The PROTEUS Workbook for Implementing Patient-Reported Outcomes in Clinical Practice:

A Companion to the PROTEUS Practice Guide

A Resource from the

PROTEUS

CONSORTIUM

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Introduction

The PROTEUS Consortium (Patient-Reported Outcomes Tools: Engaging Users & Stakeholders) works with clinicians, researchers, patient advocates, health systems, and methodologists to ensure that patient-reported outcomes (PROs) are both scientifically robust and responsive to the needs of end-users. In 2023, the consortium published the PROTEUS Practice Guide ('PROTEUS Guide to Implementing Patient-Reported Outcomes in Clinical Practice: A Synthesis of Resources'), which provides consolidated guidance for designing, implementing, and managing PRO systems to support patient care.

This workbook is a practical companion to the PROTEUS Practice Guide. Each section mirrors a chapter of the PROTEUS Practice Guide and includes space for reflection, decision-making, and documentation. Not all chapters will be relevant to all PRO applications. Users can focus on the chapters relevant to their work in the order that makes sense for their current focus and skip chapters that are less applicable.

In each chapter, key questions are provided to help PRO teams clarify goals, anticipate barriers, design workflows, strengthen the representativeness of patients completing PROs (equity considerations), and evaluate success over time. The workbook may be used during planning meetings, implementation workgroups, grant development, workflow redesign, patient engagement, and continuous quality improvement efforts.

The workbook was designed to support the multidisciplinary teams responsible for putting PROs into practice as they design, implement, and manage their own PRO systems. These teams may include clinical champions, health system leaders and administrators, quality improvement and operations staff, informatics and information technology (IT) partners, researchers, and patient and caregiver advisors. It can be used both by groups developing PRO systems for the first time, or those aiming to improve an established PRO system. Its value is in translating the high-level guidance of the PROTEUS Practice Guide into a structured set of questions that can guide reflection and decision making. The workbook can serve as a living implementation record of their system.

A new contribution of this workbook is an emphasis on equitable PRO implementation. Extending the PROTEUS Practice Guide, this workbook incorporates equity-focused reflections adapted from a checklist to guide equity considerations in health technology assessment (Benkhalti et al. Int J Technol Assess Health Care 2021). The framework prompts implementers to consider how systems may differentially benefit specific patient subgroups. Questions informed by this framework are integrated throughout the workbook to support implementers in holistically considering equity throughout the PRO system integration process. A stand-alone version of the checklist is also included as an appendix. By integrating structured equity prompts and examining risk for unintended exclusion, this workbook encourages implementers to design PRO systems that are valid, inclusive, and useful across diverse clinical populations.

How to Use This Workbook

- Move through the workbook in the order that makes sense for the focus areas of interest – chapters need not be completed linearly.
- Review workbook sections alongside the aligned chapter in the PROTEUS Practice Guide.
- Use the Key Questions to guide reflection and decision-making, and to document rationales, technical choices, and workflow planning.
- Store completed sections as a living implementation record.
- Refer to the appendices for additional materials and tools to support PRO implementation.

Acknowledgements & Referencing

This workbook draws from content in **The PROTEUS Guide to Implementing Patient-Reported Outcomes in Clinical Practice: A Synthesis of Resources** and from foundational materials synthesized by the Guide. The guide itself may be referenced using the following citation:

> The PROTEUS Guide to Implementing Patient-Reported Outcomes in Clinical Practice
> A Synthesis of Resources. Prepared by Crossnohere N, Brundage M, Snyder C, and the Advisory Group, 2023. Available at: TheProteusConsortium.org.

A summary of the Guide was published in *Nature Medicine* and may also be referenced:

> Crossnohere N, Anderson N, Baumhauer J, Calvert C, Esparza R, Gulbransen S, Haverman L, Li Y, Petersen C, Retzer A, Sidey-Gibbons C, Stover A, Thorner E, Ursin G, Velikova G, Walker E, Brundage M, Snyder C. 2024. A Framework for Implementing Patient-Reported Outcomes in Clinical Care: The PROTEUS-Practice Guide. Nature Medicine. 10.1038/s41591-024-02909-8

To refer to this workbook companion specifically, please use this reference:

> The PROTEUS Workbook for Implementing Patient-Reported Outcomes in Clinical Practice. Prepared by Crossnohere N, Kyte D, Stover AM, Schuster A, Snyder C. 2026. Available at: TheProteusConsortium.org.

Finally, please cite the foundational resources listed in the PROTEUS Practice Guide when you referred to them for more in-depth information.

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Chapter 1 | Defining Goals

An essential first step when implementing PROs in practice is defining the goals for the PRO system. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 1 on Defining Goals. The questions below are intended to help your PRO team clarify the purpose, intended uses, and contextual considerations of the PRO system. By the end of this section, the team should have a clear, shared statement of PRO system goals to guide subsequent implementation decisions. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What are the PRO system's goals?

What will your PRO system be used for? ***Check all that apply***

- ☐ Enhance individual patient care
- ☐ Improve population health
- ☐ Facilitate research
- ☐ Improve quality of care (beyond using PRO data to aid in management)
- ☐ Inform billing, reporting, value-based purchasing
- ☐ Other (specify):

If a goal is to improve individual patient care, how will the PRO responses be used at the individual patient level? ***Check all that apply***

- ☐ Screening for problems
- ☐ Symptom monitoring and management
- ☐ Self-monitoring and management
- ☐ Needs assessment
- ☐ Patient-centered care
- ☐ Outcomes assessment
- ☐ Shared decision making
- ☐ Other (specify):

What are the primary objectives for collecting PROs?

What specific outcomes are you aiming to achieve?

What inclusion considerations are particularly important for your patient population?
Check all that apply

- ☐ Language accessibility
- ☐ Literacy considerations
- ☐ Digital access
- ☐ Digital literacy

- [ ] Rural vs urban population
- [ ] Cultural relevance
- [ ] Disability accommodation
- [ ] Other (specify):

Where will PRO measure collection occur? *Check all that apply*

- [ ] At the clinic on a tablet
- [ ] At the clinic on paper
- [ ] At the clinic asked by a staff member
- [ ] At home between visits with a web-based PRO measure
- [ ] Staff will call patients to complete PRO measure over the phone
- [ ] Other (specify):

Please expand on your selections and describe any relevant considerations

B. Context and PRO system goals

How will your PRO system goals guide the design of the PRO system?

How can this project support the use of PRO measures for all members of the intended group?

Notes and Next Steps

Chapter 2 | Barriers and Facilitators

PROs have tremendous potential benefit to patient care, but barriers in the collection, analysis, interpretation, and integration of PRO data can hinder application in practice. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 2 on Barriers and Facilitators, which emphasizes the importance of identifying the barriers and facilitators present in your system. The questions and table below are intended to prompt discussion across multiple levels of the health system, from patients and providers to administrative and organizational contexts. By the end of this section, teams should have a shared/prioritized understanding of the most important barriers to address and the facilitators they can actively build on to develop strategies. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

Which of these common barriers and facilitators are the most important for your health system or clinic? ***Check all that apply***

	BARRIERS	FACILITATORS
Patient-level	☐ Language accessibility ☐ Literacy considerations ☐ Digital access ☐ Digital literacy ☐ Rural vs urban population ☐ Cultural relevance and appropriateness ☐ Disability accommodation ☐ Mistrust in the healthcare system ☐ Lack of understanding of PROs ☐ Unclear how PROs will be used in their care ☐ Concerns for privacy / how PRO data will be used by health system and secure storage ☐ General difficulty navigating the health care system ☐ Other:	☐ Volunteer(s) or staff who can help patients complete a PRO in the waiting room ☐ Volunteer(s) or staff who can help patients complete a web-based PRO at home ☐ Front desk staff who can hand out tablet or paper PRO to patients ☐ QI or other staff skilled in engaging patients ☐ Other:

Provider- and Staff-Level	☐ No time during visit to review PRO responses with patients ☐ Not wanting to receive automated alerts for concerning PRO responses ☐ Lack of training for PROs ☐ Unclear on how to find PRO responses in EHR ☐ Unclear about the value added by using PROs during care delivery ☐ Uncertainty in how to interpret the PRO information ☐ Uncomfortable if there is no clear management strategy for the identified issue ☐ Unclear on how to talk with patients about PRO responses ☐ Other:	☐ Clinician champion(s) for PROs identified ☐ Organizational climate promotes QI ☐ QI or other staff skilled in engaging clinicians and staff ☐ Reimbursement from payors to perform service ☐ Provider(s) who can conduct peer-to-peer training and coaching ☐ EHR experts experienced in integrating PROs ☐ Other:
Clinic or Administrative Level	☐ Unclear how PROs will fit into workflow ☐ Lack of EHR integration ☐ Previous unsuccessful attempt(s) at implementing PROs in clinic ☐ Lack of shared values/purpose ☐ Uncertainty in how to assess the impact of PRO collection on quality of care ☐ Uncertainty about how to evaluate if PRO implementation was successful ☐ Legal/regulatory constraints ☐ Other:	☐ Leadership support for PROs ☐ Clinic manager who can track PRO use at clinic level ☐ Staff who can track missing PROs ☐ QI expertise and support from health system ☐ EHR staff experienced in integrating PROs ☐ Other:
System-Level	☐ Unclear how PROs fit with organizational priorities ☐ Legal/regulatory constraints ☐ Lack of EHR integration ☐ Lack of system-wide plan for PRO integration ☐ Lack of governance for PRO implementation ☐ Lack of quality control for PRO implementation ☐ Cost ☐ Other:	☐ Leadership support for PROs ☐ EHR staff experienced in integrating PROs ☐ QI and evaluation experts ☐ Other:

EHR=electronic health record; QI=quality improvement

Notes and Next Step

Chapter 3 | Training & Engagement

There are numerous relevant perspectives to consider when developing a PRO system. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 3 on Training and Engaging. By the end of this section, teams should have a clear plan outlining key stakeholders, training objectives, delivery approaches, and engagement strategies to support effective and sustained use of the PRO system. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. Whose perspectives should be included in the development of a PRO system?

B. What topics will they advise on?

Who are the key stakeholders, their roles, and their responsibilities in supporting system implementation? Consider everyone involved in the workflow (front desk staff who hand PRO to patients, patients, clinicians, clinic manager, staff, etc.), electronic health record (EHR) analysts, health system leadership, quality improvement (QI) groups, patient advisory councils, and others.

Name	Role	Implementation Responsibilities
	Front desk staff	
	Clinician(s)	
	Clinic manager	
	Staff	
	Health system leadership	
	QI group	
	Patient advisory council	
	EHR analyst(s)	

Who will engage clinicians, staff, and leadership? ***Check all that apply***

- [ ] QI group in health system
- [ ] Peer(s) (e.g., champion)
- [ ] Implementation or research team
- [ ] Internal QI support
- [ ] External QI support
- [ ] Other:

Who will engage patients? *Check all that apply*

- [ ] QI group in health system
- [ ] Clinic staff
- [ ] Implementation or research team
- [ ] Internal QI support
- [ ] External QI support
- [ ] Other:

C. What are the goals of training for PRO system users?

What topics will training cover? *Check all that apply*

- [ ] Understanding the purpose and value of PROs
- [ ] How and when to collect or administer PROs
- [ ] How to access and review PRO results
- [ ] How to interpret PRO responses or scores
- [ ] How to use PRO data in clinical decision-making
- [ ] How to talk with patients about PRO responses and the importance of acknowledging PRO completion
- [ ] Equity considerations for patients and impact on missing PROs
- [ ] Protocol for tracking missing PROs and attempts to collect from patients
- [ ] Protocol for when patients report moderate or severe symptoms
- [ ] Evaluation/QI plans
- [ ] Other:

Who will receive training? *Check all that apply*

- [ ] Providers
- [ ] Pharmacists
- [ ] Nurses or clinical staff
- [ ] Administrative staff
- [ ] Patients
- [ ] Caregivers
- [ ] Other:

Describe your approach to training:

D. What training approaches will be used?

Who will conduct the training session(s)? *Check all that apply*

- ☐ QI group in health system
- ☐ Peer(s) (e.g., clinician)
- ☐ Implementation or research team
- ☐ External trainer(s)
- ☐ Other:

Which training formats will be used? *Check all that apply*

- ☐ Group training sessions
- ☐ One-on-one training
- ☐ Written guidance or reference materials
- ☐ Recorded videos or online modules
- ☐ Job aids or quick reference guides
- ☐ EHR tip sheets
- ☐ Other:

How will training be updated or maintained as the PRO system evolves?

E. How will providers and staff be motivated to use the PRO system?

Which strategies may support provider and staff engagement? *Check all that apply*

- ☐ Identifying clinical champions
- ☐ Integrating PROs into existing workflow
- ☐ Providing feedback on PRO system use
- ☐ Recognizing or celebrating successes
- ☐ Conducting continuous quality improvement processes
- ☐ Other:

Describe your approach to provider motivation and engagement in the PRO system:

F. How will patients be encouraged to complete PROs?

Which strategies will support patient participation? *Check all that apply*

- ☐ Explaining the value of PROs in their care
- ☐ Thanking the patient for completing the PRO (acknowledgement)
- ☐ Sharing results with patients
- ☐ Providing patient-friendly reports or displays

☐ Sending reminder prompts (e.g., portal messages, staff reminders)
☐ Making PRO completion easy and accessible (e.g., offering multiple ways to complete PRO like paper and web-based)
☐ Having staff or volunteers available who can help patients complete the PRO
☐ Other:

G. How will stakeholders be engaged throughout the lifecycle of the PRO system?

Which engagement approaches will be used? ***Check all that apply***

☐ Stakeholder interviews or consultations
☐ Advisory groups or committees
☐ Co-design workshops
☐ Iterative feedback during implementation
☐ Ongoing evaluation and improvement processes
☐ Other:

How will stakeholder feedback inform ongoing improvements to the PRO system?

Notes and Next Steps

Chapter 4 | Identifying Patients

Determining which patients will complete PROs is a critical step in the design of a PRO system. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 4 on Identifying Patients, which outlines approaches for how to determine which patients will complete PROs. By the end of this section, teams should have a clearly defined target population for PRO completion, documented eligibility criteria, and an agreed approach for ensuring that all intended patients (including those at risk of exclusion) can be identified and invited to participate. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What patients are the intended audience for completing PROs?

Which approach will your system use?

- ☐ All patients in the healthcare system
- ☐ All patients in a specific clinic or service
- ☐ Patients with a specific condition
- ☐ Patients receiving a specific treatment or procedure
- ☐ Other:

What criteria will be used to identify eligible patients?

How will you ensure the PRO system reaches all eligible patients?

B. What considerations should be made when collecting PROs from patient proxies?

How will you handle proxy reporting for patients unable to self-report?

Notes and Next Steps

Chapter 5 | Selecting PROs & PRO Measures (PROMs)

The selection of the outcomes to assess (the PROs) and the measures to assess them (the PROMs) should be guided by the system's goals, patients served, and measurement and practical considerations. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 5 on Selecting PROs & PROMs. This section supports teams in selecting PROs that are aligned with system goals, relevant to patients and clinicians, and feasible to implement in practice. By the end of the section, teams should have identified a justified set of PROs and PROMs to measure them, with a clear rationale for their selection and an understanding of their strengths, limitations, and suitability for the intended context. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What PROs will we collect?

What approaches will you use to select PROs?

What outcomes are most relevant to system goals? To patients and providers?

B. What are the different types of measures that can be used to collect PROs?

Will you use Generic or Disease-Specific Measures?

- ☐ Generic (i.e., for use in any condition)
- ☐ Disease-specific (i.e., for use in specific condition)
- ☐ Both (generic + disease-specific battery)

Will you use Single-Items or Multi-Item Domain Scales?

- ☐ Single-item
- ☐ Multi-item scale
- ☐ Both

Will you administer Static Questionnaires or Computer Adaptive Tests (CATs)?

- ☐ Static fixed-item form (all items presented to every patient)
- ☐ Computer adaptive test (algorithm selects next best item based on prior response, only available for some measures, requires online administration)

C. What response format will be used?

Note that this is driven by the questionnaire.

- ☐ Verbal descriptions
- ☐ Numerical ratings
- ☐ Both

D. What are the characteristics of the PRO measures?

What is the level of evidence supporting the appropriateness of the candidate PRO measures for the intended use?

Psychometric criteria	Substantial evidence supporting	Some evidence supporting	Unclear
Validated in target population	☐	☐	☐
Reliable	☐	☐	☐
Responsive to change	☐	☐	☐
Normative values or thresholds available	☐	☐	☐
Appropriate recall period	☐	☐	☐
Suitable reading level	☐	☐	☐
Implementation criteria	**Substantial evidence supporting**	**Some evidence supporting**	**Unclear**
Acceptable patient burden	☐	☐	☐
Licensing or cost manageable	☐	☐	☐
Available translations	☐	☐	☐
Proxy version available (if needed)	☐	☐	☐
Compatible with PRO system/electronic health record	☐	☐	☐
Stakeholder buy-in	☐	☐	☐

E. Should PROs/PROMs be harmonized or standardized across the system?

Would adopting this PROM: ***Check all that apply***

☐ Reduce duplication across clinics?
☐ Streamline training?
☐ Facilitate benchmarking or shared data use?

F. Is the PRO/PROM a good fit for the system?

What are indications that the PROs and PROMs are a good fit:

What are indications that the PROs and PROMs are a poor fit:

Notes and Next Steps

Chapter 6 | Determining Administration Timing and Frequency

The optimal timing and frequency of collecting PROs will vary depending on the healthcare system's PRO system data collection goals. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 6 on Determining Administration Timing and Frequency. By the end of this section, teams should have a clear and agreed plan for PRO administration that specifies timing, frequency, collection mode(s), and follow-up processes for incomplete data. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. When can PROs be completed?

When will PROs be collected? ***Check all that apply***

- ☐ At a single clinic visit
- ☐ At multiple clinic visits
- ☐ Between visits (remote monitoring)

How often will PROs be collected?

What considerations are particularly important for your patient population? ***Check all that apply***

- ☐ Language accessibility
- ☐ Literacy considerations
- ☐ Digital access
- ☐ Rural vs urban population
- ☐ Cultural relevance
- ☐ Disability accommodation
- ☐ Other:

What resources are required to collect PROs?

What reminders/escalations occur if surveys are incomplete?

How will you balance data needs with patient and clinician burden?

Notes and Next Steps

Chapter 7 | Administering and Scoring Process

PROs can be administered across different settings and using different modalities. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 7 on Administering and Scoring. By the end of this section, teams should have a clearly defined approach to PRO administration and scoring, including agreed methods for ensuring data quality, managing missing data, and supporting equitable participation. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. Where and how will PROs be administered and scored?

Where will PROS be administered? ***Check all that apply***

- ☐ In the clinic
- ☐ At home
- ☐ Both
- ☐ Other:

What technologies will be used for data collection? ***Check all that apply***

- ☐ Paper
- ☐ Patient-owned devices (e.g. smartphone/computer/tablet)
- ☐ System-owned devices (e.g. computer/tablet)
- ☐ Patient portal
- ☐ Voice activated system
- ☐ Phone call from staff

Will you offer multiple PRO completion options? If so, how will data be combined into one system?

B. What quality and error checks can be included in computer assisted/online PRO administration?

How will data quality be ensured?

C. How can the system monitor compliance/alert to missing questions?

How will you alert to and handle missing/incomplete data?

How will PROs be scored? ***Check all that apply***

- ☐ Automatically in the system
- ☐ By hand
- ☐ Other:
- ☐ Not applicable (responses to every item are presented to clinicians or staff)

Can demographic and clinical data on historically disadvantaged groups be used to identify groups at-risk for missing PROs and implement initiatives to support them?

How will you ensure that PROMs are accessible to all patients? For example, how will patients with digital access issues or who speak a different language be reached to complete PROMs during their care?

Notes and Next Steps

Chapter 8 | Incorporating in Clinical Workflow

Incorporating PROs into a clinical workflow is largely an exercise in implementation. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 8 on Incorporating into the Workflow. The questions and tables below are intended to help teams define where PRO processes fit within existing workflows, clarify roles and responsibilities, and anticipate barriers to integration. By the end of this section, teams should have a clearly articulated workflow for PRO collection and use, with defined responsibilities, agreed review points, and a plan for monitoring and improving workflow integration over time. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What are the initial considerations for incorporating PROs into the clinical workflow?

Workflow Step	Where should this occur in your workflow?	Who is responsible?
Deploy PROs to patients		
Collect completed PROs		
Track missing PROs		
Review PRO results		
Document results in record		

B. How do you design a workflow that efficiently captures PRO data?

Describe your current process for each of the following workflow areas, and outline how those processes might need to change to accommodate the implementation of PRO measures.

Workflow Area	Current Process	Needed Change
Patient check-in		
Clinical intake		
Provider visit		
Documentation		
Follow-up processes		
PROs between visits		

Who needs access to PRO data? ***Check all that apply***

- ☐ Physicians
- ☐ Pharmacists
- ☐ Nurses
- ☐ Physical, occupational, and other therapists
- ☐ Psychologists
- ☐ Medical assistants, navigators, or other staff
- ☐ Care coordinators
- ☐ Administrators
- ☐ Other:

How will team members access PRO results during patient care?

When will PRO data be reviewed?

- ☐ Before the visit
- ☐ During the visit
- ☐ After the visit
- ☐ Between visits for monitoring

Describe your approach:

C. What are potential barriers to integrating PROs into the workflow?

Describe potential barriers to PRO integration (also see Chapter 2).

D. How will you evaluate whether the PRO system is well integrated into the workflow?

From whom will you gather feedback about the workflow? ***Check all that apply***

- ☐ Staff

- ☐ Clinicians
- ☐ Leadership
- ☐ Patients generally
- ☐ Patients who lack access/confidence in web-based PROs (e.g., age, sex, race, language, and other demographic characteristics who may have challenges completing PROs)
- ☐ Caregivers
- ☐ Workflow observation
- ☐ Pilot study
- ☐ Formal evaluation through a research study
- ☐ Implementation review meetings

How will this feedback be obtained?

Metrics to consider tracking

Integration Metrics	How will it be measured?	What threshold or indicators will be used to indicate success (e.g., a specified percentage)
PRO completion rate	• % of patients completing at least one PRO • % of patients completing all requested PROs • Number of PRO reports completed over a specified period of time (e.g., 6 or 12 months) • Other:	
Missing data	• % of patients who never completed a PRO • % with decreasing engagement with PROs over a specified period of time (e.g., missing some PROs at 6 or 12 months) • % who stopped completing PROs at any point • Other:	
Representativeness	• Demographic characteristics of patients who never completed a PRO, missed a PRO, etc. • Other:	
Clinician and staff use	• % of providers and/or staff who review PROs with patients during visit(s) • Other:	

Describe your improvement process for metrics not meeting targets:

E. Principles or frameworks guiding evaluation

Will your implementation evaluation be guided by any principles or frameworks for implementation science or quality improvement? Describe.

Notes and Next Steps

Chapter 9 | Presenting Results

Presenting PRO results is an important step in using the information to inform care. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 9 on Presenting Results. By the end of this section, teams should have a clear plan for the presentation of PRO results that specifies timing, audiences, level of detail, and how results will be used to inform conversations and care decisions. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. When should PRO results be presented?

When will PRO results be presented to clinicians or staff? *Check all that apply*

- ☐ Before the visit to help prepare for the encounter
- ☐ During the clinical visit to support discussion and decision-making
- ☐ After the visit for follow-up or monitoring
- ☐ Between visits to support remote monitoring

How will presenting results at these times support patient care?

Who will be responsible for reviewing the results at these points in the workflow?

Which groups should receive PRO results in your setting? *Check all that apply*

- ☐ Patients
- ☐ Caregivers
- ☐ Physicians
- ☐ Pharmacists
- ☐ Nurses or clinical staff
- ☐ Physical, occupational, or other therapists
- ☐ Psychologists
- ☐ Care coordinators
- ☐ Administrators
- ☐ Other:

How will each group use the results?

Audience	How will they use the information?
Patients	
Providers	
Clinical team members	

C. What PRO data from the patient will be presented?

What level of information will be presented in your system? *Check all that apply*

- ☐ Individual item responses (the answers to each question)
- ☐ Domain or subscale scores
- ☐ Overall instrument scores
- ☐ Summary statistics

What additional context will help users interpret the results?

How will the presentation of results support conversations between patients and clinicians?

Notes and Next Steps

Chapter 10 | Visualizations to Aid Interpretation

Presenting PRO results in clear visual formats can help both patients and clinicians interpret the information accurately. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 10 on Visualizations to Aid Interpretation. By the end of this section, teams should have a clear data visualization strategy that specifies which display formats will be used, how results will be contextualized, and how visualizations will support interpretation and discussion across settings and users. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What different ways will be used to display the data?

Which formats will your system use? ***Check all that apply***

- ☐ Numeric scores without labels
- ☐ Numeric scores with labels
- ☐ Tables
- ☐ Line graphs showing change over time
- ☐ Bar charts
- ☐ Color-coded indicators or thresholds for concerning responses
- ☐ Pictographs or icon arrays
- ☐ Other:

How will the chosen formats help patients and clinicians understand the results?

B. What graphics are appropriate for visualizing different types of PROM results?

Which strategies will your system use? ***Check all that apply***

- ☐ Display trends over time
- ☐ Highlight meaningful changes or thresholds
- ☐ Include labels or explanations to clarify responses or scores
- ☐ Provide comparison values (e.g., reference groups or norms)
- ☐ Use color or symbols to indicate severity or concern
- ☐ Other:

What additional information will be included to help interpret the results?

C. How will visualizations support use across different users and settings?

What considerations will guide visualization design in your system? ***Check all that apply***

- ☐ Displays readable on both computer and mobile devices
- ☐ Accessible formats (e.g., screen reader compatible, audio)

- [ ] Simple displays suitable for broad audiences
- [ ] Detailed displays available for those who want more information
- [ ] Integration within existing clinical systems (e.g., electronic health record)
- [ ] Imagery designed for children and adolescents

How will visualizations support discussions between patients and clinicians?

What extra considerations will be needed for patients to be able to interpret the visualization?

Notes and Next Steps

Chapter 11 | Responding to Issues

Collecting and reviewing PRO data is only useful if there are clear processes for responding to issues identified through the results. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 11 on Responding to Issues and helps teams plan how they will respond to concerning PRO data in practice. By the end of this section, teams should have a clear and agreed approach for responding to concerning PRO data, including thresholds for concern, notification processes, roles and responsibilities, and escalation pathways (where required). This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. Should providers have to "accept" PRO data into the record or will PRO responses automatically become part of the patient record?

How will PRO data enter the patient record in your system?

- ☐ PRO data will automatically populate the patient record
- ☐ Providers must review and accept PRO data before it is added
- ☐ A hybrid approach will be used depending on the type of data

How will providers be notified when new PRO data are available?

- ☐ No notification unless there is an alert
- ☐ Notification for all new PRO data

B. What constitutes a concerning PRO response or score?

How will your team determine when PRO responses or scores indicate a potential concern? *Check all that apply*

- ☐ Evidence-based cut points
- ☐ Changes from previous response or score
- ☐ Domain-specific thresholds
- ☐ Clinical judgment
- ☐ Other:

How will alerts be triggered when concerning PRO responses or scores are identified?

C. What should providers do when they receive concerning PRO responses or scores?

What protocols will be in place for responding to PRO data? *Check all that apply*

- ☐ Standard operating procedures for reviewing PRO results
- ☐ Protocols linked to specific PRO thresholds
- ☐ Documentation requirements for responses
- ☐ Clinical follow-up procedures
- ☐ Other:

How will clinicians determine appropriate next steps when concerning results are identified?

Are PRO thresholds used to define improvement or deterioration appropriate for all patient groups?

D. What approaches can be used to notify providers of PRO results?

How will alerts for concerning PRO responses be communicated to providers? ***Check all that apply***

- ☐ Electronic health record notifications
- ☐ Secure clinical messaging
- ☐ Email notifications
- ☐ Text or paging systems
- ☐ Dashboard monitoring systems
- ☐ Other:

How will alerts be managed?

E. What methods will be used to respond to alerts identified by the PROs?

Which approaches will your team use to respond to PRO alerts? ***Check all that apply***

- ☐ Discuss PRO results with the patient
- ☐ Discuss PRO results with the caregiver (requires patient authorization)
- ☐ Follow established disease management pathways
- ☐ Engage multidisciplinary care team members
- ☐ Refer patients to supportive services
- ☐ Provide patient education or self-management resources
- ☐ Other:

What standardized care pathways and referral lists can be linked to common problems?

F. Who should be notified of PRO results?

Who should receive PRO results or alerts in your system? ***Check all that apply***

- ☐ Patient
- ☐ Caregiver (requires patient authorization)
- ☐ Ordering provider
- ☐ Primary care provider
- ☐ Specialist provider
- ☐ Pharmacist
- ☐ Patient navigator or care coordinator
- ☐ Other:

Who will be responsible for addressing alerts?

Team Member	Role in responding to alerts
Physician	
Pharmacist	
Nurse / clinical staff	
Care coordinator	

G. Are PROs ready to drive clinical decision-making?

In your setting, how will PRO data inform clinical decisions?

How will you ensure timely and appropriate responses to concerning results? ***Check all that apply***

- ☐ Defined response time expectations
- ☐ Clear alert thresholds
- ☐ Automated routing of alerts to the appropriate team member
- ☐ Escalation procedures for urgent concerns
- ☐ Other:

Notes and Next Steps

Chapter 12 | Evaluating the PRO Intervention

Evaluating a PRO intervention helps determine whether the system is achieving its goals and where improvements may be needed. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 12 on Evaluating the Intervention and supports developing the PRO system assessment plan. By the end of this section, teams should have a clear evaluation plan that specifies what will be evaluated, how it will be assessed, and how findings will be used to refine and strengthen the PRO system over time. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What outcomes will be evaluated?

Which implementation outcomes will you evaluate? *Check all that apply*

- ☐ Acceptability of the PRO system among patients, caregivers, and/or clinicians
- ☐ Appropriateness for the clinical setting (fit with culture and workflow)
- ☐ Feasibility of implementation
- ☐ Adoption or uptake by clinicians and staff
- ☐ Fidelity to intended workflows
- ☐ Reach or penetration across the patient population
- ☐ Representativeness of patients completing PROs vs. those who are missed (demographic and clinical characteristics)
- ☐ Costs of implementation and maintenance
- ☐ Sustainability of the PRO system
- ☐ Other:

How will these implementation outcomes be measured?

Which patient outcomes might be evaluated? *Check all that apply*

- ☐ Symptom and side effects
- ☐ Use of emergency or acute care services
- ☐ Survival
- ☐ Quality of life
- ☐ Physical function
- ☐ Patient satisfaction with care
- ☐ Other:

How will these patient outcomes be measured?

B. What evaluation methods will be used?

Which evaluation methods will you use? *Check all that apply*

- ☐ Plan-Do-Study-Act (PDSA) cycle(s)

- [ ] Quality improvement study
- [ ] Randomized clinical trial
- [ ] Cluster randomized trial
- [ ] Other experimental study design
- [ ] Quasi-experimental design
- [ ] Time series analyses
- [ ] Observational study
- [ ] Other:

Will the evaluation use:

- [ ] Quantitative methods
- [ ] Qualitative methods
- [ ] A mixed-methods approach

Describe the evaluation approach your team plans to use.

C. What should you do with the results of the intervention evaluation?

How will evaluation results be used? *Check all that apply*

- [ ] Inform improvements to the PRO system
- [ ] Share findings within the organization
- [ ] Share findings with patient advisory boards, patient navigators, and/or patient educators
- [ ] Inform leadership or governance groups
- [ ] Disseminate findings through presentations or publications
- [ ] Guide future implementation or expansion

How will the results be communicated to stakeholders?

If evaluation findings show that the PRO system is not meeting its goals, how will the program be adjusted?

Notes and Next Steps

Chapter 13 | Integrating with Electronic Health Records

Integrating PROs with the electronic health record (EHR) helps ensure that PRO data are accessible to clinicians and incorporated into patient care. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 13 on Integrating with Electronic Health Records and helps teams plan how PRO data will be captured, stored, and accessed within health information systems. By the end of this section, teams should have a clearly articulated approach to EHR integration that specifies how PRO data will be captured, transferred, accessed, and used within clinical systems. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What methods will be used to integrate PROs with the EHR?

Which integration approach will your system use?

- ☐ Full integration within the EHR
- ☐ Stand-alone PRO system connected to the EHR
- ☐ Stand-alone PRO system not connected to the EHR
- ☐ Manual entry or scanned PRO forms uploaded to the EHR
- ☐ Hybrid approach
- ☐ Other:

If not fully integrated in the EHR, how will PRO data move between systems?

- ☐ Automatically transferred from PRO platform to EHR
- ☐ Imported at scheduled intervals
- ☐ Manually entered by staff
- ☐ Other:

Describe your planned integration approach.

What factors will influence your integration approach? *Check all that apply*

- ☐ Compatibility with existing EHR systems
- ☐ Compatibility with patient portal
- ☐ Information technology support
- ☐ Cost of development or licensing
- ☐ Data security and privacy requirements
- ☐ Ability to generate real-time scores and alerts
- ☐ Ease of use for clinicians and patients
- ☐ Other:

How will these factors influence system design decisions?

Notes and Next Steps

Chapter 14 | Governing the System

Governance structures help guide decision-making, oversight, and long-term sustainability of PRO systems. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 14 on Governing the System and supports planning how governance responsibilities will be organized. The questions below are intended to help teams clarify who is responsible for key decisions, how those decisions will be made, and how governance will support safe, effective, and sustainable use of PRO data over time. By the end of this section, teams should have a clearly defined governance structure with agreed membership, responsibilities, and decision-making processes for the PRO system. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. Who should be involved in governing the PRO system?

Who will participate in governance?

Stakeholder Group	Representative(s)/Notes
Clinical leaders	
Physicians	
Pharmacists	
Nurses or clinical staff	
Health system administrators	
Information technology specialists	
Data analysts and informaticians	
Researchers	
Patient representatives	
Clinic manager	
Champions	

How will the governance group be structured?

B. What responsibilities should the governance group have?

Which responsibilities will the governance body have? *Check all that apply*

- ☐ Defining priorities and goals for the PRO system
- ☐ Selecting and updating PRO measures
- ☐ Monitoring system performance and evaluation results
- ☐ Establishing policies for data access and use
- ☐ Coordinating training and stakeholder engagement
- ☐ Identifying future needs or system improvements

☐ Other:

How will governance decisions be made?

Notes and Next Steps

Chapter 15 | Pooling and Exchanging Data

Pooling and exchanging PRO data across systems or institutions can support benchmarking, research, and quality improvement. This section of the workbook aligns with the PROTEUS Practice Guide Chapter 15 on Pooling and Exchanging Data and helps teams planning to pool/exchange data outline the process for doing so. By the end of this section, teams should have a clear plan for pooling or exchanging PRO data that aligns with system goals, supports data quality and equity, and is consistent with governance/ethical requirements. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What are the different architectural approaches?

How will PRO data be pooled and shared across sites, systems, or organizations?

What data architecture or common data model will be used to support pooling and exchange of PRO data?

B. What are the considerations for choosing a data model?

How will your team ensure data consistency, standardization, and interoperability across participating systems?

How will your team track missing PROs across participating systems and how will missing data be remedied? Keep in mind the characteristics of the patient population to ensure everyone is reached (e.g., digital access, speak a different language, etc.)

Does the selected approach allow for disaggregated data when needed?

Are there any existing common data models you will follow?

If so, how will your organization map local data to the chosen model?

Notes and Next Steps

Chapter 16 | Considering Ethical and Legal Issues

This section of the workbook aligns with the PROTEUS Practice Guide Chapter 16 on Ethical and Legal Issues, which emphasizes the importance of considering aspects such as disclosure, consent, and liability of PRO systems. By the end of this section, teams should have a clearer understanding of the ethical and legal implications of their PRO system and an agreed approach to disclosure, consent, data use, and liability. This chapter is designed to be revisited over time, allowing you to build on and refine your responses as your planning and implementation progress.

A. What diversity, equity, and inclusion considerations should be addressed when using PROs?

What strategies will you use to ensure equitable access to PRO completion? ***Check all that apply***

- ☐ PROs available in multiple languages
- ☐ Measures validated for the populations served
- ☐ Non-digital completion options available (e.g., paper)
- ☐ Accessibility accommodations (e.g., visual, audio, cognitive, physical)
- ☐ Monitoring participation across patient groups
- ☐ Staff or volunteer(s) available to help patients complete PROs
- ☐ Other:

How will your system address barriers related to technology access, literacy, or language?

B. What disclosures will be provided to patients when collecting PROs?

What approach will your organization use to inform patients about PRO collection?

- ☐ No disclosure
- ☐ General disclosure about PRO use
- ☐ Brief specific disclosure about how PRO data will be used
- ☐ Detailed disclosure with formal consent
- ☐ Other:

What information will be shared with patients about how their PRO data may be used?

C. How will consent be handled when PRO data are used for multiple purposes?

How will your organization approach consent for reuse of PRO data?

- ☐ No consent for reuse
- ☐ General disclosure about data reuse
- ☐ Specific disclosure with opt-in consent
- ☐ Other:

What types of secondary uses of PRO data may occur?

- ☐ Clinical care
- ☐ Quality improvement
- ☐ Research
- ☐ Population health monitoring
- ☐ Reporting or benchmarking
- ☐ Other:

How will patients be informed about these potential uses?

D. What liability considerations should be addressed?

Who will review legal and regulatory issues related to PRO use?

- ☐ Legal counsel
- ☐ Compliance or regulatory staff
- ☐ Privacy or data security experts
- ☐ Research ethics representatives
- ☐ Community and/or patient advisory boards
- ☐ Other:

How will responsibility for reviewing and responding to concerning PRO results be defined?

How will responses to PRO alerts or concerning results be documented?

Notes and Next Steps

Appendix Materials

This appendix contains resources that may be useful for teams designing, implementing, and managing PRO systems in care. We are grateful to the authors and developers of these tools for allowing us to include them in this workbook.

Appendix A | Organizational Readiness for Implementing Change (ORIC)

ORIC is a validated measure to assess an organization's readiness to implement a specific change. ORIC measures two core components: change commitment and change efficacy. Readiness is an important aspect of implementation for a new intervention, as organizations with higher readiness are more likely to initiate and sustain change, while lower readiness signals a need for additional preparation.

From: Shea, Christopher M., et al. "Organizational readiness for implementing change: a psychometric assessment of a new measure." *Implementation science* 9.1 (2014)

	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree
1. People who work here feel confident that the organization can get people invested in implementing this change.	☐	☐	☐	☐	☐
2. People who work here are committed to implementing this change.	☐	☐	☐	☐	☐
3. People who work here feel confident that they can keep track of progress in implementing this change.	☐	☐	☐	☐	☐
4. People who work here will do whatever it takes to implement this change.	☐	☐	☐	☐	☐
5. People who work here feel confident that the organization can support people as they adjust to this change.	☐	☐	☐	☐	☐
6. People who work here want to implement this change.	☐	☐	☐	☐	☐
7. People who work here feel confident that they can keep the momentum going in implementing this change.	☐	☐	☐	☐	☐
8. People who work here feel confident that they can handle the challenges that might arise in implementing this change.	☐	☐	☐	☐	☐
9. People who work here are determined to implement this change.	☐	☐	☐	☐	☐
10. People who work here feel confident that they can coordinate tasks so that implementation goes smoothly.	☐	☐	☐	☐	☐
11. People who work here are motivated to implement this change.	☐	☐	☐	☐	☐
12. People who work here feel confident that they can manage the politics of implementing this change.	☐	☐	☐	☐	☐

Scoring: 1 = Disagree | 2 = Somewhat Disagree | 3 = Neither | 4 = Somewhat Agree | 5 = Agree

Total score:

Change commitment subscale (items 2, 3, 6, 9, 11,):

Change efficacy score (items 1, 4, 5, 7, 8, 12):

Higher scores indicate higher change commitment and efficacy

Appendix B | Field Observation Method: Site Visit Checklist

This field observation method site checklist presents a structured observation protocol to inform context-specific PRO implementation workflows.

Adapted from: Kaur M. et al., "Field observation as a method to guide patient-reported outcome measurement integration in community cancer centers." *Implementation Science Communications* 7, 39 (2026).

During Clinic Visit

Initial engagement

- Introduce study team members to clinic staff
- Provide a concise overview of visit aims and purpose
- Explain observation methodology and non-disruptive approach
- Answer any questions from clinical staff
- Express appreciation for site participation

Environmental documentation

- Capture photographs of clinic space (if permitted)
- Document clinic layout, workflow patterns, and physical arrangement
- Note the availability and placement of patient education materials
- Observe the placement of technology and potential PRO integration points
- Map patient flow through physical space

Professional protocol

- Maintain non-interference with healthcare team huddles or clinical conferences
- Position observers strategically to minimize disruption
- Avoid patient care areas during sensitive discussions
- Follow all institutional regulations regarding observation
- Ensure that no protected health information is collected

Structured data collection

- Utilize approved forms to document field observations – refine iteratively as needed
- Record timing of key workflow events (patient arrivals, transitions, provider interactions)
- Document observed barriers and facilitators to potential PRO implementation
- Note staff interactions, communication patterns, and workflow bottlenecks
- Document patient characteristics relevant to implementation (e.g., language diversity)

Post-Visit Procedures

Immediate Activities

Data organization

- Consolidate all field notes in the designated secure study folder
- Scan any paper documentation in electronic format
- Organize photographic documentation with appropriate labeling
- Create backup copies of all collected data

- Verify completeness of observation documentation

Confidentiality protection

- Review all field notes for potentially identifying information
- Redact or transform sensitive details to protect confidentiality
- Apply consistent anonymization protocols to all documentation
- Verify compliance with IRB and institutional requirements

Post-Visit Analysis

Team debriefing

- Conduct structured debriefing sessions with the research team
- Document initial impressions, key observations, and emergent themes
- Refine field observation data form as appropriate for subsequent visits
- Identify potential implementation barriers and facilitators
- Discuss methodological challenges and process improvements
- Compare observations with prior implementation site visits

Initial synthesis

- Identify preliminary implementation strategies based on observations
- Document contextual variations that may influence implementation
- Begin mapping observed workflow to potential PRO integration points
- Identify site-specific adaptation needs for the intervention

Stakeholder Engagement

Site feedback loop

- Prepare a summary of field observations for site review
- Send structured observation documentation to the site team
- Request feedback on accuracy and completeness
- Document any clarifications or corrections from site personnel
- Express appreciation for site participation

Integration planning

- Begin drafting site-specific implementation workflow based on observations
- (If appropriate) Identify necessary adaptations to PRO intervention
- Document technology integration requirements
- Develop preliminary training needs assessment
- Prepare for subsequent implementation phases

Appendix C | Equity Checklist for PRO Implementation in Care

This resource is a checklist adapted from the Benkhalti et al. Checklist for Equity Consideration's in Health Technology Assessment to fit considerations related to equitably implementing PROs in clinical practice.

Adapted from: Benkhalti M et al. "Development of a checklist to guide equity considerations in health technology assessment." *International Journal of Technology Assessment in Health Care* (2021);37(1):e17. doi:10.1017/ S0266462320002275

Category	Key Question
Scoping phase	
Defining the problem	Define: equity of what?
	Define population subgroups to consider through the use of a logic model and/or theoretical basis.
	Could the scope of the PRO implementation lead to potential biases for or against specific population groups?
Contextual considerations	What are the opportunity costs of conducting PRO implementation over another? How will the PRO measure be funded and what would be the distribution of the opportunity cost?
	Are there legal contexts to consider regarding institutionalized discrimination?
	Are there historical disadvantages to consider that might impact the choice of variables to assess, the choice of methods, etc.?
Stakeholder involvement	Were all relevant stakeholders included in the scoping process? Does the inclusion of different stakeholders impact/change the process?
	Which are the most appropriate ways of including patient perspectives?
Evaluation	
Outcome measures	Are the outcome measures chosen relevant to patients' perspectives?
	Do outcome measures include the different aspects through which inequities can emerge?
	Are the thresholds used to define improvements or deteriorations in outcome measures appropriate for all population groups?
	Is there an economic analysis and does it include an equity analysis?
Data collection and analysis	Are the methods used to collect and/or identify data conducive to finding data on disadvantaged population groups?
	Are analytical methods appropriate for all groups?
	Do the tools used to assess the evidence incorporate the consideration of equity elements?
	Does the analysis of potential inequities consider the cumulative life experiences of those impacted?
Contextual considerations	Are there any institutional biases that might contribute to inequalities?
	Are there care processes that might contribute to discrimination?
	Does the distribution and supply of services in your context impact inequities in health outcomes?
Stakeholder involvement	Are the methods used to include patient perspectives appropriate and avoid systematic exclusion or under-representation of certain population groups?
	Do the methods used to involve stakeholders allow for all relevant parties to be represented?
Recommendations and conclusions	
Scope	Were the results synthesized using a summary table that included findings relating to inequity?
	Do the recommendations account for the different aspects through which inequities can emerge?
	Are recommendations generalizable to all population groups?
	Could certain recommendations increase inequities?
Contextual considerations	Are there legal contexts to consider in the recommendations?
	Are there historical disadvantages to be considered in the recommendations?
	Are there recommendations relating to a change in culture and/or the institutional system which could contribute to inequities?
Stakeholder involvement	Were all relevant stakeholders included in the scoping process?
	Do the methods used to involve stakeholders allow for all relevant parties to be represented?

	Could certain recommendations increase inequities for specific stakeholder groups?
Knowledge translation and implementation	
Methods and stakeholders	Do the approaches selected to implement recommendations favor certain population groups above others?
	Does the prioritization of recommendations to be implemented favor certain population groups above others?
	Do certain population groups within each stakeholder category require targeted knowledge translation approaches?
Reassessment	
Methods	Does the methodological approach chosen allow for the analysis of disaggregated data by relevant population groups?
Contextual changes	Were certain population groups not considered in previous phases impacted differently?
	Are there contextual changes that might impact PRO implementation outcomes in regard to different population groups?