

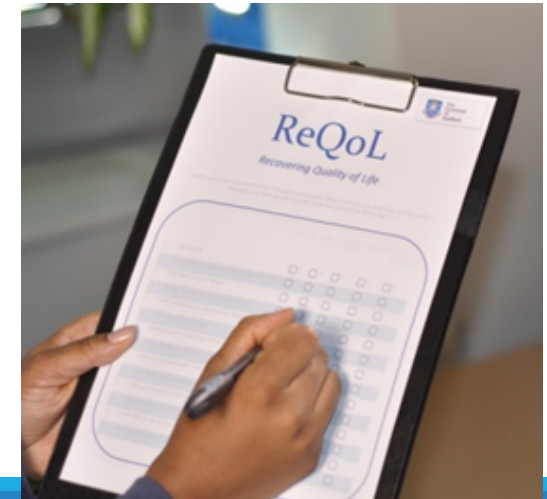
Developing a recovery and quality of life outcome measure for mental health services

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Why was ReQoL developed?

No health without mental health and *Closing the Gap* highlight the importance of measuring recovery from service users' perspectives

At the heart of recovery is a person's right to build a meaningful life with or without symptoms

There are three main principles underlying the recovery philosophy: hope; agency or control; opportunity (Shepherd et al., 2008)

Why was ReQoL developed?

Measures traditionally used in mental health services:

- Focus on symptoms (e.g. PHQ-9)
- Focus on clinician assessment (e.g. HoNOS)
- Were not developed for mental health services and so are too generic (e.g. EQ-5D and sWEMWBS)
- Fail to capture the wide spectrum of mental health conditions and severity (Boardman et al, 2013)

We need a new measure

A new measure is needed that:

- Focuses on recovery and quality of life
- Is not exclusively focused on wellbeing, but incorporates both positive and negative aspects
- Has been developed with mental health service users to focus on issues that are relevant and important to them

Capturing what matters to service users

A measure is needed to capture the concerns of service users, such as those identified by Leamy et al (CHIME):

- Connectedness
- Hope
- Identity
- Meaning and Purpose
- Empowerment

ReQoL is a Patient Reported outcome measures (PROM)

There are different ways of measuring outcomes:

**User rates
outcome
(PROM)**

**Clinician rates
outcome
(CROM)**

**User rates
satisfaction
(PREM)**

ReQoL is a PROM

Aims of ReQoL

To develop a brief measure of recovery and quality of life for users of mental health services to complete themselves

To work collaboratively with service users and clinicians to produce a measure that captures issues that are important to them

Stages of ReQoL development

1. Identify themes

2. Generate items

3. Gather service user's views

4. Gather clinician's views

5. Psychometric field testing

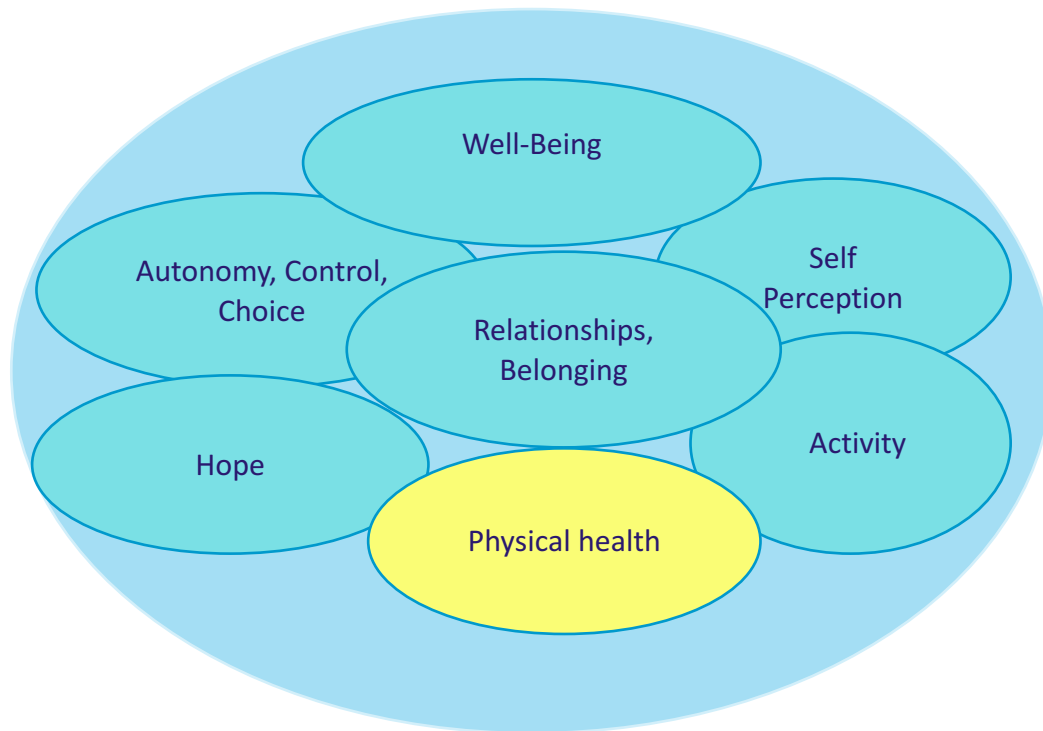
Service user involvement

Service users were integral to the research process as members of steering and advisory groups, researchers and participants. The research included:

- Interviews with service users to identify the themes
- Over 80 further interviews to establish face and content validity of the items
- Field testing with 6494 service users

Themes identified in Stage 1

The first stage of the research identified seven themes:



The themes identified in Stage 1 map onto CHIME

Domains of mental health related quality of life from Connell et al.

Belonging/Relationships

Hope

Self perception

Activity (meaningful/enjoyable)

Autonomy/Choice/Control

Well-Being

Physical Health

Recovery framework from systematic review and narrative synthesis by Leamy et al.

Connectedness/support/stigma and discrimination/community participation

Hope

Identity

Meaning

Empowerment

Stage 2

Once the themes had been identified items were generated for these themes

1597 items were identified from relevant existing measures and transcripts from service user interviews

Service users and clinicians helped select the most appropriate items to go through to the next stage

Stages 3 & 4

Service users were interviewed individually or in groups to establish the face validity and content validity of potential items

Focus groups were also held with clinicians to get their feedback on potential items

Stage 5

Two rounds of field testing took place to reduce the number of items using psychometric analysis

The first round involved 2261 service users in secondary care, primary care and voluntary sector

For the second round, 4253 service users were recruited

The analysis looked for: missing data; high residual correlations; misfitting items; coverage of measurement range; differential functioning; sensitivity to change

Principles informing item selection

All six mental health domains identified in Stage 1 of the project are represented in the final two versions of ReQoL.

Service user acceptability and clinician acceptability and usefulness

Acceptable psychometric properties

For each of the following statements, please tick one box that best describes your thoughts, feelings and activities over the **last week**.



Last week	None of the time	Only occasionally	Sometimes	Often	Most or all of the time
1. I found it difficult to get started with everyday tasks	<input type="checkbox"/> ₄	<input type="checkbox"/> ₃	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
2. I felt able to trust others	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I felt unable to cope	<input type="checkbox"/> ₄	<input type="checkbox"/> ₃	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
4. I could do the things I wanted to do	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I felt happy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I thought my life was not worth living	<input type="checkbox"/> ₄	<input type="checkbox"/> ₃	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
7. I enjoyed what I did	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. I felt hopeful about my future	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I felt lonely	<input type="checkbox"/> ₄	<input type="checkbox"/> ₃	<input type="checkbox"/> ₂	<input type="checkbox"/> ₁	<input type="checkbox"/> ₀
10. I felt confident in myself	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

	No problems	Slight problems	Moderate problems	Severe problems	Very severe problems
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Please describe your **physical** health (problems with pain, mobility, difficulties caring for yourself or feeling physically unwell) over the last week

₄ ₃ ₂ ₁ ₀

ReQoL-20

1. I felt unable to cope
2. I felt hopeful about my future
3. I found it difficult to get started with everyday tasks
4. I felt happy
5. I thought my life was not worth living
6. I felt lonely
7. I enjoyed what I did
8. I could do the things I wanted to do
9. I felt able to trust others
10. I felt confident in myself
11. I did things I found rewarding
12. I avoided things I needed to do
13. I felt irritated
14. I felt like a failure
15. I felt in control of my life
16. I felt terrified
17. I felt anxious
18. I had problems with my sleep
19. I felt calm
20. I found it hard to concentrate

Strengths of ReQoL

Developed collaboratively with service users and clinicians

Consistent with the themes of recovery

Suitable for routine use

Robust methodology

Developed with service users and clinicians

ReQoL was developed with service users and clinicians as advisors, researchers and participants

Service users and clinicians were involved in the decision-making stages of the development process

ReQoL has high face and content validity with clinicians and service users

Service users from ethnic minority populations were included in the research (South Asian and Polish)

Consistent with the themes of Recovery

Meets the gap identified by Boardman et al (2011)

Measures what matters to service users

Maps to CHIME

Can be used as a therapeutic tool

Can be used at multiple time points to build a picture or tell a story about recovery

Can be used to support formulation, care planning and discharge

Can be used to inform conversations between clinicians and service users

Can be used to guide and focus the sessions

Suitable for routine use

Suitable for adults aged 16 and over with a range of mental health conditions from mild to very severe

Simple, quick and free to use

Electronic and paper versions

Easy to calculate the score

Easy to interpret score – visualisation of results with and without norms will soon be available

Robust Methodology

ReQoL has been developed using modern and classical psychometrics

Initial validation shows that ReQoL is responsive, internally consistent and a valid measure