



# Guide to Using Patient Reported Outcome Measures (PROMs) Inclusively

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**Comments or Questions?**

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# Summary

**This research-based guide provides an overview of PROMs and aims to help prevent the exclusion of people with low literacy skills and/or learning disabilities from PROM administration**

- Patient reported outcome measures (PROMs) are questionnaires patients complete on their health, and functionality. The information collected from PROMs can help to monitor patient progress or for healthcare quality improvement
- Patients are meant to be involved in the development of PROMs to ensure they make sense but people low literacy skills and/or learning disabilities are generally excluded. This exclusion means that people low literacy skills and/or learning disabilities may not be able to complete PROMs
- To address this issue, patient and professionals were consulted about their views on making PROMs accessible and easy to use as part of a 2 year project with the Universities of Glasgow and Dundee and Healthcare Improvement Scotland
- The results suggested many practical adjustments to PROMs including larger font sizes and flexible administration
- This guide presents these results along with case studies and resources for health professionals administering PROMs, to support the inclusion of people with low literacy skills and/or learning disabilities in PROMs initiatives

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# Background

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## Background

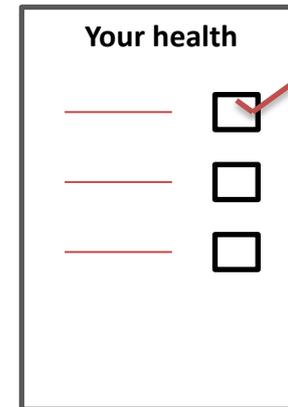
# What are PROMs?

Patient Reported Outcome Measures (PROMs) are questionnaires about people's health.

They are used to gather information directly from patients about their symptoms, condition and overall quality of life.

There are condition-specific PROMs, for instance the St George Respiratory Questionnaire for respiratory conditions.

There are also PROMs that can be used for any conditions, for instance the EQ-5D for health-related quality of life.



Your health

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[View example PROM](#)

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## Background

# How are PROMs used?

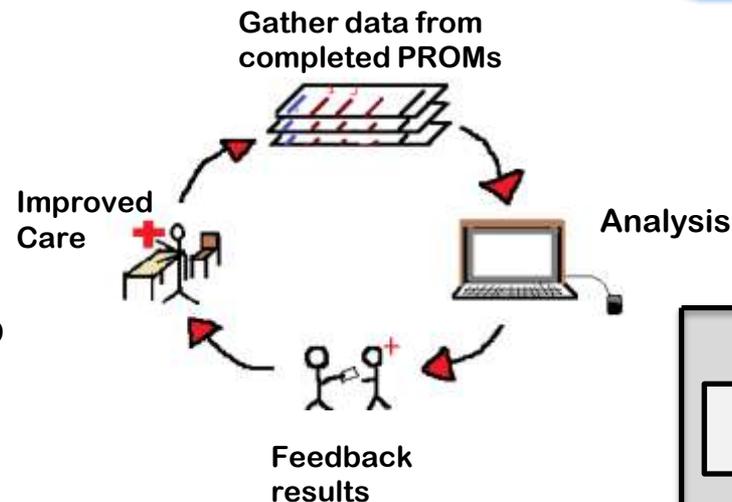
PROMs are used to measure the outcome of a health service intervention from people's own perspectives.

The information collected directly from patients can be collated, analysed and fed back to inform others about how well a service intervention has worked. This can lead to changes in the way services are delivered if necessary.

Health professionals can also use PROMs to monitor individual patient outcomes (like symptoms and quality of life). This information can be used to make appropriate adjustments to treatment and care.

**For example**, PROMs are used for *person-centred quality improvement*. In England, PROMs data for certain conditions is compiled, analysed and fed back to services for them to use in quality improvement. NHS Scotland is considering something similar.

[More on English PROMs programme](#)



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## Background

# How are PROMs developed?

**The process of development can take several months or even years.**

Ideally PROMs are co-developed between researchers, patients and subject experts to make sure they cover what really matters to patients and what professionals consider good outcomes.

They come up with a list of possible items for the PROM which are put through statistical testing that reduces the number of items that are finally included to a minimum.

This testing ensures that the PROM makes sense to patients and ensures that the PROM will give us valid, useful information.

Your health

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# A problem with PROMs

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2. [Why is this exclusion an important problem?](#)
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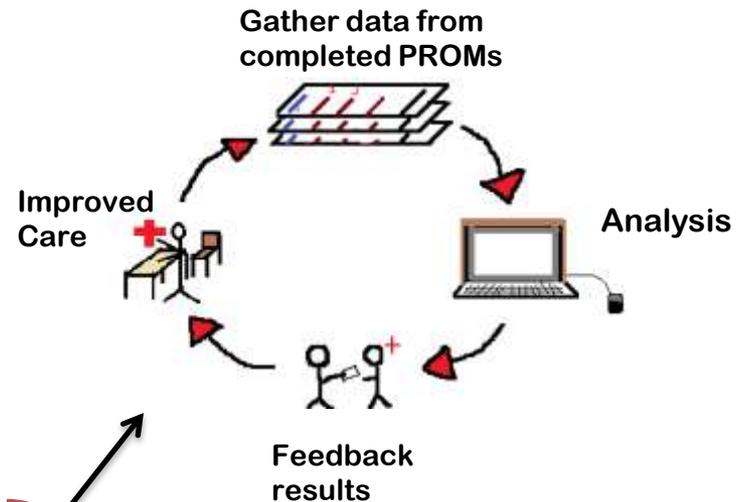
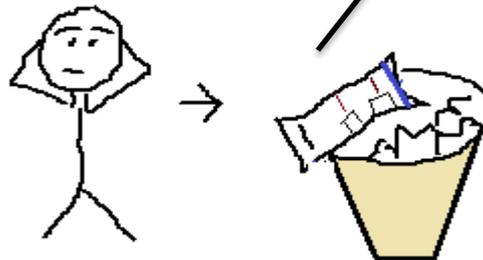
## Problem with PROMs

# Who might be excluded from using PROMs?

While researchers generally discuss PROMs with patients to decide on the content before finalizing it, they do not generally include people with learning disabilities or low literacy skills.

When PROMs are put into practice, **people with learning disabilities or low literacy skills may struggle to complete them.**

This means they may be left out of quality improvement and/or condition monitoring processes that use PROMs



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## Problem with PROMs

# Why is this exclusion an important problem?

**Lots of people may not be able to complete a PROM.**

As many as 1 in 5 adults have low literacy skills and there are approximately 1.5 million people with learning disabilities in the UK.

**Professionals should not assume literacy.**

Patients sometimes feel ashamed or embarrassed to ask for help if they cannot read and have instead developed cover up and coping mechanisms that keep their struggle hidden.

Giving PROMs to those who will struggle to read them might result in inaccurate completion or further alienation of these patients from healthcare practices.

Excluding these groups also counters NHS policies to achieve full inclusion and the [UN Convention on the Rights of Persons with Disabilities](#).

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# What is being done to overcome this problem?

**Users can consult this guide to help make sure their PROMs practice is as inclusive as possible and help to collectively address exclusion and maximize PROMs' potential.**

Over a year long research project between the University of Glasgow, University of Dundee and Healthcare Improvement Scotland, people with low literacy skills, learning disabilities, other patients and health professionals were consulted to gather their views on how to make PROMs more accessible and easy to use.

The focus was chronic obstructive pulmonary disease (COPD) but the results are applicable beyond this condition. The team also looked at other case studies where organisations have made health information accessible.



**This guide is the product of this university and NHS research.** It is geared towards those planning on implementing and using PROMs in NHS Scotland.

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# Practical Guidance to Use PROMs

## 1. Challenges & Suggestions

- a. Comprehension
- b. Reading
- c. Format

## 2. Other Considerations

- a. Assistance
- b. Modifications

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## Practical Guidance

### *Challenges & Suggestions*

# Comprehension

## Challenges

Certain question types and phrasing in PROMs are particularly difficult:

- questions requiring long recall
- questions with too many options
- questions that try to address many things at once
- scales with a large number of options, like the visual analogue scale on the EQ5D, which has a 1-100 scale

## Suggestions

Select questionnaires without too many of the above question types, with consistency in questions and response options.

It can be difficult to find the 'perfect' PROM, and if you cannot find a PROM that addresses these challenges and meets your needs, consider the suggestions offered under 'Reading' after introducing the PROM to the patient.

A good example of a PROM with consistency in questions in response types is the [Chronic Respiratory Questionnaire](#) used for people with respiratory conditions.

[More information on instrument selection](#)

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## Practical Guidance

### *Challenges & Suggestions*

# Reading

## Challenges

People may not be able to read the PROM, particularly if it is handed to them unexpectedly. It is not easy to judge who will have difficulties because reading issues are often hidden.

PROMs with more detail and harder words are also intimidating. People may not be able to complete such PROMs accurately.

## Suggestions

After explaining what a PROM is, offer the patient a choice of whether to complete it with the health professional or take it away. **This choice allows s/he to decide whether they want the professional's help, a family member/care taker's help at home, or to complete it alone.**

Read through PROMs to gauge their complexity and level of detail before you decide on one to use with all patients.

Asking a few patients for their thoughts on a PROM before using it with all patients can also help make sure it is not particularly difficult.

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## Practical Guidance

### *Challenges & Suggestions*

# Format

## Challenges

The 'look' of a PROM can make it intimidating and hard to use if it makes the PROM seem difficult.

Complicated formatting includes **inconsistent alignment, unclear fonts, small font sizes, a lack of white space, and non prominent headings.**

## Suggestions

Selecting a PROM that most closely adheres to these guidelines or working with someone with experience in accessible information to adjust the PROM can help to prevent difficulties associated with formatting.

Resources and people to help with this are listed in [Case Studies & Resources](#)

Key points from [Mencap's accessible information guidelines applicable to PROMs](#) include:

- text is straight across a page rather than in columns
- pictures, if any, should be on the left, words on the right
- Arial is a clear font
- font size should be at least 16 pt
- important words (like headings) should be bold

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## Practical Guidance

### *Other Considerations*

# Assistance

**It is fine, and even helpful, if patients would like help to complete PROMs.**

Help in completing PROMs can sometimes improve its accuracy although there is always the risk that the PROM will represent the helper's views rather than the patient's.

Although this is hard to prevent, it helps to observe any differences between what is written on a PROM and how a patient behaves, or whether the helper seems overbearing and continually corrects a patient.

Patients can also complete PROMs by proxy but this is a last resort.

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## Practical Guidance

### *Other Considerations*

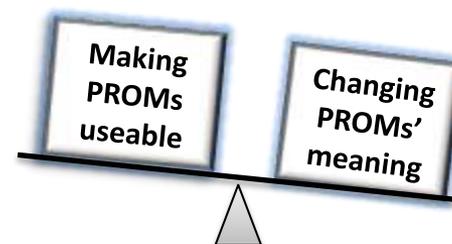
# Modifications

Modifying a substantial part of the PROM itself like wording, content or adding pictures, or only using some of the questions, can affect its meaning.

This is because PROMs are developed with rigour so that every item has been tested as it stands.

Evidently people should be able to use PROMs so it is important to find a balance between minor modifications and the potential to change PROMs' meaning. **For example, font size changes are fine, since they will help lots of people and do not compromise the PROMs' meaning to a large extent.** But adding pictures can change the PROMs' meaning, so it is important to carefully consider if this is beneficial to enough people to make it worth it.

As much as possible, **try to modify the process by which the PROM is administered** (for instance, given to complete at home or in a practice) so that patients can complete it more easily, rather than changing the PROM itself.



# Case Studies & Resources

## 1. Help to judge the accessibility of PROMs

- Mencap Guidelines: <http://www.mencap.org.uk/>
- Communication for Health: <http://www.nhsfife.scot.nhs.uk/easyread/>
- Contact: Billy Pate, Community Learning Disabilities Nurse (NHS Forth Valley):  
[wpate@nhs.net](mailto:wpate@nhs.net)

## 2. Examples of accessible questionnaires

- Adults with Learning Difficulties Questionnaire:  
[www.solihull.gov.uk/akssolihull/images/att4030.doc](http://www.solihull.gov.uk/akssolihull/images/att4030.doc)

## 3. More information on PROMs

- Instrument Selection: <http://phi.uhce.ox.ac.uk/instruments.php>
- Overview of PROMs' potential by the King's Fund:  
[www.kingsfund.org.uk/document.rm?id=8607](http://www.kingsfund.org.uk/document.rm?id=8607)
- NHS England programme: <http://www.ic.nhs.uk/proms>

### General Comments or Questions?

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