Patient-Reported Outcomes Measures (PROMs)

Implementation Guidebook

Version 1.0

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Introduction

The healthcare sector in Saudi Arabia is currently undergoing one of the most significant reforms in its history, as outlined in Vision 2030. The Healthcare Sector Transformation Program (HSTP), as part of Saudi Vision 2030, aims to restructure the health sector to provide effective, integrated, and person-centered care. Central to this agenda is the transition to Value-Based HealthCare (VBHC).

The Council of Health Insurance (CHI) is advancing this national shift towards value-based and beneficiary-centered care by implementing sector-wide initiatives focused on three main pillars (Figure 1):

- Designing healthcare around the patient
- Improving health outcomes for all
- Developing innovative healthcare payment models

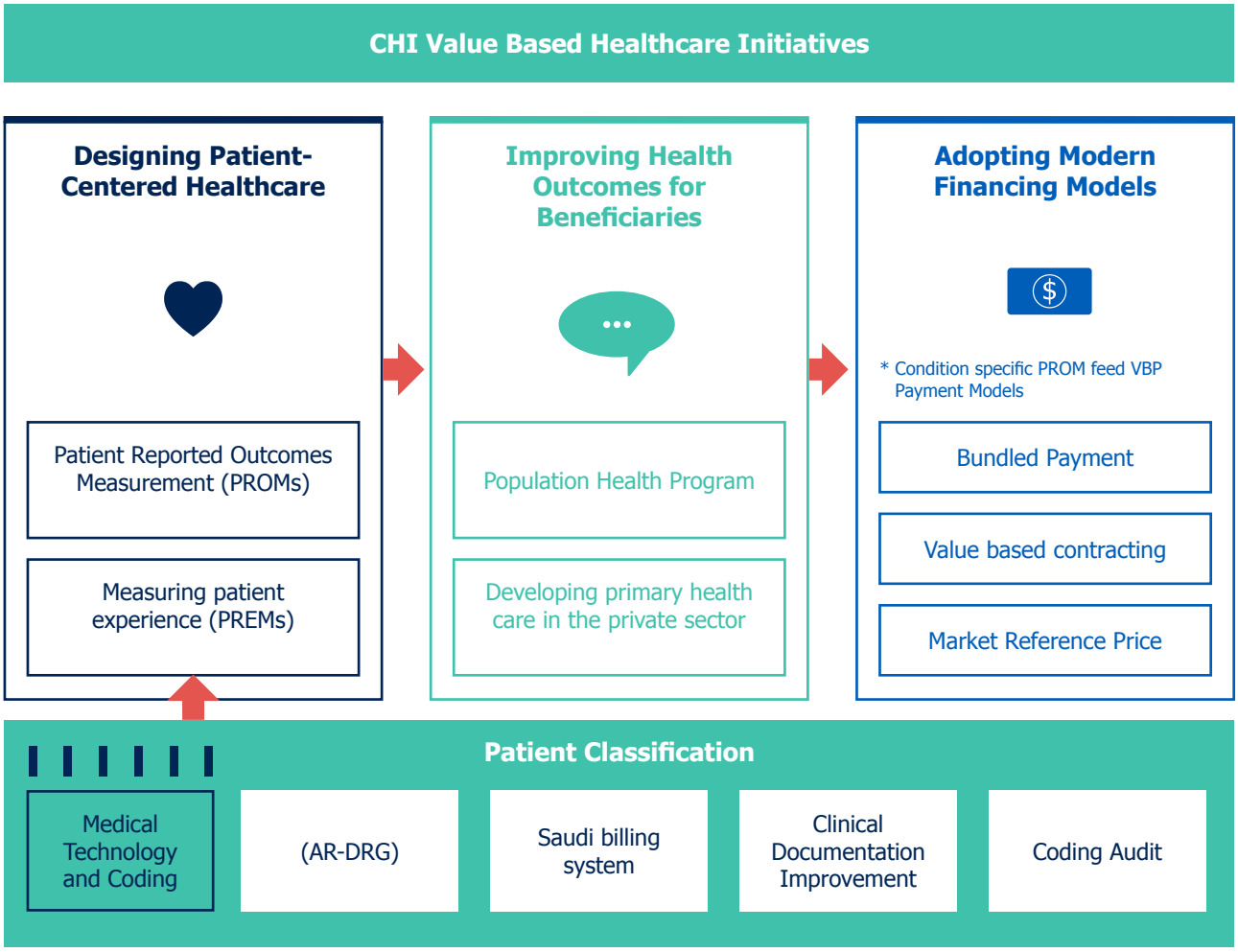

Figure 1: CHI VBHC Initiatives

Value-Based Healthcare (VBHC)

Value-Based Healthcare (VBHC) reframes the concept of performance around value, meaning the health outcomes achieved per unit of cost, as defined by Porter and Teisberg (2006). VBHC aligns providers' incentives with measurable improvements in quality and efficiency, thereby shifting the focus from the quantity of services to quality and value creation. Value in healthcare is achieved by first addressing the patient's particular health needs around the outcomes that matter to them most, across their full cycle of care, from monitoring and prevention to treatment and ongoing disease management.

Since the primary function of healthcare services is improving people's health through compassionate care, it is integral to ensure that the delivered care accomplishes this. Healthcare organizations track the effect of care by measuring outcomes across multiple domains that matter to patients.

One useful framework for measuring quality of care is the Donabedian framework (1988), which covers three components: Structure, Process and Outcomes (Figure 2). Most healthcare organizations primarily focus on structural and process measures. While these are important, measuring outcomes that matter to patients should be the ultimate yardstick in the provision of health and care aiming at 'improving health and making patients better.' Process metrics and actions should be evaluated against those health outcomes.

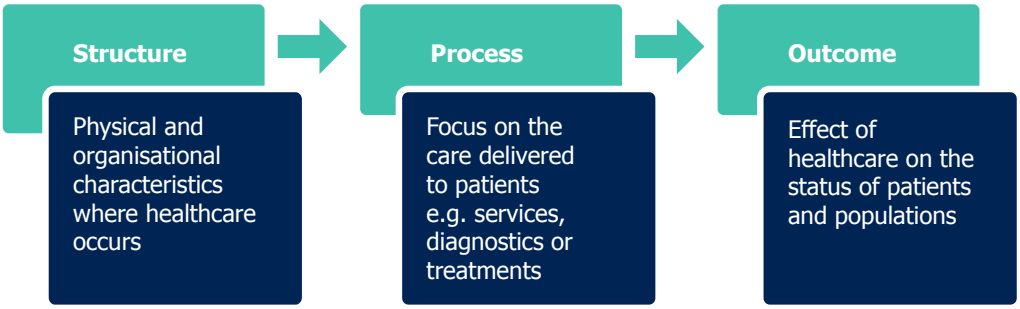

Figure 2: measuring quality of care

Below is an example of diabetes-related measures under the Donabedian framework, with the inclusion of outcome measures that matter to patients.

Structure	Process	Outcomes
1. Certified diabetes educators' diabetes clinics 2. Availability of Point-of-Care Testing (POCT) for HbA1	3. Patients compliant to annual HbA1c testing 4. Patients enrolled in diabetes education programs	1. Improvement in HbA1c 2. Satisfaction with diabetes education 3. Improvement in diabetes distress (e.g. measured via PAID questionnaire) 4. Improvement in quality of life (mobility, discomfort, etc.)

Outcomes that Matter in Healthcare

Measuring outcomes that matter most to patients is the foundation of VBHC and provides the information needed to put VBHC into practice. Within this framework, outcomes refer to measurable healthcare results that help assess the value provided to patients, including:

- Clinical- Reported Outcome Measures (CROMs)
- Patient-Reported Outcome Measures (PROMs)
- Patient-Reported Experience Measures (PREMs)

Patient-Reported Measures capture patients' own assessment of their health and experience. They provide insights that complement clinical outcomes by examining how patients experience their health. PREMs and PROMs are instruments used to capture the holistic patient's perspective.

PROMs are psychometrically validated standardized tools or instruments used to measure patient-reported outcomes (PROs), including but not limited to, functional capabilities (e.g., mobility, pain interference), psychological well-being, ability to perform daily activities, and quality of life. PROs are defined as reports coming directly from patients about their perception of their health condition, symptoms, and treatment. PROMs can be generic, which assess general health across many conditions (for example, EQ-5D) and condition-specific measures such as the Problem Areas in Diabetes (PAID) questionnaire. PROMs also bring value to other stakeholders, which is essential for building a continuous improvement and learning system in healthcare. PROMs provide valuable medical information and insights from a patient standpoint.

PREMs assess patients' experiences with care processes, such as access, communication, and care coordination. Some examples of widely used and standardized PREMs instruments are the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and NHS Family.

The Importance of Patient Reported Outcomes

There is a growing recognition of the value proposition PROs can bring into clinical practice. PROs enhance patient care by helping providers capture health outcomes from the patient perspective and health-related quality of life (HRQOL), symptoms burden and functional status. This can complement clinical outcomes by assessing how medical interventions impact the overall patient's life and to identify improvement or deterioration in the patient's health status. When PROs are systematically collected, analyzed and embedded in care pathways they will help clinicians track patient progress, improve shared-decision making SDM, and personalization of care.

There are also reported advantages for quality improvement, informing value-based payment, research, and health technology assessment HTA. However, it is essential for organizations initiating PROMs to identify the goals and intended uses of collecting PROs in the planning phases. (see Section 6: PROMs Reporting).

Creating Value in Healthcare

The starting point for healthcare providers to create effective strategies and improve their performance is by defining the right goal, which must be excellence in patient value. For patients, value is created if outcomes are improved. This value can only be measured at the level of medical conditions, which requires well-coordinated and integrated care. Aligning healthcare professionals and systems to deliver medically integrated care is challenging. However, to be strategic, organizations need to ensure that all relevant clinical and non-clinical stakeholders involved in care delivery have a common goal centered on the patient, and a shared commitment to the overall results.

To start this care delivery model, organizations need to systematically analyze the process of care at the medical condition level, which will help them develop their value chain. Within VBHC frameworks, one widely used tool is the Care Delivery Value Chain (CDVC), which is used to map, delineate, and analyze all activities and services, clinical and non-clinical, during the full care cycle. It is important to note that this mapping does not only focus on systems or processes, but on all the activities included in the care pathway for the selected condition. Each medical condition has its own CDVD and can vary somewhat in the same condition for different patient groups due to their individual circumstances. Conducting CDVD for the selected conditions establishes the foundation for embedding PROMs in routine clinical practice. It can demonstrate how achieving outcomes depends on effective team coordination across all phases/milestones: prevention, diagnosis, treatment, recovery, and ongoing management / follow-up.

CHI PROMs Strategy

The PROMs Strategy, launched in 2023, identified four priority conditions for measuring PROMs: diabetes, obesity management, maternity health, and cataract surgery. This strategy provided understanding and direction regarding PROMs and their link to VBHC. Subsequently, CHI continued this movement in 2024 by building sector capabilities through two initiatives:

- Feasibility study, Assessing Market Readiness: Implementing Patient Reported Measures in the Healthcare Private Sector
- Value-Based Payment VBP pilot project focused on measuring PROMs for cataract surgery at five private providers.

Findings from the feasibility study and ongoing engagement with the sector revealed the growing adoption of VBHC initiatives, including measuring PROMs. However, several challenges, if not addressed, will impede the success and scalability of PROMs across the sector, including:

- Limited standardization of measurements
- Variation in practices
- Lack of proper leadership and physician level engagement
- Limited analysis and usage of outcome data
- Unavailability of standardized data at a national level for benchmarking and comparison

To address these issues and to support leading transformation towards VBHC, CHI developed this guide to unify practices and enable providers across the Kingdom to measure and improve what matters most to beneficiaries. The guide provides healthcare professionals and leaders with actionable steps to initiate the implementation of PROMs for any selected condition.

Guidebook Development Methodology

This guidebook was developed in a collaborative way using the EPIS (Exploration, Preparation, Implementation, Sustainment) Framework; (see Glossary and Appendix). Developing the guidebook included a team of primary authors, contributors and reviewers. The primary authors developed a 'PROMs Implementation Pathway' which consists of sequenced set of steps demonstrating a full cycle of implementation, which healthcare providers can follow to initiate and operationalize their PROMs implementation program. The steps outlined were developed after reviewing local and international case studies, literature, and conducting interviews with leaders from different hospitals that implemented PROMs, which resulted in an initial set of ten phases (steps) representing the 'PROMs Implementation Pathway'.

Thirteen healthcare providers, both private and public, one third-party partner, and a consulting firm participated in the co-design of the guide. Participating entities were selected based on their maturity in implementing PROMs through CHI data, alignment with in CHI projects, or previous CHI PROMs maturity reports. In the co-design workshop, the participants provided input on the phases using an evaluation tool (Appendix). All feedback was carefully reviewed and combined, resulting in an updated pathway consisting of eight phases.

The same group participated in a follow-up webinar to review the updated pathway and reach consensus. This resulted in a modification and merging of some phases which resulted in eight phases pathway which are presented as 'sections' in this guide.

The final sections are:
Section 1 – Governance and Leadership
Section 2 – Condition and Patient Population Selection
Section 3 – Care Pathway Design (Defining and Developing CDVC)
Section 4 – Outcome Measures Selection
Section 5 – PROMs Collection and Analysis
Section 6 – PROMs Reporting
Section 7 – Stakeholders' Engagement
Section 8 – Scaling and Sustainability

Five contributing authors conducted the write up for the sections. Then the primary authors continued the write up that included full review, expanding sections, alignment, consistency, editing, examples additions and multiple iterations. A first completed draft underwent external review by four experts.

A final virtual review session conducted including a quality 'non editorial review' included three participants from the co-design group: government and private hospitals who implemented PROMs. And an additional participant from a hospital that did not implement PROMs (full guidebook write up team in Appendix). The full duration of the guide development took 6 months.

Using the Guidebook

The implementation of PROMs using this guidebook is not strictly a linear process. Although the guidebook breaks down key phases and suggests actions, activities such as stakeholder engagement, communication, training, and monitoring data quality typically occur continuously during the entire implementation process. However, condition selection, patient segmentation, care pathway design, selection of outcome measures must be in this sequence before PROMs collection and analysis. Additionally, when more conditions are introduced or the process is scaled up, certain steps may need to be repeated or adjusted accordingly.

Using a recognized implementation framework, such as the Plan–Do–Check–Act (PDCA) cycle (see Appendix) or the EPIS framework (see Appendix), is recommended to help ensure successful implementation. These structured approaches can support the implementation of the guidebook, iterative testing of changes, and sustaining the meaningful use of PROMs over time.

Section 1: Governance and Leadership

Successful PROMs implementation requires the adoption of a VBHC strategy, strong leadership sponsorship, clear governance, clinical ownership, and a phased, tailored change plan aligned with international best practices to ensure accountability, compliance, and sustainability of the program. This section covers executive sponsorship, the establishment of governance structures, the embedment of PROMs in strategy, planning, and change management.

Action 1: Executive Sponsorship and Strategic Alignment

One of the essential enablers of PROMs implementation is executive sponsorship and leadership commitment. Establishing strong leadership sponsorship and commitment to drive the implementation of PROMs is achieved through:

- Identifying senior leaders (e.g., CEO, CMO, Director of Quality) who serve as executive sponsors
- Recognizing PROMs implementation barriers and facilitators and provision of necessary support
- Leading by example through implementation (if the leader is a clinician) and active participation in engagement activities
- Securing resources including human, financial, and technology
- Aligning PROMs objectives with the overall organizational strategy and performance
- Ensuring continuous engagement with clinical teams and VBHC champions, on the VBHC process, PROMs collection, and use in patient care pathways
- Ensuring PROMs scoring, interpretation, and, where possible, benchmarking is made available to crucially guide clinician engagement and utility

Action 2: Governance Framework

A well-defined governance framework is essential to ensure defined accountability, effective oversight, and sustained delivery of the PROMs program. A key step is to define the governance structure of PROMs in an official document (committee, charter, program, etc.) in accordance with the organization's regulations.

The governance framework should include, at a minimum:

- Scope and objectives
- VBHC/PROMs multidisciplinary teams
- Governing committees
- Accountability, roles, and responsibilities (i.e., RACI Matrix)
- Required policies, procedures and guidelines
- Integration and cross functions
- Monitoring, compliance standards, and audit procedures
- Reporting lines and escalation mechanisms

The organization should have a governing structure or steering committee to provide oversight, guidance, and decision-making for PROMs implementation. The choice of creating a separate committee or integrating it into an existing value-based or related committee depends on the organization. This governing committee will provide oversight for the 'condition-specific' multidisciplinary VBHC/PROMs teams and subcommittees. The VBHC/PROMs governance committee should follow the organizations' regulations for committee establishment, reporting, etc. For alignment and integration, the committee includes the following members:

- Executive sponsor or senior leader (to serve as chair)
- Clinical leads from prioritized pathways
- IT/Data management lead

- Patient representative or advocate
- Quality improvement lead
- Case management lead
- Patient experience lead

The terms of reference of the VBHC/PROMs Committee or structure should include the following:

- Mission and objectives
- Scope, roles, and responsibilities of the committee
- Decision-making authority including escalation processes
- Performance KPIs and targets
- Meeting frequency (recommended monthly)

Action 3: Strategy Alignment and Planning

A successful PROMs program requires a strategy and careful planning. Depending on the situation, it may serve as an independent strategy or be integrated into a broader organizational strategy. In both cases, it is essential to have an approved document that highlights the plan to implement PROMs programs in accordance with the organization's regulations. Key stakeholders should work together to develop the plan, which will then be distributed to ensure that everyone is aware of and understands what is expected. The plan shall include, but not be limited to, the following:

- Clear VBHC and PROMs goals and objectives – these goals are typically unmet needs that PROMs will help address
- Implementation roadmap with clear timelines, phases, and success metrics
- Pilot planning and scalability
- Communication plan
- Resources, including budgets, staffing, and technology needs

Embedding VBHC and PROMs into the overall organizational strategy and performance is necessary for collective action and the successful implementation of the strategy. It is also essential to ensure that the VBHC and PROMs program has a clear and explicit alignment with national priorities, the organization's strategy, its objectives, and its key performance metrics. Mapping and alignment are an important initial step.

See the following example for Diabetes PROMs alignment:

PROMs Goal	Organizational/ Clinical Objective	National Objectives
• Achieve ≥ 10-point reduction in PAID score within 6 months of personalized care plan	• Improve glycemic control and reduce diabetes-related complications	• Improve quality and efficiency of healthcare services • Promote prevention of health risks

A clear and well-planned implementation roadmap is essential for successful project implementation. The assigned team must establish a phased, realistic rollout plan with clear responsibilities, milestones, timelines, metrics, and risk mitigation. The program can be organized into different phases, for instance:

A suggested 6-month pilot phase could be:

- Month 1: governance setup, champion selection, and IT readiness assessment.
- Month 2: care pathway (CDVC) mapping and staff training.
- Month 3: "Go-Live" (start of data collection).
- Month 4 & 5: active collection and bi-weekly meetings.
- Month 6: pilot evaluation, final data analysis, and decision scale.

The plan should include all the required resources and how to secure them, including the following:

- PROMs licensing and localization, if needed
- Budget for PROMs platform/licensing, EHR integration
- Patient engagement and awareness activities
- Staff time (project manager, clinical champions, IT, trainers)
- Training costs and materials

The plan should also include a risk mitigation plan that addresses issues such as the following:

- Delays in IT integration
- Low patient engagement and response rates
- Clinician resistance

Some suggestions to reduce barriers and resistance to the implementation of PROMs include:

- Assignment of a "PROMs Champion" or "PROMs Lead." Who is responsible for the day-to-day coordination, act as an Inter-departmental Liaison to resolve "roadblocks" immediately, monitor daily completion rates and outcome flags and take the appropriate actions needed
- Outsourcing some of the PROMs collection operations to reduce staff burden to a third-party vendor
- Integration of PROMs data into technology infrastructures (electronic medical records, performance dashboards from third party platform vendors)
- Providing training on data collection, analysis, and interpretation while setting protected time slots to help staff perform these tasks
- Training of clinicians to introduce PROMs to patients, properly educate them using relevant material (tailored pathway specific brochures, educational videos, etc.) and include PROMs results during consultations to prove their value to patients

Action 4: Change Management: Embracing a Patient-Centered Culture:

Effective implementation of PROMs requires a structured change-management approach, including leadership commitment, clinician engagement, workflow integration, continuous feedback loops, and iterative refinement of systems and processes. It is recommended to incorporate a change management model as early as Phase 1, which focuses on preparation.

One of the models to be used (as a suggestion) is Kotter's 8-Step Change Model:

- Create urgency (pinpoint pressing unmet needs, and highlight VBHC and PROMs ability to address them)
- Bring together a guiding coalition by involving leaders, clinicians, and key supporters to support the change
- Develop a vision & strategy (align VBHC and PROMs with the organization's overall strategy)
- Communicate the vision (multi-channel, clear messaging)
- Empower broad-based action (reduce barriers, provide training)
- Generate short-term wins (pilot successes)
- Consolidate gains and produce more change (scale-up)
- Anchor innovative approaches in the culture (ongoing monitoring, celebrating success)

It is important to have a communication plan, especially in the early phases, to help structure communication and clarify intent (see Section 7: Stakeholders' Engagement).

Governance and Leadership Minimum Requirements to Initiate PROMs
1. Approval from executive sponsors or senior leaders to initiate PROMs
2. Workshop/meeting to engage and inform relevant leaders about PROMs
3. Establishment of PROMs Multidisciplinary Team reporting to or linked to VBHC/PROMs/Quality steering committee (existing or newly established) with clear roles and responsibilities
4. A phased implementation roadmap with realistic timelines

Section 2: Condition and Patient Population Selection

A successful VBHC implementation begins with clearly defining the patient population, which includes the patient segments whose health conditions and life circumstances create a relatively consistent set of needs. Organizing care around patient segments with shared needs, such as diabetes, enables clinical teams to anticipate and focus on solving patients' needs, standardize care pathways, deliver frequently required services more efficiently, and achieve better outcomes.

A clear definition of the target patient population includes the condition of interest and expected case-mix profile. The careful selection and segmentation of patient groups support valid comparisons across providers, improves the interpretation of results, and promotes the efficient use of resources by ensuring that outcome comparisons are fair and meaningful. This section provides a detailed methodology for defining eligible populations, prioritizing conditions, establishing inclusion and exclusion criteria, and identifying case-mix variables.

Step 1: Select Priority Conditions and Patient Population

Organizations can start selecting the conditions to start measuring PROMs based on multiple factors such as burden, high volume, excessive cost, and a clearly defined pathway. It is also essential to have a clear articulation of what constitutes a "clinical condition or pathway" within the VBHC and PROMs framework. This definition varies significantly depending on whether the condition follows an episodic care pathway (with defined start and endpoints) or a chronic disease trajectory (requiring longitudinal management). Defining the scope of a clinical condition involves precise specification of the target population. This includes:

- Diagnostic Criteria: Using standardized classification systems (ICD-10 codes) to define inclusion criteria.
- Age and Demographic Boundaries: Many PROMs are validated only for specific age groups. Pediatric populations require distinct instruments.
- Disease Stage and Severity: Some conditions require separate outcomes for different stages. For instance, ICHOM has developed separate standard sets for localized prostate cancer versus metastatic prostate cancer, acknowledging that treatment goals and relevant outcomes differ fundamentally.
- Care Setting Specification: Conditions should be scoped to specific care environments (e.g., outpatient specialty clinics, inpatient surgical wards, primary care) to ensure feasibility of workflow integration.

Step 2: Identify the case-mix variables

Case-mix adjustment is essential to account for patient characteristics that influence outcomes independent of care quality. In her seminal work on risk adjustment for health outcomes, Iezzoni (1994) outlines a broad set of risk factors grouped into six overarching categories: demographic and other patient characteristics; prior health-related factors; clinical factors; patients' attitudes and perceptions; socio-economic factors; and variation attributable to differences in the quality of care delivered by the provider unit. This framework for case-mix adjustment poses four critical questions:

- Risk of what outcome? (e.g., HbA1c control in diabetes)
- Over what time frame? (e.g., 6-month chronic disease outcomes)
- For what population? (e.g., all Type 2 diabetes patients)
- For what purpose? (e.g., public reporting, value-based payment, internal quality improvement)

A minimum set of risk factors, used as variables for case-mix adjustment of clinical and PROs, helps evaluate illness severity and prognosis, determines the effect of specific risk factors on outcomes, and allows for adjusted comparisons. For example, in episodic surgical care, key adjusters include age, body mass index (BMI), comorbidity burden (Charlson Comorbidity Index), ASA (American Society of Anesthesiologists) physical status score, and baseline functional status. For chronic diseases, the adjusters included disease duration, baseline severity (e.g., baseline HbA1c levels in diabetes), socioeconomic status (which affects access to healthy food and medications), and multimorbidity. Hospitals can use case mix variables as stated in ICHOM Diabetes set as reference in pilot phase, considering hospital context as well.

Step 3: Define Patient Inclusion and Exclusion Criteria

Defining appropriate patient groups ensures comparability across providers, the validity of results, and the efficient use of resources. Patient segmentation means identifying "who is in" the PROMs program and ensuring that these patients are similar enough to make outcome comparisons fair and meaningful. Applying the inclusion and exclusion criteria involves considering a range of factors beyond clinical issues.

Inclusions: e.g.

- Adults or adolescents are capable of self-reporting or with suitable proxy arrangements
- Patients with access to at least one feasible reporting mode (EHR portal, kiosk, paper, or assisted entry)
- Functional abilities (both cognitive and physical)

Exclusions: e.g.

- Vulnerable populations (young, old, fragile)
- Severe cognitive impairment without a proxy
- Language barriers
- Inability to engage with any reporting mode (paper, digital, or assistance)
- Low literacy

Examples of inclusion and exclusion criteria for diabetes are as follows:

Inclusion	Exclusion
- Type 2 diabetes - Age ≥ 18 years - At least one visit in the previous six months - Ability to self-report in Arabic or English - Access to any reporting mode	- Type 1 diabetes or gestational diabetes - Severe cognitive impairment without proxy support - Presence of multiple comorbidities - Only English and Arabic speaking patients

Mapping the patient groups (all patients, clinical setting, specific conditions, treatment-specific) to determine which patient segmentation is most appropriate for PROMs implementation can include:

- Patients in a defined clinical setting will be included through the deployment of generic PROMs within that setting. For example, all patients attending primary healthcare will complete the WHO-5 Well-Being Index or PHQ-9 during follow-up visits.
- The defined patient population, segmented by specific conditions, will include the deployment of disease-specific PROMs. For example, patients with type 2 diabetes will complete the PAID-5 questionnaire at baseline, after six months, and annually.
- Patients that receive a specific treatment or under a procedure with a clear episode of care, will include collecting PROMs before and after the procedure. For example, Catquest-9 can be deployed for cataract surgery patients at baseline and after three months to assess perceived improvement.

Condition and Patient Population Selection Minimum Requirements to Initiate PROMs
1. Selection of one or two priority conditions for initial pilot
2. Clear case-mix variables
3. Clear patient segment characteristics
4. Clear inclusion and exclusion criteria

Section 3: Care Pathway Design (Defining and Developing CDVC)

This section guides hospitals through the practical steps of defining, mapping, and implementing a care pathway for any prioritized condition (e.g., diabetes or acute coronary disease). Hospitals planing to implement PROMs should at least start with a basic pathway that aligns with PROMs collection touchpoints (explained in Section 5). It is essential to note that having a basic care pathway with clear PROMs collection points is considered a minimum requirement to launch PROMs, and CDVC shall be considered as hospitals when progressing into mature implementation.

CDVC is a structured, patient-centered model that maps the full cycle of care, from prevention and early diagnosis to treatment, recovery, and follow-up, while embedding PROMs at points where they can most effectively inform decisions.

Clinical departments should develop an evidence-based care pathway for the particular condition, specifying how PROMs data will be collected, evaluated, and combined with the CDVC to enhance patient care. CDVC aligns data collection with the actual workflow, makes measurement focused on decision points that matter, and supports stakeholders' understanding of why PROMs exist and how they inform care.

Developing a CDVC involves mapping activities, decisions, and responsibilities across the full cycle of care. This process shows how value is generated for patients and identifies areas where patient outcomes can be assessed and improved. The following steps present a structured outline for designing a CDVC that aligns clinical practice, measurement, and patient engagement, using type 2 diabetes as an example:

Step 1: Define the scope and objectives

Specify where the care cycle starts, such as the first referral, initial screening, or diagnosis, and where it ends, whether at discharge, long-term follow-up, or transition to primary care. This step requires the development of a concise scope statement that outlines the inclusion and exclusion criteria for the selected condition and the desired clinical and PROs.

For the type 2 diabetes care pathway, the cycle of care may begin with the identification of patients through a primary care screening or an endocrinology referral and continue through assessment, treatment initiation, lifestyle modification, and ongoing monitoring. The pathway will first include adults aged 18 years and older with type 2 diabetes, while excluding those with type 1 diabetes, gestational diabetes, or severe uncontrolled comorbidities. Expected outcomes include achieving glycemic control (HbA1c within the target range), improving the quality of life as reflected in PROMs such as the PAID-5 and EQ-5D (3L or 5L) questionnaires, and reducing the acute complication rate.

Step 2: Form an interdisciplinary team

Establishing an interdisciplinary team is a critical step in developing an effective CDVC. The goal is to bring together all stakeholders who contribute to the patient's care and outcomes, ensuring that the pathway reflects both clinical expertise and the patient's perspective. The team may include physicians, nurses, dietitians, pharmacists, data analysts, IT personnel, quality officers, and patient representatives, as relevant. This approach promotes accountability, shared ownership, and appropriate integration. The team shall meet regularly (at least weekly) with open communication to sustain engagement and decision-making throughout the process.

In the type 2 diabetes care pathway example, a sample interdisciplinary team may include an endocrinologist, primary care physician, nurse, diabetes educator, dietitian, pharmacist, psychologist, and data analyst. To ensure that patient needs influence the design, a representative, typically someone from a diabetes support group, should also be involved. Together, the team defines the clinical workflows, determines the key measurements, and coordinates the care.

Step 3: Identify the major phases of care

Clearly defining the major phases of care is a critical step in developing a CDVC. Each phase represents a core segment (i.e., milestone) of the patient care pathway, where distinct clinical activities, decisions and outcome measurements occur. By dividing care into separate phases, healthcare teams can better identify where they add value, ensure smooth transitions between services, and choose the most effective times to use PROMs for precise measurement of patient outcomes. Typically, the major phases of care include:

- Prevention: reduce risk factors through education, screening, and lifestyle changes
- Diagnostics: confirm the condition using clinical assessments, history, and tests
- Preparation: develop individualized care plans, engage patients, and set treatment goals
- Intervention: deliver medical, pharmacological, surgical, or behavioral treatments based on best evidence
- Recovery: support recovery, self-management and sustained improvement
- Monitoring: assess disease control, complications, and outcomes through follow-up

There are also four elements that cut across the six steps: knowledge development, information, measurement, and access. Together, they can all support a feedback loop to create a learning system that supports improving value for patients, as illustrated by Porter and Teisberg (2006) in Redefining Health Care.

Step 4: Select outcomes

Selecting outcomes is vital for translating the CDVC from a conceptual framework into a practical performance tool. Although not strictly required, it is recommended that every stage of the CDVC includes clear outcomes that demonstrate the effectiveness of care for both clinicians and patients. The selection of outcomes should be evidence-based and balance clinician-reported outcomes with patient-reported experiences, and outcomes to capture the full spectrum of value. Careful attention should be given to determining the type of the patient-reported measures to be collected, such as symptoms (e.g., pain, fatigue, nausea, and depressive mood), functioning (e.g., activities of daily living and cognitive functioning), or quality of life (e.g., mental, physical, and social well-being).

In the type 2 diabetes care pathway, outcomes are specified throughout the CDVC phases. In the prevention phase, improved screening rates support early detection, while the preparation phase emphasizes setting individualized treatment goals and capturing baseline PROs, such as quality of life. During the Intervention phase, outcomes include improved glycemic control and patient satisfaction, whereas the monitoring phase focuses on tracking the rate of acute and chronic complications.

Step 5: Visualize and Validate the CDVC

After the CDVC phases are established, the corresponding steps are converted into a concise, single-page visual diagram. The interdisciplinary team should review the diagram and evaluate it in real clinical settings to ensure its feasibility. Such piloting allows teams to verify whether workflows, data collection, and PROMs integration operate as intended. This also identifies barriers, such as low PROMs completion, inefficient clinical engagement, time constraints, or unclear responsibilities, enabling adjustments before full implementation. Subsequently, ongoing improvement activities help refine the CDVC and sustain its value over time.

In a type 2 diabetes care pathway, the designed CDVC can be piloted in one outpatient clinic with a small group of patients to verify the workflow and test the collection of baseline PROMs (such as PAID-5 or EQ-5D-5L) and clinical measures (such as HbA1c, BMI, lipid profile). During implementation, clinicians would use the PROMs results for lifestyle counseling or medication adjustments. Over time, this cycle strengthens coordination between primary and specialty care and ensures that the CDVC consistently delivers measurable value.

Defining the care pathway through the CDVC (figure 3) represents a fundamental shift from fragmented, process-driven care towards an integrated condition- and outcome-driven model. By systematically mapping the value creation process for patients throughout prevention, diagnosis, treatment, and long-term management, hospitals can integrate clinical practice, data collection, and patient engagement into a unified, coherent

framework. The CDVC not only clarifies roles, decision points, and outcomes but also ensures that PROMs become an inherent part of everyday clinical practice rather than an isolated measurement exercise.

Through the structured steps outlined in this section including, defining the scope, forming interdisciplinary teams, identifying care phases, selecting outcomes, visualizing pathways, and piloting implementation, hospitals can create an evidence-based and patient-centered care model. After the activities are explicitly described in the CVDC, teams can discuss ways to increase the value of services for patients. The configuration of these activities should determine how integrated practice units (IPUs) are best structured organizationally. When fully integrated, the CDVC transforms care delivery into a continuous learning system in which patient feedback drives quality improvement, resource optimization, and enhanced health outcomes.

Finally, hospitals are expected to redesign their care pathways around patient needs and outcomes, embedding PROMs across the full cycle of care to make care patient centered. Activities such as CDVC mapping will enable hospitals to identify high value steps, reduce waste, and systematically progress towards more effective Integrated Practice Units (IPUs).

The Care Delivery Value Chain for an Integrated Practice Unit

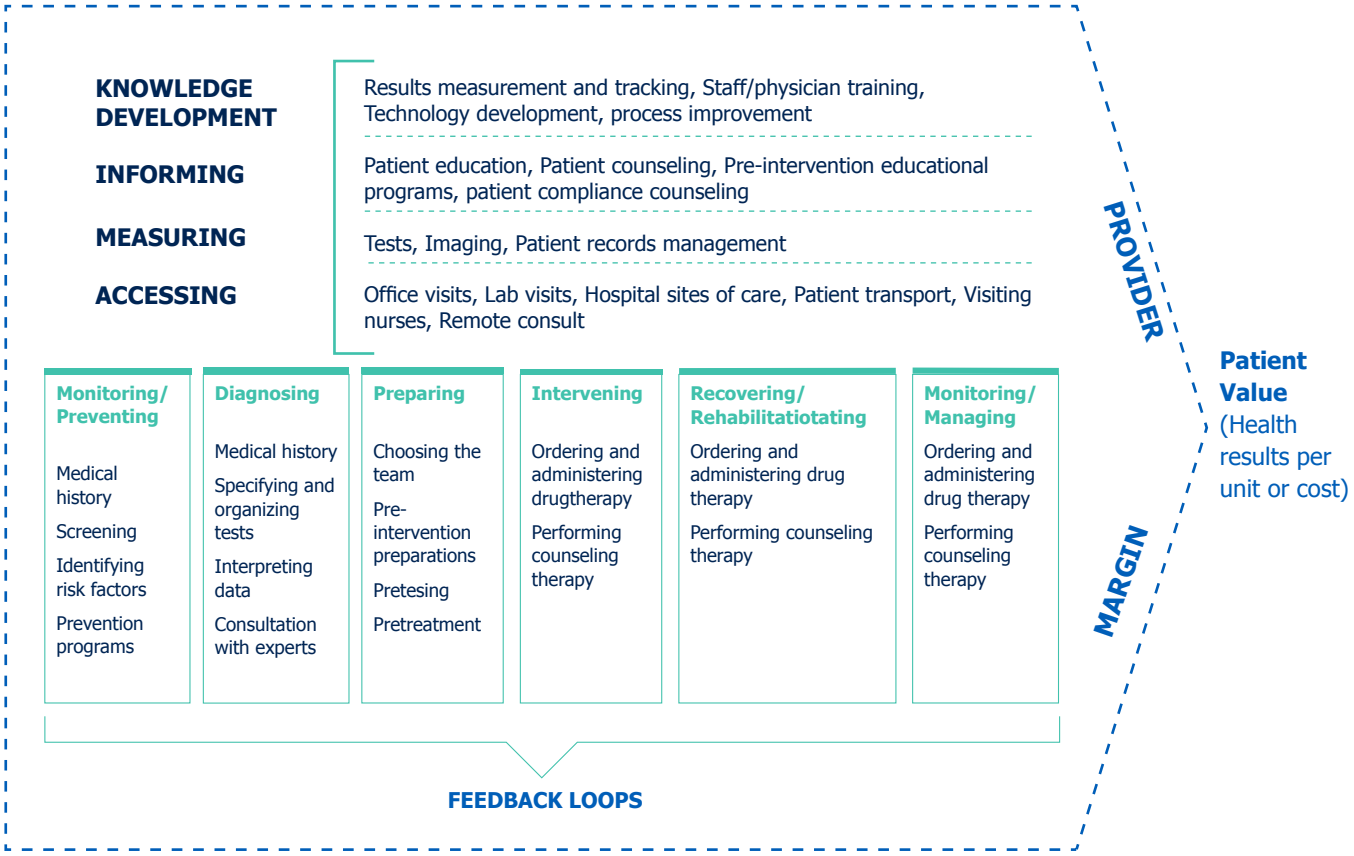

Figure 3: CVDC framework. Adapted from Porter and Teisberg (2006). Redefining Health Care: Creating Value-Based Competition on Results. Harvard Business School Publishing.

Care Pathway Design Minimum Requirements to Initiate PROMs
1. Basic care pathway with clear PROMs collection points.
2. Clear data collection points of PROMs in one cycle (baseline, post-intervention etc.)

Section 4: Outcome Measures Selection

Once the patient population, inclusion criteria, and segments are clearly defined, the next step is to identify the most appropriate types of measures for the selected condition. First, these measures should be tracked by medical condition (such as diabetes), not by specialty (endocrinology) or intervention (eye examination). For the selected condition and patient population, this collection of measures presents a 'set' which will include at least the PROMs, CROMs, and PREMs.

The measures represent a fundamental and thoroughly comprehensive minimal set of metrics that encompass the entire care cycle for the selected condition while monitoring the patient's health status throughout the care delivery process. These sets are comprehensive as they track not only traditional clinical outcomes but also outcomes that are important for improving well-being, physical and psychological functioning, and recovery, ensuring that interventions do not create an added burden on patients and their families. The measures set will enable providers to begin monitoring what matters to patients at the most essential level, with the goal of scaling up to a more comprehensive set implementation.

This section describes how to choose the right PROMs for the right patients, including a review of tool validation and aligning the tools with the intended use. Additionally, it offers guidance on planning and piloting the feasibility of the chosen tool with clear and measurable success metrics.

Action 1: Select measures

For each measure set, identify the included data/metrics to be collected for the selected condition by reviewing:

- Literature and best international practices such as those detailed by ICHOM, WHO etc.
- Internal organizational priorities and consensus
- Availability and quality of data
- Cost

In addition to PROMs, PREMs, and CROMs, the set should include metrics that examine the services or processes related to the selected condition and can impact the patient's health status. This will help providers adopt a holistic and integrative approach for care improvement. For example, a service-related metric for diabetes can be "eye examination compliance." Including this measure will provide insights into the correlation with other outcomes and identify patients at risk. Table 1 provides the recommended ICHOM set for diabetes that can be used as a guide to select measures.

Outcome Category	Measure	Baseline	6 Months	Annual
Glycemic Control	HbA1c	✓	✓	✓
Glycemic Control	Intermediate (glucose, hypoglycemia)	✓	✓	
Acute Events	DKA/HHS	✓	✓	
Acute Events	Severe hypoglycemia	✓	✓	
Acute Events	Acute CV events	✓	✓	
Acute Events	Amputation	✓	✓	
Chronic Complications	Vision (retinopathy)	✓	✓	
Chronic Complications	Neuropathy (peripheral & autonomic)	✓	✓	
Chronic Complications	Foot ulcers	✓	✓	✓
Chronic Complications	CKD (eGFR, albuminuria)	✓	✓	✓
Chronic Complications	CVD (IHD, cerebrovascular, PAD)	✓	✓	
Chronic Complications	Heart failure	✓	✓	
Chronic Complications	Periodontal health	✓	✓	
Chronic Complications	Sexual dysfunction	✓	✓	
Health Services	Hospitalizations	Continuous or annual	Continuous or annual	✓
Health Services	ED utilization	Continuous or annual	Continuous or annual	✓
Health Services	Financial barriers	✓	✓	
Mortality	Vital status	✓	✓	
PROMs	HRQoL (PROMIS Global, EQ-5D-3L)	✓	✓	✓
PROMs	Psychological wellbeing (PHQ-2, PHQ-9, GAD-7)	✓	✓	✓
PROMs	Diabetes distress (PAID-5)	✓	✓	✓
PROMs	Obstructive Sleep Apnea screening (STOP-BANG)	✓	✓	✓

Action 2: Identify sources of data collection

Once the measures are selected and the set is finalized by the multidisciplinary team assigned to develop it, a score card should be developed for all the measures per the selected condition. These score cards should contain each measure type, its definition, formula, and included data. After the measures are identified, the sources of data and their availability in the organization must be assessed. PREMs and PROMs will be collected from validated and localized patient-reported surveys and tools.

- CROMs measures are available in the patient medical records: HIS/EMR such as Glycemic Control.
- PREMs in Saudi Arabia are available from the Ministry of Health reports or if the organization conducts its own patient experience surveys. In both cases, ensuring access to the recommended measures is necessary. For example, for the diabetes ICHOM Data Dictionary, the suggestion is to include (access to care and access to medications).
- PROMs should be collected from instruments that are standardized, validated, translated, and localized.

As defined in the introduction, condition-specific PROMs evaluate aspects of health status for a specific condition and help assess changes in specific aspects of health. Generic PROMs, on the other hand, assess quality of life and emotional well-being. Since both instruments have their respective value, it is often recommended to combine generic and condition-specific PROMs with one instrument. If the decision is to use a combined instrument, it is important to check and map the domains or questions between the items to reduce burden, avoid redundancy and ensure compliance with repeated assessments over time. It is essential that the decision on instruments' selection is guided by the literature and recommended best practices. In addition, copyright instructions and licensing must be followed and considered. Localization should also be ensured for proper data collection.

Other aspects that need to be included during the selection of PROMs instruments include patient-related factors, cost, and internal priorities. The table below from (Framework to Guide the Collection and Use of Patient-Reported Outcome Measures in The Learning Healthcare System) gives an example of some principles to guide instrument selection and decisions.

Domain	Description
PROM content	Items specific to single condition and/or treatment; or assess global health status
Patient acceptance	Language and cultural appropriateness for users; literacy level appropriate for users
Costs, licensing	Proprietary with use fees or publicly available
Ease of completion	Number of items, administration time, and patient burden; valid across (multiple modes of administration (electronic, paper, oral
External considerations	Legacy or concurrent benchmarks available to guide interpretation; mandates for specific measures; legacy inclusion in disease-specific registries

Organizations that choose an instrument not translated into the intended language may undertake a translation. However, caution is required, as poorly translated instruments can threaten the validity of research data and compromise the reliable aggregation of global datasets. The Translation and Cultural Adaptation—Principles of Good Practice should be followed to ensure validity before the instrument is used. (Appendix)

Action 3: Plan measures' intended use

The aim is to select measures that support intended uses at the micro (patient–clinician), meso (organizational), and macro (system/regulatory) levels, ensuring the continuity and standardization of outcome measurements over time. Because needs, contexts, and resources differ across settings, PROMs selection should be treated as an iterative process that weighs evidence from all steps and adapts to the clinical context, patient population, and implementation capacity. It is essential for the multidisciplinary teams to clarify and define how each measure will be used before initiating the pilot.

- Individual clinical care: to guide shared decision-making with patients
- Quality improvement: to benchmark and track progress across facilities
- Policy and contracting: to inform value-based purchasing or accreditation decisions
- Population health: to understand disease burden, overall well-being and to identify risk

Action 4: Plan and prepare the pilot

Before implementation, conduct a limited pilot within a selected clinic/unit to test the workflow and tool performance (ensure you follow the guidance from previous phases).

Key steps include:

- Developing a pilot plan outlining patient segments, site or clinic selection, duration, and sample size
- Defining success metrics for quality assurance, such as response rate, missing responses, and physician acceptance
- Training of clinicians and staff on data collection (using native EMR or third-party platform) and communication of results (use of dashboards)
- Engaging patients through consent, information, and education (brochures, videos, etc)
- Integrating PROMs into the existing clinical workflow or digital platform (e.g., Microsoft Forms, app, or hospital EMR)
- Planning for feasibility indicators (success metrics)

The pilot will help evaluate the performance against predefined success metrics, document lessons learned, and refine the workflow or tool selection accordingly before full rollout.

Outcome Measures Selection Minimum Requirements to Initiate PROMs
1. Collection of measures presents a minimum 'set' including PROMs, CROMs, PREMs
2. Sources of data collection for the 'set'
3. Pilot plan

Section 5: PROMs Collection and Analysis

In earlier sections, we defined the CDVC and how to select the most appropriate measures for each condition while engaging relevant stakeholders in the process. These steps established which outcomes matter and which tools will be used to measure them. The hospital transitions from design to execution by outlining the consistent collection of PROMs, identifying who is responsible at each stage, determining the frequency of collection throughout the patient care pathway, and specifying how the resulting data should be stored, scored, analyzed, and interpreted.

The aim is to ensure that PROMs are not treated as isolated surveys but are integrated into decision-making, patient engagement, clinical follow-up, quality improvement, and performance benchmarking. This section covers the full PROMs measurement cycle, including data collection and analysis. PROMs collection includes Phase 1: (pre-collection preparation), Phase 2: (the collection workflow including mapping of collection points, selecting collection methods, and using sample scripts and messages), and Phase 3 (post-collection processes such as data quality review, engagement monitoring, and interpretation with clinical integration). The PROMs analysis will include three levels: patient-level, service-level, and organizational-level analyses.

PROMs Pre-Collection

Before PROMs are collected, hospitals must first ensure that the required operational foundations are in place. This phase focuses on confirming clarity in scope, defining clinical touchpoints, assigning staff roles, building staff capabilities, ensuring that digital systems and infrastructure are ready to support PROMs administration, and preparing communication messages/scripts that help patients understand the importance of providing their input. PROMs collection must be explicitly linked to predefined goals at the patient, service, and policy levels, including symptom screening, monitoring over time, quality improvement, and policy oversight.

Practical factors should be considered to ensure that PROMs can be embedded into routine clinical workflows and reduce patient burden. Factors to be considered included:

- The length of the instrument (longer questionnaires increase patient burden and can reduce completion rates)
- Simplicity of administration (e.g., clear and intuitive question formats)
- Availability of multiple modes and languages (e.g., paper, digital/web-based, proxy completion, and validated translations)

PROMs Collection Workflow

PROMs collection points need to be clearly identified, along with the collection method (e.g., e-survey, tablet, SMS link), and the required action on results (e.g., no action, referral to other health providers, updating the care plan).

Step 1: Specify the collection timepoints

Timing and measurement frequency require careful planning because they directly affect the feasibility of the workflow. Baseline PROMs should be collected before the intervention or treatment. Follow-up PROMs should be collected at standardized, clinically meaningful intervals to enable longitudinal analysis to specify the time point (e.g., baseline pre-consultation, 3-month follow-up, and 6 weeks post-operative). For Diabetes, the illustration below shows the collection points of outcomes measures including PROMs and others as recommended by ICHOM (figure 4).

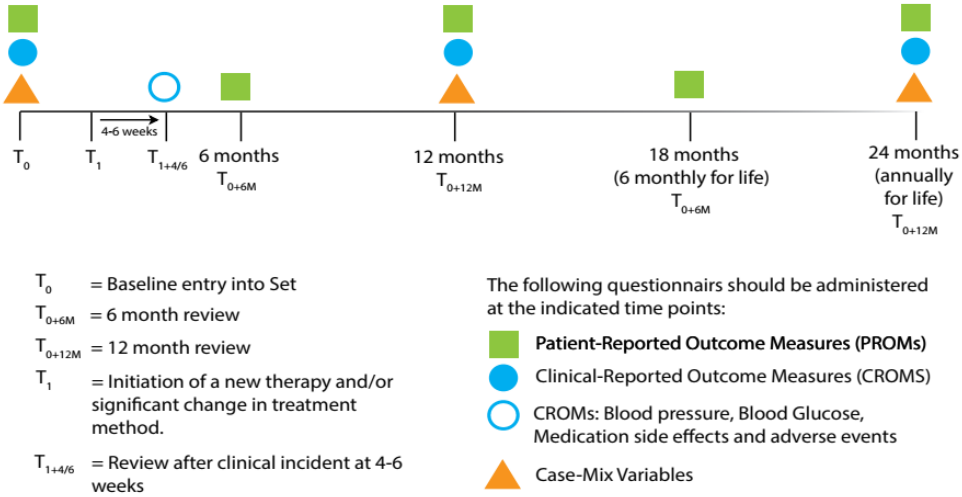

Figure 4: Data collection points for diabetes. Adapted from ICHOM Diabetes Guide.

It is essential to follow established recommendations, such as those specified in international best standards sets such as ICHOM timelines in their respective standard sets. The measurement frequency must balance psychometric validity, clinical utility, and respondent burden. These parameters should be tailored to the clinical context:

- For discrete interventions, such as surgery, PROMs are commonly collected pre-intervention and at one or more post-intervention points. This depends on the type of surgery and when expected changes are to be seen.
- For chronic conditions, PROMs may be administered at each clinic visit or at defined monitoring intervals.

Step 2: Define the Data Source

PROMs data source refers to who provides the information? PROMs may be based on self-reports, where patients directly report their outcomes, or by using a proxy who will provide responses on their behalf (e.g., guardian, caregiver, or clinician). This should be accepted only when self-reporting is not feasible for patients. In this situation, it is essential that proxies are identified in terms of their relationship to patients, and it should be explicitly noted when proxy reporters vary from administration to administration. Identifying the right type of patients including their abilities to report is needed during the planning phases (discussed in Section 3: Condition and Patient Population Selection). It can be convenient in early implementation efforts or pilots to include self-reporting abilities in the inclusion criteria.

Step 3: Choose an Administration Approach

The administration approach is divided into modes and methods. The mode of administration is categorized as either self-administration or interviewer-administration. The method of administration, on the other hand, refers to the tool or medium used for administration, including paper, e-forms, telephone, or computer-based platforms. The CHI recommends electronic collection and discourages the use of paper wherever possible. For example, a patient may self-complete a questionnaire via telephone or computer, or an interviewer may administer the assessment using paper or digital systems.

Choosing the appropriate PROMs collection method is essential to ensure accuracy, practicality, and patient engagement. The technique should fit smoothly into the clinical workflow, be easy for patients to complete, and allow clinicians to access and use the results effectively. The following are some of the suggested modes to collect PROMs:

- Self-administered Assessments through links, patient portals, or QR Codes, where responses are captured directly into a database in real time. This method is also ideal for PROMs follow-up and can reduce the staff workload for data entry

- Telephone Administration for patients lack internet access, and to increase response rates. In this case, schedule the call and follow the scripted questionnaire. The tool should be able to be administered over the phone, by a trained agent.

In addition, the following characteristics and practical implications should be considered:

1- Language, Physical, and Cognitive Abilities:

- Patients with limited literacy or non-dominant language skills: need translated or culturally adapted tools.
- Individuals with dexterity impairments (e.g., arthritis) can benefit from touchscreens.
- Patients with cognitive limitations: may require proxies or simplified tools for assessment.

2- Age-Related Considerations:

- Children under 7 years: use observer-reported measures (caregiver or clinician) and child-friendly tools
- Adolescents: use self-reporting with support, if needed
- Older adults may be less comfortable with digital platforms; therefore, it is important to ask for their preferences and provide assistance

Step 4: Decide the Sample Approach

PROMs assessments are commonly administered using either a census-based approach (offered to the entire eligible population) or a sample-based approach (administered to a representative subset). If the target population is small, include all eligible patients. For large conditions, such as diabetes, sample-based collection should be applied to ensure representativeness. Sampling should follow best practices and guidelines. As an example, ICHOM recommends the following as minimum requirements in initiating phases, which can be used as a reference:

- The minimum sample includes 50 patients per condition per measurement cycle for a period of 6–12 months. However, it is safer to recruit more than the intended sample size to account for incomplete assessments or dropouts.
- Response rate of at least 25% of the target patient pool (baseline to follow-up for the cycle) per the defined inclusion criteria (at least fifty patients should be in the final pool).

For example, in type 2 diabetes, baseline PROMs are collected at the first clinic visit using an assessment link, with follow-up PROMs collected at 6, 12, 18, and 24 months. If PAID-5 result ≥ 8, it indicates high distress. As a result, the patient is referred to a diabetic educator or psychologist; if EQ-5D-5L declines by ≥ 0.10, the physician reviews and adjusts the care plan.

Step 5: Pilot the PROMs Project

Before scaling across the organization, the chosen PROMs should be tested in the intended setting. The pilot should include feedback mechanisms, such as short surveys, interviews, and qualitative narratives from patients, frontline users (data collectors), and data analysts. Piloting enables the assessment of patient and clinician acceptance, identifies workflow and operational barriers, and surfaces contextual issues not detected during selection. Findings should be formally reported to the VBHC/PROMs committee/multidisciplinary team, including lessons learned on workflow integration, early analytic outputs, and perceived value, to enhance the program and guide the subsequent rollout.

The collection and analysis of PROMs are essential components of patient-centered, VBHC approaches. By following a structured process, beginning with careful pre-collection planning, mapping collection workflows, selecting appropriate methods, and preparing patient communication channels, hospitals can ensure that PROMs are collected consistently and accurately, and in a way that minimizes the burden on patients and staff.

PROMs Post-Collection and Analysis

Once PROMs data are collected, the priority is to ensure that the data is reliable, clinically useful, and consistently applied to both, individual patient care and system-level improvements. It is important to note that each PRO's instruments have its unique analysis methodology and calculation, these are usually included after obtaining the license for use, and some are published in the literature. Moreover, some venders offer solutions that aid in analysis and reporting. An important aspect of PRO's analysis accuracy is the quality of data collected. This phase comprises two critical steps: (1) Data Quality Review and (2) PROMs Analysis.

Step 1: Data Quality Review

PROMs data must be audited for completeness, validity, and accuracy to ensure that it can guide decision-making; this involves validation and a clinical review. During the review, the following key validation principles should be followed:

Data Quality Principle	Practical Advice
1. Completeness (all required items answered)	• Ensure that mandatory items are answered (i.e., no missing items) • Set a method for handling missing items (can be found in instruments' data analysis protocols)
2. Consistency (answers logical)	• Set logic rules to flag inconsistency (e.g., severe pain and "no mobility problems") for quick review • If inconsistency arises due to a misunderstanding, assist the patient by clarifying questions
3. Timing validity	• Define acceptable time window in advance (e.g., follow-up PROMs collected ±2 weeks from scheduled interval). • Use automated reminders (e.g., SMS) to prompt completion within the valid window

Example: in type 2 diabetes, after PROMs are collected in the clinic, routine data quality checks should be performed to ensure completeness and accuracy. This includes screening for: (1) any missing items in the PAID-5 questionnaire, (2) a drop of more than 0.2 in the EQ-5D-5L index compared to the previous visit, and (3) any other unusual responses that may suggest inaccurate reporting. When concerns are identified, the patient should be asked to re-complete the PROM either during the same visit via SMS, portal link or at the next scheduled clinic visit, depending on feasibility.

Step 2: PROMs Analysis

PROMs analysis transforms the collected data into meaningful insights that guide both, individual patient care and system-level improvements. The analysis should occur at two levels: (1) patient-level / clinical interpretations, where scores inform decisions during clinical encounters, and (2) service-level analysis, where aggregated results are reviewed periodically to identify trends, areas for improvement, and inequities across patient groups. They can also be used to guide quality improvement initiatives. The goal is to ensure that PROMs data directly contribute to better outcomes, improved care experience, and more efficient resource use.

Patient-level analysis aims to inform decisions for individual patients. The focus is on reviewing individual PROMs scores, trends and making actionable decisions based on them. Ideally, PROM results are displayed on a single dashboard, showing the baseline scores, changes over time, thresholds, and appropriate clinical responses. Clinicians should be able to check the granular scores of each PROM collected at the different touchpoints. For instance, if the baseline for the PAID-5 score is ≥ 8, the next readings should be displayed, and with the right interventions, further readings should start to show improvement. The following is recommended when analyzing PROMs at the patient level:

Analysis Principle	Practical Advice
Review PROMs	• PROMs scores are visible in the EHR chart, clinical dashboard, or any other means to ensure access and utilization by the clinician. • Interpret trends, not just one score (i.e., compare the current score to previous ones) • Visualize individual PROM scores in a detailed level (per question level) • Use defined action thresholds
Discuss results with the patients	• Use simple language and connect the result to pre-defined goals • Adjust clinical management depending on PROM scores

PROMs are valuable only when interpreted correctly and used to inform clinical care, personalize care plans, guide treatment decisions, and encourage shared decision-making. The following practical principles outline the use of PROMs in routine care:

Integration Principle	Practical Advice
Clinical review & interpretation	• Treat PROMs like a routine vital sign and a necessary part of visit • Interpret PROM scores in the context of the patient's condition • Define actionable thresholds • Encourage multidisciplinary team PROM discussions (at least once weekly or in department meetings)
PROMs outcome monitoring	• Sharing PROMs results with patients in a clear, understandable format to support shared decision-making • Track how PROMs interpretation influences care decisions and patient outcomes to continuously improve clinical integration

Example: in type 2 diabetes, PROMs results are automatically integrated into the EHR before the patient visits the clinic. Clinicians review PAID-5 and EQ-5D-5L scores alongside laboratory results and treatment history. As available, clinicians compare the scores to previous scores to assess improvement or deterioration. Significant changes, such as a PAID-5 score ≥ 8 or a decline of ≥ 0.10 in EQ-5D-5L, trigger targeted interventions. For instance, a PAID-5 score ≥ 8 triggers a referral to a diabetes educator or psychologist.

Service-level analysis aims to evaluate outcomes across patient groups to support continuous improvements. This analysis is typically conducted monthly or quarterly to track trends, guide management decisions, identify areas for improvement, and lead a quality improvement project. Routine service-level analyses include measuring changes from baseline (mean, median, and percentage of patients achieving clinically meaningful improvement), generating time-to-recovery curves to show progress over time, and applying case-mix adjustment to ensure fair comparisons across clinics or patient groups. Usually, these reports are displayed in management and quality dashboards on a weekly or monthly basis.

Step 1: Start with the basic question

Before adjusting anything, be clear. Ask "Outcomes for whom, and compared how?". Comparisons are made either between hospitals (e.g., Hospital A vs. Hospital B) or across different time periods within the same hospital. Be specific about the outcome being measured, such as improvement in patient-reported measures of distress, pain, mobility, or other relevant PROMs.

Step 2: Define the case-mix variables (risk adjusters)

Case-mix adjustment means to statistically control patient factors that influence outcomes but are not under the direct control of the provider, like age, sex, baseline PROMs score, key comorbidities (such as diabetes or heart disease), and indicators of disease severity. For each patient, the expected outcomes are calculated based on these characteristics, and then each hospital's observed outcomes are compared with the expected outcomes to generate an observed-to-expected (O/E) ratio, and a risk-adjusted outcome rate.

Separate multilevel linear (or logistic) regression models are then estimated with patients nested within providers. A null model (no adjusters), can first be fitted to quantify the baseline variation between providers. Subsequent models add candidate adjusters one by one, and finally incorporate them collectively, allowing to estimate how much of the between-provider variance is explained by each factor. Variables that produce a meaningful reduction in between-provider variance (indicating they materially affect comparisons) are retained as case-mix adjusters, while those with minimal impact can be excluded to avoid unnecessary complexity.

This allows hospitals that treat older, sicker, or more complex patients to be compared on a "like-for-like" basis, so that differences in PROMs results reflect more accurately the quality of care rather than the underlying population risk. In routine reporting, the guide should present both crude and risk-adjusted PROMs results, accompanied by a brief explanation of the case-mix variables used, to support transparency and build trust in the comparisons among providers.

International best practices use regression-based models to adjust PROMs scores before comparing providers. The following steps were used for case-mix adjustment:

- Collect Variables: collect demographic, clinical, and social variables at baseline
- Build Statistical Model: most common approaches are linear regression for continuous PROMs results and logistic regression for categorical outcomes (e.g., improvement vs no improvement, Yes or No)
- Predict Expected Score: the model generates each patient's expected PROM score, based on their risk factors
- Calculate Adjusted Score: Adjusted Score = Observed Score – Expected Scored (or ratio / residual depending on model)
- Compare Providers: use adjusted scores to compare clinics or hospitals

Organizational level analysis focuses on understanding how PROMs outcomes reflect the overall performance of the hospital or health system. The objective is to use PROMs data to inform strategic planning, resource allocation, quality improvement priorities, and value-based care performance. This level looks across multiple services, specialties, or hospitals to identify system-wide patterns, variations, and long-term outcome trends. Ideally, PROMs results of multiple services are presented to leadership, with defined KPIs and improvement actions (usually assigned by the leadership team during the first phase of any VBHC and PROMs project). Typically, this analysis is conducted quarterly or biannually and used to guide strategic decisions. Hospitals may opt to benchmark their performance publicly on an annual basis.

In the post-collection phase, rigorous data quality checks, engagement monitoring, and clinical integration, guarantee that data is reliable, interpretable, and actionable. Analysis across patients, services, and overall organizational levels allows hospitals to translate individual scores into personalized care decisions, identify trends and disparities across services, and guide strategic, system-wide improvements. When implemented effectively, PROMs become more than an assessment; they serve as a continuous feedback loop in the CDVC that informs clinical care, drives quality improvement, supports shared decision-making, and strengthens overall hospital performance and value-based care outcomes.

PROMs Collection and Analysis Minimum Requirements to Initiate PROMs
1. Minimum sample includes 50 patients per condition per measurement cycle for a period of 6–12 months
2. Implementation of the pilot as planned
3. Quality review of the data (audit)
4. Data analysis

Section 6: PROMs Reporting

Effective data reporting is the cornerstone of a successful PROMs program for care pathway for medical conditions management. This phase transforms the collected data into actionable insights that drive clinical decision-making, quality improvement initiatives, and patient-centered care optimization. A robust reporting framework ensures that PROMs data reach the right stakeholders in formats that facilitate understanding, engagement, and meaningful action.

Multilevel Reporting Framework

The primary purpose of data reporting in VBHC and PROMs programs is to translate patient-reported experience and outcome measures into evidence that informs multiple levels of healthcare service delivery. At the micro-level (individual patient care), data reporting enables clinicians to monitor individual patient progress, adjust treatment plans, and engage in shared decision-making. At the meso-level (organizational performance), reporting facilitates internal benchmarking, identifies care gaps, and guides resource allocation and quality improvement projects. At the macro-level (regulatory or health system), aggregated reporting informs policy decisions, supports national quality indicators, and enables cross-institutional comparisons.

Level	Audience	Purpose	Example (Diabetes)
Micro	Patient and care team	Guide individual care	Discuss PAID-5 results during consultation, and suggest psychological counselling if distress levels are high. Results shall be also used to re-design the care pathway.
Meso	Hospital/clinic management	Quality improvement	Analyze PROMs trends and inform quality improvement projects.
Macro	CHI, payors and system-level providers	Benchmarking and contracting	Use PROMs for VBHC reimbursement.

Multiple steps are involved in reporting PROMs, including:

Step 1: What to present from the PROMs

- Response rates at different touchpoints (depending on agreed upon collection schedule during first stage of any project)
- Percentage of enrolled patients who completed the PROMs during the measurement period (cycle of care)
- Breakdown by clinic site, provider, and patient demographic characteristics
- Mean scores for key PROMs domains
- Percentage of patients achieving defined outcome targets
- Domain scores and changes
- Percentage of abnormal scores per questionnaire at each touchpoint
- Minimally important clinical difference (MICD): (smallest change perceived as important by the patient or clinician that could lead to a change in treatment).

Examples of CHI reports are in the appendix.

Step 2: How to Visualize Data and Report PROMs

PROMs reporting should include three things in parallel: unadjusted mean scores, adjusted mean scores (using the performance indicator approach or the condition-specific dimension models), and distributional information (median, IQR, shifts in quartiles over time). This visualization enhances interpretation and action. The following chart types are recommended for use in hospital settings:

A. Bar Charts and Histograms

Well-designed bar charts are highly effective for displaying distributions or comparing groups. Bar charts can show:

- Comparison of mean PROMs scores across treatment groups (ex: distress levels across patients receiving oral medications only, insulin only, or combination therapy)
- Comparison of PROMs scores across different providers
- Response rates for PROMs completion by demographic characteristics to identify groups with low participation

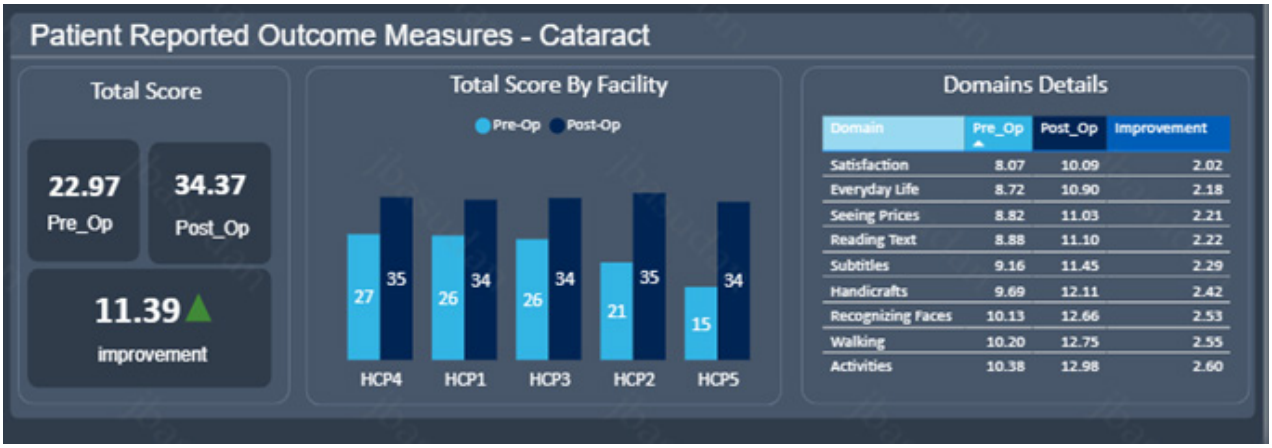

Figure 5: CHI Cataract pilot dashboard. Comparison between providers and delta of improvement.

Line/Trend Chart

Longitudinal line graphs effectively display changes in PROMs over time for individual patients and patient populations.

B. Funnel Plot

When comparing outcomes across multiple settings, funnel plots provide a statistically rigorous visualization method that accounts for differences in patient volumes. A funnel plot displays the mean outcome of each hospital on the y-axis and the number of patients on the x-axis, with control limits that form a funnel shape. Hospitals that fall outside the control limits are statistical outliers.

C. Heat Maps

When reporting PROMs outcomes across multiple dimensions simultaneously (e.g., by clinic site, age group, diabetes type, and treatment modality), heat maps provide an efficient visualization approach. Color intensity represents the magnitude of the outcome measure (e.g., mean diabetes distress score), enabling the rapid identification of subgroups with particularly good or poor outcomes that merit further investigation.

D. Radar Chart

A radar chart (also known as a spider or web chart) is ideal for displaying multidomain data on a single image, making it easy to compare multiple health domains or patient profiles simultaneously. In healthcare, radar charts allow clinicians or researchers to visualize multiple outcome domains simultaneously (e.g., pain, mobility, emotional well-being) for a single patient, clinical group, or hospital. This allows to quickly capture strengths and weaknesses across domains, highlight disparities, and track progress over time or after interventions.

E. Box-and-Whisker Plot

A box-and-whisker plot (box plot) is used to display the distribution of data along a single dimension, showing the median (the line inside the box), interquartile range (the box edges), minimum and maximum (whiskers), and outliers (points beyond the whiskers). In healthcare outcome reporting, box plots are particularly effective for displaying the spread, central tendency, and variability in scores for one outcome domain across all patients, hospitals, or time points. Examples of CHI reports are in the appendix.

Comprehensive PROMs reporting closes the loop from data collection to improvement by making outcomes visible for action. By using tailored dashboards and benchmarking, and by prioritizing patient-relevant domains, PROMs reporting empowers better clinical decisions, more engaged patients, focused quality initiatives, and higher-value care. By delivering timely, relevant, and actionable insights to all stakeholders, robust reporting systems create the feedback loops necessary for continuous learning and improvement, which are essential in creating value for patients in activities such as CDVD.

PROMs Reporting Minimum Requirements to Initiate PROMs
1. Reporting plan: micro, macro and meso levels
2. Data included in the report
3. Data visualization plan

Section 7: Stakeholder's Engagement

The successful implementation of VBHC and PROMs is a human-centric endeavor. While technology and processes are fundamental enablers, the people from executive leaders to frontline clinicians and patients determine their success and sustainability. It is crucial that, prior to implementation, a consensus is reached among the involved stakeholders on the purpose of PROMs, including detecting previously unrecognized health issues, monitoring disease progression, stimulating better communication, and promoting shared decision-making (Amini et al., 2021). This section provides actions and guidance on engaging healthcare professionals, and patients, including tips for engagement, communication plans, and training.

Stakeholder engagement is the catalyst that drives VBHC and PROMs projects from passive data collection exercises to a transformative element that improves patients' health and achieves value. By systematically addressing the unique motivations, barriers, and needs of leadership, providers, and patients, hospitals can foster a culture of shared ownership and reduce the barriers to implementation. Organizations need to invest in well-designed training activities that meet the needs of all of the stakeholders involved and support them in developing the competencies needed to ensure proper implementation.

Action 1: Engaging Healthcare Professionals

Healthcare professionals (clinical and non-clinical) are directly impacted by the use and implementation of VBHC and PROMs initiatives. The goal is to ensure that PROMs become an essential and integrated part of clinical practice, rather than an administrative burden. Assigning PROMs entails a responsibility to engage other healthcare professionals. Some helpful steps to facilitate this engagement are as follows:

- Identify the different staff members who participate in the implementation across the organization: their roles, dependencies, and cross-functions should also be described
- Co-design the clinical workflow using the CDVC framework
- Design a role-specific competency-based training course on VBHC and PROMs

Capability Building and Training

Embedding PROMs into routine care requires capability building at the clinical, administrative, and leadership levels. Organizations must ensure that staff training is based on their needs and roles in implementing VBHC and PROMs. Building capability requires continuous efforts along formal training programs such as reflections, debriefing, coaching, and micro-learning. Before initiating any training, it is strongly advised to conduct a learning needs assessment based on the identified roles. The following are the suggested topics for each stakeholder:

- Leaders and Executive Sponsors: understanding VBHC, the value and purpose of PROMs, and the linking of value-based payment, and national priorities
- Clinical Staff: understanding VBHC and PROMs, using and administering PROMs following suggested workflow/timelines, patient engagement, interpreting PROMs results, using data for shared decision-making, and identifying patients at risk
- Administrative (Quality, IT, case manager): understanding VBHC and PROMs, patient engagement, data management, privacy and security, building and maintaining PROMs dashboards, workflow integration, and technical support

Action 2: Engaging Patients: Ensuring Partnership and Understanding

Patients are partners in care; their engagement ensures that PROMs are relevant and that the process respects their time and perspectives. It is essential to communicate with patients in a language(s) they understand, using different channels and at different points of the engagement (e.g., before obtaining consent, during the consultation). The following are suggested actions to help improve patient engagement and awareness.

Pre-collection engagement techniques

The care team should introduce PROMs as a routine part of their care. The care team should clarify the importance of completing the assessments for both the patients and the organization. The goals are to improve the overall care, ensure easy access and use of instruments, and involve family members or caregivers by explaining how their support in reminding or assisting with survey completion can contribute to better care.

Patients are more likely to complete PROMs when the purpose is simply explained by their primary clinician. The following scripts can help staff to deliver a consistent message:

- Appointment SMS (pre-visit): "Dear patient, Dr. X needs you to please complete this short health assessment before your next visit. It takes 5 minutes, but it can help us understand your health status better and tailor your care accordingly. Link: <short link>. If you need help, call 0xxxx."
- Waiting-room tablet or QR Code (nurse script): "This short health assessment helps your doctor see how you are doing with your symptoms and how your quality of life is. It takes approximately 5 min and will be saved in your medical record. May I help you start it now?"
- Phone call reminder: "Hello [patient name], this is [your name] from [hospital name]. We sent you a short health assessment regarding your symptoms and health status. Completing this questionnaire helps your clinician personalize your care. Do you require any assistance?"

Post-collection engagement techniques

PROMs must be completed carefully and accurately. Strong engagement depends on how easy it is to complete the tool, how clearly its purpose is explained, and how efficiently its recollection is managed. The following principles can enhance engagement:

- Train clinicians to start consultations by referring to the patient's PROMs score. For example: "I see from your questionnaire that you are still experiencing quite a bit of fatigue. Let's talk about that."
- Create "You Said, We Did" posters or infographics showing how aggregate PROMs data led to service improvements (e.g., "You reported needing more dietary support, so we started a new nutrition workshop.")

Engagement Principle	Practical Advice
1. PROMs ease of completion	• Use multiple contact strategies (e.g., email, SMS,…) • Tablets • Use mobile-friendly surveys via SMS for follow-up PROMs • Use short, validated, culturally appropriate surveys • Provide surveys in multiple languages, including Arabic • Assist older adults
2. Communicate purpose to patients	• Train • Place visual prompts in clinic areas (e.g., "Your voice matters": We use your answers to track your symptoms and to make sure your treatment is working for you.") • Develop educational patient brochures on the use of PROMs in care pathways • Integrate PROMs into patient education
3. Monitor and Sustain Engagement	• Assign a PROMs coordinator to monitor the process • Set targets (e.g., baseline ≥ 70%, follow-up ≥ 50%) • Use automated reminders if a PROM is not completed • Track engagement rates by clinic/provider with monthly updates • Encourage physicians to interpret the data and show findings in department meetings • Ensure use of PROMs scoring and local benchmarking where available, as it provides invaluable insights that clinicians cannot afford to miss • Recognize units with high PROM completion rates • Use small

Example: In type 2 diabetes, PROMs are integrated into the care workflow at the relevant clinics. Patients complete PAID-5 and EQ-5D-5L using a tablet during check-in, while automated SMS/WhatsApp reminders are sent if follow-up assessments are pending. Clinicians reference the PROMs results during the visit to highlight their relevance to care, and the clinic dashboard tracks completion rates, enabling the nurse to facilitate re-completion during the same visit or through the patient portal/mobile application.

Action 3: Developing a Communication Plan

A structured communication plan is particularly important during the early phases of implementation to ensure consistent messaging and to clearly articulate the intent and expectations. It is strongly recommended to develop and disseminate communication materials that address the following:

- The purpose and value of PROMs
- How PROMs benefit both patients and clinicians
- Frequently asked questions

Example: Communication Plan

Goal	Audience	Key Message	Channels	Frequency
Build awareness and secure buy-in	Executive Leadership	PROMs as a strategic enabler	Executive Briefing Sessions, One-on-one meetings	Pre-launch
Announce initiative and explain "What's in it for me?"	All Hospital Staff	PROMs help improve patient care and clinical decision-making	Email, Newsletters, Intranet	Launch and ongoing
Equip clinicians with required "know how"	Physicians, Nurses, Allied Health	How to educate patients on importance of PROMs	Role-Specific Training Sessions, Quick Reference Guides, Huddles	Pre- and post-launch
Inform and motivate patients	Patients and Families	Your feedback is essential and directly influences your plan of care	"PROMs Kit" (brochures/videos), Portal Messages, Clinic Posters, Patient brochures	At point of care and follow-ups
Sustain momentum and demonstrate value	All Stakeholders	Celebrating successes and showing PROMs data	"PROMs in Action" Spotlights, Quarterly Scorecards, "You Said, We Did" Boards	Ongoing (e.g., monthly/quarterly)

Patients and families should be engaged and empowered to ensure that their voices are heard and acted upon. Active engagement will ensure that their lived experiences of symptoms, functional status, and quality of life, which are the outcomes that matter most to them, are systematically quantified, valued, and integrated into clinical decision-making.

Stakeholders' Engagement Minimum Requirements to Initiate PROMs
1. Training of staff who are directly involved (PROMs multidisciplinary team)
2. Patient engagement plan

Section 8: Scaling and Sustainability

After successful pilot implementation and evaluation, the next steps focus on embedding and expanding VBHC and PROMs within care delivery processes to achieve a sustainable and scalable impact. This step covers actions to guide the expansion and scalability of PROMs implementation horizontally to other conditions and vertically across hospitals/branches, all whilst integrating the process into care delivery and design, improvement efforts, technology, and contracting models to ensure sustainability.

Horizontal and Vertical Expansion

Horizontal expansion includes gradually scaling a VBHC and PROMs implementation by adding more priority conditions, procedures, or patient populations. For example, if a hospital piloted PROMs for type 2 diabetes, expansion would be achieved by PROMs for hypertension or type 1 diabetes (different patient populations). Along with including more conditions, work processes need to be enhanced to address increasing the project patient sample size from 50 to 80, improving response rates from 25% to 50% through patient engagement and workflow integration, and ensuring that outcome sets are implemented with a high degree of completeness, validity, and accuracy (similar to the ones set by international organizations like ICHOM).

Vertical expansion involves extending PROMs integration across additional clinics, departments, or branches. For example, if a hospital piloted PROMs for diabetes in family medicine clinics, the subsequent expansion will be through implementing PROMs in internal medicine clinics. As maturity develops, PROMs become integrated into everyday clinical practice, enabling clinicians to use outcome results to improve care at the individual level, support shared decision-making, and assist patients with special or unmet needs. In addition, as organizations start to have aggregated data over time, it can inform and support system-wide improvements and service designs.

Insights gained from the pilot phase shape this process by supporting adjustments to specific contexts without compromising methodological consistency, or data accuracy. For PROMs to be sustainable over time, they need to be officially embedded within organizational strategies, governance structures, and quality improvement efforts, such as clinical governance processes and hospital committees dedicated to medical care, quality, and VBHC.

Capacity Building and Workforce Readiness

A sustainable PROMs program requires building its staff capabilities and certain aspects of its organizational capacity. Hospitals and healthcare organizations should introduce and mandate VBHC and PROMs training programs and certification pathways to ensure ongoing staff competence in the collection, interpretation, and use of data. As the use of PROMs expands, incorporating PROM-related skills into orientation, clinical training, and leadership development is advised to support ongoing knowledge retention.

Technological Integration and Data Interoperability

Long-term scalability depends on digital integration. Hospitals aiming to implement PROMs should consider investing in digital solutions that meet their requirements for data collection. To ensure efficient data collection, real-time visualization and automated feedback, PROMs should be incorporated into electronic health records, patient portals, and mobile applications. To facilitate data exchange across platforms and promote benchmarking and system-wide learning, it is essential to adopt interoperability standards between EHRs and a robust outcomes collection platform.

Incentives and Value-Based Contracting

Connecting PROMs data with incentive systems and value-based payment models is key to maintaining motivation and ensuring alignment. To successfully transition to VBHC, providers must work closely with payors to design and implement payment models that prioritize rewarding outcomes over volume. The steps to activate VBP are as follows:

1. Developing Shared Metrics with Payors

Collaborate with insurance partners to establish shared performance metrics that determine incentives or reimbursement payments. In the diabetes example, one option is to create a contract with payers in which 20% of the total value depends on better HA1c levels (15%) and patient-reported results based on PAID-5 results (5%).

2. Implementing Bundled or Episode-Based Payments

Transitioning from fee-for-service to bundled payments means hospitals receive a single payment for an entire episode of care, which promotes better coordination and efficiency. For example, in a bundled payment for diabetes, the hospital receives a single, comprehensive payment covering the full episode of care for a defined period (SAR 8,000 per one patient for 12 months). This payment encompasses all services necessary for managing a patient's condition, including consultations, diagnostics, treatments, complication prevention, and patient education.

3. Establishing Value-Based Contracting Frameworks

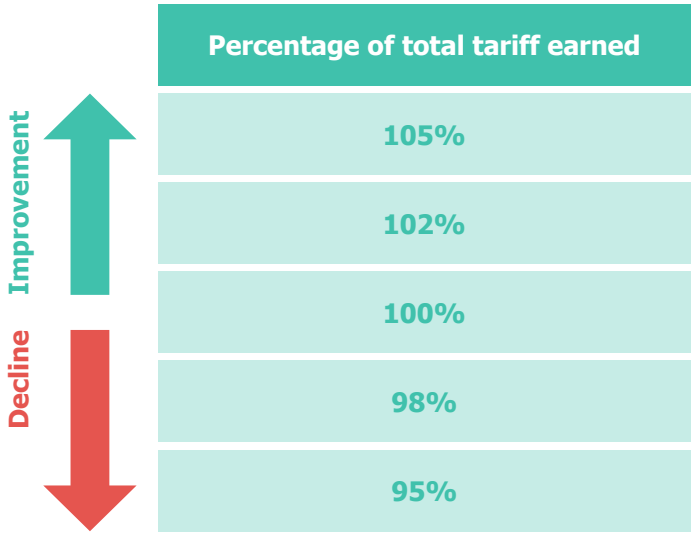

Figure 6: Value-based reimbursement example from Santeon Case (ICHOM).

After establishing shared metrics and payment models, the next step is to create formal contracts that specify expectations, accountability, and reimbursement methods, ensuring compliance with relevant policies and regulations. This is where providers move from designing to executing VBP models. See example of reimbursement from the Santeon Case (ICHOM) in Figure 6.

Scaling and Sustainability Minimum Requirements to Initiate PROMs
1. Lessons learned and insights from the pilot implementation to inform next steps
2. Expansion plans after pilot is completed (horizontal and vertical)

Glossary

- Patient-Reported Outcome Measures (PROMs): Standardized, validated tools or instruments used to systematically measure patient-reported outcomes including functional capabilities (mobility, pain interference), psychological well-being, symptoms, and quality of life.
- Patient-Reported Outcomes (PROs): Health assessments and reports coming directly from patients about their perception of their health condition, symptoms, functional capabilities, psychological well-being, and ability to perform daily activities.
- Generic PROMs Patient-reported outcome instruments that assess general health and well-being applicable across many different conditions, rather than condition-specific aspects.
- Condition-Specific PROMs: Targeted patient-reported outcome instruments designed specifically for a particular health condition or disease, measuring aspects of health most relevant to that condition.
- EQ-5D: Standardized generic PROM measuring health-related quality of life across 5 dimensions: Mobility, Self-Care, Usual Activities, Pain/Discomfort, Anxiety/Depression. Each dimension rated 1-5 (no problems to extreme problems).
- PAID 5 (Problem Areas in Diabetes): Condition-specific PROM measuring emotional distress related to living with diabetes. 5-item questionnaire; scores range 0-20 (higher scores = more distress). Score ≥8 indicates clinically significant diabetes distress; often triggers referral to diabetes educator or mental health support.
- PHQ-2 (Patient Health Questionnaire-2): A brief, two-item depression screening tool derived from the first two questions of the PHQ-9. Each item is scored from 0 (not at all) to 3 (nearly every day), giving a total score range of 0–6.
- Clinical Outcome Measures (CROMs): Objective, clinically derived measurements of health status collected by healthcare providers or extracted from medical records and reflect clinical assessment and physiological markers.
- Patient-Reported Experience Measures (PREMs): Standardized instruments that assess patients' experiences with care processes and systems, including access to care, communication quality, care coordination, respect for preferences, and overall satisfaction with care delivery.
- Care Delivery Value Chain (CDVC): Structured, patient-centered model that maps the full cycle of care for a medical condition, from prevention and early diagnosis through treatment, recovery, and long-term management. Identifies all clinical and non-clinical activities, decision points, and embed PROMs at locations where data most effectively informs care.
- Case-Mix Adjustment: Statistical process to account for patient characteristics that influence outcomes independent of care quality (age, sex, baseline disease severity, comorbidity burden, socioeconomic factors).
- Minimally Important Clinical Difference (MICD): The smallest change in a PROM score that is perceived as meaningful or important by patients or clinicians and could lead to a change in treatment or management strategy.
- ICHOM International Consortium for Health Outcomes Measurement: Is an independent nonprofit with a global focus to advance patient-centered healthcare by developing and promoting standardized Patient-Centered Outcome Measures (Sets) that prioritize the clinical and quality-of-life outcomes most important to patients. ICHOM supports healthcare systems worldwide to measure, compare, and improve outcomes that matter most to patients. It supports providers, policymakers, industry, and patient groups worldwide to drive VBHC.
- PDCA (Plan-Do-Check-Act) is a four-step, iterative management method used for control and continuous improvement of processes, products, or services. Developed by Walter Shewhart and popularized by W. Edwards Deming, this "Deming Cycle" enables organizations to test changes, analyze results, and standardize improvements. Running a PDSA cycle is another way of saying testing a change — you develop a plan to test the change (Plan), carry out the test (Do), observe, analyze, and learn from the test (Study), and determine what modifications, if any, to make for the next cycle (Act).
- The EPIS Framework highlights key phases that guide and describe the implementation process and enumerates common and unique factors within and across levels of outer context (system) and inner (organizational) context across phases.

References

Porter and Teisberg (2006). Redefining Health Care: Creating Value-Based Competition on Results. Harvard Business School Publishing.

Steinberger J, Chowdhry M, Tzeng J, et al. Systemwide integration of patientreported outcome measure collection through an electronic medical record system: a statewide retrospective study. Spine J. 2024;24(3):45664.

Smith JA, Holdsworth D, Cooke C, et al. A review of PROM implementation in surgical practice. Ann Surg. 2022;276(4):61220 .

MacDonald A, Shetty A, Bhatti AF, et al. Electronic health record–integrated approach for collection of patientreported outcome measures: a retrospective evaluation. BMC Health Serv Res. 2021;21:626.

O'Byrne L, Maher GM, Khashan AS, et al. Patient-reported outcome measures in childbirth and postpartum maternal quality of life: a protocol for systematic review of measurement properties. HRB Open Res. 2024;4:117.

Aboumatar HJ, Carroll MB, Watkins JD, et al. PatientReported Outcome Measures Within a National Multispecialty Surgical Quality Improvement Program. JAMA Surg. 2024;159(2):15260.

Al Sayah F, Lahtinen M, Bonsel GJ, Ohinmaa A, Johnson JA. A multilevel approach for the use of routinely collected patientreported outcome measures (PROMs) data in healthcare systems. J PatientRep Outcomes. 2021;5 (Suppl 2):98.

Nelson, T. A., Gudenkauf, L., Epstein, A. J., & Chang, S. (2020). Planning for patient-reported outcome implementation. Cambridge University Press.

Fortuna RJ, GomezRioja R, Rossom RC, et al. Feasibility of implementing a codesigned patientreported outcome measures (PROMs) collection system for older adults in acute and subacute hospital settings. BMC Health Serv Res. 2023;23:710.

Donabedian, A. (1988). "The quality of care. How can it be assessed?". JAMA, 260(12), 1743–1748. doi:10.1001/jama.260.12.1743.

Saly E, Simon J, Fischer C. Healthcare professionals' perspectives on assessing selected patientreported outcome measures in specialist palliative care institutions: a multicountry mixedmethods study. BMC Palliat Care. 2025;24:135.

Bull, C., Teede, H., Watson, D., & Callander, E. J. (2022). Selecting and implementing patient-reported outcome and experience measures to assess health system performance. JAMA Health Forum, 3(4), e220326. https://doi.org/10.1001/jamahealthforum.2022.0326

NHS. Quality, Service Improvement and Redesign Tools: A model for measuring quality care:

https://www.med.unc.edu/ihqi/wp-content/uploads/sites/463/2021/01/A-Model-for-Measuring-Quality-Care-NHS-Improvement-brief.pdf

Lambert, S., et al. (2025). Real-world patient-reported outcome measure. JCO Oncology Practice. Advance online publication.

International Society for Quality of Life Research (ISOQOL). (2018). ISOQOL companion guide to implementing patient-reported outcomes assessment in clinical practice (Chan, E. K. H., Edwards, T. C., Haywood, K., Mikles, S., & Newton, L., Contributors).

Kotter's Change Management Theory Explanation and Applications. (PROSCI, 2024).

NSW Agency for Clinical Innovation. Patient-reported measures change and adoption strategy. Sydney: ACI; 2024.

NSW The Agency for Clinical Innovation (2024). Patient-reported measures change and adoption strategy.

Carberry, K (2023). How to Measure Health Outcomes A Hands On Guide to Getting Started. Cambridge University Press

NHS Improvement. Quality, Service Improvement and Redesign Tools: A model for measuring quality care. ACT Academy

Marzyeh Amini (2021). Facilitators and barriers for implementing patient-reported outcome measures in clinical care: An academic center's initial experience. Health Policy. Vol 125, Issue 9. Pages: 1247-1255

Pe, M., Sloan, J., Basch, E., Bonnetain, F., Calvert, M., Campbell, A., Bottomley, A. (2018). Setting international standards in analyzing patient-reported outcomes and quality of life endpoints data in cancer clinical trials: A SISAQOL initiative. Quality of Life Research, 27(8), 2021–2033.

The International Society for Quality of Life Research (2015): User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice Version 2: January 2015. 2015 User's Guide-Rev 1

Institute for Health Improvement (2017). QI Essentials Toolkit.

Ministry of Health, Saudi Arabia. (2021). Saudi standards for human-centered care.

Central Board for Accreditation of Healthcare Institutions (CBAHI). CBAHI hospital standards.

ICHOM (2025). Diabetes Data Collection: Reference Guide. Version 5.1.1

ICHOM. (2019). Atrial fibrillation reference guide (Version 1.0.0).

ICHOM (2017) Case Study: COLLABORATING FOR VALUE: THE SANTEON HOSPITALS IN THE NETHERLANDS.

ICHOM (2016) Case Study: IMPLEMENTING ICHOM'S STANDARD SETS OF OUTCOMES: CLEFT LIP AND PALATE AT ERASMUS UNIVERSITY MEDICAL CENTRE IN THE NETHERLANDS.

ICHOM Accreditation Program.

EPIS Framework. EPIS Framework

Council of Health Insurance (2023). Measuring Meaningful Patient Outcomes: PROMs Strategy.

Council of Health Insurance (2024). Value-Based Healthcare Action plan: For the Saudi health insurance market.

Council of Health Insurance (2025). Assessing Market Readiness White Paper: implementing patient-reported measures in the healthcare private sector.

Diane et. al (2005). Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. Value in Health. Volume 8, number 2.

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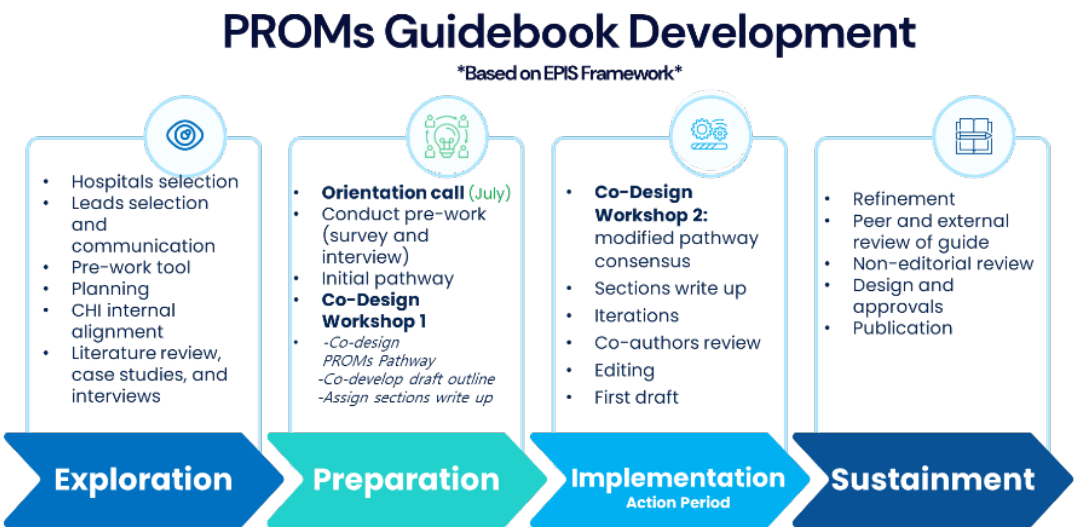
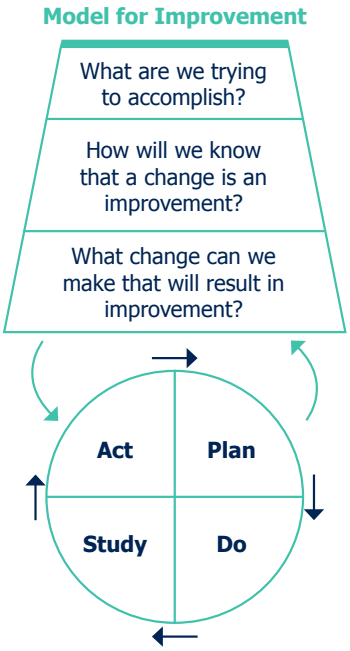
Specialized Medical Center Hospital - King Fahad Branch
Magrabi Health
Aster Sanad Hospital
Capadev
Lean Business Services
PwC Middle East

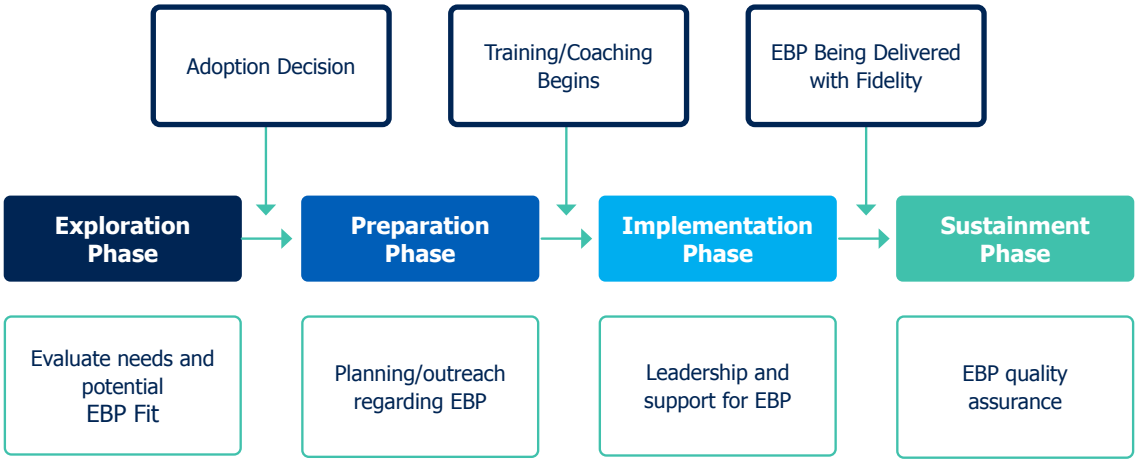
Appendix

Guidebook Development Methodology (EPIS)



Suggested Implementation Frameworks





CDVC Example

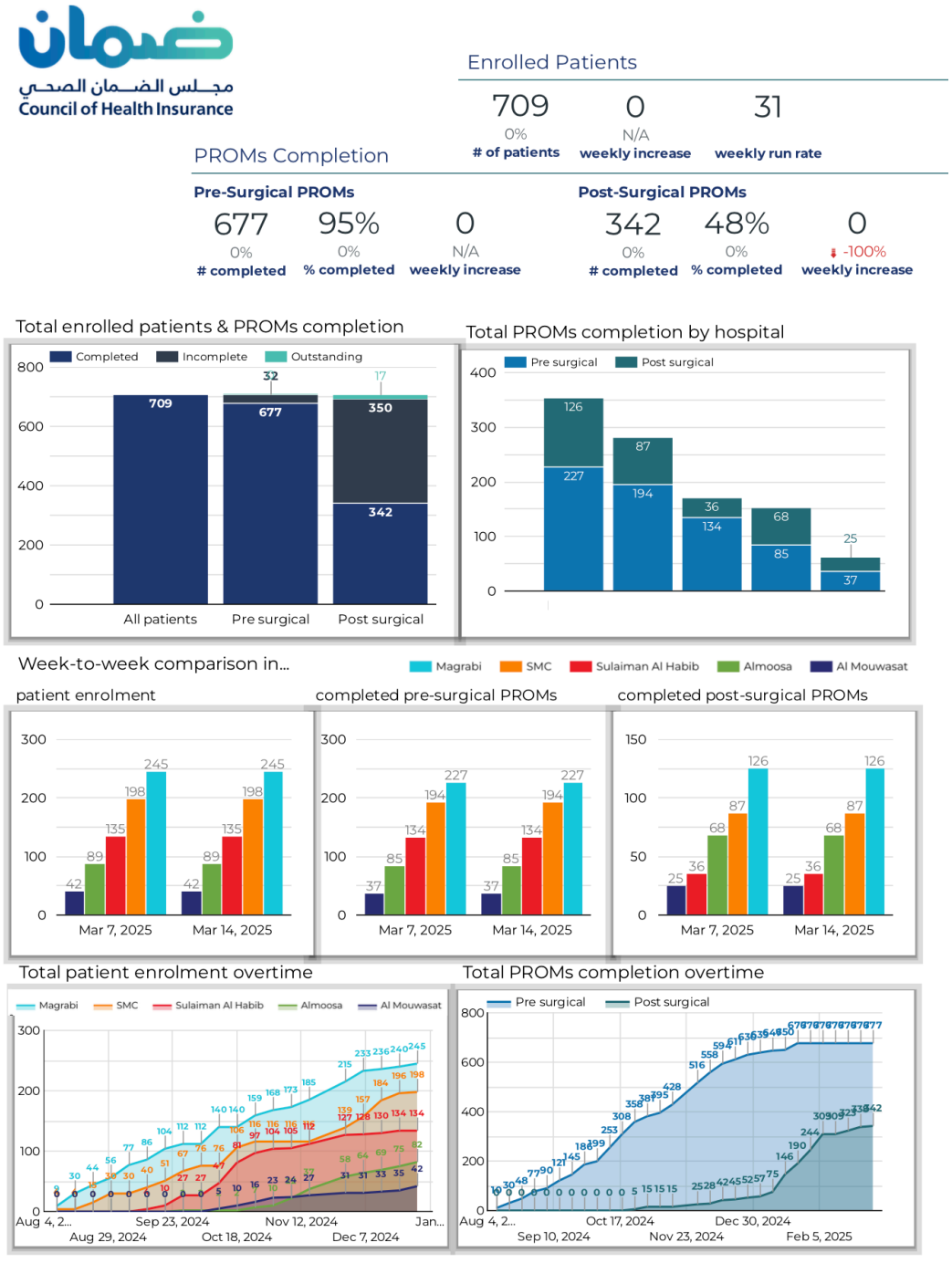
INFORMING AND ENGAGING What do patients need to be educated	• Importance of exercise, weight reduction, proper nutrition	• Meaning of diagnosis • Prognosis (short-and long-term outcomes) • Drawbacks and benefits of surgery	• Setting expectations • Importance of nutrition, weight loss, vaccinations • Home preparation	• Expectations for recovery • Importance of rehab • Post-surgery risk factors	• Importance of rehab adherence • Longitudinal care plan	• Importance of exercise, maintaining healthy weight
MEASURING What measures need to be collected?	• Joint-specific, symptoms and function (e.g. WOMAC scale) • Overall health (eg. SF-12 scale)	• Loss of cartilage • Change in subchondral bone • Joint-specific symptoms and function • Overall health	• Baseline health status • Fitness for surgery (e.g. ASA score)	• Blood loss • Operative time • Complications	• Infections • Joint-specific symptoms and function • Inpatient length of stay • Ability to return to normal activities	• Joint-specific symptoms and function • Weight gain or loss • Missed work • Overall health
ACCESSING Where do patient care activities take place?	• PCP office • Health club • Physical therapy clinic	• Specialty office • Imaging facility	• Specialty office • Pre-op evaluation center	• Operating room • Recovery room • Orthopedic floor at hospital or specialty surgery center	• Nursing facility • Rehab facility • Physical therapy clinic • Home	• Specialty office • Primary care office • Health club
TYPICAL PATH OF PATIENT CARE	MONITORING/ PREVENTING	DIAGNOSING	PREPARING	INTERVENING	RECOVERING/ REHABBING	MONITORING/ MANAGING
CARE DELIVERY What activities are performed at each stage? ORTOPEDIC SURGEON	**MONITOR** • Conduct PCP exam • Refer to specialists, if necessary **PREVENT** • Prescribe anti-inflammatory medicines • Recommend exercise regimen • Set weight loss targets	**IMAGING** • Perform and evaluate MRI and x-ray - Assess cartilage loss - Assess bone alterations **CLINICAL EVALUATION** • Review history and imaging • Perform physical exam • Recommend treatment plan (surgery or other options)	• Overall prep • Conduct home assessment • Monitor weight loss **SURGICAL PREP** • Perform cardiology pulmonary evaluations • Run blood labs • Conduct pre-op physical exam	**ANESTHESIA** • Administer anesthesia (general, epidural, or regional) **SURGICAL PROCEDURE** • Determine approach (eg, minimally invasive) • Insert device • Cement joint **PAIN MANAGEMENT** • Prescribe preemptive multimodal pain meds	**SURGICAL** • Immediate return to OR for manipulation, if necessary **MEDICAL** • Monitor coagulation **LIVING** • Provide daily living support (showering, dressing • Track risk indicators (fever, sweling, other) **PHYSICAL THERAPY** • Daily or twice daily • PT sessions	**MONITOR** • Consult regularly with patient **MANAGE** • Prescribe prophylactic antibiotics when needed • Set long-term exercise plan • Revise joint, if necessary

Care Delivery Value (CDVC) of severe knee osteoarthritis. Adopted fom Kaplan R, porter M. How to solve the cost crisis in healthcare. Harv Bus Rev. 2011 Sept;89(9): 46-52.

Translation and Cultural Adaptation Process

Step 1—Preparation	Contact the developer to obtain permission before beginning any translation work.
Step 2—Forward translation	Conduct at least two independent forward translations by native speakers with experience in patient-reported outcomes translation. Translations should capture the conceptual meaning of the questions rather than being a literal translation and should be understood by lay people.
Step 3—Reconciliation	Conduct reconciliation to reach a single forward translation by an independent translator without prior knowledge of the translation.
Step 4—Back translation	Back translation of the reconciled translation into the source language to be carried out either in parallel, sequentially or have a back translation panel.
Step 5—Back translation review	Review of the back translation against the original being the key function. Discrepancies identified in this step would lead to further assessment of the reconciled version and further revisions to eliminate the discrepancies.
Step 6—Harmonization	Can be achieved via a harmonization meeting, in which key in-country consultants, or back translators representing each language, compare all translations with each other and the original.
Step 7—Cognitive debriefing	This is conducted with patients drawn from the target population.
Step 8—Review of cognitive debriefing results and finalization	Results are reviewed and the translation finalized.
Step 9—Proofreading	The finalized translation is proofread to check for minor errors which have been missed during the translation process
Step 10—Final report	Report is written on the development of the translation to clearly explain the reasons for all translation/wording choices made throughout the translation process.
Adapted from: Diane et. al (2005). Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. Value in Health. Volume 8, number 2.	

Examples of PROMs reports (source: CHI)



Cataract Means for Pre, Post and Delta Scores (CHI Pilot Project)				
Provider	N	Pre-score	Post-score	Delta-score
1	10	24.4	33.4	9
2	4	15	26.7	11.7
3	6	25.5	36.3	10.8
4	1	18	36	18
5	24	25.2	0	0
Total		21.6	26.5	10