

Recovering Quality of Life

DEVELOPMENT OF A NEW PATIENT REPORTED OUTCOME MEASURE FOR MENTAL HEALTH SERVICES



The University Of Sheffield.

#ReOoL

Contact: <u>reqol@sheffield.ac.uk</u> Website: <u>www.reqol.org.uk</u>



Recovering Quality of Life

DEVELOPMENT OF A NEW PATIENT REPORTED OUTCOME MEASURE FOR MENTAL HEALTH SERVICES



The University Of Sheffield.

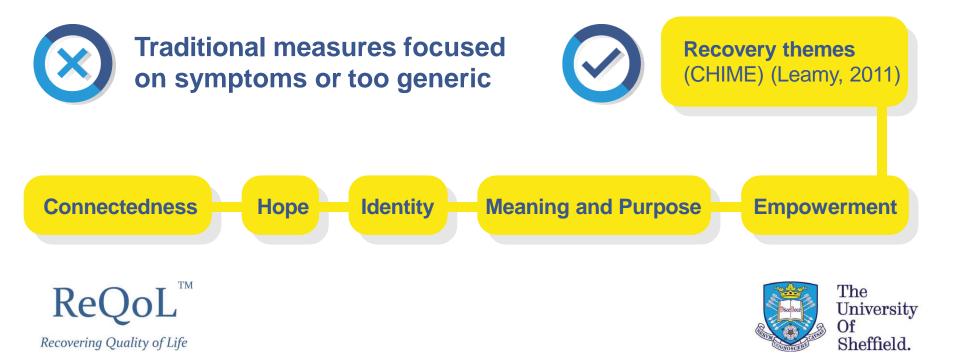
John Brazier

School of Health and Related Research Contact: <u>reqol@sheffield.ac.uk</u> Website: <u>www.reqol.org.uk</u>

Rationale for commissioning a new measure

Current Policy Context

- Mental health policy
 No health without mental health
 Five-year forward view mental health
- Payment system National tariff
- NHS outcomes framework
- Value for money



Scope of ReQoL

Aim: Develop a brief measure of recovery and quality of life for users of mental health services

For whom?



For mental health populations aged 16 and over



Suitable across all mental health populations including common mental health problems, severe and complex and psychotic



For primary, secondary and tertiary mental health services



For self-completion



Recovering Quality of Life

Brief version (10 items) and longer version (20 items)



Development process



Four main governance groups

Expert users involved in all stages and in decision making





Consultation at the end of each stage





Stage 1: Identifying themes

Methods used

Systematic review of qualitative literature

Qualitative interviews with 19 service users

Framework analysis to identify themes

ReQoL (QoL literature) Connell et al.

1. Belonging and Relationships

2. Hope

3. Self perception

4. Activity

5. Autonomy, Choice and Control

6. Well-Being

7. Physical health

Recovery literature Leamy et al.

Connectedness

Hope

Identity

Meaning

Empowerment

Well-being/Symptoms



The University Of Sheffield.

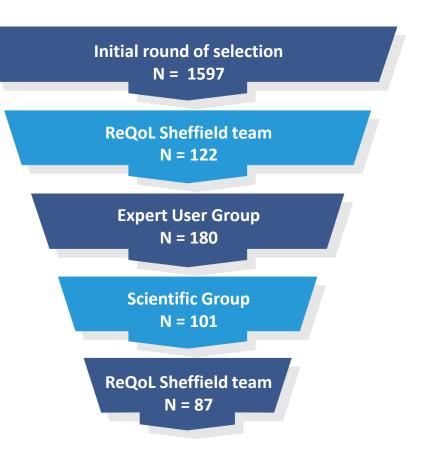


Stage 2: Generating items

Methods used

- 1. Identified items under each theme from:
- Manuscripts from qualitative interviews (mainly)
- Existing QoL measures
- Existing recovery measures

2. Applied *Streiner and Norman* criteria to sift through to reduce the number of items







Stage 3: Face to face validity testing

Methods used

- Participants were presented with a subset of 87 questions
- Commented on the questions
- Chose their favourite ones and rephrased items



- 59 adult service users interviewed across 4 NHS trusts
- 17 younger service users aged 16-18
- 22 participants from South Asian and Polish backgrounds
- Translatability assessment (MAPI Group)

Wide range of self-reported diagnosis:

Schizophrenia, Depression, Bipolar, Psychosis, OCD, Anxiety, Asperger's syndrome, PTSD, Personality disorder, Eating disorder, Alcohol problems, Cognitive impairment, Agoraphobia, Tourette's syndrome.

Items falling in the following categories were eliminated:

- Potentially distressing
- Judgmental
- Difficult to respond to
- Not too relevant to everyone
- Difficulties with interpretation





Stages 4 and 5: Psychometric testing

Methods used

Recruitment took place in secondary care, primary care and voluntary sector



Service users completed item pools

Mode of administration

- Face to face in clinics
- Post
- Online

6514 service users required A subset were followed up (N = 1237)

20 Trusts	64%	Age Category
6 GP practices	20%	16 to 29
Casper Trial Cohort	6%	30 to 59
Online panels	8%	60 to 79
Voluntary sector	2%	79 and over

Self report main diagnosis	
Depression	44%
Anxiety	28%
Psychotic disorders	17%
Bipolar	11%
Personality disorder	6%
Eating disorders	6%



The University Of Sheffield.

10%

45%

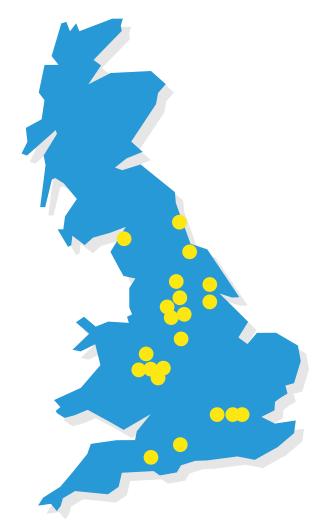
23%

22%



Stages 4 and 5: Psychometric testing

Recruiting Organizations		
Birmingham and Solihull NHS FT	McPin	
Black Country	My Space – voluntary organisation	
Bradford District Care FT	Northumberland Tyne and Wear NHS FT	
CASPER Trial Cohort	Rotherham, Doncaster and South Humber	
Central and North West London	Sheffield Children's Hospital	
Central and North West London Recovery College	Sheffield Health and Social Care Trust	
	Solent	
Chesterfield Royal Hospital (Adolescents)	Southern Health	
Cumbria	South Staffordshire and Shropshire NHS SP	
Dorset	South West Yorkshire FT	
Dudley and Walsall MHT	South West London St George's Trust Tees, Esk and Wear Valleys	
GP surgeries in Sheffield (6)		
Leeds and York FTP		





The University Of Sheffield.



Criteria for informing item selection

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

2. Service user acceptability (based on data collected in Stages 2,3,4 and 5) and clinician acceptability and usefulness (based on data collected on the 40 item pool through focus groups with clinicians)

3. Robust **psychometric properties** using classical and modern techniques like factor analysis and item response theory





ReQoL - 10

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	4	3	2	1	0
2. I felt able to trust others	0	1	2	3	4
3. I felt unable to cope	4	3	2	1	0
4. I could do the things I wanted to do	0	1	2	3	4
5. I felt happy	0	1	2	3	4
6. I thought my life was not worth living	4	3	2	1	0
7. I enjoyed what I did	0	1	2	3	4
8. I felt hopeful about my future	0	1	2	3	4
9. I felt lonely	4	3	2	1	0
10. I felt confident in myself	0	1	2	3	4
	No problems	Slight problems	Moderate problems	Severe problems	Very severe problems
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	•

ReQoL - 20

- 1. I found it difficult to get started with everyday tasks
- 2. I felt able to trust others
- 3. I felt unable to cope
- 4. I could do the things I wanted to do
- 5. I felt happy
- 6. I thought my life was not worth living
- 7. I enjoyed what I did
- 8. I felt hopeful about my future
- 9. I felt lonely
- 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

Please describe your physical health (problems with pain, mobility, difficulties caring for yourself or feeling physically unwell) over the last week





Why use ReQoL?



Consistent with the themes of recovery

9		0
	<u> </u>	

Constructed using inputs from service users and clinicians at all stages



Acceptable to service users and clinicians



Suitable for a range of mental health conditions from mild to very severe



ReQoL is a psychometrically sound – robust methodology



Short and simple



ReQoL can measure change in QoL – responsiveness has factored in item selection





Acknowledgments



All members of governance groups; Participants in the study; NIHR – CRN Mental health; MAPI Group staff at all participating trusts; charities and GP surgeries



After lunch there will be a collaborative implementation workshop focusing on

Practical aspects of using ReQoL Implementing ReQoL in your service Data visualization

After a short presentation you will be asked to join in two group discussions



