GUIDE

Patient Reported Measures Team

Patient Reported Outcome Measures

The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- **service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
- **specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment
- **initiatives including guidelines and models of care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system
- **implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW
- **knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement
- **continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

www.aci.health.nsw.gov.au
Acknowledgements

The Agency for Clinical Innovation (ACI) acknowledges the traditional owners of the land that we work on, the Cammeraygal people of the Eora nation. We would like to acknowledge any Elders past or present.

The ACI would also like to thank and acknowledge all contributors to this guide which has been developed by the Patient Reported Measures Program team at ACI.

Glossary

<table>
<thead>
<tr>
<th>ACI</th>
<th>The NSW Agency for Clinical Innovation</th>
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</thead>
<tbody>
<tr>
<td>ACSQHC</td>
<td>The Australian Commission on Safety and Quality in Health Care</td>
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<tr>
<td>HRQoL</td>
<td>Health related quality of life</td>
</tr>
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<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>PREMs</td>
<td>Patient reported experience measures</td>
</tr>
<tr>
<td>PROMs</td>
<td>Patient reported outcome measures</td>
</tr>
<tr>
<td>PRMs</td>
<td>Patient reported measures</td>
</tr>
<tr>
<td>REDCap</td>
<td>Research electronic data capture</td>
</tr>
</tbody>
</table>
# Contents

Acknowledgements .................................................. ii
Glossary ............................................................. ii

## Contents

iii

### Introduction

- Patient Reported Measures .................................. 1
- Patient Reported Outcome Measures ....................... 1
- Purpose of this guide ........................................... 1
- Intended audience ................................................. 1

### Patient Reported Outcome Measures

- Data collection ................................................ 2
- User access to the PRM system ............................... 2
- User types ....................................................... 2
- Access to the PRMs system via portable devices ......... 3
- Log in to REDCap .............................................. 4
- Register a patient .............................................. 5
- Access PROM survey selection ............................... 8
- To access the PROM survey for patients to complete .... 11
- Edit a record .................................................... 12
- Accessing Individual Patient Reports ...................... 13

### Implementation questions

- Questions for services considering implementing PROMs .... 16
- Frequently Asked Questions .................................. 16

### Appendix – Quick reference guide

18
Patient Reported Measures

Patient Reported Measures (PRMs) capture outcomes and experiences that matter to patients. The NSW Agency for Clinical Innovation (ACI) PRMs Program aims to enable patients to provide direct, timely feedback about their health related outcomes and experiences. This feedback is intended to drive improvement and integration of healthcare across NSW. Additionally the program aims to add value to the patient and clinician, the healthcare service and the system. PRMs can be broken into two specific groups:

- Patient Reported Outcome Measures (PROMs)
- Patient Reported Experience Measures (PREMs).

Patient Reported Outcome Measures

PROMs capture the patient’s perspectives about how illness or care impacts on their physical, mental, emotional health and wellbeing. PROMs are used to provide real time feedback to clinicians about what matters most to patients in regards to their care, treatment and overall quality of life.

In the PRMs Program, standardised and validated tools are used to measure patient outcomes including quality of life and symptoms related to specific treatments, symptoms, diseases or conditions. It is important that PROMs are completed directly by the patient (or carer). This information can then be used in care planning and decision making to provide timely person-centred care and ensure appropriate referrals based on identified patient needs.

The diagram below shows a typical patient journey for a participant in the PROMs program.

Purpose of this guide

This guide explains PROMs and outlines the process for administering and reporting PROMs to ensure that:

- measuring PROMs becomes business as usual for patients and clinicians
- PROMs data is integrated into shared decision making and care planning with patients.

Intended audience

This guide is intended for use by NSW clinicians and service administrators who are implementing PROMs and using PROMs data. Users will include clinicians, managers, service providers, care coordinators, and project staff across NSW Health, primary care and community-based settings.
Data collection
Currently a secure web based application, REDCap, is used to support the collection and use of PROMs and to manage the online surveys and database. PROMs data is hosted in a ‘.gov’ domain and adheres to NSW Health’s privacy and confidentiality policies. As part of the NSW Health Integrated Care Strategy, aggregated and de-identified data may be used to evaluate the integration of care across NSW. The ACI PRM team will be implementing a new IT solution in mid 2018, all existing sites will be migrated across to the new IT solution.

User access to the PRM system
The term ‘Users’ in this context, are healthcare providers or clinicians who have access to the web-based REDCap application and PRMs reporting. ‘Participants’ are patients who will be completing PROMs surveys. You will receive your user name and password for the below links when you start working with the ACI PRMs team – if you haven’t yet, please contact your ACI PRMs team support person.

Clinicians register patients and access the individual patient PROMs surveys via: prm.health.nsw.gov.au

Individual patient responses following completion of the PROM surveys generate the patient’s individual report which can be accessed via the reporting portal. prm.health.nsw.gov.au/reports/

User types
There are two types of user access to the system: local project users and local super users.

Local project user
Local project users are all PROMs users at sites capturing PROMs. They can:
• add new patients
• review survey responses
• generate patient specific survey codes
• view reports

Local Super Users
Local super users are the PROMs project coordinators at sites capturing PROMs. They can:
• do all the functions of local project user
• edit responses to surveys.


Access to the PRMs system via portable devices

Electronic portable devices can be used to access the surveys and patients reports. Note that registration of patients should be completed on your local computer and not on the portable devices.

The diagram below shows the icons on the front screen of the portable device to access:

- PROMs survey codes (PRM website)
- the PROMs surveys (PRM question sets)
- the completed individual patient reports following completion of the surveys (PRMs reports)
- To access training videos (FileDock).

You can also access Patient Reported Experience Measures (PREMs) through the Surveyor icon if your service is collecting these as part of their PRMs program (see PREMs guide for further information).
Log in to REDCap


2. Enter your PRMs username and password in the boxes shown.
   If you forget your password click the ‘Forgotten Password?’ link and follow the instructions.

3. Click on the ‘Log In’ button.

4. Click on the ‘My Projects’ tab in the top toolbar.

5. Select ‘PROM’ from the Project title list shown.
Register a patient

Patients who have agreed to participate in the PRMs program are enrolled via the patient registration form. Note: Patients need to be registered before they can access a PROMs survey.

Once you have logged in you can register a patient.

1. To register a patient, click on ‘Add/Edit Records’ from the Data Collection menu.
2. Click on the ‘Add new record’ button.
3. Click on the grey dot next to the Patient registration form in the Data Collection Instrument column.
4. In the next screen the patient registration form will appear. Complete all required details.
5. Select ‘Complete’ from the form status dropdown box.
6. On the ‘Save and Exit Form’ button.
7. Document the Record ID.

The Record ID for this patient will be displayed on the record home page. This Record ID number will be the patient’s unique identifier number for the PROMs system. ACI has a spreadsheet you can use to document these numbers, or you can develop a local process.

A green dot on the record home page indicates the registration was completed.

Training facility for new users to gain competency with the PROM process

PROM TEST has been set up on the system for training purposes.

PROM should only be used for patients joining your PRM Program.
To add/register a patient, click Add/Edit Records.

Click on Add new record.

Click on the grey status icon (dot) to access the Patient Registration Form.
In the next screen the Patient Registration Form will appear. Complete all required details.

On completion of the registration form select Complete. Click Save & Exit Form.

This shows the Record ID number for the patient registered.

The green dot identifies that the registration form is complete. The legend box outlines the colour codes for issues with completion of forms.
**Access PROM survey selection**

1. After registering a patient go to the left hand panel and select ‘Record Status Dashboard’ from the Data Collection Menu. The Dashboard shows the patients – described by Record ID – and the surveys available. The status icons indicate if a survey has been completed.
   - See ‘Editing a record’ section for how to search for a patient’s record id.
2. Click on the grey status icon in the patient row and survey column to open the survey for that patient.
3. Select the language.
4. Click on the ‘Survey options’ drop down box.
5. Select the way your patient will access their survey.
   a. Survey Access Code and QR Code (preferred option) - to administer the survey on a portable device.
      i. Note down the long or short access code (lasts for 1 hour) alongside the patient Record ID or print for file. If you lose the access code you can go through the process again and it will give another code to access the survey.
   b. Open survey – this will access the survey for completion on your computer.
      i. Click on compose survey invitation.
      ii. Complete To, Subject and Compose box.
      iii. Click send invitation.
   c. Compose survey invitation – use this to email the survey to a patient.
      i. Click on open survey.

Select Record Status Dashboard to see the surveys available for a patient.
Record Status Dashboard (all records)

Displayed below is a table listing all existing records/responses for every data collection instrument (and if longitudinal, for every entry of the colored buttons in the table to open a new tab/window view that record on that particular data collection instrument. Form-level user privileges are restricted for certain data collection instruments: you will only be able to view those instruments, and if you belong to a group, you will only be able to view records that belong to your group.

Displaying: instrument status only | Lock status only | All

<table>
<thead>
<tr>
<th>Record ID</th>
<th>Patient Registration Form First Appointment</th>
<th>PROMIS 10 Global Health Form First Appointment</th>
<th>DASS 21 First Appointment</th>
<th>COPD (CAT) First Appointment</th>
</tr>
</thead>
<tbody>
<tr>
<td>229-1</td>
<td>●</td>
<td>●</td>
<td>( )</td>
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<tr>
<td>229-2</td>
<td>●</td>
<td>●</td>
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<td>( )</td>
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<tr>
<td>229-3</td>
<td>●</td>
<td>●</td>
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</tbody>
</table>

This page identifies the Record ID for patients registered on your PROMs program.

Click the grey dot against the PROM you would like to access. This will then take you to the requested survey.

1. Select language.
2. Click Survey options drop down box.

Select the way your patient will access their survey:
- open survey – this will access the survey for completion on your computer, or
- compose survey invitation – use this to email the survey to a patient, or
- to administer the survey on a portable device (preferred option), click Survey Access Code and QR Code.
This screen will now be displayed.

This access code is unique for this patient and only for this survey.

The short access codes will only last one hour if you choose this option. If you lose the access code you can go through the process again and it will give another code to access the survey. 

Note down the access code alongside the patient Record ID for use with the portable device.
To access the PROM survey for patients to complete
- click ‘open survey’ in REDCap on your computer or
- click ‘PRM Question Sets’ on the portable device or
- go to prm.health.nsw.gov.au/surveys/

Enter the patient’s unique access code to begin the survey and click submit. The chosen survey will now be displayed.

Choose the language required for completion.

Once the patient has completed the survey they should click submit located at the bottom of the last screen.

Press Close survey to complete the process.
Edit a record

1. Click on ‘My Projects’ from the left hand navigation panel.
2. Click on ‘PROM’ from the Projects list.
3. Click on ‘Add/Edit Records’ from the Data Collection section of the left hand navigation panel.
4. Under Data search select the appropriate search parameter and enter the information into the subsequent text box.
5. Select the appropriate patient from the ‘select record’ drop down menu.
6. Click on the green status icon of the Patient Registration Form to open the patient record.
7. Edit the information.
8. Click on the Save & Exit Form button.
Accessing Individual Patient Reports
To access the patients individual reports go to: prm.health.nsw.gov.au/reports/ on your computer.

1. Go to prm.health.nsw.gov.au/reports/ or click on the ‘PRM reports’ icon on your portable device.
2. Login using the healthcare provider email address and the password assigned to you.
3. Click on the Global Health Report button.
4. Click on the name of the patient from the Patient List. The report will be displayed.
   a. To save the report to another system see Appendix 2
   b. To print click the ‘PDF’ button.
   c. To access the PROMs questions, click the ‘Question set’ button.
The report will include the patient’s previous results for comparison.

If you would like to save the report to another system see Appendix 2 or to print click PDF.

To access the PROMs questions, click Question set.

All your patients’ names will be listed. Select the patient’s First Name to review their PROM reports.
Print and save options are located in the header tool bar. Close the report by clicking X in top right hand corner of the screen.

To log out of the reporting portal click logout in top right hand corner of the screen.
Implementation questions

Questions for services considering implementing PROMs

- What is your practice or service setting?
- What existing local software are you using and how will it link with REDCap?
- Which patients would you like to select? Are you considering all patients or a condition-specific cohort?
- What validated tools would you like to use? A quality of life survey and/or condition-specific?
- Who will be involved in each part of the patient journey process?
- How will your practice or service manage the informed consent to participate in PRMs?
- Registering patients – who will complete this action and when and where will it take place?
- How will you document patient record identification and access codes for surveys?
- How will you help patients to complete the survey on the portable device if they require guidance and support?
- Who will access the patient reports in your practice or service setting?
- Who will discuss the reports with the patients? The reports are available immediately after completion and ideally should be discussed during the consultation.
- Who will refer patients on to other services if required?
- Who will support the patient with information including:
  - invitation to register
  - information about the PRMs program
  - information to support clinical needs?
- Who will coordinate the follow up appointment for scheduling the next set of PROMs?

Frequently asked questions

Why should my service partner with the ACI to implement a PRMs Program?

The PRMs Program staff have found that although services may be capturing outcomes measures for some patients, this process does not always occur systematically and routinely, or in a way that consistently enables patients to provide direct timely feedback to inform care. Capturing PROMs in a consistent and structured way allows tracking and trending of patient outcomes, and evaluating experiences, over time. The ACI have now worked with many teams and can share lessons learnt about implementation to include challenges, barriers, facilitators and enablers. In addition the PRMs staff from ACI can provide education, training and support to help you to implement a robust PRMs system in your service.

What are the benefits of using PROMs for my service?

PROMs enable a consistent and structured method for capturing and using patient reported outcomes in real time, supporting services to identify and respond to outcomes that matter to patients. The use of PROMs aligns with accreditation standards regarding partnering with consumers and ensuring that care is responsive to the needs and preferences of patients.

What financial and time investment is there?

Engaging with the ACI for your PRMs Program is free of charge. It is advised that local services establish a small dedicated project team to implement and sustain the PRMs Program in their setting. The implementation of a PRMs program certainly involves some workflow changes and sometimes also cultural change. The identification of a small group of key team members, from the clinical and administrative staff, to facilitate and champion implementation, can provide services with the support that is needed to implement and sustain change.

How do I receive my PROMs results?

PROMs results are presented in real time for individual patients via the reporting portal. The reports can be filed locally.

Where does the PROMs data go?

All data in the PRMs portal sits in a secure location on the NSW Health server. As part of the NSW Health Integrated Care Strategy, aggregated and de-identified data may be used to evaluate the integration of care across NSW.
Will the PRMs information technology system integrate with the systems currently used in my service?

It is anticipated that the new information communication technology system for collection of PRMs, currently being developed, will integrate with existing electronic medical record systems, in the next phases of the PRMs Program.

When can my service start with the PRMs Program?

Your service can start as soon as staff have received appropriate education and training, and local processes for implementing PRMs in your setting have been determined.

How will my patient population use the PRMs system?

While some patients may need support with their initial engagement with the devices used to record PRMs, most find it acceptable after an initial explanation.

What are the right validated questions sets to use?

There are hundreds of questions sets that exist across the world. It is important to find validated tools for your patient population or condition specific questions for your setting. The PRMs Program staff from ACI can spend time with you upfront to ensure that the selected surveys suit your patients and service.

How do we build the collection and use of PROMs into business as usual?

Initially, getting the process to fit in with current work flows can take some extra time and consideration. However once this is achieved, clinicians and services have advised ACI that collecting PROMs can fit in with business as usual and sometimes the collection of PROMs can even save them time in their consult by honing in early in the consultation on outcomes that matter to patients.
<table>
<thead>
<tr>
<th>1. <strong>How do I log in to PRMs?</strong></th>
<th>4. <strong>How do I know if patients have completed their surveys?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Enter username</td>
<td>You will be taken to a new screen</td>
</tr>
<tr>
<td>3. Enter password</td>
<td>2. Review the information presented on your screen for each patient using the legend in the top right hand corner.</td>
</tr>
<tr>
<td>4. Click the ‘Log In’ button.</td>
<td></td>
</tr>
<tr>
<td>If you forget your password click the ‘Forgotten Password?’ link and follow the instructions.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. <strong>How do I register a patient?</strong></th>
<th>5. <strong>How do I access the patients live reports?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>You will be taken to a new screen</td>
<td>You will be taken to a new screen</td>
</tr>
<tr>
<td>2. Click the ‘Add New Record’ button</td>
<td>2. Login using the healthcare provider email address and the password assigned to you.</td>
</tr>
<tr>
<td>3. Click ‘Patient Registration Form’ from the screen or the left hand navigation panel</td>
<td>3. Click on the ‘Global Health Report’ button.</td>
</tr>
<tr>
<td>4. Complete the form with patient details</td>
<td>You will be taken to a new screen</td>
</tr>
<tr>
<td>5. Click save and exit form (bottom of the form)</td>
<td>4. Select the patient whose report you want to review from the drop down box.</td>
</tr>
<tr>
<td>You will be taken to a new screen</td>
<td>5. Click submit.</td>
</tr>
<tr>
<td>6. Note the Record ID listed at the top of the form.</td>
<td>You will be taken to a new screen</td>
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<thead>
<tr>
<th>3. <strong>How do I access the surveys for patients to complete?</strong></th>
<th>6. <strong>How do I edit a patient’s details?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If you have the patients Record ID go to ‘Record Status Dashboard’. If you need to search for a patient go to ‘Add/Edit Record’ and search name.</td>
<td>1. Click ‘My Projects’</td>
</tr>
<tr>
<td>2. Search for a patient as per the editing a patient’s detail instruction.</td>
<td>2. Click ‘PROM’.</td>
</tr>
<tr>
<td>3. Select the survey from the available list which you would like the patient to complete for example PROMIS10.</td>
<td>3. Select ‘Add/Edit Records’ from the left hand navigation panel.</td>
</tr>
<tr>
<td>You will be taken to a new screen</td>
<td>You will be taken to a new screen</td>
</tr>
<tr>
<td>4. Click on survey options drop down box in the top right hand corner.</td>
<td>4. Under ‘Data search’ select the appropriate search parameter and enter the information into the subsequent text box.</td>
</tr>
<tr>
<td>a. To complete on tablet device (preferred choice):</td>
<td>5. Select the appropriate patient from the drop down menu.</td>
</tr>
<tr>
<td>i. Click ‘Survey Access Code’. Note down long code or short code (lasts for 1 hour) or print for file.</td>
<td>You will be taken to a new screen</td>
</tr>
<tr>
<td>b. To send a patient a survey via email:</td>
<td>6. Edit the information and click save and exit form.</td>
</tr>
<tr>
<td>i. Click on ‘Compose survey invitation’.</td>
<td></td>
</tr>
<tr>
<td>ii. Complete To, Subject and Compose box.</td>
<td></td>
</tr>
<tr>
<td>iii. Click on ‘Send invitation’.</td>
<td></td>
</tr>
<tr>
<td>c. To complete the survey in clinic:</td>
<td></td>
</tr>
<tr>
<td>i. Click on open survey.</td>
<td></td>
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</tbody>
</table>