Patient Reported Outcome Measures (PROMs) for People with Severe Mental Illness in Community Mental Health Settings

Implementation guidance

Contents

Foreword 2

1. What are outcomes and why is it important to measure them? 4

1.1 Outcomes and outcome measurement 4

1.2 Patient reported outcome measures 5

1.3 The benefits of PROMs to people who use services 6

1.4 The benefits of PROMs to practitioners and services 7

2. Which PROMs should be used? 10

2.1 The three recommended PROMs 10

2.2 Quotes from the developers of the PROMs and patients 13

2.3 How the recommended PROMs fit with existing guidance 14

3. When and how often should the PROMs be used? 15

3.1 The case for the routine use of the PROMs 15

3.2 Frequency of use 16

3.3 Recognising and responding to individual circumstances when using the PROMs 18

4. Using the PROMs with patients with different needs: example pathways 19

4.1 A working-age adult (1) 20

4.2 A working-age adult (2) 22

4.3 An older adult 24

4.4 An autistic person 26

4.5 A young adult 28

5. How can the PROMs be used effectively in practice? 30

5.1 Supporting patients to use the PROMs 30

5.2 Infrastructure 36

5.3 Collection of PROMs data 41

5.4 Training and support for frontline staff, managers and clinical leads 41

5.5 The role of a patient's support network 43

6. Glossary and abbreviations 45

6.1 Glossary 45

6.2 Abbreviations 46

Appendix 1: Additional resources for DIALOG, GBO and ReQoL-10 47

Appendix 2: Steps taken to develop the guidance 49

Appendix 3: Guidance for practitioners on introducing and discussing the PROMs with patients 51

THIS GUIDANCE IS FOR ANYONE WORKING IN NHS-COMISSIONED COMMUNITY MENTAL HEALTH SERVICES FOR ADULTS AND OLDER ADULTS WITH SEVERE MENTAL ILLNESS.

Foreword

As co-chair, with Tim Kendall, of NHS England's Community Mental Health Outcomes Task and Finish Group, our brief for the group was to review and choose outcome measures for use in adult and older adult community mental health services.

This guidance was developed to help implement that work, and to ensure that everyone with severe mental illness (SMI) being treated and cared for in the community has the opportunity to fill in their own patient reported outcome measures (also known as PROMs).

This is so important for patients, because without outcome measures it is much more difficult for both patients and practitioners to understand the impact that support, care and treatment are having on their mental health and quality of life.

The three PROMs that were chosen –ReQoL-10, DIALOG and GBO – were picked because they all do different things but complement each other well.

The guidance sets out clearly how often someone should complete each of the PROMs, and summarises the characteristics of each PROM and when and how it is best to use them.

For me, having outcome measures is critical on an individual, service, trust, regional and national level for so many reasons. I genuinely believe that PROMs can and do make a fundamental, positive difference to the way support, care and treatment are delivered, and this guidance is a key step in making that change.

Chris Lynch, former Adult Mental Health Team Lived Experience Advisory Network Co-Lead, NHS England

I am delighted to introduce this guidance, with Chris, on the use of PROMs in community mental health services.

This document doesn't take any knowledge about PROMs for granted, and it sets out succinctly and clearly why it is so important to use PROMs.

Of great help to practitioners is a section on supporting patients to use PROMs, and there is practical advice throughout on how the approach to filling in the questionnaires can be tailored to suit older adults, people with learning disabilities and autistic people.

As well as making sure that as many people complete the questionnaires as possible, it is crucial that they do so with enough frequency that we can get paired outcome data. Without this data we can't track changes to patients' mental health over time, we can't demonstrate the effectiveness of interventions and services, we can't build quality improvement programmes, and people who want to use a service can't see how well a service is working before using it.

It is therefore critical that we have the digital systems in place to collect the data, and this guidance sets out the key features of such systems.

As Chris has said, PROMs can have significant positive impacts on mental health care, and it is hoped that in time their use will become second nature in community mental health services, but until then we have this helpful guidance to make sure we have a consistent approach.

Professor Tim Kendall, National Clinical Director for Mental Health, NHS England

1. What are outcomes and why is it important to measure them?

1.1 Outcomes and outcome measurement

The word ‘outcomes’ is often used in healthcare, but it is not always understood. In broad terms, ‘outcomes’ refers to the results of any care or treatment provided. In mental health, the outcomes of support, care and treatment might be that a person is able to lead a more fulfilling life, have reduced or no symptoms, volunteer in the community or return to a job that they love.

However, there is little point in knowing what people want to get out of support, care and treatment unless we know where they are starting from. For instance, if we were worried about our blood pressure and we wanted to bring it down (the outcome), most of us would want to know at the start what our blood pressure reading was by measuring it (the outcome measure) before doing more exercise and cutting down on alcohol (the interventions). Once we know where we are starting from (the baseline), regularly checking our blood pressure lets us see whether the plan is working or we need to make more changes to our diet and exercise (make adjustments). Unless we measure our blood pressure from the start, we will never really know if we have achieved our goal, as shown in the diagram above.

We use this comparison not to imply that mental and physical health conditions can be treated in the same way, but to show that outcome measurement can give us a lot of useful information using a relatively straightforward method. We need to start by finding out what a person wants to achieve from their support, care and treatment, and then take ‘measurements’ at the start, throughout and at the end of care. These measurements can help us find out if the work we are doing together is having an effect and if a person’s goals have been reached.

And yet, with some exceptions, this process is rarely followed in mental health care. While practitioners often know they are helping people, we do not know objectively whether most community mental health services help people to achieve their goals. This is because there is little measurement in place. Instead, services and commissioners often focus on easily measurable things, such as waiting times and the number of people accessing a service, which are important to people who use services but are not indicators of quality.

Different outcome measures have been developed so that everyone can understand whether healthcare interventions are meeting patients' goals for treatment and what patients hope to get out of their time with a healthcare service. One type of outcome measure is the **patient reported outcome measure (PROM)**.

1.2 Patient reported outcome measures

PROMs are questionnaires completed by patients, as opposed to clinician reported outcome measures (CROMs), which are completed by practitioners. PROMs have been designed to help patients and their practitioners to understand and measure their health and wellbeing before, during and after support, care and treatment. Patients may also be asked to fill in questionnaires about their personal experience of services, called patient reported experience measures (PREMs).

PROMs can provide an overall rating or score for a particular area of health, or personal or social functioning. These scores can be used to measure change in someone's mental health, functioning or overall wellbeing, to see if they are getting better, staying the same or getting worse.

PROMs do not replace the building of a genuine, trusting and supportive therapeutic relationships, or detract from those relationships. Indeed, PROMs are designed to facilitate conversations between patients and practitioners, and can thereby enhance the therapeutic relationship.

PROMs should never be the sole focus of a therapeutic session, and inevitably some patients' needs, experiences and circumstances will not be captured by PROMs. PROMs are broad outcome measures that are not designed to ask specific questions related to, for example, protected characteristics, and they will not capture everything that is important to a person.

However, PROMs provide a standardised way of asking fundamental questions that all practitioners should be asking all patients, of any background: 'What

do you want out of coming to mental health services?', 'How well do you feel you're doing?', 'How do you feel about your life in general?' and 'Do you think things are getting better?'.

When using PROMs, it is crucial to consider patient choice, foster shared decision-making and address patient needs while effectively managing time constraints. By doing so, healthcare experiences can become more personalised, leading to improved treatment outcomes and enhanced healthcare services.

Three PROMs for use in community mental health services

The three PROMs selected by NHS England and recommended for use in NHS-commissioned community mental health services are:

DIALOG scale

Goal-Based Outcomes tool (GBO)

Recovering Quality of Life – 10-item scale (ReQoL-10)

See Section 2 and Appendix 1 for more information about these measures.

1.3 The benefits of PROMs to people who use services

Most patients report finding routine outcome monitoring helpful, with patients seeing the use of outcome measures as a way to:

- express themselves
- clarify how they are feeling
- feel understood
- enable them to focus on what really matters
- demonstrate that they are making progress.

PROMs are seen as valuable tools in supporting practitioners to offer personalised and appropriate care that focuses on and responds to patient need.

Sharing decision-making, understanding an individual's experience, focusing on their needs and finding a way to deliver on their priorities are central to personalised care. Key to this is practitioners developing an ongoing mutual relationship with a patient. However, this is not always achieved; for example, in the annual national patient survey the majority of patients reported that their clinical team do not understand what is important to them. PROMs can change this.

Completing PROMs helps patients prepare for meetings with their practitioners. Completing them before a meeting with a health or care professional can identify issues beforehand, and allow the patient to focus on their needs and then raise the issues with the health or care practitioner. The completed PROMs can provide structure for the meeting: together, scores can be reviewed, their implications understood and then future plans developed.

As PROMs can help people feel that their practitioners have better understanding of what is important to them, the patient experience is improved. Their feedback can also be used to co-produce improvements to the service. It is important to note that for people to see the benefits of using PROMs, different organisational and infrastructure components need to be in place that support effective implementation (discussed in Section 5.2).

> *"They're not just questionnaires, pieces of paper that need to be filled, a tokenistic approach. They need to be used to improve services so that people receive proper treatment and are looked after properly. They need to be followed up, in particular the ones that ask if you need help in a certain area [of your life]. Or even signposting you to other services. The coordination between services is vital for tailored care for the patient."*
>
> A person with lived experience

1.4 The benefits of PROMs to practitioners and services

The benefits that PROMs can bring for practitioners are essentially the same as for patients. A more collaborative relationship with patients, in which they and practitioners are working towards goals set through shared decision-making and with a shared understanding of the progress the patient is making, will be more fulfilling for everyone. Such a relationship can foster greater patient engagement and ensure that their needs and priorities are understood.

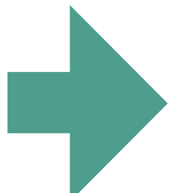
The routine use of outcome monitoring with PROMs can also support practitioners and services to reflect more broadly on whether they are offering the most effective support, care and treatment for people who access services by:

- starting or continuing a conversation with the patient about what matters to them (whether or not these are reflected in individual PROMs)
- ensuring that they understand and are meeting the changing needs of patients throughout their course of treatment
- understanding the difference that they are making
- identifying gaps in the service
- demonstrating the safety, quality, effectiveness and efficiency of the service
- helping to guide co-produced service improvement and delivery
- benefitting commissioners through being able to develop evidence-based co-produced commissioning
- tackling inequalities in treatment outcomes, as PROMs data can highlight whether some groups of patients (for instance those with certain protected characteristics) have different outcomes than others
- demonstrating the broader benefits that investment in mental health care can have on other health and wellbeing outcomes, by linking patient data collected across different health services.

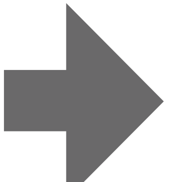
PROMs can support shared decision-making reflective of a person's needs at any given time. For example, ReQoL-10 provides a sensitive and responsive measure of personal recovery. Evidence shows that the ReQoL-10 can capture changes in needs, meaning that this PROM can be effectively integrated into care planning.

Implementing PROMs is an important part of the community mental health service transformation and will support the continued improvement of services, placing the patient at the centre of this transformation. Use of PROMs data will enable comparison across community mental health services. It will also support integrated care systems and national and regional NHS England teams to understand the impact of the community mental health transformation on patients. On the next page, there is a summary of the benefits of using PROMs in patient pathways.

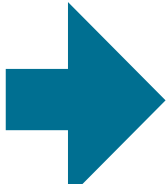
Benefits of using PROMS



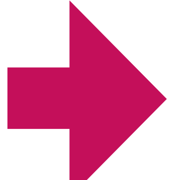
Discussion about PROMs between patients and practitioners **helps to establish dialogue and fosters shared decision-making**



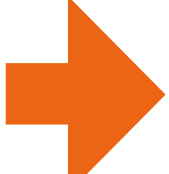
The use of PROMs can **help practitioners understand and respond better to patient needs**



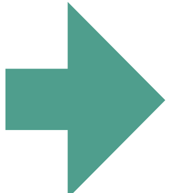
PROMs can be used collaboratively to **understand and track progress**, offering insight into a patient's perspective on their care



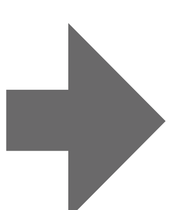
Routine outcome measure collection is associated with **better outcomes for patients and improved experience of care**



PROMs help to identify inequality of outcomes within a patient population, and so support targeted work to advance equality



Making outcome measure data publicly available **enables a culture of transparency and openness** about the impacts of treatment



PROMs data can be used to **support evidence-based quality improvement** within teams

2. Which PROMs should be used?

2.1 The three recommended PROMs

The PROMs recommended for use in NHS-commissioned community mental health services for adults and older adults with SMI, including voluntary, community and social enterprise (VCSE) services, are:

DIALOG scale – which looks at the person's satisfaction with different areas of their health and life, as well as with their support, care and treatment

Goal-Based Outcomes tool (GBO) – which focuses on what the person wants to get out of their support, care and treatment, and measures their progress against each goal

Recovering Quality of Life – 10-item scale (ReQoL-10) – which is about understanding the person's quality of life and how that is linked to their recovery.

These three PROMs have been chosen because they work well together as a **complementary suite**, and all are reliable and valid. They were chosen because they provide the best overall assessment of a patient's needs and progress through support, care and treatment. Taken together, and in addition to other areas that patients feel are important, the three PROMs can:

- provide a broad understanding of the patient's needs and track whether these are being met
- be used to assess the areas that patients consider are most significant for their mental wellbeing
- help practitioners to provide personalised care to their patients
- support shared decision-making
- inform conversations across the patient's support, care and treatment journey
- help to monitor patients' progress towards their goals.

The use of all three PROMs can be combined with other methods of evaluation, such as CROMs, PREMs and other specific measures, to fully capture the experiences of patients and understand the impact of services on patients. Regular reporting using these measures to assess a service's overall progress annually would support an evaluation of a service's overall effectiveness, highlight areas for improvement and be used to make co-produced changes to services.

All three tools are **free to use** in NHS-commissioned services. Copyright agreements and licenses are available from the National Clinical Content Repository (Copyright Licensing Service) on the NHS Digital website.

There are descriptions of and links for DIALOG, GBO and ReQoL-10 in the table below. Links to further resources and information (including translations, guidance, videos and journal articles) can be found in Appendix 1.

PROM	Description
DIALOG Link to PROM	• Already used in routine care in parts of the NHS and can support effective care planning in line with The Community Mental Health Framework for Adults and Older Adults. • Contains eight questions on satisfaction with different life domains (i.e. quality of life) and three on satisfaction with different treatment aspects (i.e. treatment satisfaction). • Satisfaction with each of the life domains and treatment aspects is rated on a scale of 1–7, with 1 being totally dissatisfied and 7 being totally satisfied. Each item is meaningful and can be interpreted on its own. Mean scores of the relevant items can be formed for quality of life and treatment satisfaction. • Has been tested and used extensively in the East London NHS Foundation Trust since 2017 and in >15 other countries on four continents. • DIALOG is different from DIALOG+, which is a full therapeutic intervention that encompasses the use of the DIALOG scale. • DIALOG offers transparent content for clinicians and patients. This approach not only provides actionable insights for informed decision-making on care but also ensures straightforward interpretation, fostering improvement and monitoring across all stakeholders involved in patient care at every level.

PROM	Description
Link to PROM	• Informs discussions with patients and helps focus these conversations on what the patient wants help with, and whether the support being provided is helping them to make progress towards their goals. • Tracks one of the most important things to measure in any intervention: "Is this helping you make progress towards the things that you really want help with?" • Patients can choose their goals and measure how far they have been achieved. • Progress towards each goal is rated on a scale of 0–10, allowing progress to be measured at each contact.
ReQoL-10 Link to PROM*	• Assesses quality of life and personal recovery for people with a wide range of mental health conditions. • Assesses and tracks improvements in the 'CHIME' (Connectedness, Hope, Identity, Meaning and Empowerment) factors that have been identified as central to personal recovery. • Can be used with people experiencing different mental health problems. More than 6,000 patients were involved in its development, ensuring the questions focus on the issues patients identify as most important to their mental health. • Includes an item on physical health.

* To obtain the ReQoL-10 scale for free use in an NHS setting, contact: clin.licences@nhs.net

2.2 Quotes from the developers of the PROMs and patients

“ *This tool [GBO] empowered me to have the freedom to set myself goals realistic and practically achievable to me, which were then beneficial in improving my life, and therefore my mental health...I learnt to take small steps towards achieving one goal, being supported with failures and mishaps with continuous encouragement by my support worker along the way, this increased my confidence in achieving other goals in my life, and gave me the hope that I can create a positive future for myself."*

A person with lived experience, on GBO

“ *The key strengths of the measure are its face and content validity, it is a well-accepted measure that is used across services already.... Various language translations are available and it has international legitimacy. Clinicians like to use the measure.”*

An outcome measures developer, on ReQoL-10

“ *... I think it [DIALOG] is very comprehensive and it’s very, very well designed as well because it doesn't just show if you are satisfied or dissatisfied...it’s very comprehensive... it’s important to know if there are problems not just about my mental health but my physical life, so the care can be tailored to my needs."*

A person with lived experience, on DIALOG

“ *The content and the relevance are totally transparent and clear, and again, not just to an academic like me but to everyone.”*

An outcome measures developer, on DIALOG

“ *It [ReQoL-10] allowed my therapist to explore the areas where I was not doing well in my life, to see how this can be improved, to help me work towards recovery in a way where I could collaborate on it with the therapist. The tool was helpful to discuss my feelings to different areas of my life, that I could explore further in depth with my therapist, without the questionnaire feeling too long and too time consuming to fill in.”*

A person with lived experience, on ReQoL-10

“ *If we listen well to our clients, their goals emerge from the stories they tell us about their lives, and things they would like to be different. Listening to these stories is what we all do in good therapeutic conversations. Using the GBO is a small step beyond usual clinical practice where we simply write down the agreed goals and are curious about where the client feels they are at in their journey towards making the changes that are important to them”*

An outcome measures developer, on GBO

2.3 How the recommended PROMs fit with existing guidance

The three recommended PROMs should be used in all adult community mental health services. However, in some specialist services there is existing national guidance for outcome measurement, including early intervention in psychosis (EIP) and adult eating disorders services, which will be aligned with the measures recommended in this guidance.

DIALOG had always been a recommended measure for EIP services as set out in Guidance on outcome measures in early intervention in psychosis services. Updated guidance due to be published in 2023/24 will add GBO and ReQoL-10 to the choice of outcome measures for new EIP patients. EIP services will move towards further alignment with outcome measurement in other community mental health services from 2024/25. The updated guidance will include any considerations for those under 18 years old in EIP services.

Current Guidance on adult eating disorders services already recommends the use of GBO. NHS England is carrying out further work to map how the three PROMs recommended for use in community mental health services can be best used alongside measures already recommended in the adult eating disorders guidance.

Can the Health of the Nation Outcome Scale (HoNOS) still be used in community mental health services?

HoNOS is a CROM that was used for care clustering in community mental health services. Mental health clusters are no longer mandated for payment purposes, though systems may choose to continue using them at their own discretion.

HoNOS should not be used in place of the three recommended PROMs. However, where services are already using HoNOS as a CROM, they can decide to continue to do so.

3. When and how often should the PROMs be used?

3.1 The case for the routine use of the PROMs

Routine use of the PROMs should be consistent across the patient pathway. It is only through routine use of outcome measures (at every session providing care, treatment or support) that **complete paired data** (pre-care, post-care and at regular reviews of care, support and treatment) will be consistently captured.

As has been found in the use of outcome measurement in NHS Talking Therapies for anxiety and depression (formerly called Improving Access to Psychological Therapies [IAPT]), complete paired data is crucial to understanding how effective services are in meeting the needs of their patients.

Collecting outcome measures only at the beginning and end of treatment can be challenging. If a patient thinks that treatment is not working for them and decides not to attend any more appointments, their final ('post') outcomes could be missed, which would lead to fewer paired outcomes being collected. This means that patients who drop out of treatment are under-represented in the data, and yet we want to know about them so that services can fully evaluate the benefits they provide to patients. As patients who lose contact with services are more likely to have worse outcomes than those who complete treatment, we risk over-estimating the effectiveness of services and not understanding why treatment is not working for some people.

The routine use of the PROMs to understand a person's goals and the progress they are making towards them is more likely to keep people engaged with services.

This guidance sets out the evidence-based approach to using the PROMs routinely to improve patient care, which all services should be working towards. It is recognised that full implementation of the PROMs will require changes in practice and efficient digital systems to store and process data. Advice on the implementation of routine outcome monitoring is provided in Section 5.3 and Section 5.4.

3.2 Frequency of use

We recommend that **ReQoL-10 and GBO should be completed at or before every meeting providing support, care or treatment**.

ReQoL-10 and GBO should also be used during initial assessment to help understand a patient's goals and obtain a baseline score. During the process, patient choice should be central and the frequency of the different measures must be tailored to align with the patient's preferences.

> **NOTE:** ReQoL-10 can be completed by the patient before an appointment. The same is true for GBO although it is advised that the patient completes this together with a practitioner when they see them **for the first time.**

DIALOG should be used as part of planning treatment and care, and **during the initial conversation with the patient about their mental health needs**. DIALOG should also be used whenever a patient has a formal care review, a **subsequent assessment** or a **transfer of care.**

3.2.1 Responding to individual circumstances when using the PROMs

Individual patient circumstances may make this frequency of use difficult to achieve, and information is provided in Section 3.3 on recognising and responding to individual circumstances when using PROMs. Patients should be strongly encouraged to use the PROMs as part of their care, while always respecting patient choice.

If after being informed about the PROMs and their potential benefits the patient decides not to complete the PROMs routinely, efforts should be made to reach an agreement on how, if at all, they might be used. Some people may go through periods of time when they are too unwell to be able to complete the questionnaires. If this happens, use of the PROMs should be revisited with the person when they are well enough.

3.2.2 Use of the PROMs with patients having multiple weekly contacts with services

Some people will have contact with one or more members of the service multiple times in the course of a week. In these circumstances, the team should agree with the patient how often the PROMs will be completed and which practitioner will monitor the process. At most, patients should complete PROMs once a week.

Frequency of PROMs use summary

ReQoL-10 and GBO should be used:

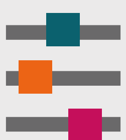
- **as part of initial assessments**
- **at every meeting that involves support, care and treatment.**

DIALOG should be used:

- **as part of planning treatment and care**
- **during the initial conversation with the patient about their mental health needs**

DIALOG should also be used whenever a patient has:

- **a formal care review**
- **a subsequent assessment**
- **transfer of care.**



Depending on individual need, including in relation to any protected characteristics, PROMs may be collected at a different frequency.

Shared decision-making should determine how often to complete PROMs.

See the Equality Impact Box on frequency of PROMs for more detail.

NOTE: Boxes labelled **Equality impact consideration** can be found throughout this guidance, highlighting situations in which it is helpful to think about the needs of particular patients, based on protected or other characteristics.

3.3 Recognising and responding to individual circumstances when using the PROMs

While it is expected that the PROMs will be collected routinely for most patients, there will be some variation in how the PROMs are used. It is important to take a shared decision-making approach about any variation from the recommendations in this guidance in how the PROMs are used.

Using the PROMs in a way that is **collaborative, appropriate and meaningful** for patients is fundamental to their proper use. There will be circumstances when it may not be appropriate to use the three PROMs as recommended. A decision to use the PROMs differently should be based on a clear understanding of the reasons for doing so, including patient choice, clinical judgement and a consideration of other ways in which outcomes may be assessed. Some examples are in the 'Equality impact consideration' box to the right.

Case study examples that demonstrate how the PROMs could be used with patients with different needs are provided in Section 4. There is also advice on how to support patients to complete the PROMs in Section 5.2.

> *"We saw [the GBO] as a clinical tool to be used pragmatically by clinicians. We did say that the default is to use it every session. But leaving it to the clinician and the person to decide how often they should use this in a way that's meaningful for them... the default is every session, but there might be good clinical reasons not to use it every session."*
>
> A GBO developer

Equality impact consideration: Frequency and routine use of PROMs

People who may require a different approach regarding frequency might include:

- People with **learning disabilities**, for whom reduced frequency of use might be appropriate due to extra time and support being needed
- **Autistic people**, who may experience challenges describing their experiences or feelings using numerical scales
- People with **cognitive decline or impairment**, for whom a reduced frequency of use might be appropriate due to extra time or support being needed

4. Using the PROMs with patients with different needs: example pathways

The five case studies in this section illustrate how the three PROMs could be used in practice. Some of these examples are based on co-produced, fictionalised patient stories from the Community Mental Health Framework. Pathways were developed by drawing on:

- advice from the Expert Reference Group (ERG) and Equality Advisory Group (EAG)
- care pathways that have already been developed and are in use by several NHS services
- consultation and engagement exercises with service providers, PROMs developers and lived experience advisers
- discussions with experts working with older adults, autistic people and people with learning disabilities.
- More information on how this guidance was developed can be found in Appendix 2.

4.1 A working-age adult (1)

Working age adult 1:
'Mei Lin' – Age 37

Mei Lin is a survivor of physical and emotional childhood abuse, and has struggled throughout her life with depression and difficulties in her relationships. She has harmed herself in the past and has been admitted to general and psychiatric wards as a result of this.

She continues to experience low mood and periods of intense anxiety, and is quite socially isolated.

She was previously referred to the community mental health (CMH) service, but did not feel supported so she did not engage in treatment.

She is not currently taking any medication.

Use of PROMs in Mei Lin's care pathway

REFERRAL (GP)

Mei Lin attends an appointment with the GP. The GP is aware of Mei Lin's mental health history, is concerned, and they discuss her recent self-harm. The GP refers her to a CMH service and encourages Mei Lin that they can help her.

Mei Lin receives an appointment letter along with **written information on outcome measures**. The letter includes the web address for a **video explaining the measures**. There are also **instructions on how to complete ReQoL-10 and DIALOG online before the appointment**, if she wishes, and that they will be discussed with the practitioner in their first appointment. Mei Lin watches the video before the appointment.

ASSESSMENT (CMH service)

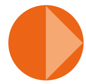
Mei Lin attends an appointment with the CMH service where she has an assessment. The **key worker takes her through GBO, ReQoL-10 and DIALOG** during the appointment. Mei Lin finds the measures helpful and together with the key worker, they use the measures when developing a care plan. Together, they decide that Mei Lin should receive support from a peer support worker (PSW) and meet with the psychologist in the team to consider treatment options.

Mei Lin is offered an appointment with the psychologist.

ASSESSMENT (Psychologist)

Mei Lin attends a psychologist appointment for assessment and they discuss her goals. She then **completes GBO to identify the specific goals** that she will work on with the psychologist. They also **discuss her previously completed ReQoL-10 form**, which had been done less than 2 weeks before. The psychologist works with Mei Lin to develop a treatment plan informed by the assessment **including the measures completed for her initial assessment**. Mei Lin is depressed and has symptoms associated with a diagnosis of personality disorder. The psychologist and Mei Lin discuss treatment options and agree on mentalisation-based therapy (MBT).

Mei Lin is supported to arrange fortnightly sessions with a PSW from a local VCSE organisation.



INTERVENTION (PSW)

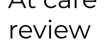
Mei Lin meets with the PSW to begin to begin to receive support from them. **The PSW has access to her completed PROMs, and they complete GBO together and add a goal.**

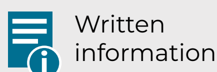
INTERVENTION (MBT)

A few weeks later, Mei Lin begins psychological therapy. **At the first session, Mei Lin and her psychologist complete GBO and ReQoL-10 together,** as well as specific measures relating to her treatment. In subsequent psychology sessions, the practitioner uses the tools to help Mei Lin discuss her feelings.

Mei Lin **completes GBO and ReQoL-10 before each psychology treatment session**. The PSW has access to Mei Lin's completed PROMs and uses them to discuss her progress.

Her key worker has a subsequent care review after 6 months and asks Mei Lin to **complete DIALOG and reviews her progress against her last GBO and ReQoL-10.**





4.2 A working-age adult (2)

Working age adult 2: 'Frank' – Age 51

Frank has experienced symptoms of psychosis for most of his life, with the first episode when he was 19 years old.

Frank has a number of physical co-morbidities, including chronic obstructive pulmonary disease (COPD).

Frank has had several admissions to hospital under the Mental Health Act due to attempts to harm himself, and has had a long stay on an inpatient rehabilitation ward.

Frank is supported by his 83-year-old mother.

Frank would like to socialise more and get involved in the community.

Use of PROMs in Frank's care pathway

REFERRAL

Frank attends an annual physical health check with his GP, who recommends an assessment with the CMH service as it is evident that Frank is struggling with some activities of daily life since being discharged from inpatient care.

Frank receives an assessment appointment letter along with **written information on outcome measures**. The letter includes the web address for a **video explaining the measures and how to complete ReQoL-10 and DIALOG online** before the appointment, if he wishes, and that these will be discussed in the first appointment. He does not access the video before the appointment.

ASSESSMENT (CMH service)

Frank attends an appointment with the **CMH practitioner, who helps him to complete GBO, ReQoL-10 and DIALOG**, and conducts a mental health needs assessment.

A formal care review is set up with Frank's care team.

MULTIDISCPLINARY CARE REVIEW (MDT)

The MDT review Frank's care, and **review the PROMs he completed at his assessment**. His medication is reviewed along with his care and support needs. **It becomes apparent from GBO and DIALOG** that he would like to seek out meaningful activities in the community as a goal and may benefit from community engagement support.

Frank receives an appointment letter to meet with his key worker to discuss community engagement.

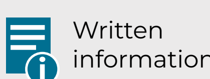
INTERVENTION (Community engagement)

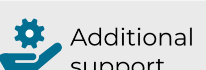
Frank has an appointment with his key worker to discuss community engagement opportunities that could help him gain more independence and rely less on his mother for support. **The key worker and Frank use GBO to help Frank set goals. They use GBO and ReQoL-10 at each subsequent session to track progress together**.

Frank continues to **receive a prompt to complete measures** shortly before each intervention session with the key worker. **He does not always manage to complete the PROMs, so the key worker helps him when needed.**

STEP DOWN (community engagement)

At the end of the community engagement intervention, Frank has a **final review session** and **completes the ReQoL-10 and DIALOG measures.** Frank and his key worker discuss Frank's progress, including what he has learned during his support, care and treatment, and what he can carry forward after stepping down his care.





4.3 An older adult

Older adult:
'Diane' - Age 72

Diane has a diagnosis of bipolar disorder.

She has had previous contact with the CMH service and has been admitted to hospital more than once under the Mental Health Act.

Diane has some physical health issues (rheumatoid arthritis and some limited mobility problems).

Her mood has been up and down recently and her family are concerned she is not attending to her self-care properly.

Diane is supported by her daughters who check in on her regularly and live nearby.

Use of PROMs in Diane's care pathway

REFERRAL (GP)

Diane and her daughter attend a GP appointment where they discuss Diane's physical health issues and mobility. Diane's daughter mentions her mother's mood changes and increasingly poor self-care. Diane, her daughter and the GP agree that she should be assessed by the CMH service.

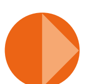
Diane receives an appointment letter from a CMH service psychiatrist along with **written information on outcome measures**. The letter includes the **web address for a video explaining the measures**, how to complete the ReQoL-10 and DIALOG online, and that they will be discussed in the first appointment. Diane tries but does not manage to access the link or complete the measure online.

ASSESSMENT/REVIEW (Psychiatrist)

Diane (her daughter accompanying her) attends the appointment. Diane tells the psychiatrist that she is **reluctant to complete the PROMs because it is difficult and she isn't sure it will be helpful**. The **psychiatrist explains how completing the PROMs can help Diane track her progress** against her goals, and how the results will be used. Diane's daughter encourages her to complete the PROMs.

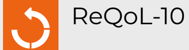
Diane feels reassured, and agrees to try completing all of them. Together, they **complete ReQoL-10, GBO and DIALOG in the appointment**. The psychiatrist explains to Diane and her daughter how to complete the measures online. An initial care plan is developed to support Diane and her family, which includes a review of medication and long-term support from the CMH service.

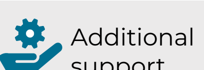
Diane receives appointments letters from the CMH service. In each letter, there is a web address to complete the PROMs, but Diane **struggles to access and complete the PROMs without support.** She **completes the PROMs with help from daughter before the next appointment.**



INTERVENTION (CMH service)

Diane's medication is changed and she has regular support from the CMH service, which includes monthly appointments and 3-monthly MDT reviews. Diane is supported in attending a group at a local community centre. Diane and the CMH practitioner **regularly discuss the PROMs results and her progress, and adjustments are made as necessary**.





4.4 An autistic person

Autistic person:
'Omari' - Age 36

Omari has a long-standing diagnosis of severe depression and anxiety, which has only partially responded to psychological and pharmacological treatment and which has seriously affected his quality of life.

Omari is autistic.

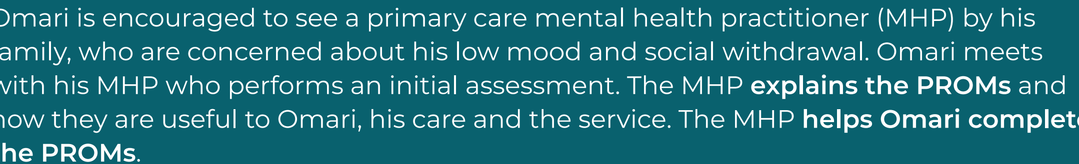
He lives with his family who are very supportive.

Omari has struggled with gaining and retaining employment and developing personal relationships.

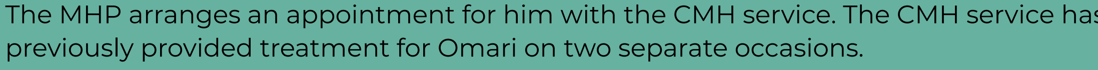
Recently Omari has become depressed and has not been leaving the family home.

PROMs in Omari's care pathway

REFERRAL AND INITIAL ASSESSMENT (MHP)



Omari is encouraged to see a primary care mental health practitioner (MHP) by his family, who are concerned about his low mood and social withdrawal. Omari meets with his MHP who performs an initial assessment. The MHP **explains the PROMs** and how they are useful to Omari, his care and the service. The MHP **helps Omari complete the PROMs**.

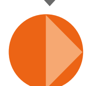


The MHP arranges an appointment for him with the CMH service. The CMH service has previously provided treatment for Omari on two separate occasions.

ASSESSMENT/REVIEW (Key worker)

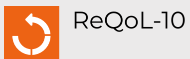
Omari has an appointment with the CMH service. **Omari and his key worker discuss his completed PROMs from the MHP**, and the role they play in Omari's care. Through shared decision-making, a are plan is developed with revised medication, further psychological intervention and employment support.

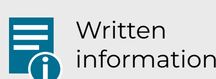
Omari's care plan involves long-term support from the CMH service, so he has regular appointments. With his appointment letters, Omari finds **information on outcome measures and how to complete GBO and ReQoL-10 online**. After receiving some advice, Omari is usually able to complete the measures before the appointments and finds the process helpful.

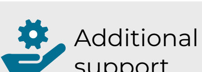


INTERVENTION (CMH practitioner/VCSE)

Omari receives continuing treatment and support from the CMH service and **continues to complete the GBO and ReQoL-10 before appointments and DIALOG at any care reviews**. Omari, his family and the team review his progress against the measures. They are pleased to see that some of his ReQoL-10 scores have improved. On reviewing his GBO, Omari decides that one of his goals is no longer as important to him, so they remove it and add a new goal towards building relationships. Omari is also supported by a local VCSE employment service.







4.5 A young adult

Young adult:
'Ali' - Age 22

Ali is in their first year at university, living in university accommodation.

Ali was seen by the Early Intervention in Psychosis (EIP) service when they were 18 years old – they benefited from the service and were discharged.

Ali has been seen on two separate occasions by mental health services when they have presented with psychotic symptoms at A&E.

Recently, Ali has been struggling with the pressures of studying and their self-care has deteriorated. Ali is no longer using drugs and doesn't think they are unwell.

PROMs in Ali's care pathway

REFERRAL (CRHTT)

Ali's university housemates noticed they had been expressing paranoid ideas and were not taking good care of themselves. Ali was adamant there was nothing wrong but was becoming increasingly agitated and distressed. Their housemates persuaded Ali to go with them to A&E. At A&E, it was decided to make a referral to the crisis response home treatment team (CRHTT). Ali saw the CRHTT and was re-started on medication. The CRHTT provided additional support at home over the next 3 weeks and then discharged Ali back into the care of the CMH service.

Ali receives an appointment letter along with **written information on outcome measures**. The letter includes the web address for a **video explaining the measures**. There are also **instructions on how to complete ReQoL-10 and DIALOG online before the appointment**.

ASSESSMENT (Key worker)

At their appointment with the CMH service, Ali had an assessment. Ali had a**lready completed ReQoL-10 and DIALOG online**, and they **completed GBO together** and agreed a care plan.

Ali receives prompts **to complete ReQoL-10 and GBO online before appointments** with the CMH service.

INTERVENTION (CMH service)

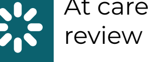
Ali continues to have appointments with the CMH service for ongoing support in which their **PROMs results are discussed regularly**.

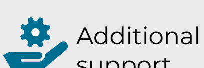
INTERVENTION (CMH service)

Ali continues work with the CMH service according to the care plan. However, Ali's symptoms start to worsen and they are not consistently taking their medication. At an appointment with the CMH service, the practitioner notices that Ali seems very distressed and appears to be quite unwell. **The PROMs have not been completed online. They discuss this together, but decide that completing the PROMs is not in Ali's best interest this time** due to their levels of distress and symptoms. They **agree to attempt the PROMs at another time**.

CONTINUING TREATMENT & SUPPORT (CMH service)

Ali attends another appointment with the CMH service. Since the last appointment, Ali has been more consistent with medication and their symptoms are improving. **Ali is supported to complete GBO and ReQoL-10 in their appointment. DIALOG is also completed at care reviews.** The CMH service links Ali to the University Support Service for help with managing their studies and workload.





5. How can the PROMs be used effectively in practice?

This section covers four key areas in the effective implementation of the PROMs in practice:

1. Supporting patients to use the PROMs
2. The infrastructure required for the effective roll-out and implementation of the PROMs
3. Collection of the PROMs data
4. Training and support for frontline staff, managers and clinical leads.

It also discusses the benefits of including members of the patient's support network in the completion of the PROMs.

5.1 Supporting patients to use the PROMs

Practitioners should support patients, as part of shared decision-making, to understand the PROMs and their potential benefits as well as the overall importance of routine outcome measurement. This support should be offered within a safe and trusting relationship (see the 'Equality impact consideration' box below). It is important to communicate to patients that the PROMs can form a key and standard part of their support, care and treatment and can help to plan out the sessions if they are properly integrated into the person's care and are not treated as a 'tick box exercise' (see also the box on the administrative burden of PROMs to staff and patients in Section 5.2.3).

Clear and accessible information about the PROMs should be made available to all patients to aid this process. This should include, but not be limited to, information that is: easy to read, translated to patient's language, and in different formats (such as braille, sign language or large print) according to patient's needs.

To effectively support patients to use the PROMs, it is crucial to address three key stages: introduction, completion and results. These stages should be adequately covered during staff training to ensure a personalised healthcare experience.

Equality impact consideration: A supportive, safe and trusting relationship between practitioners and patients using PROMs

It is essential that patients feel safe, supported and trusting of professionals involved in their care when being asked to complete PROMs. The therapeutic relationship between patients and practitioners is vital in fostering this safety and trust in engagement with services. Professionals should work closely across services to adopt a shared approach to working with patients that places importance on ensuring patients feel safe enough to engage with PROMs completion as part of treatment.

People at increased risk of withdrawing engagement due to safety concerns or distrust may include:

- People belonging to some minoritised ethnic communities who may have had poor experiences with mental health services in the past or are more likely to have had access to services via coercive means
- People who have may have experienced discrimination due to their gender or sexual identity
- People who have experienced trauma such as victims of abuse or exploitation and refugees and asylum seekers
- People who are in vulnerable social and personal situations such as sex-industry workers, people with gang-affiliation or a criminal justice history or refugees and asylum seekers
- People with more complex needs who are in contact with multiple community mental health services
- People with substance misuse issues.

5.1.1 Introducing patients to PROMs

When introducing and discussing the PROMs with patients, it is best to be transparent about their purpose, and to highlight the benefits they can bring (see Section 1.3). How to introduce PROMs to patients should form part of practitioner training on their use (see Section 5.4). As part of any introduction to PROMs, it is good practice to:

- At the earliest opportunity, **engage in a conversation about PROMs** with the patient.
- Clearly **explain the specific PROMs that will be used** and their features in plain, jargon-free language and respond to any questions or concerns the patients may have. **Offer additional written information**: if requested, provide a one-page sheet with key information on each PROM – the table in Section 2 can be used as a template.
- Talk to the patient about **how often they will be asked to complete PROMs**, and explain the importance of routine outcome measurement. Maintain a collaborative approach during this stage and agree with the patient how frequently they will complete the different PROMs.
- Give **clear information about how their answers will be used and stored**, and who will have access to them.
- Emphasise to the patient **that when they give answers that truly reflect their situation it will help them in the long run**, and be unlikely lead to any negative outcomes such as being admitted to the hospital or losing access to care.

Further guidance for practitioners on introducing and discussing PROMs with patients can be found in Appendix 3.

5.1.2 Helping patients complete PROMs

It is important that, where possible, patients complete the PROMs before their contact with services to maximise their use of the appointment time, and that they complete the PROMs themselves so that there is an accurate record of how they are feeling. But it is recognised that some people might need more time and support to do this. It is recommended that systems are in place to support patients to complete PROMs independently, outside of appointments. However, some patients may not be able to do this or may need support from practitioners to complete the measures, in which case additional time should be built in to allow for this.

This section provides some advice about how practitioners can work with patients to achieve that.

Where possible, patients should complete the PROMs on a digital device (a mobile phone, tablet or computer). This is more efficient as it means that the data goes straight into the service's IT system. It also helps to facilitate effective review of patient progress. Most of the PROMs can be completed outside of appointment time, allowing for dedicated discussion time during sessions to focus on what the person's care, including areas prompted by the PROMs. The exception to this is GBO – when completing this PROM for the first time, it is best filled in during the session as a through a collaborative shared decision-making process between patient and practitioner.

If a patient does not have access to a digital device, then it might be better to complete the PROM in the session, with the practitioner providing support to complete the form(s).

It's important to note that certain items of DIALOG or ReQoL-10 may not be answered by patients. While it's advisable to encourage the completion of all questions, as it contributes to a more comprehensive understanding of the patient's situation, patient choice should be respected. Non-completion should be accounted for in the digital systems that support the completion of PROMs as well as in the analysis of the results made by staff. Concentrating on individual items during the analysis prevents misleading interpretation of the data, which can happen when there are missing items. Some services prompt their patients to fill in the PROMs, for example by:

- **having digital champions in the service** who can support people who don't have access to a digital device or find using technology challenging
- **sending patients a link to each PROM** by text message or email
- **having reception staff prompt patients to complete the PROMs** before their session, on tablets or other digital devices, in the reception or waiting area.

Further advice on completing PROMs digitally is in the 'Equality impact consideration' below.

People experiencing digital poverty are not the only patients who might need more time and support to complete the PROMs – see the 'Equality impact consideration' box below for further information. It is important to make reasonable adjustments to the format in which PROMs are delivered, based on patient need.

Equality impact consideration: Completing PROMs digitally

While digital completion of PROMs is the ideal, some patients may not be able to do this without support. If this is just not possible, and a paper form is completed, then there should be measures in place to ensure the transfer of data into systems efficiently and safely.

People who may wish to use other completion methods might include:

- People experiencing digital poverty (for whom access to digital devices is not consistent or possible)
- People who may experience challenges using technology (such as people with learning disabilities, cognitive impairment or complex needs, and some older adults).

Equality impact consideration: Extra time and support to complete PROMs

For some patients, completing PROMs in their own time, before appointments, will be challenging. Building in sufficient time to support patients to complete the PROMs is therefore encouraged.

People who may need extra time and support to complete the PROMs might include:

- Autistic people, who may find numerical scales challenging
- People experiencing digital poverty, who may not have access to devices
- Some older adults, who may need more time or would prefer to have support when completing the PROMs
- People with low literacy skills
- People with conditions that create challenges with reading or comprehension (such as people with learning disabilities or cognitive decline/impairment)
- People with visual impairment
- People with limited English proficiency
- People for whom cross-cultural dynamics affect their interpretation and understanding of mental health and its treatment.

5.1.3 Making adjustments for patients when completing PROMs

For people with a visual impairment, assistive technology such as screen readers can support access to PROMs. For use on a screen reader, the PROMs need to be in formats, fonts or colours that can be read by the technology on the patient's device. Printed PROMs forms may need to be in large print or braille.

Although there are translations of the PROMs in a range of languages (see Appendix 1 for links to translations), support from an interpreter or extra time with the practitioner may be needed to help some people read and understand the measures in the session if they are not able to complete them independently.

Some people may find that some questions are not relevant to them. For example, a question in DIALOG about 'job situation' won't always be applicable. The developers advise that this question is adapted according to the patient's needs and circumstances. If, for example, the person is not in paid work or is retired, the practitioner can ask, 'How satisfied are you with your financial situation?'. If this needs to be expanded on, then the developers have suggested several prompts, such as, 'Do you have any money worries?', 'Do you get to spend money on the things that you enjoy?', and 'Do you get involved in local activities or any pastime activities or vocational work?'. If the person is older, you could ask, 'Are you retired?'. However, the question about job situation should not be changed on IT systems because it could affect the data.

Some practitioners may feel uncomfortable asking questions related to patients' treatment satisfaction, and some patients may be hesitant to answer and may be worried about the consequences, but it is important to ask and find out answers to these questions. Data on patient satisfaction with professionals plays a pivotal role in developing and evaluating services.

> *"We know that a lot of people with mental health issues don't work, can't work, and may never work. So being asked how satisfied are you with your job situation over and over again? To some, some people said it felt like there was an implication that you were a scrounger, or maybe didn't want to work."*
>
> A person with lived experience

5.1.4 Discussing PROM results with patients

For PROMs to be meaningful for both practitioner and patient, they should involve making shared decisions about their ongoing personalised care and influence the content of discussions during the sessions between them. This will make the process feel less like a 'tick box exercise' for patients, and will ultimately have wider benefits, as set out in Section 1.3 and Section 1.4.

The discussion is an opportunity for practitioners to explore specific areas that the PROMs results have highlighted, and also a chance for patients to raise issues about particular areas, such as relationships or their physical health.

5.2 Infrastructure

The infrastructure of a service includes the buildings, facilities, technology, equipment and staff, and the systems that are used to run the service. What is available in a service and how it is organised is essential to delivering support, care and treatment, and to the effective implementation of PROMs.

5.2.1 Data quality and reporting metrics

It is important that PROMs scores are submitted accurately, to ensure a good quality dataset that enables data monitoring, which can lead to service improvement.

Work is underway at NHS England to consider how outcomes will be reported at a national level using the three recommended PROMs. A group of expert stakeholders are contributing to this work, including lived experience practitioners, clinicians, service managers and the developers of the PROMs.

Having nationally reported metrics not only helps us assess the quality of care and better understand the outcomes achieved by patients, but can also encourage all services to provide more complete outcome data. We can learn from other areas of mental health that already have outcome metrics in place, such as NHS Talking Therapies, which report recovery rates, and children and young people's services, which report measurable improvement. From these services we can see that having metrics that report outcomes against all referrals instead of only reporting against those with paired scores improves data completeness.

With complete, good-quality data, we are able to link outcomes data with demographic data including protected characteristics. That allows us to better understand the outcomes of specific communities, and helps us identify and address health inequalities.

NHS England will share updates on metric developments as the work progresses.

Reporting DIALOG

It is important to report each of DIALOG's domains individually and to note that the last three questions are PREMs and not PROMs. Because of this, it is possible that the experience questions will not be completed at baseline by some patients if they are new to the service. Therefore, these scores may be missing for the first contact. However, this will not be a problem if all domains are considered and reported separately, and a total score is not reported.

5.2.2 Embedding PROMs into digital systems

A critical aspect of infrastructure for standardised PROMs implementation is their integration into the digital systems used in community mental health care. This includes having user-friendly and intuitive software solutions that streamline the administration, collection and management of PROMs data. Also, the digital infrastructure should support a multi-agency approach that includes VCSEs, and facilitates analysis and reporting of PROMs from practitioners, line managers and clinical leads. Analysis of collected data can support quality improvement initiatives and be used for benchmarking against national or regional standards, to monitor outcomes for groups with protected characteristics, and to guide service-level decision-making.

Recently, NHS England have undertaken work to identify digital tools and electronic patient record bolt-on systems that providers use to support the digital collection and use of outcome measures. Information about these tools and systems will be on the Future NHS Collaboration Platform, in a bid to share examples of good practice and highlight where potential digital solutions are already available.

See the box below for features of digital systems that have been established in other services (such as NHS Talking Therapies) for the collection, analysis and display of PROMs data.

A digital system for PROMs data needs to:

- ensure that the data goes directly into the patient record
- be easy to use for the patient, ensuring minimal time and effort
- allow PROMs data to be recorded by the practitioner when a patient completes a paper form
- allow PROMs data to be recorded if one or more items are missing
- be easy to access from other clinical documentation systems, aligned to assessments, care plans and care reviews
- allow practitioners and patients to access and view PROMs results in real-time during care sessions, so the results can be discussed together and feedback given
- integrate data analysis tools so that:
- changes in real-time and over time can be displayed (see the quotes below)
- data can be displayed visually (for example, using graphs) that the patient and practitioner can view together, and which is presented in a meaningful and engaging way
- allow data to be viewed at different levels (individual, team, service, integrated care board, and so on)
- be able to immediately generate local reports
- enable services to see differences across groups of patients (for example, protected characteristics)
- be flexible and have procedures in place to promote digital inclusion and consider those in digital poverty
- be able to securely store and share PROMs data when appropriate, adhering to privacy and data protection regulations
- be able to feed data into the Mental Health Services Data Set (MHSDS) (see also Section 5.2.5).

Visualisation of data

It's really helpful for support planning to be able to see live visualisation … because it means we [practitioners] can look at trends over time. The different components of quality of life, for example, and where we're having more of an impact, where we're having less of an impact. And things we can potentially change about our services to try and improve the impact across those different areas.”

A VCSE research manager

Analysing data on different protected characteristics

[By] applying filters to the data, we could see that we were getting more positive outcomes for women compared to men, and we were seeing specifically that Asian men were seeing improvements. It’s important because we're now able to put in place culturally appropriate care and specific interventions based on the data that we've got.”

A VCSE research manager

5.2.3 Implementation challenges

Administrative burden of PROMs to staff and patients

The effective roll-out of PROMs in community mental health services depends on efficient methods of delivery that do not add an administrative burden to staff. This is where having electronic systems in place that support PROMs completion and data collection is vital. The implementation of PROMs offers practitioners a consistent and dependable way to understand patients' needs and gauge the effectiveness of the support, care and treatment they provide. This insight can be shared with teams to facilitate a well-informed allocation of resources. Importantly, the completion of PROMs should not interfere with time spent with the patient; rather, it can serve as a tool to guide and focus conversations.

The administrative burden of PROMs should be looked at and reduced wherever possible for:

- **Practitioners** working to support patients to complete PROMs, especially where alternative or flexible strategies are needed (for example, by providing extra support or when PROMs are completed on paper)
- **Staff** responsible for collating or managing PROMs data
- **Patients** receiving treatment, so as not to take away from therapeutic contact, to reduce the risk of 'questionnaire fatigue' and to ensure there is not unnecessary repetition of PROMs when a person has frequent contact with services over a short period of time.

Implementing PROMs in services brings several challenges that must be acknowledged and addressed for their successful adoption and meaningful use:

- **Lack of meaningful use**: If PROMs data is collected but not effectively used by practitioners during sessions, it can remain disconnected from the decision-making process, and its true potential in enhancing patient care and outcomes can remain untapped. To overcome this, infrastructure must enable the seamless integration of PROMs data into clinical workflows. Strategies should be put in place to encourage practitioners to review and use PROMs results to inform personalised support, care and treatment that is based on shared decision-making.
- **Adapting to new processes**: Implementing PROMs, with or without appropriate infrastructure,

often introduces a learning curve for staff. Adapting to new processes, incorporating PROMs into workflows, and understanding the interpretation and application of PROMs data can be challenging. This can be mitigated through comprehensive training programmes (see Section 5.4) and ongoing support for staff. Infrastructure should provide access to educational resources, clear guidelines and tools to facilitate the learning process. Regular feedback loops and opportunities for staff to share their experiences and best practice can further help in overcoming this challenge. Reflective practice and clinical/peer supervision may provide a good space for this in teams.

Successful implementation of PROMs in community mental health services requires effective collection and use of the data. The key components of the infrastructure needed to support such implementation are set out in the subsections below.

5.2.4 Developing protocols for PROMs integration

To ensure that the PROMs are consistently and effectively integrated into clinical workflows, appropriate protocols need to be established for each service in community mental health care. The protocols should outline the specific steps to be taken and the responsibilities of different staff involved in the PROMs process, including assessment, data collection, interpretation and use. The protocols should also specify the frequency of use of PROMs and the points in the care pathway at which they are to be used. Clear communication channels, and defined roles and responsibilities among staff members, are essential for facilitating the smooth integration of the PROMs into each patient's support care and treatment.

5.2.5 Data flow to Mental Health Services Data Set

Outcome measure scores should be included in monthly MHSDS returns, as specified in the national Information Standards Notice DCB001. For outcomes data to be reported as part of the MHSDS, at least two suitable contacts using appropriate outcome measures must be reported.

Information about the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) codes for reporting outcomes data to the MHSDS can be found in the MHSDS Technical Output Specification.

Technical guidance for recording outcome measures can be found on the FutureNHS Collaboration Platform.

To aid transparency and comparison across systems, NHS England has provided information about the use of outcome data on NHS Futures. Paired scores are reported in the Commissioning for Quality and Innovation (CQUIN) dashboard, which allows providers to see the number of referrals with a paired score by assessment type.

There are plans to further develop the CQUIN dashboard and the community mental health dashboard in 2023/24. All VCSE providers commissioned by the NHS to provide community mental health services are required to submit data to the MHSDS, as specified in Schedule 6A of the NHS Standard Contract and the national Information Standards Notice DCB001.

Some VCSE providers work in partnership with their mental health trust, and the trust submits data on their behalf. Local partners are encouraged to discuss how they can efficiently support local data sharing and national returns in line with their individual model of delivery.

5.3 Collection of PROMs data

Efficient and consistent use of PROMs across community mental health services relies on consistent and close communication between NHS, social care and VCSE services, a collaborative approach to care and close cross-organisational working. Local agreements on PROMs use and data collection methods to be used should be established across community services.

If a patient is in contact with more than one practitioner from community mental health services, including VCSE organisations, it should be agreed in advance who is responsible for sending the PROMs forms to patients to complete or asking them to complete them at an appointment. As previously noted, asking patients to fill in the same PROM in different services within a short time frame should be avoided.

5.4 Training and support for frontline staff, managers and clinical leads

Evidence has shown us that training can enhance the implementation of routine outcome measurement. Therefore, training for frontline staff, managers, clinical leads, VCSE and social care partners is an essential step in the successful implementation of PROMs in adult and older adult community mental health services. Appropriate training can also help to address any practitioners' concerns about using routine outcome monitoring with patients.

An effective approach to training staff involves the co-design and co-delivery of training programmes with patients or experts by experience. This ensures that the training content and delivery methods are informed by the real-life experiences and perspectives of people who have direct experience of the services. Training should focus on the benefits to patients of using outcome measures.

Because staff at all levels of mental health care will be involved in implementing PROMs in community mental health care, training should reflect this.

Frontline staff training may focus on practical skills, communication techniques, providing PROMs in a personalised context, through shared decision-making and understanding digital systems and discussing PROMs data with patients.

Training for managers and clinical leads would need to have more of a focus on strategic planning, team management and the infrastructure needed for effective PROMs implementation.

Training needs to include something very practical around what forms need to get completed on which clinical records system, by whom and when and how. [It should also include] some very clear instruction and guidance as well as something much more philosophical about hearts and minds, which is about the wider philosophy of some of these tools .... Otherwise, you miss the point of it or it becomes a 'feeding the beast' activity."

A trust programme director

5.4.1 Outline of training

The training for frontline staff may include:

- Introduction to routine outcome measurement and PROMs
- Benefits of PROMs to patients and services
- Frequency of use
- Equality considerations when using PROMs
- Introducing outcome measurement to patients and carers
- How to use PROMs to inform care
- How to use digital systems to support the use of PROMs
- Data interpretation
- Space for reflective discussion in integrating the use of PROMs into people's practice.

This outline can be tailored to create a version for managers and clinical leads, by having more of a focus on leadership, supportive management and values so they can support practitioners to understand the PROMs and their benefits.

Managers could also be trained and supported to monitor implementation and integrate discussion of PROMs in supervision.

5.5 The role of a patient's support network

Some patients may want to involve people from their support network (such as friends, family members, peer support workers or paid/informal carers) in the completion of their PROMs questionnaires, their care planning and in their support, care and treatment. Sometimes, a patient may need reassurance from someone in their support network to take part in sessions, or they may only be able to access a service with their support. This should always be facilitated, to enable patients from all backgrounds to have equitable access to services. Patients also have the right to make reasonable adjustments, under the Equality Act 2010.

Involving members of a patient's support network in the completion of PROMs can offer several valuable benefits to the therapeutic process and the wellbeing of the patient. People from a patient's support network can:

- **Provide a holistic perspective**: They often have a unique and comprehensive understanding of the person's daily life, behaviours, challenges and progress. Their insights can provide a more complete picture of the patient's experiences, which can be essential for accurate assessment and effective care and treatment planning
- **Enhance communication**: They can improve communication between the therapist, the patient and people within the support network. This improved communication can lead to a more cohesive and collaborative treatment approach, ensuring that everyone is working towards the same goals.
- **Support implementation**: They are often responsible for helping the patient implement the strategies and interventions discussed in sessions. Their involvement can ensure that the patient is consistently applying them in their daily life, leading to more effective outcomes.

- **Provide consistency and reinforcement**: They can provide consistent support and reinforcement outside of sessions. This consistency is crucial for reinforcing new behaviours, skills and coping strategies, which may lead to more sustained improvements. They can also reinforce the importance of the PROMs and the importance of monitoring them regularly.
- **Reduce stigma and isolation**: They can help reduce the stigma associated with mental health treatment. When members of their support network are actively involved, the person can feel more supported and less isolated, knowing that their loved ones are engaged in their wellbeing.
- **Measure progress**: They can offer input and observations that the person may not be aware of, leading to a more accurate representation of progress.
- **Share in decision-making**: Involving members of the support network in care decisions empowers patients to be part of the decision-making process, fostering a sense of ownership and responsibility in the treatment journey, as part of a patient personalised care approach.
- **Co-produce**: Co-producing with people in the patient's support network, in the design, delivery and evaluation of a service, can help ensure that the people they are supporting receive improved services, with better outcomes.

The patient may want members of their support network to be involved with all or some aspects of their care. It is important that there is a regular dialogue with the patient about who they want to be involved, as this might change.

We also recommend that time is set aside to discuss and consider the support needs of the people who are supporting patients. Supporting someone can be emotionally and physically demanding. Involving people from the patient's support network in sessions can provide them with a platform to express their own challenges and emotions, ensuring they receive the support they need and preventing burnout.

6. Glossary and abbreviations

6.1 Glossary

Clinician reported outcome measure (CROM)

A questionnaire that practitioners use to record a patient's day-to-day functioning, symptoms, quality of life and other aspects of their health and wellbeing, based on their clinical judgement and assessment of the patient.

Co-production/co-produced

This refers to patients, members of their support network (such as family members, carers and friends) and staff in services working together to develop and shape care delivery, rather than staff making decisions alone. Co-production advocates that to provide truly effective public services, equal partnerships are needed between patients and providers of a service. It encourages transparency about how and why things are done.

DIALOG

A patient reported outcome measure that asks patients questions about their health and life, and about their support, care and treatment.

Goal-Based Outcomes (GBO)

A patient reported outcome measure that asks patients about their goals for the mental health support, care and treatment.

Mental Health Services Data Set (MHSDS)

A national-level dataset that records information on people in contact with mental health, learning disabilities and autism services.

Patient reported experience measure (PREM)

A questionnaire that enables a patient to report on their experience of healthcare services.

Patient reported outcome measure (PROM)

A questionnaire that records a patient's view of their own health. It enables them to report on their quality of life, day-to-day functioning, symptoms and other aspects of their health and wellbeing.

Recovering Quality of Life – 10-item (ReQoL-10)

A patient reported outcome measure that asks patients about their quality of life and factors supporting mental health recovery.

Routine outcome monitoring/ measurement

The practice of using outcome measures, such as PROMs, at pre-defined regular intervals with patients during support, care and treatment.

Severe mental illness (SMI)

In this context, SMI covers a range of needs and diagnoses including but not limited to psychosis, bipolar disorder, 'personality disorder' diagnoses, eating disorders and severe depression. Some of these may coexist with other disorders, such as substance use, long-term and complex physical health problems, autism spectrum conditions and learning disabilities.

6.2 Abbreviations

CQUIN	Commissioning for Quality and Innovation
CROM	Clinician reported outcome measures
EIP	Early intervention in psychosis
EAG	Equality Advisory Group
ERG	Expert Reference Group
FAQ	Frequently Asked Questions
GBO	Goal-Based Outcomes tool
HoNOS	Health of the Nation Outcome Scale
MHSDS	Mental Health Services Data Set
NCCMH	National Collaborating Centre for Mental Health
ODDESSI	Open Dialogue: Development and Evaluation of a Social Network Intervention for Severe mental health problems
PREM	Patient reported experience measure
PROM	Patient reported outcome measure
ReQoL-10	Recovering Quality of Life – 10-item scale
SMI	Severe mental illness
VCSE	Voluntary, community and social enterprise

Appendix 1: Additional resources for DIALOG, GBO and ReQoL-10

DIALOG

Access the DIALOG scale here

DIALOG demo app (web page)

DIALOG scale video (YouTube)

DIALOG scale – analytical framework for mental health services (PDF)

DIALOG translations (web page)

Psychometric properties of DIALOG (article, BMC Psychiatry)

Routine measurement of satisfaction with life and treatment aspects in mental health patients – the DIALOG scale in East London (article, BMC Health Services Research)

Structured patient-clinician communication and 1-year outcome in community mental healthcare. Cluster randomised controlled trial (DIALOG) (article, BJPsych)

Using DIALOG in a meaningful way in older adult services (PDF)

GBO

Access the GBO tool here

GBO translations (web page)

The Goal-Based Outcome (GBO) Tool Guidance Notes (PDF)

Test–retest stability, convergent validity, and sensitivity to change for the Goal-Based Outcome tool for adolescents: Analysis of data from a randomized controlled trial (article, Journal of Clinical Psychology)

Tools and guidance for working with goals across applied psychology and therapeutic settings (web page)

The use of goal-based outcome measures in digital therapy with adults: What goals are set, and are they achieved? (article, Counselling & Psychotherapy Research)

Video: Using Outcome Monitoring in Therapy Sessions and Supervision – Dr Duncan Law (YouTube)

ReQoL-10

Access the ReQoL-10 scale here

ReQoL Overview (web page)

Essential ReQoL ™ Resources (web page)

ReQoL translations (PDF)

ReQoL visualisation tool (web page)

Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties (article, British Journal of Psychiatry)

The Recovering Quality of Life 10-item (ReQoL-10) scale in a first-episode psychosis population: Validation and implications for patient-reported outcome measures (PROMs) (article, Early Intervention in Psychiatry)

The importance of content and face validity in instrument development: lessons learnt from service users when developing the Recovering Quality of Life measure (ReQoL) (article, Quality of Life Research)

Video: Implementing a patient outcome measure – an implementation success story! (YouTube)

Appendix 2: Steps taken to develop the guidance

The Community Mental Health Outcomes Task & Finish group was established in October 2021, following feedback from NHS community mental health services that a clearer national position was needed on the use of outcome measures in services.

The goal of the group was to recommend a consistent approach to outcome measurement nationally across community mental health services for adults and older adults with SMI.

The group recommended the use of three PROMs in community mental health services to increase focus on understanding individual needs, leading to more personalised care, and to enable a consistent way of measuring the effectiveness of interventions.

The National Collaborating Centre for Mental Health (NCCMH; see the project team below) was commissioned by NHS England in April 2023 to develop this guidance. The NCCMH convened three ERG meetings, conducted semi-structured interviews, and engaged with stakeholders across the community mental health system over 3 months to gather evidence to underpin this guidance.

Development included:

Drawing from work undertaken by:

- The NHS Implementation Network
- The NHS Task & Finish Group
- NHS England in the development of an FAQ.

Engagement with professionals and stakeholders in:

- ERG[a] meetings
- The NHS Task & Finish Group
- Semi-structured interviews (conducted with service leads, PROMs developers and VCSE organisations)
- Consultation with older adults, autism and learning disability specialists.

Engagement with people with lived experience in:

- ERG meetings
- The NCCMH EAG[b]
- The ODDESSI[c] Lived Experience Advisory Panel.

Development of case studies and example pathways:

- Using examples from existing work, findings from interviews and ERG suggestions
- Drawing on patient journeys presented in the Community Mental Health Framework.

Development of recommendations and implementation guidance:

- Using findings from engagement activities listed above
- Incorporating example pathways demonstrating how PROMs can be used along the patient journey
- Using outputs of an Equality Impact Assessment of proposed recommendations by the EAG.

Consultation of draft iterations of guidance with:

- The ERG
- The NCCMH EAG
- The ODDESSI Lived Experience Advisory Panel
- Other specialist advisers.

Draw from work undertaken so far

Engagement with professionals

Engagement with people with lived experience

Development of case studies and example pathways

Development of recommendations and implementation guidance

Consultation period

Stages of work carried out in the development of the PROMs implementation guidance

NCCMH project team

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[a] The ERG informed the development of the guidance and provided support for the project as a whole. The ERG comprised a number of practitioners who have experience of implementing PROMs in community mental health services, as well as experts by experience.

[b] The EAG is a standing group, with people who have lived experience of using or providing care for people who use mental health services, and who have expertise in equality and inequalities in mental health care.

[c] ODDESSI (Open Dialogue: Development and Evaluation of a Social Network Intervention for Severe Mental Illness) is a large-scale programme of research into crisis and continuing mental health care in the NHS.

Appendix 3: Guidance for practitioners on introducing and discussing the PROMs with patients

Below you can find some conversational examples to support the introduction, completion and discussion of PROMs.

Introduction to PROMs

- I'd *like to introduce to you some questionnaires that can help us work together to tackle the things that are most important to you. Most people find these helpful as a way of keeping track of how things are progressing while they are meeting with us. These measures are valuable in understanding your experiences, needs and priorities, and in tailoring your care toward your needs.*
- *In our service, we use three different outcome measures which we'll describe as we go through them. If you'd like, I can send you a more detailed description of each questionnaire or print them out for you.*
- *By the way, please don't worry about your answers to the different questionnaires or if you don't want to complete them. It won't have a negative impact on the care you receive.*

Practitioners may also wish to explore alternative or supplementary methods of discussing PROMs with patients, which could include providing written information or the use of visual aids, depending on individual patient need.

Completion of PROMs

- *To make our session more effective and focused on you, I suggest filling out the PROMs on a digital device (mobile phone, tablet or computer) before our appointments. This way, we can focus on your answers. However, if you prefer, we can go through them together during our first session to help you feel more confident in answering the questions.*
- *You can fill out the PROMs on a paper* form instead if you prefer.

Results of PROMs

Begin by asking an open question to give the person some space.

- *I noticed that you completed DIALOG, ReQoL-10 and GBO [pick the one/ones that has/have been completed] before our session, which is great. Do you have any thoughts about what you answered? Did it bring up anything you'd like to talk about?*

Probe their answers (e.g., 'Can you say more about that?').

At the end, tie up any specific aspects that haven't been discussed – for example:

- *There are a couple of aspects I would like to discuss... [e.g.] Regarding GBO, it's wonderful to see that you feel you've made progress in your goal of being able to talk about your feelings with your partner. That's great news. Can you tell me some more about it?*

This guidance was updated in: February 2024: The Goal-Based Outcome (GBO) Tool logo, quotes from the PROMs developers, characteristics of the PROMs and URL links were updated. May 2024: Minor typographical corrections to headers, and to link to REQoL-10 scale on p. 48.

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