#### A toolkit to increase adoption

Navigating Patient Reported Outcomes in Cancer Care

# **Mission Statement**

This toolkit represents a call-to-action under the Biden Administration's Cancer Moonshot and dedication to Patient Reported Outcomes across the federal agencies.

We have come together under the belief that patient voices should be centered in all cancer care and understand there is always more work to be done. This resource was developed as a starting point for organizations implementing Patient Reported Outcomes while providing care to patients with a cancer diagnosis.

Patient Reported Outcomes are valuable and impactful across the spectrum of health care, and we encourage all who provide care to consider how to bring Patient Reported Outcomes into their institutions and systems.





# Disclaimers

This toolkit should be considered guidance rather than definitive guidelines and is the result of interagency collaboration and the summation of known best practices.

This toolkit is aimed at organizations looking to kick-start their implementation of Patient Reported Outcomes.

The views and recommendations expressed herein are those of the authors and do not reflect the official policy or position of the Department of Veterans Affairs, the Department of Health and Human Services, or the U.S. Government.

We acknowledge the depth of resources available across public and private organizations dedicated to patient care and improving outcomes using Patient Reported Outcomes.

## User Guide



# How to Navigate



How to Navigate through the PRO Toolkit

#### **Scroll and Jump**

Each of the sections is linked. You'll be able to jump around to different sections using the menus at the top and on the left to find the scenario or topic most important to you.

#### **Materials Access**

- There are downloadable materials sprinkled throughout. You'll be able to 'right-click' or CTRL+click to download them directly to your computer.
- Some materials live on government-hosted websites and are hyperlinked.
- Internet access will be required to access all materials in the toolkit.
- This toolkit is meant to jumpstart the use and implementation of Patient Reported Outcomes within health care organizations.

# **Toolkit Background**

Relaunched by President Joe Biden and First Lady Dr. Jill Biden, Cancer Moonshot aims to mobilize a national effort to prevent more than 4 million cancer deaths by 2047 and improve the experience of people who are touched by cancer. In response to the Cancer Moonshot goals, a federal inter-agency workgroup was chartered to improve Patient Reported Outcomes (PROs) as one of the workgroups charged within the Cancer Moonshot Supporting Patients and Caregivers taskforce.

#### **Reason for Action**

While PROs have been in existence for quite some time, variation still exists in how PROs are defined, used, and adopted across health care settings for cancer care.

#### Goal

To develop and provide a unified federal resource to increase national awareness and adoption of tools that effectively integrate the patient's voice into cancer care by Fall 2024.

#### **Project Deliverables**

- 1. Develop resources in the form of a PRO Toolkit that will support organizations looking to adopt PROs to support people with cancer
- 2. Develop a report to demonstrate the value and use of PROs in clinical research and care, showcasing efforts across the federal government.

# How to Apply the PRO Toolkit

This toolkit provides evidence and federal perspectives using PROs to integrate patients' voices into their care plans.

The resources within this toolkit are to be considered guidance rather than definitive guidelines, and not part of a systematic review. Recommended actions to successfully collect PROs are outlined below.

#### **Step 1: Identify Your Specific Needs**

- Each user is at a different PROs implementation stage contemplation, just starting, working to increase adoption, PRO expert
- Set clear PRO implementation goals
- Review the Getting Started checklist and align your needs

#### **Step 2: Understand How to Navigate the Materials**

• Read the "Getting Started" section of this toolkit fully

#### **Step 3: Review Tools and Resources**

• Explore tools, templates, guides, and resources provided in this toolkit that are relevant to your needs

#### Step 4: Customize Materials as Needed

Use this toolkit as a starting point and customize the materials to meet your needs

## Step 5: Using the Implementation Checklist to Develop an Implementation Plan

• The PRO Implementation Checklist found in the "Getting Started" section of this toolkit is a recommended guide to efficiently set up and use PROs

#### **Step 6: Implement Recommendations**

- Apply the recommendations, strategies, and/or best practices according to your team's identified needs
- Monitor results and make adjustments as needed

#### **Step 7: Share with Others**

 Share the toolkit and actions that worked for you to help others increase their use of PROs

#### Step 8: Stay Updated

• Stay up to date by periodically visiting this toolkit

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#### **PROs Overview**

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# What are PROs?

#### **Patient Reported Outcome (PRO)**

Any report of a patient's health that comes directly from the patient, without amendment.

#### Patient Reported Outcome Measure (PROM)

A structured tool used to collect data on patient-reported outcomes, tested for validity and reliability in the population of interest.

## electronic Patient Reported Outcome (ePRO)

The electronic capture of a patient reported outcome.

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## **Getting Started**

Implementing patient-reported outcomes measurement (PROMs) tools in a health care organization is a crucial step towards enhancing patient-centered care and understanding patient experiences. This checklist is intended to be used as a starting point to help healthcare organizations implement PROMs successfully. Healthcare organizations are encouraged to modify these recommendations to meet their needs.

#### **PROM Implementation Checklist**

Pre-Implementation Checklist

Implementation Checklist

Post-Implementation Checklist



### Patient Reported Outcomes (PRO)

IMPLEMENTATION CHECKLIST (DATE)



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#### PROs Overview

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## **Executive Summary**

This PRO Toolkit was developed to support health care settings in their implementation efforts championed by multiple agencies across the Department of Health and Human Services and the Department of Veterans Affairs. Jointly, these federal agencies recognize the value of:

- Patient-reported outcomes (PROs) for cancer patients and providers
- Creating a cohesive strategy to increase collection and use of PROs to inform cancer clinical trials and for use in cancer care delivery.
- Using PROs to evaluate treatment effectiveness and improve care quality and the patient experience for every cancer patient
- Promoting methods to engage patients and caregivers in shared-decision making and treatment goals
- PROs data to support researchers, clinicians, and health systems to collect, assess and monitor meaningful health information from all patients
- Identifying ways to identify patient needs more in-real-time and facilitating the connection of supportive services to address barriers identified, particularly for minoritized and underserved cancer populations

The contents of this toolkit will serve to support the integration of patients' voices through PROs in their care. We recognize the ongoing work and resources available across the PROs community.

# Importance of PROs

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**Importance of PROs** 

Uses for PROs

Patients with cancer often experience adverse symptoms, as well as a decrease in their ability to function, work, or carry out their day-to-day activities, that are caused by their disease or side effects from treatment.

Cancer treatments can be associated with acute and chronic side effects and late effects can emerge years later.

PROs have been associated with increased patient-provider communication, improvements in survival and other health outcomes, such as decreased emergency department visits and hospitalizations, and improved patient satisfaction with their care experience and quality of life. The continued development of new therapeutic approaches support the collection of health information from patients to track patient symptoms and functioning systematically and effectively. PROs can also support timely intervention when problems are indicated.

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# **Uses for PROs**

Increase patient engagement in their health care because with this information, providers can change their care plans to achieve the outcomes desired by patients.

- Understand and manage disease and treatment-related symptoms and functional deficits
- Understand components of well-being
- Interpret side effects during drug development
- Interpret clinical trial outcomes
- Understand tolerability and safety
- Manage symptoms as they arise
- Understand patient goals and care plan priorities

Safety data have historically been captured exclusively from clinicians; however, it has been recognized that PROs can be used to inform and complement clinician reports. PROs also have the potential to address several areas of unmet need in cancer care.

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Educate the clinical team about PROs and offer courses to meet license renewal requirements and offer continuing medical education credits



Consider using phone or inperson measurement administration instead of a

or broadband is limited

patient portal if internet access



Utilize remote monitoring Current Procedural Terminology codes that could support PROs implementation costs

Partner with private industry (drug, medical equipment companies, EHR and 3rd party vendors) to educate patients on PROs and advance PROs use in patient care Leverage community activities and educate patients about PROs, e.g. in-office, county health departments, fairs, public events, public health websites

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## Health Care Orgs and Providers

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# **Key Considerations**

This section outlines common barriers and recommended strategies to successfully using PROs in health care settings. Please see the Additional Resources section for specific strategies to address each barrier!

#### **Consistent Engagement with Patients.**

It is important to continue engagement with patients, so they know PROs are being viewed by the care team and used to improve their care and care experience.

#### **Electronic Health Record (EHR) Integration Capabilities.**

Engage with vendors to embed PROs into EHR and patient portals to improve workflow integration and actionability of information; select platforms that meet your organization's needs; engage practice leadership including, but not limited to, the Chief Technology Officer (CTO) for your organization early and often in the process of considering what PROs/ePROs makes sense for your organization.

#### Provider Buy-In.

Physicians and other care providers may already be inundated by patient load, reporting burden and other clinical requirements – as such, bringing the Provider into the process early is critical to both show the benefits of PROs but also to inform PROs implementation. Having a provider champion is key to wider adoption of PROs and for successful PROs implementation.

#### Lengthy Surveys.

It is important that measures are brief, relevant, and can be completed in a short period of time (e.g., no longer than 5-10 minutes per assessment). The goal of PROs are to be collected often to identify and monitor concerns in real-time. There are now many options to minimize the number of questions asked while still providing the relevant information.

## Health Care Orgs and Providers

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Preparing for Questions About PROs

# Preparing for Questions About PROs

#### What are patient-reported outcomes (PROs)?

PROs are any report of a patient's health that comes directly from the patient without amendment of the patient's response.

#### Why are PROs important?

PROs provide insights into the patient's perspective on their health and well-being, helping to inform clinical decisionmaking, evaluate treatment effectiveness, and enhance patient-centered care.

#### How are PROs collected?

PROs are typically collected through standardized questionnaires, surveys, or interviews administered to patients either in person, over the phone, or electronically.

#### What types of information do PROs capture?

PROs capture a wide range of information, including physical symptoms, emotional well-being, functional status, social interactions, and overall quality of life.

#### What are some common PRO measures?

Common PRO measures include health-related quality of life (HRQOL) questionnaires, disease-specific symptom scales, functional assessment tools, and psychosocial well-being measures.

## Health Care Orgs and Providers

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# Preparing for Questions About PROs

#### How are PROs used in clinical practice?

PROs are used in clinical practice to monitor patient symptoms and functioning over time, assess treatment outcomes, support shared decision-making, and evaluate healthcare interventions and programs.

#### What are the benefits of using PROs?

Benefits of using PROs include enhancing patient-centered care, improving communication between patients and healthcare providers, identifying unmet needs, tailoring interventions to individual patients, and promoting patient engagement in their own care.

#### What challenges are associated with using PROs?

Challenges may include patient/provider burden associated with completing PROMs instruments, interpreting PRO scores and timeliness of response in clinical practice, integrating PRO data into electronic health records, and selecting appropriate PRO measures for specific populations and contexts.

#### How can health care organizations incorporate PROs into their practice?

Health care organizations can incorporate PROs into their practice by implementing standardized PRO measures, training staff on PRO administration and interpretation, integrating PRO data into clinical workflows, and using PRO data for quality improvement initiatives.

#### Where can I find more information about PROs?

More information about PROs can be found through professional organizations, research publications, clinical practice guidelines, and online resources provided by government agencies and health care institutions. Additional resources are available at the end of this toolkit.

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# Patients and Caregivers

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#### Social Media Template Images

# Information for Patients and Caregivers

By leveraging multiple channels of communication, healthcare systems implementing PROs are more likely to reach patients with the right information at the right time.

#### Light touches, multiple times

In rolling out PROs, it's important to consistently explain what PROs are in multiple "areas" of a patient's interaction with the organization. More than just a single social media post, or a mention by a medical assistant, PROs need to be messaged consistently and through multiple mechanisms.

#### Leveraging the Toolkit

This toolkit contains multiple patient-facing education and outreach materials that can be used with minimal customizing. One communications roll-out strategy might be to use the digital posters (on right) within patient waiting rooms while having the patient education flyer available as a hand-out to take home after the appointment, prior to the collection mechanism being sent out to the patient.



Patient Reported Outcomes ensures you get fair treatment, helps manage any symptoms you might have, all while improving standards of care.

#### Your Voice Matters and Your Care Team is Listening

Introducing Patient Reported Outcomes: self-reported assessments of your health status, experiences, and outcomes. You might be thinking, "Another survey? Really?" But rest assured, what you share directly impacts the care you receive. It's not just about ticking boxes—it's about making sure you get the best possible support tailored to your needs. When you share your experiences, your care team gains a deeper understanding of your unique situation, and can work closely with you to make decisions about your care.

> Patient Reported Outcomes ensures you get fair treatment, helps manage any symptoms you might have, all while improving standards of care.

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## Patients and Caregivers

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# Information for Patients and Caregivers

By consistently messaging how PROs are informing care delivery, patients can feel confident that they are connected to their care team, feel heard, and feel better.

#### Heard, Connected, and Concerns Addressed

PROs help patients directly and clearly communicate about their symptoms, experiences, and health goals. PROs empower patients.

#### Self-Reported Information

PROs are relevant at every stage of a patient's care journey – from routine primary care encounters to complex cancer treatments and palliative care.

#### INCENTIVES FOR USING PATIENT REPORTED OUTCOMES

Another survey? What are Patient Reported Outcomes?



Patient-Reported Outcomes are self-reported assessments of your health status, experiences, and outcomes. Your care team will use the information to make sure you get the care you need.

#### Whats in it for me?

#### Feel Heard

#### PROs can

- · Help you share your symptoms and experiences clearly with your health care providers
- · Support your care team in planning your treatment and anticipating your care needs
- Help your care team understand your Treatment goals Detection of Health Status Changes

#### Feel Better

#### PROS can

- · Help find symptoms and side effects early so they can be managed effectively
- Help your team of caregivers do a better job of keeping track of your health in the long-term

#### Feel Connected

#### PROS can

- Help the health care team understand the full picture of your quality of life, including your
  emotional and social well-being
- Empower you having a say in your care planning that reflect your individual priorities.

Patient Reported Outcomes (PROs) are a report of a patient's health that comes directly from the patient without amendment or interpretation of the patient's response.

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## Information for **Health Care Agencies**

PROs implementation has a number of potential benefits including but not limited to, improving the financial health of your organization and furthering value-based care and guality improvement initiatives. PROs may lead to more effectively leverage resources and enhanced patient-provider communication.

#### **Holistic Benefits**

As a leader in a healthcare system, being able to address how implementing PROs is holistically beneficial for the organization can significantly increase buy-in.

#### **Buy-in & Strategic Practices**

By leveraging pieces of this toolkit, including the flyer to the right, you can begin to engage the system's different stakeholders. Check out the Promising Practices section in the appendix for more ways to increase buy-in!

#### **INCENTIVES FOR USING** PATIENT REPORTED OUTCOMES

Patient Reported Outcomes (PROs) is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else. The adoption of PROs offers a wide range of incentives across the health care landscape.

#### HOW PROS BENEFIT YOUR FACILITY

PROs implementation can positively influence the financial health of your organization, operate as a direct demonstration of value-based care, more effectively leverage resources, and support quality improvement initiatives.



#### FINANCIAL INCENTIVES

Financial incentives can play a significant role in encouraging health care providers and organizations to actively adopt PROs. Incentives may take the form of:

- Reimbursement adjustments Quality-Based Payment programs
- Grants and funding opportunities Value-based care contracts
- Pay-for-Performance models
- Performance bonuses These incentives are designed to offset costs, recognize efforts, and promote the integration of PROs into routine clinical practice.

#### DEMONSTRATE VALUE-BASED CARE

- Shows health care organization's commitment to providing and improving patient-centered outcomes
- Increases ability to achieve better overall health care value

Targeted interventions and timely

hospitalizations, emergency department visits, and other

expenditures.

referrals can prevent unnecessary

Decreases cost long-term

#### ENCOURAGE MORE EFFICIENT USE OF RESOURCES

PROs allow health care agencies an increased ability to proactively monitor patients' symptoms and functional status, leading to better management and allocation of resources

#### INITIATE QUALITY IMPROVEMENT

- Aids health care organizations in identifying trends in patient-reported data and helps identify areas for improvement
- Increases ability to target interventions to both the individual and populations of patients
- Contributes to trending outcomes of clinical and non-clinical interventions



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Example Email Template

Are you planning to collect patient-reported outcomes in your organization? Keep your patients informed with this handy email and postcard template. Just copy and paste into your organization's email or letterhead template and send! Remember to modify as appropriate if you're a larger system rather than a clinic!

Subject: We want to hear from you! Join Our New Patient Program

Dear [Patient's Name],

Our [clinic] is starting a new program to help us understand your symptoms between visits. The program will implement patient-reported outcomes into your care. Patient-reported outcomes are tools used to monitor treatment-related symptoms between clinical visits.

If you agree to participate, you'll fill out a short questionnaire for every [insert cadence] that will be sent via email. It takes 5-10 minutes to complete. This will help you share how you're feeling with your care team. Your care team will see your answers and may discuss them with you at your next visit or give you a call.

The questionnaire includes [XX] questions about how you feel. For example, one of the questions might be: "On a scale of 0 to 10, how would you rate your pain?" Every [insert cadence], we will provide you with an opportunity to respond to questions.

Please remember, if you have a medical emergency, call 9-1-1. Do not use the questionnaire for emergencies.

The program starts on [insert start date]. If you have questions during the program, please contact [insert contact here].

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## **Example Postcard Template**

Our [clinic] is starting a new program to help us understand your symptoms between visits. The program will implement patient-reported outcomes into your care. Patient-reported outcomes are tools used to monitor treatment-related symptoms between clinical visits and can measure disease-related symptoms and function, and the overall impact of your cancer treatments. You'll hear from us again soon via [email] so you can share about your experience!

Your team may already be implementing PROs and we encourage you to tailor this language as appropriate.



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- Sample Social Media Posts
  - [Name of Healthcare Organization] just empowered patients to share their health experiences by adopting and using **#PROs4CancerCare #YourCareYourVoice**
  - Data from Patient Reported Outcomes helps our healthcare providers at [Name of Healthcare Organization] tailor treatments to individual needs! #YourCareYourVoice #PROs4CancerCare
  - [Name of Healthcare Organization] used the #PROToolkit to identify strategies to increase the value and adoption of PROs across our organization. #PROs4CancerCare #YourCareYourVoice
  - Tracking Patient Reported Outcomes at [Name of Healthcare Organization] has led to earlier interventions and better management of chronic conditions. #PROToolkit #PROs4CancerCare
  - Your healthcare needs are important! [Name of Healthcare Organization] uses PROs to strengthen patient-provider relationships! #YourCareYourVoice #PROs4CancerCare

Stay connected with your patients and remind them about the value of filling out their PRO surveys with these social media posts!

Use the Official Hashtags

#### #PROs4CancerCare #PROToolkit #YourCareYourVoice

Using the official hashtag is a best practice that helps audiences find your post and connect with others around the health care industry!

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Template 2

Your

are Your

Voice

## For Health Care Systems

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#### **Template 1**



**Template 4** 



#### Template 3



**Template 5** 

#YourCareYourVoice



Stay connected with your patients and remind them about the value of filling out their PRO surveys with these social media posts!

#### Enhancing Patient Reported Outcomes

# **Additional Resources**

# 5 Strategies to Increase Buy-In

Increase your buy-in from patients, providers, and practice leadership using these 5 strategies:

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### Educate

Educate patients, providers, and practice leadership about the value of **PROs** 

#### Make PRO Collection 03 Easy

Embed PRO collection into the clinical workflow, including, but not limited to **EMR** integration

#### Actionable 05

Use PROs data to track, monitor and evaluate individual and population health trends to improve patient care."



### Communicate

Launch a communications campaign to demonstrate the value of PROs



#### Demonstrate

Show how PROs can be used to inform clinical decisions, drive improvements, and enhance outcomes

## 5 Strategies to Maximize Resources

Maximize your resources using these 5 strategies across the organization.

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**Clear Roles and** 01

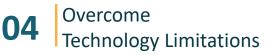


Ensure all staff understand the entire PRO collection process: reason for survey, questions, data collection, responses, audits



## **Team Effort**

A variety of options exists for using and administering PROs – determine available resources to fit your needs



Consider using alternative modalities to collect PRO data: telephone, in-person, mail, etc.

#### **Embed PRO Data** 03 Into EHR/Patient Portal

Engage with vendors and select platforms that best meet your organization's needs

#### Train Your Staff 05

All staff can benefit training on the value and use of PROs

# <u>5 Strategies to Maximize Responsiveness</u> with Patients

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Ensure staff fully understand how to administer or use PROs and what actions to take on the responses

#### **D3** Leverage Community Outreach

Partner with community organizations to connect patients with resources identified by PROs (e.g., transportation barriers, food insecurity etc.)



Offer multiple options: Electronic collection (ePROs), App, patient portal or website, interactive voice response systems, SMS Text systems, waiting room via tablets



#### Increase Completion Rate

Select meaningful questions and limit the number of questions. Be intentional about question content as each question will impact completion rate. Monitor responsiveness, so patients know their information is being received and their voices are heard

#### 04 Minimize Cognitive, Language or Physical Barriers

Engage with supportive services to assist with health literacy and comprehension of PRO questions during survey completion. Provide language translation or interpretation services in accordance with federal law and policy

# <u>3 Strategies for Monitoring and Using PROs for Cancer</u> Care & Treatment Improvements

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Define Expectations For HowYou Plan To Use Pros For YourPatient Population

Expected impact on patient outcomes, thresholds for action, symptom management, patient/provider communication, satisfaction



Establish clear process for managing the use, storage and analysis of data



Integrate PROs as part of your organization's culture by consistently messaging the importance of the patient's voice in their care planning

# A Responding to Patient Feedback

Establish clear process and threshold that necessitates outreach to a patient about feedback.

# <u>3 Strategies to Standardize PROs</u> at Your Organization

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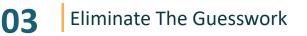
Acknowledgements

**01** Clearly Define Success

Promote the use of PROs by setting clear measures of success and sharing the results

**02** Standard Operating Procedures

Create clear SOPs for 1) What actions to take when interpreting PROs, 2) How Often To Collect PROs, and 3) Tools to use to Collect PROs



Use the PRO Toolkit Implementation Guide to guide you through your journey for adopting and using PROs at your organization

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# Federal Agency Resources

Federal Agencies have launched guidance and resources to support the use of PROs, which remain a critical resource for utilizing PROs. Below is a list of resources you can review that might be beneficial for your adoption of PROs and use of PROMs.

AHRQ – Integrating Patient-Generated Health Data into Electronic Health Records in Ambulatory Care Settings: A Practical Guide

**CMS/CMMI** – Enhancing Oncology Model (EOM) Electronic Patientreported Outcomes Guide & EOM ePROs Factsheet This guide has great provider-patient scripts in the appendix!

**ASTP** - <u>Advancing the Collection and Use of Patient-Reported Outcomes</u> <u>through Health Information Technology</u> Additional Resources

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A very sincere thank you to the inter-agency workgroup representatives who contributed to the development of this toolkit. Their dedication, knowledge, insights, and time have been instrumental in bringing this resource to fruition.

- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Medicare and Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- The National Cancer Institute (NCI)
- Assistant Secretary for Technology Policy\*
- The Department of Veterans Affairs (VA)

Together, this team has created a comprehensive resource that will empower patients, caregivers, and healthcare agencies to utilize PROs meaningfully and effectively.

The views and recommendations expressed herein are those of the authors and do not reflect the official policy or position of the Department of Veterans Affairs, the Department of Health and Human Services, or the U.S. Government.

# Acknowledgements

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