.

This approach would allow us to:

- Assess patients holistically with particular emphasis on their quality of life
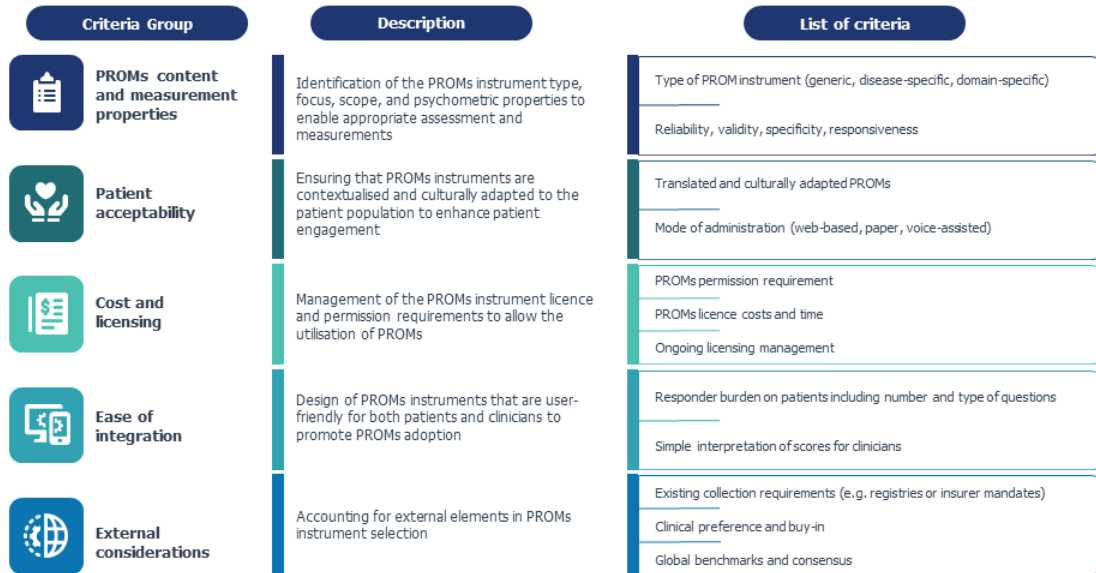
- Build data capabilities at a micro, meso and macro level (in other words for the different user groups)

Ensure focus on the right criteria for selecting the instruments (these were localisation, feasibility, psychometrics, financial and licence)

Selecting PROMs instruments

We followed an evidence-based approach to selecting the PROMs instruments, comprising an extensive literature review (peer-reviewed articles, research articles, policy documents, international organisation frameworks such as ICHOM), in addition to a review of global PROMs combined with subject matter recommendations.

From our longlist, we developed the final shortlist of PROMs instruments for each of the priority areas, using 12 criteria to guide our final selection process. These criteria span five categories:

Criteria Group	Description	List of criteria
PROMs content and measurement properties	Identification of the PROMs instrument type, focus, scope, and psychometric properties to enable appropriate assessment and measurements	Type of PROM instrument (generic, disease-specific, domain-specific) / Reliability, validity, specificity, responsiveness
Patient acceptability	Ensuring that PROMs instruments are contextualised and culturally adapted to the patient population to enhance patient engagement	Translated and culturally adapted PROMs / Mode of administration (web-based, paper, voice-assisted)
Cost and licensing	Management of the PROMs instrument licence and permission requirements to allow the utilisation of PROMs	PROMs permission requirement / PROMs licence costs and time / Ongoing licensing management
Ease of integration	Design of PROMs instruments that are user-friendly for both patients and clinicians to promote PROMs adoption	Responder burden on patients including number and type of questions / Simple interpretation of scores for clinicians
External considerations	Accounting for external elements in PROMs instrument selection	Existing collection requirements (e.g. registries or insurer mandates) / Clinical preference and buy-in / Global benchmarks and consensus

The recommended PROMs instruments, summarised in the table below, will be used for patient-reported outcome measures for the four identified priority conditions/medical interventions during the Stage 1 pilot implementation phase of the National PROMs programme. PROMIS-10 will be the generic PROMs instrument for all priority areas.

Conditions	Cataract Surgery	Bariatric Surgery	Diabetes	Pregnancy and Childbirth
Condition specific PROMs	Catquest-9 / AVFT	BODY-Q	PAID	Wexner / ICIQ-UI SF / EPDS / PBQ
Generic PROMs	PROMIS - 10			