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ReQoL

Recovering Quality of Life

Recovering Quality of Life (ReQoL)

Development of a new outcome measure for mental health services

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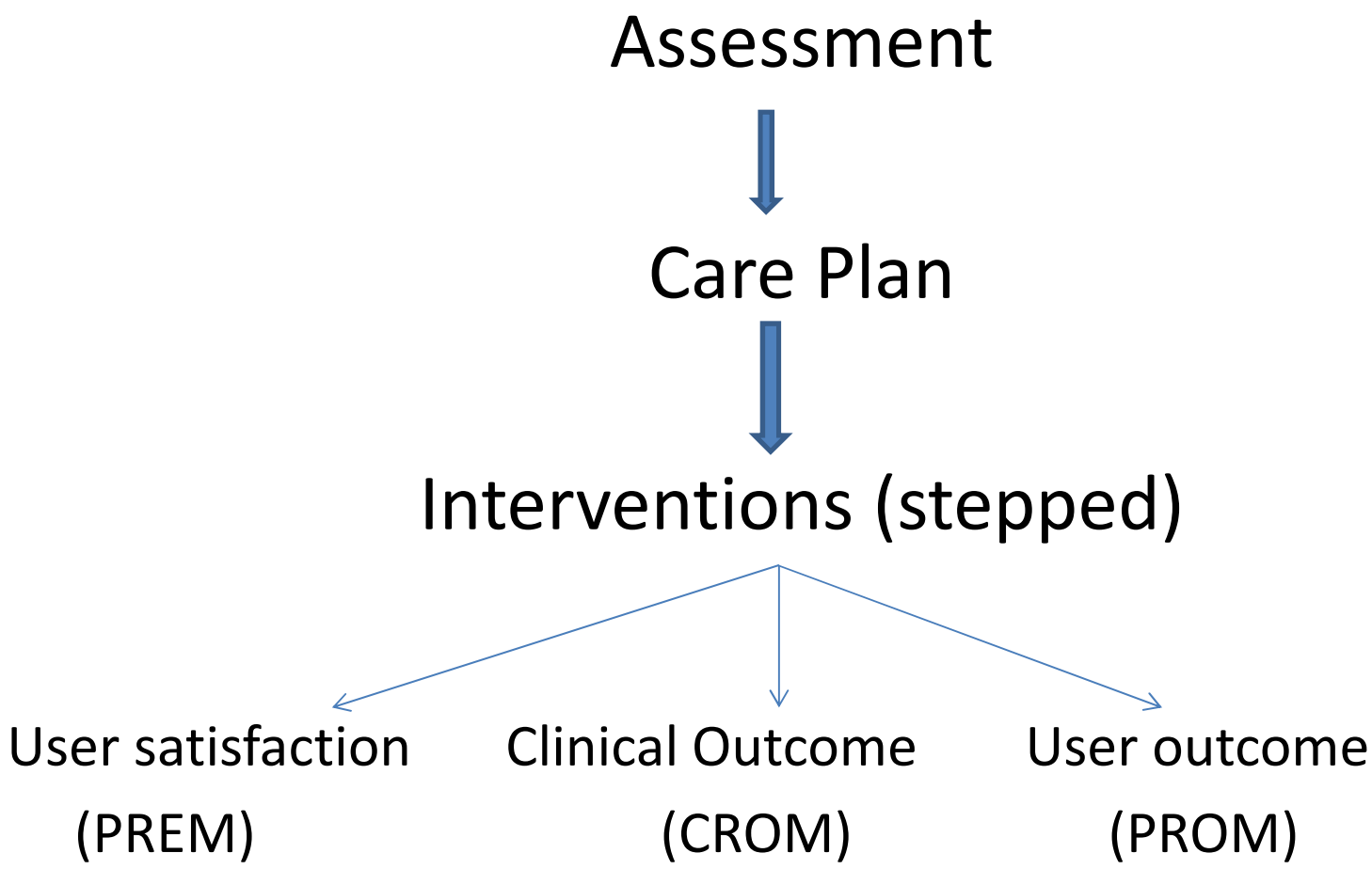
Place of user outcomes



Demand for an outcome measure

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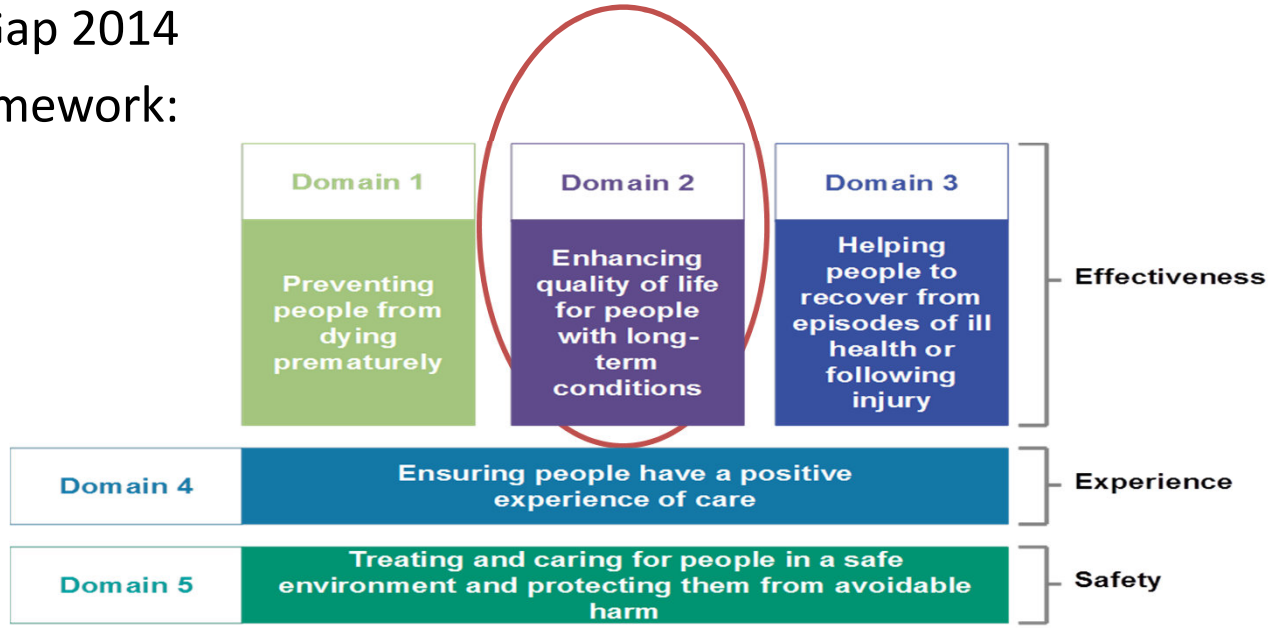
- DH published: '*No health without mental health: a cross-government mental health outcomes strategy for people of all ages*' with emphasis on recovery from user point of view
- DH – Closing the Gap 2014
- NHS Outcome Framework:



- NHS England: National Tariff Payment System(aka PbR) – piloting the sWEMWBS
- NICE – concerns with limitations of EQ-5D in calculating QALYs for assessing cost-effectiveness

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Rationale for developing a new measure

- Traditionally measures focused on symptoms (e.g. PHQ-9) and/or involved clinical assessment (e.g. HONoS), or too generic (EQ-5D and sWEMWBS)
- Existing measures not able to capture wide spectrum of mental health conditions and severity (Boardman et al, 2013)
- Measure required that captures the concerns of service users, such as those identified by Leamy et al (2011): Connectedness, Hope, Identity, Meaning and Purpose, and Empowerment (CHIME)
- An outcome measure from the perspectives of service users (Rose 2011)

Recovery and quality of life

- User focused outcomes should be concerned with the way mental health impact on the quality of their lives – as they see it
- Typically quality of life rather than symptoms
- Recovery QoL is multi-dimensional (e.g. not exclusively focused on wellbeing) and covers positive and negative aspects
- Recovery outcomes assessed by measuring QoL at multiple time points

Aim and scope of research project

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Aim

- to develop a brief measure of recovery and quality of life for users of mental health services

Scope

- For mental health populations aged 16 and over
- Generic – suitable across all mental health populations including common mental health problems, severe and complex and psychotic disorders (clusters 1-17) (not dementia or learning disabilities)
- For primary, secondary and tertiary mental health services
- For self completion – though will have interview and proxy versions
- Long version (20-30 items) and brief version (max 10 items)

Who is developing ReQoL?

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- Project team: Michael Barkham, John Brazier, Jill Carlton, Janice Connell, Tom Ricketts, Lizzie Taylor-Buck and Kirsty McKendrick
- Scientific Group (14 members) : Project team with Mike Slade, Jed Boardman, Suzanne Heywood-Everett, Andrew Papadopoulos, Diana Rose, Dan Robotham, Jo Hemmingfield and Andrew Grundy.
- Advisory group (≈ 25 members): academics (national and international) , clinicians and expert users
- Stakeholders group (≈ 30 members): academics, clinicians, DH, CPPP, think tanks, charities and separate Expert Users Group

NB: Advisory and Stakeholder groups consulted at every stage. Expert service users in all groups and collaborating in the research

Funder: Department of Health through the Policy Research Unit in Economic Evaluation of Health and Care Interventions (EEPRU). With support from the NIHR funded Yorkshire and Humber CLAHRC. Usual disclaimer applies.

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Project timetable

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Stage 1 (Feb – Apr 14)
Agree themes (from service users)(Connell 2012; Boardman 2013)
Output: List of domains

Stage 2 (May 14 – Jul 14)
Generate items
Output: Long list of items

Stage 3 (Sep – Feb 15)
Test face and content validity with service users (focus groups and interviews)
Output: Refined long questionnaire

Stage 4a (Mar - Aug 15)
Item reduction and finalise questionnaire
(service users across clusters and diagnoses in various settings)
Output: A long and brief questionnaire handed to DH by AUG 2015

Stage 4b (Sept 15 – Feb 16)
Psychometric testing of questionnaires
(service users routine practice)
Output: Validated brief questionnaire and long questionnaires

Stage 5 (Mar 16 – May 16)
Valuation
(Survey of general population)
Output: QALY scoring methods

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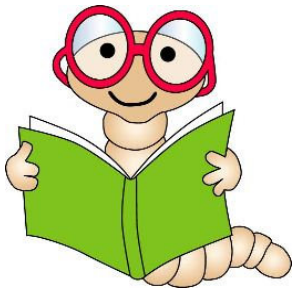
MRC Study 1: Systematic review

- Reviewed 13 studies
- Canada/UK/Sweden/USA/Australia/NZ
- Occupational Therapy (5); Nursing (4); Psychology (2); Psychiatry (1) Social worker (1)
- Schizophrenia (3); Bi-polar (3); Panic Disorder (1); Mixed (6)
- Limitations: focus on severe mental health: schizophrenia/bi-polar

Analysis: data extracted and reviewed using framework analysis to develop themes of how mental health problems impacted on people's lives



MRC Study 2: Service User Interviews

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- 19 depth interviews
- Broad range diagnosis and severity
  - Severe and enduring (CMHT x 2)
    - Schizophrenia; Personality Disorder;
    - Severe Depression/Anxiety; PTSD
  - Mild to Moderate (IAPT)
    - Anxiety/Depression
  - Limitations – No OCD / Bipolar

Analysis: Interviews transcribed and analysed using the results from the review as a framework

Themes from qualitative analysis

Self-Perception

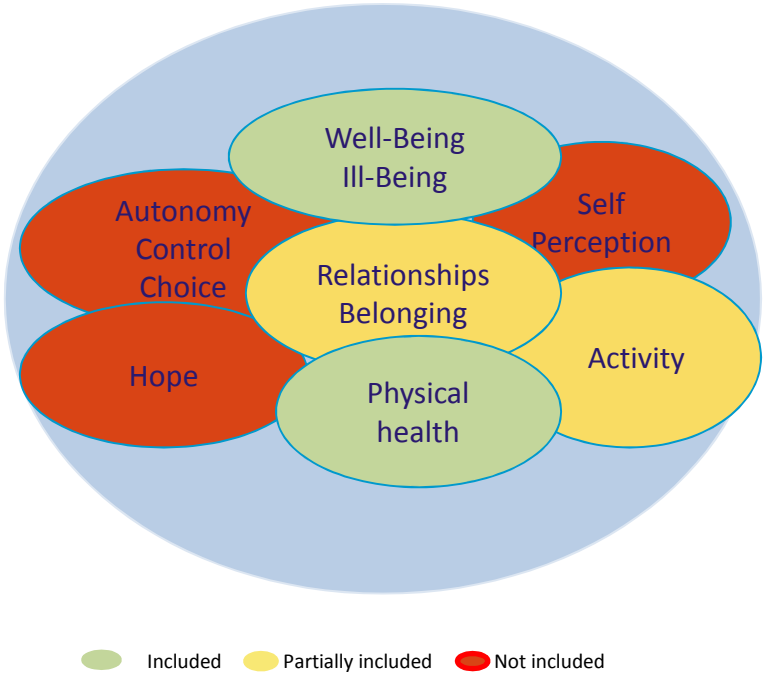
"The worse part is the lack of self worth and having to accept that one is disabled, one has a stigma which stops you from doing anything else really other than being worthless"

Well/Ill-Being

"I would lose this anxiety that I seem to be constantly carrying with me"

Activity

"I went on a year's course at engineering and I was absolutely scared about going on that, but I did it and I did it, you know, quite well … and at that time, I was really happy in my life"



Hope

"The one thing that I used to do a lot is not think about the future, think only a couple of days ahead … now, I'm more willing to think further ahead, I'm more willing to say, well in a year's time I'd like to be at this place"

Physical Health

".. my body aches and like I think I just become really tense and that is what makes my body ache and I feel like erm I feel like my chest is being crushed and erm I can't breath"

Relationships and Belonging

"I have feelings of err not belonging to the human race…, it's not an outcast. I just don't feel a connection…I would just like to be supported by other people.. and helping other people, that's all I ever wanted to do"

Autonomy, control and choice

"I do feel reliant on my parents … I would like to be able to have my own house and be on the property ladder and like live the life like I thought that I was going to"

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Recovery and Quality of Life

Quality of Life Connell et al.	Recovery* Leamy et al.
Belonging/Relationships	Connectedness/support/stigma and discrimination/community participation
Hope/Hopelessness	Hope
Self perception	Identity
Activity (meaningful/enjoyable)	Meaning
Autonomy/Choice/Control	Empowerment
Well-Being/Ill-Being	Well-Being/Symptoms
Physical Health	

*Boardman et al - Assessing recovery: seeking agreement about the key domains (domain 2)

Theme	Positive sub-themes	Negative sub-themes
Well-being and Ill-being	Happiness/enjoyment	Depression/sadness
	Relaxed/Calm	Fear/anxiety/worry
	Positive energy/motivation	Loss of energy/motivation
Sense of Belonging/ Relationships	Sense of belonging	Not belonging - outsider
	Positive relationships	Negative relationships
	Friendship and camaraderie	Lack of friends
	Caring for others/ability to contribute	
	Supportive relationships	Unsupportive relationships
Activity/Meaning	Enjoyable activity	Unenjoyable/ stressful activity
	Meaningful/valued/purpose-full/constructive	Boring/meaningless/not valued
	Ability e.g. self care	Lack of ability
Self-perception/Identity	Positive self-identity	Negative self-identity/fragmented sense of self
	Positive self-confidence	Negative self-confidence
Autonomy/Control/Choice/Empowerment	Autonomy	Dependence
	Choice	Lack of choice
	Control/coping	No control/not coping
Hope/Hopelessness	Hope	Hopelessness
	Plans and goals	Lack of plans and goals
Physical Health	Good health	Poor Health

Stage 2: Generating items

Aim:

- to identify a long list of items covering the agreed themes

Sources:

- Review content of existing generic (e.g. WEMWBS), mental health (e.g. CORE-OM and GHQ-12) and recovery measures
- Transcripts from interview data
- New items constructed by team and Expert Service User Group

Process:

- Research team sifted through 1597 to develop a long list using agreed criteria (e.g. avoid ambiguity, double-barrelled questions, jargon, value laden words etc.)
- Presentation to Expert User Group, Advisory Group and Stakeholder Group
- Consultation with Expert User Group to ensure all domains covered – added new items
- Consultation with Advisory group and Stakeholder group

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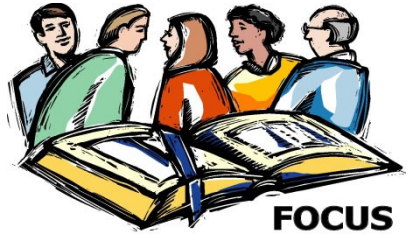
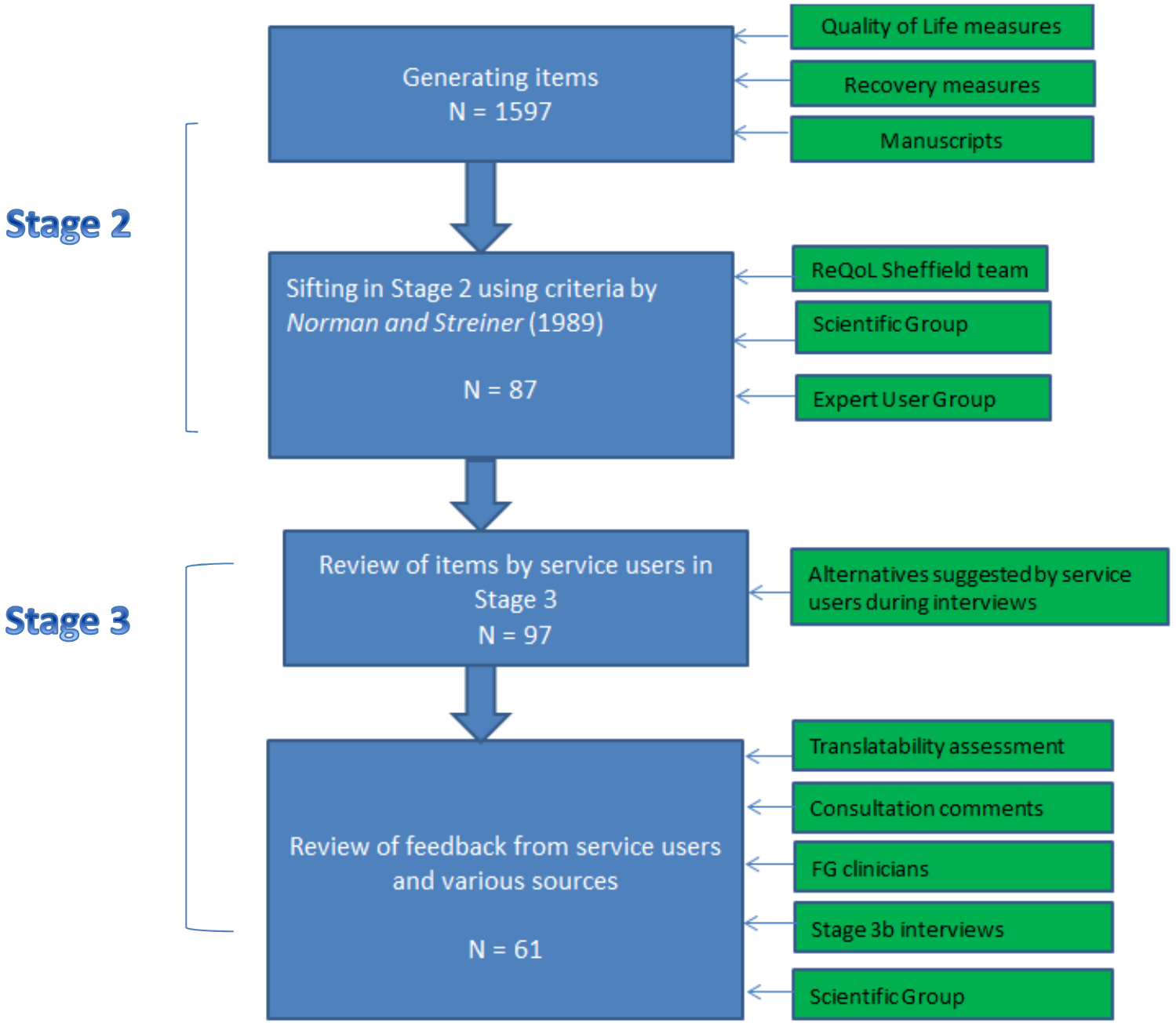
Stage 3 – Face and content validity testing (1)

- Total number of service users n = 59 – 4 trusts
- 40 individual interviews
- 2 focus groups
- 4 ‘pseudo focus groups’ with only 2 people
- Quite a wide range of diagnoses: Schizophrenia, Depression, Bipolar, Psychosis, OCD, Anxiety, Asperger's Syndrome, PTSD, Cognitive impairment, Agoraphobia, Eating disorder
- Mean age = 42 years (range 19 – 79)
- 77% of those interviewed were of white ethnicity




Stage 2
Stage 3
Generating items
N = 1597
Quality of Life measures
Recovery measures
Manuscripts
Sifting in Stage 2 using criteria by
Norman and Streiner (1989)
N = 87
ReQoL Sheffield team
Scientific Group
Expert User Group
Review of items by service users in
Stage 3
N = 97
Alternatives suggested by service
users during interviews
Review of feedback from service users
and various sources
N = 61
Translatability assessment
Consultation comments
FG clinicians
Stage 3b interviews
Scientific Group

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Number of items currently in the ReQoL questionnaire by theme

Theme	TOTAL	No of positive items	No of negative items
Control, Autonomy, Choice	8	5	3
Hope	6	2	4
Relationships	9	5	4
Self-perception	9	4	5
Well/Ill-being	18	4	14
Activity	7	3	4
Physical Health	4	0	4
Total	61	23	38

First page of the questionnaire

Below are some statements about feelings, thoughts and activities.

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 felt calm	☐	☐	☐	☐	☐
2.	I had difficulty controlling my worry	☐	☐	☐	☐	☐
3.	I had choices about what I did	☐	☐	☐	☐	☐
4.	I felt safe	☐	☐	☐	☐	☐
5.	My mental health limited day to day activities	☐	☐	☐	☐	☐
6.	I felt happy	☐	☐	☐	☐	☐
7.	I felt unsure of myself	☐	☐	☐	☐	☐
8.	I tended to blame myself for bad things that have happened	☐	☐	☐	☐	☐
9.	I found it difficult to get started with everyday tasks	☐	☐	☐	☐	☐
10.	I could do the things I wanted to do	☐	☐	☐	☐	☐
11.	I was disturbed by unwanted thoughts and feelings	☐	☐	☐	☐	☐
12.	People around me caused me distress	☐	☐	☐	☐	☐
13.	I felt like a failure	☐	☐	☐	☐	☐
14.	I felt irritated	☐	☐	☐	☐	☐

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Stage 4a

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Aim: to reduce number of items using psychometric analyses (including Rasch) to test items performance and inform optimum item selection

RECRUITMENT (March – May 2015)

- Sample size n > 1200
- 12 NHS trusts: Bradford District Care Trust, Leeds and York Partnership Trust, Humber, Sheffield Health and Social Care Trust, Sheffield Children's Hospital, RDASH, South West Yorkshire FT, Birmingham and Solihull, Dudley and Walsall, South Shropshire and Staffordshire, Central and North West London, South West London and St Georges Trust (in person and mail out)
- 3 GP practices in Sheffield (mail out)
- 4 charities – MQ, McPin, Sheffield Mind, OCD London (online)
- **CASPER trial – 65 +**
- Online panel – MH service users + healthy population
- To date n = 900+
- **Long and short ReQoL measures will be handed to DH by August 2015**

Next Steps

- Further validation of ReQoL and comparison to other measures (Stage 4b Sept 2015- March 2016)

  n = 2000 + with follow-up for a sample
- Development of QALY from ReQoL – valuation survey with general population (Stage 5 April- June 2016)
- Cross cultural validation: Bradford study in Urdu and Polish through Y&H CLAHRC (led by Suzanne Haywood-Everett)
- Translation into various European languages (currently in discussions with MAPI research)
- Implementation of ReQoL for clinical use: Y&H CLAHRC study
- OFFICIAL LAUNCH – September 2015

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Acknowledgements

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- All participants in the study
- MHRN for their assistance with recruitment - Divisions 4 &5 Yorkshire and Humber
- All participating Trusts, GP practices, charities and CASPER trial

Bradford District Care Trust NHS
Birmingham and Solihull Mental Health NHS Foundation Trust NHS
Humber NHS Foundation Trust NHS
Central and North West London NHS Foundation Trust NHS
Dudley and Walsall Mental Health Partnership Trust NHS
Leeds and York Partnership NHS Foundation Trust NHS
Rotherham Doncaster and South Humber NHS Foundation Trust NHS
Grounded@Research RDASH
Sheffield Health and Social Care NHS Foundation Trust NHS
South West London and St George's Mental Health NHS Trust NHS
South Staffordshire and Shropshire Healthcare NHS Foundation Trust NHS
MQ Transforming mental health
ocdaction it's time to act
A Keele University Teaching Trust
South West Yorkshire Partnership NHS Foundation Trust NHS
With all of us in mind
McPin Foundation Transforming mental health research
mind for better mental health Sheffield
Sheffield Children's NHS Foundation Trust NHS
CASPER