APPENDIX 2: The Published Works

List of papers comprising this thesis and summary table (abstracts, impact, citations).

7 publications in total, including 5 academic papers from 4 original research studies, one review and one NICE Learning Tool. A linked HYMS SSIP is also listed.

- Blenkiron P, Mo KH, Cuzen J and Hammill AC. Involving service users in their care: the CUES Project. *Psychiatric Bulletin (The Journal of Psychiatric Practice)*, Oct 2003; 27(9): 334-338 (Print). Published online by Cambridge University Press 2 Jan 2018 https://doi.org/10.1192/pb.27.9.334
- 2. Blenkiron P, Hammill CA. What determines patients' satisfaction with their mental health care and quality of life? *Postgraduate Medical Journal*, 2003; 79(932): 337-340. http://dx.doi.org/10.1136/pmj.79.932.337
- Blenkiron, P, Brooks A, Dearden R & McVey J. Use of the Distress Thermometer to Evaluate Symptoms, Outcome and Satisfaction in a Specialist Psycho-oncology Service. General Hospital Psychiatry 2014; 36(6): 607-612 https://doi.org/10.1016/j.genhosppsych.2014.06.003
- 4. Keetharuth AD, Brazier J, Connell J, et al, on behalf of the ReQoL Scientific Group: Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. *British Journal of Psychiatry*, 2018; 212(1):42-49. https://doi.org/10.1192/bjp.2017.10
- 5. Blenkiron P & Goldsmith L. Patient Reported Outcomes Measures in Community Mental Health Teams: Pragmatic Evaluation of PHQ-9, GAD-7 and SWEMWBS. *BJPsych Bulletin* Oct 2019; 43(5): 221-227 http://dx.doi.org/10.1192/bjb.2019.20
- 6. Lynch S, Clarkson P, Blenkiron P, Fraser J. Scale based protocols for the detection and management of depression. *Primary Care Psychiatry* 2002; 8(3): 77-84. https://doi.org/10.1185/135525702125001506
- Blenkiron P, Byng R, Chew-Graham C, Goldberg D, Ivbijaro G, Nipah R, D, Rathod S, Shafran R. NICE: Common Mental Health Problems: Clinical Case Scenarios for Primary Care. A learning & development resource to support the NICE guideline CG123 (Common Mental Health Disorders: Identification & Pathways to Care). Ch7: Active Monitoring & Psychoeducation. National Institute for Health and Clinical Excellence, 2012. https://www.nice.org.uk/guidance/cg123/resources/clinical-case-scenarios-pdf-version-pdf-181726381
- 8. Ransom S & Blenkiron P: Mental Health Outcome Measures: A clinical review and descriptive survey of psychiatrists' current practices. Scholarship & Special Interest Programme (SSIP) Project & Poster, Hull York Medical School (Unpublished).

| Blenkiron P, Mo KH, Cuzen J and Hammill AC. Involving service users in their care: the CUES Project. <i>Psychiatric Bulletin (The</i> |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Journal of Psychiatric Practice), Oct 2003; 27(9): 334-338 (Print). Published online by Cambridge University Press 2 Jan 2018 http://rcpsych.org/content/abstract/27/9/334?ct . PDF HTML Export citation https://doi.org/10.1192/pb.27.9.334 |
| Original Clinical Research |
| PB designed the study, led the clinical implementation and data collection, analysed the data, led the writing of the published paper and disseminated results to peers |
| CUES-User version. Questionnaire booklet covering 16 key areas of life and service (social, physical and mental health). Nationally coproduced by the RCPsych, DoH & NSF. Mixed qualitative and quantitative format: each question has 3 parts: a) extent of agreement with an 'ideal' statement b) satisfaction with own situation c) free text response |
| 120 service users with mental health problems lasting over 6 months who were currently in contact with the CMHT, Selby, NY. |
| Aims and Method : To assess the impact of Carers' & Users' Expectations of Services - User version (CUES-U) upon clinical care planning in working age adults with mental health problems. 86 individuals who were receiving input from the community mental health team gave their views. |
| Results: Life and service satisfaction ratings ranged from 49% to 88%. The CUES-U discussion led to a change in clinical care for 49% of respondents. Care coordinators rated CUES-U as a good use of their time in 64% of cases. Women and those with a shorter duration of mental disorder were rated as more engaged in the consultation process. |
| Clinical Implications: CUES-U appears to be a useful tool for supporting individual clinical care and the evaluation of community mental health services. |
| Douglas Bennett Prize 2003 awarded to PB for this work by the Royal College of Psychiatrists for best original paper presented by a psychiatrist in the field of rehabilitation psychiatry to promote the recovery of people with severe mental illness. Joint Conference of Faculty of General & Community Psychiatry & Section of Rehabilitation & Social Psychiatry, Bristol, Oct 2003 Press Release, RCPsych: 'Carers' & Users' self-rating questionnaire supports clinical care: Its use led to improvements in care for nearly half of patients'. RCPsych Division Newsletter Article 2003. |
| |

| | Highlighted as an example of innovative good practice by the National Centre for Mental Health www.nimhe.org.uk, the Northern Centre of Mental Health www.ncmh.org.uk and Rethink: http://www.rethink.org/research/rethinkres/cues.htm MRCPsych Exam: results data and box plots used for critical review section of exam since 2015 DIALOG (see refs below) is an evolution of CUES and is one of three mandated mental health PROMS within NHS England's Community Transformation project 2022-25 |
|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Comments | A longer NHS report with additional qualitative data was published on the Primary Care Trust Website: Service user satisfaction within an adult community mental health team. Final report on Selby CUES (Carers' and Users' Expectations of Service) Project. |
| Citations (Pubmed & Google Scholar) | NHS Website NHS evidence www.evidence.nhs.uk Books |
| | Mental Health Outcome Measures by Thornicroft G and Tansella M, ISBN 9781904671923, Springer 2021 3 rd edition. http://www.rcpsych.ac.uk/files/samplechapter/MHoutcomeMeasures3edSC.pdf |
| | Social work and mental health in Scotland by S Hothersall, M Maas-Lowita and M Golightley - Learning Matters, 2008 |
| | Reports Integration of social care staff within community mental health teams. Final report. NIHR Service Delivery and Organisation programme Centre for Analysis of Social Policy (CASP) P Huxley, S Evans, C Baker, J White, S Philpin |
| | Papers Bee P, Price O, Baker J, Lovell K. Systematic synthesis of barriers and facilitators to service user-led care planning The British Journal of Psychiatry, 207(2), "015, 104-114 DOI: https://doi.org/10.1192/bjp.bp.114.152447 |
| | Coker A, Williams F, Hayes A, Hamann L, Carol J 2016. Exploring the needs of diverse consumers experiencing mental illness and their families through family psychoeducation. Journal of Mental Health, Vol. 25, Issue. 3, p. 197. |
| | Jones A, Hannigan B, Coffey M, Simpson A: Traditions of research in community mental health care planning and care coordination: A systematic meta-narrative review of the literature- PloS one, 2018 - journals.plos.org |

Magliano, Lorenza Fiorillo, Andrea Del Vecchio, Heidegret Malangone, Claudio De Rosa, Corrado Bachelet, Carla Cesari, Giampiero D'Ambrogio, Rosa Fulgosi Cigala, Francesca Veltro, Franco Zanus, Paola Pioli, Rosaria and Maj, Mario 2009. Development and Validation of a Self-Reported Questionnaire On Users' Opinions About Schizophrenia: a Participatory Research. International Journal of Social Psychiatry, Vol. 55, Issue. 5, p. 425. journals.sagepub.com

Simpson A, Hannign B, Coffey M, Jones M, Barlow A, Cohen R, Všetečková, J, Faulkner, A 2016. *Cross-national comparative mixed-methods case study of recovery-focused mental health care planning and co-ordination: Collaborative Care Planning Project (COCAPP)*. Health Services and Delivery Research, Vol. 4, Issue. 5, p. 1. orca.cf.ac.uk http://dx.doi.org/10.3310/hsdr04050

| Publication 2: CUES Satisfaction | Blenkiron P, Hammill CA. What determines patients' satisfaction with their mental health care and quality of life? <i>Postgraduate Medical Journal</i> , 2003; 79(932): 337-340. |
|-------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Weblinks | http://dx.doi.org/10.1136/pmj.79.932.337 https://pmj.bmj.com/content/postgradmedj/79/932/337.full.pdf |
| | |
| Туре | Original Clinical Research |
| PB Involvement | PB designed the study, led the clinical implementation and data collection, analysed the data, led the writing of the published paper and disseminated results to peers |
| Outcomes (PROMs) Evaluated | CUES-User version. Questionnaire booklet covering 16 key areas of life and service. See publication 1 above for details. |
| Participants/Setting | 120 service users with mental health problems lasting over 6 months who were currently in contact with the CMHT, Selby, NY. |
| Abstract | Objectives: This study investigated whether patients' satisfaction with their mental health care and quality of life is related to their age, gender, psychiatric diagnosis, and duration of mental disorder. |
| | Method: 120 adults of working age who were receiving input from a community mental health team in North Yorkshire were invited to complete the Carers' and User's Expectations of Services, User Version (CUES-U) questionnaire. This 16 item self-rated outcome measure covers the issues that those using mental health services have identified as being their priorities. |
| | Results: CUES-U ratings were lowest for "Social life" (49% satisfied) and highest for "Relationships with physical health workers" (88% satisfied). Satisfaction with psychiatric services correlated significantly with patients' age (Spearman's $r = 0.444$, p<0.001) and their satisfaction in other areas of their lives such as housing, money, and relationships ($r = 0.575$, p<0.001). Those with psychotic disorders rated their quality of life as higher than other respondents (median total satisfaction score 12 v 9, Mann-Whitney U = 377, p = 0.001). Gender and duration of disorder were unrelated to service satisfaction. |
| | Conclusions: Patient satisfaction ratings have been promoted as an outcome measure when evaluating the quality of their mental health services. Certain factors influencing an individual's satisfaction with the care provided (such as their age and general quality of life) are not directly under the control of professionals. |
| Dissemination, Impact & Comments | See publication 1 |

Citations (Pubmed & Google Scholar)

Most recent, English Language, 76 Citations, including 28% in the past 2 years. 'Compared to other publications in the same field, this is extremely highly cited. It has received 13 times more citations than average, suggesting that this paper is currently receiving a lot of interest.' Relative citation ratio = 3.05, widely distributed the world including UK, Europe, Asia, S America & Africa.

Reports

Keating F, Samele C, Furnish K et al (2006) Research Priorities for Service User and Carer-Centred Mental Health Services Report for the Sainsbury Centre and National Coordinating centre for NHS Service Delivery. http://www.scmh.org.uk/pdfs/scmh research priorities literature review final report.pdf

Quoted our finding that people who are happy with their life and social circumstances are more likely to be happy with their mental health care which 'has implications for the Government's social inclusion agenda'....

Papers

- 1. Routine measurement of satisfaction with life and treatment aspects in mental health patients the DIALOG scale in East London <u>BMC Health Services Research</u>, 20(1), 1020, 2020 https://doi.org/10.1186/s12913-020-05840-z Mosler F, Priebe S, Bird V, The DIALOG scale has been implemented as a routine patient outcome and experience measure (PROM/PREM) in...
- 2. Mosler, F., Priebe, S. & Bird, V. Routine measurement of satisfaction with life and treatment aspects in mental health patients the DIALOG scale in East London. *BMC Health Serv Res* **20**, 1020 (2020). https://doi.org/10.1186/s12913-020-05840-z
- 3. Optimising the integration of technology-enabled solutions to enhance primary mental health care: a service mapping study LaMonica HM, Davenport TA, Ottavio A et al 2021, BMC Health Services Research. Despite the widely acknowledged potential for health information technologies to improve the accessibility, quality and clinical safety of mental health care.
- 4. The Relationships between Health Professionals' Perceived Quality of Care, Family Involvement & Sense of Coherence in Community Mental Health Services. Moen Ø, Skundberg-Kletthagen H, Lundquist L-O et al, 2020, Issues in Mental Health Nursing
- 5. Unmet Need for Mental Healthcare in a Population Sample in Sweden: A Cross-Sectional Study of Inequalities Based on Gender, Education, and Country of Birth. Olsson S, Hensing G, Burström B, Löve J 2020, Community Mental Health JI Article.
- 6. Perceived Patient Satisfaction and Associated Factors among Psychiatric Patients Who Attend Their Treatment at Outpatient Psychiatry Clinic, Southwest Ethiopia, Jimma, 2019, Chalachew Kassaw, Elias Tesfaye, Shimelis Girma, Liyew Agenagnew

| | 7. Measuring the Patient Experience of Mental Health Care: A Systematic and Critical Review of Patient-Reported Experience Measures. Sara Fernandes, Guillaume Fond, Xavier Yves Zendjidjian et al, 2020, Patient Preference and Adherence. |
|-------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Publication 3: DT Project | Blenkiron, P, Brooks A, Dearden R & McVey J. Use of the Distress Thermometer to Evaluate Symptoms, Outcome and Satisfaction in a Specialist Psycho-oncology Service. <i>General Hospital Psychiatry</i> 2014; 36(6): 607-612 Ms. Ref. No. GHP-14-27R1 PII S0163-8343(14)00158-3 |
| Weblinks | https://pubmed.ncbi.nlm.nih.gov/25052476/ https://doi.org/10.1016/j.genhosppsych.2014.06.003 |
| Туре | Original Clinical Research |
| PB Involvement | PB designed the study, led the clinical implementation and data collection, analysed the data, led the writing of the published paper and disseminated results to peers |
| Outcomes (PROMs) Evaluated | The Distress Thermometer Tool and Problem Checklist: self-rated emotional distress on visual analogue scale from 0 (no distress) to 10 (extreme distress), plus tick checklist of 33 problems (practical, family, emotional, spiritual/religious, physical, other). Before (DT1) & after (DT2) psycho-oncology input. DT2 included 10-point service satisfaction linear scale & questions. |
| Participants/Setting | 111 adults receiving physical care from local cancer services who were referred to a specialist psycho-oncology outpatient service at York Hospital, North Yorkshire, UK. |
| Abstract | Objective: The National Institute for Health and Care Excellence recommends the use of structured tools to improve holistic care for patients with cancer. The Distress Thermometer and Problem Checklist (DT) is commonly used for screening in physical health settings. However, it has not been integrated into the clinical pathway within specialist psycho-oncology services. We used the DT to examine the broad clinical effectiveness of psycho-oncology intervention and to ascertain factors from the DT linked to an improved outcome. We also evaluated patients' satisfaction with their care. Method: We asked 111 adult outpatients referred to York Psycho-Oncology Service to complete the DT at their first appointment. Individuals offered a period of psycho-oncology care re-rated their emotional distress, problems and service satisfaction on the DT at discharge. Results: Median distress scores decreased significantly (from 6 to 4, Wilcoxon's $z = -4.83$, $p < .001$) indicating a large clinical effect size (Cohen's $d = 1.22$). Frequency of emotional problems (anxiety, depression and anger) fell significantly by 15–24% despite no significant change in patients' physical health or practical problems. Number of emotional problems was the best predictor of distress at discharge (beta=0.468, $p = .002$). Satisfaction was high and correlated with lower distress scores ($r = -0.42$, $p = .005$) and fewer emotional problems ($r = -0.31$, $p = .04$) at discharge but not with number of appointments attended. Qualitative thematic analysis showed patients particularly value supportive listening and advice on coping strategies from |

| | professionals independent of their physical care. Conclusion: The DT is an acceptable and useful tool for enhancing the delivery of structured psycho-oncology care. It may also provide evidence to support the effectiveness of specialist psycho-oncology interventions. |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Dissemination & Impact | 427 views/downloads in first 12 months after publication (including USA, UK, Australia & China) Poster Prize Winner, Annual Research Forum 16.10.13, Leeds & York Partnership NHS Foundation Trust. Presented at RCPsych International Congress, Edinburgh July 2013 and RCPsych Faculty of Addictions Psychiatry & Faculty of Liaison Psychiatry Joint Annual Conference, Leeds, June 2014. http://www.rcpsych.ac.uk/pdf/Poster_presentationsAL2014.pdf |
| Comments | Also published as short report: Blenkiron, P et al. Clinical impact of a psycho-oncology service: using the distress thermometer to evaluate symptoms, outcome and patient satisfaction. <i>Innovation Research and Development Newsletter</i> , Leeds & York Partnership NHS Foundation Trust, issue 15, p9, Feb 2014. |
| | https://www.leedsandyorkpft.nhs.uk/research/wp-content/uploads/sites/6/2017/04/innovation-issue15-oct13.pdf |
| Citations (Pubmed & Google Scholar) | Reports Cancer PROMs: a scoping study. Macmillan Cancer and Oxford University, 2015. Coulter A, Petter C, Peters M et al https://www.pssru.ac.uk/pub/5079.pdf |
| Most recent, English Language, | Papers 1. Pepin AJ, Lippe S, Drouin. Screening for distress in pediatric cancer survivors: A systematic comparison of one-step and two-step strategies to minimize detection errors. J of Psychosocial Oncology, May 2021 |
| | 2. Nikolskayaa NS, Khaina AE, Ekaterina A et al: Distress Screening in Russian Pediatric Oncology: Adaptation and Validation of the Distress Rating Scale. Psychology in Russia: State of the Art, 13(3), 2020, ISSN 2307-2202. Validation of a Russian version of the distress thermometer for use in children, cites our study. |
| | 3. Peters L, Brederecke J, Tfanzke . Psychological Distress in a Sample of Inpatients With Mixed Cancer—A Cross-Sectional Study of Routine Clinical Data. Front. Psychol., 30 November 2020 |
| | 4. Brederecke PL, Franzke j, de Zwaan A et al. Psychological Distress in a Sample of Inpatients With Mixed Cancer-A Cross-Sectional Study of Routine Clinical Data. Front Psychol. 2020 Nov 30;11:591771. doi: 10.3389/fpsyg.2020.591771. |

| | 5. Mehnert A, Hartung TJ, Friedrich M et al. One in two cancer patients is significantly distressed: Prevalence and indicators of distress Psychooncology 2018 Jan;27(1):75-82. doi: 10.1002/pon.4464. 6. Acquati C, Kayser K Predictors of psychological distress among cancer patients receiving care at a safety-net institution: role of younger age and psychosocial problems Support Care Cancer. 2017 Jul;25(7):2305-2312. doi:10.1007/s00520-017-3641-8. |
|-------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Publication 4: ReQoL Recovering Quality of Use | Keetharuth AD, Brazier J, Connell J, et al, on behalf of the ReQoL Scientific Group: Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. <i>British Journal of Psychiatry</i> , 2018; 212(1):42-49. PMCID: PMC6457165 (plus 5 linked papers – 2 involving PB - see below) |
| Weblinks | DOI: https://doi.org/10.1192/bjp.2017.10 PDF https://www.reqol.org.uk Overview, report & YouTube film |
| Туре | Original Clinical Research – UK-CRN (NIHR Portfolio) Multicentre National Research Study – DoH Sponsored |
| PB Involvement: Roles - 2014-2019: Academic (ReQoL | 1. ReQoL Scientific Advisory Group Core Member 2015-2016 Development via meetings and email consultations with stakeholders, users, professionals. Content wording and choice (factor analysis of 1600 statements) of final questions See invitation letter, Prof Brazier, Sheffield Univ. and BJPsych Jan 2018 Acknowledgements (p49): 'The authors would like to thank all the participants in the project and the staff who have been involved in the recruitment of participants. We are grateful to the core members of the scientific group and those who have attended the various scientific group meetings. The core members of the scientific group were: Paul Blenkiron, Jed Boardman, Suzanne Heywood Everet and Mike Slade'. |
| Scientific Group), + Strategic (PI led recruitment across 2 large NHS Trusts) | 2. Principal Investigator 2015-2016 : Leeds & York Partnership NHS Foundation Trust (LYPFT) REC no 14/WM/1062 CSP157888 KCRN ID 171 39/40 R&D no 2015/560/P. Stage 4a and 4b initial study data collection, 247 patients recruited: "Extremely successful' recruitment a fantastic result, thank you so much for your efforts'. Led recruitment personally and staff focus group CMHT 2016 a) Palace of Westminster, Parliament - launch & Implementation workshop participant 11.10.16 Paul Boating MP and NHS England and follow up with Lizzie Buck Taylor, implemented by Sarah Sewell as the outcome measure in LYPFT. |
| + Implementation (Parliament 2016, World Café 2018) | b) Published Innovation Magazine, LYPFT Oct 2016 issue 26, page 17 3. Associate Clinical Director for Research 2016-2019: Tees, Esk & Wear Valleys (TEWV) NHS Foundation Trust: REC no 14/WM/1062 IRAS ID 157888 for stage 5a and 5b: clinical validation against Clusters, HoNoS, SWEMWBS and CORE-10. a) TEWV ReQoL Principal Investigator 2016-2019: led recruitment & dissemination b) Research Funding Award, ReQoL 0.25PA 2018-2019 CRN NENC Clinical Research Network NE & Cumbria NIHR Portfolio Study (see letter). Personally interviewed & entered over 60 patients into trial, exceeding target. c) Supporting and advising on Practical NHS Implementation: Nov 2018: World Café Participant, Sheffield Univ, see 2020 paper https://doi.org/10.1186/s41687-020-00202-z & consent to publish. d) Dissemination: research conference & senior medical staff committee presentations NHS 2018 to 2019 |

| Outcomes (PROMs) Evaluated | Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people over 16 experiencing mental health difficulties. Assesses quality of life and outcomes of recovery - focus on what matters most to patients. Clinical (10 -item) and 20 item (research) versions, plus a physical health question. |
|--------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Participants/Setting | Multicentre: 12 Trusts, 4 charities, 6 GP practices, 6.5K user responses. A Sheffield University School of Health & Related Research (ScHARR) collaboration with York University Centre for Health Economics. Chief Investigator: Prof John Brazier. Funded by the Department of Health Policy Research Unit in Economic Evaluation of Health & Care (EEPRU): £200K. |
| Abstract | Background: Outcome measures for mental health services need to adopt a service-user recovery focus. Aims: To develop and validate a 10- and 20-item self-report recovery-focused quality of life outcome measure named Recovering Quality of Life (ReQoL). Method: Qualitative methods for item development and initial testing, and quantitative methods for item reduction and scale construction were used. Data from >6500 service users were factor analysed and item response theory models employed to inform item selection. The measures were tested for reliability, validity and responsiveness. Results: ReQoL-10 and ReQoL-20 contain positively and negatively worded items covering seven themes: activity, hope, belonging and relationships, self-perception, well-being, autonomy, and physical health. Both versions achieved acceptable internal consistency, test-retest reliability (>0.85), known-group differences, convergence with related measures, and were responsive over time (standardised response mean (SRM) > 0.4). They performed marginally better than the Short Warwick-Edinburgh Mental Well-being Scale and markedly better than the EQ-5D. Conclusions: Both versions are appropriate for measuring service-user recovery-focused quality of life outcomes ReQoL measures add important information to what is traditionally collected in mental health. They have excellent face and content validity and desirable properties in terms of reliability, construct validity and responsiveness. They also have excellent acceptability and feasibility in clinical practice. |
| Dissemination & Impact | Launched in Parliament 2016. See 'roles' for PB dissemination. Freely available for use by NHS Staff and for publicly funded research from the Oxford University Innovation website: http://innovation.ox.ac.uk/outcome-measures/recovering-quality-life-reqol-questionnaire/ |
| Other ReQol Publications | 5 Additional Linked Papers: Keetharuth A.D., Taylor Buck E., Conway K. et al. Integrating Qualitative and Quantitative Data in the Development of Outcome Measures: The Case of the Recovering Quality of Life (ReQoL) Measures in Mental Health Populations. International Journal of Environmental Research and Public Health. 2018 15(7). (PB named acknowledgment in paper) Taylor Buck, E., Smith, C.M., Lane, A. et al. Use of a modified World Café process to discuss and set priorities for a |
| | Community of Practice supporting implementation of ReQoL a new mental health and quality of life Patient Reported Outcome |

Measure (PROM). Journal of Patient Reported Outcomes, 4, 38, May 2020. https://doi.org/10.1186/s41687-020-00202-z (PB World Cafe Participant & Contributor)

- 3. <u>Keetharuth AD, Bjorner JB, Barkham M et al Exploring the item sets of the Recovering Quality of Life (ReQoL) measures using factor analysis. Quality of Life Research. 2018 Dec 21:1-1.</u>
- 4. Connell J, Carlton, J., Grundy, A., Brazier, J. et al. The importance of content and face validity in instrument development: Lessons learnt from service users when developing the Recovering Quality of Life (ReQoL) measure Quality of Life Research 2018;27(7):1893–902.
- 5. <u>Grundy A., Keetharuth A., Barber R. et al (2019) Public involvement in health outcomes research: lessons learnt from the development of the recovering quality of life (ReQoL) measures Health and Quality of Life Outcomes 2019 17:60; Published: 11 April 2019</u>

Citations

(Pubmed & Google Scholar) Most recent, English Language, 82 papers A feasibility hybrid II randomised controlled trial of volunteer 'Health Champions' supporting people with serious mental illness manage their physical health: study protocol Williams J, Fairburn E, McGrath R et al, Pilot Feasibility Stud. 2021; 7: 116. 2021 May 31. doi: 10.1186/s40814-021-00854-8

<u>Transitioning Transdiagnostic CBT from Face-to-Face to Telephone Delivery During the Coronavirus Pandemic: A Case Study</u> Jess Saunders J & Allen C ,Case Stud. 2021 May 19: 15346501211018278. 2021 May 19. doi: 10.1177/15346501211018278

Psychometric assessment of EQ-5D-5L and ReQoL measures in patients with anxiety and depression: construct validity and responsiveness Franklin M, Enrigue A, Palacios et al. Qual Life Res. 2021 Apr 9: 1–15. doi: 10.1007/s11136-021-02833-1

Van Aken, BC, dr Beurs E, Mulder CL, Van der Feltz-Cornelis The Dutch Recovering Quality of Life questionnaire (ReQoL) and its psychometric qualities. European J of Psychiatry, 34(2): 99-107 DOI: 10.1016/j.ejpsy.2020.01.001 <u>Download PDF</u>

Evaluating the Implementation of a Mental Health Referral Service "Connect to Wellbeing": A Quality Improvement Approach Leigh-ann Onnis L-A, Kinchin I, Pryce J et al Front Public Health. 2020; 8: 585933. 2020 Dec doi: 10.3389/fpubh.2020.585933

<u>Criteria for item selection for a preference-based measure for use in economic evaluation</u> Peasgood T, Mukuria C, Carlton J et al. Qual Life Res. 2021; 30(5): 1425–1432. Published online 2020 Dec 7. doi: 10.1007/s11136-020-02718-9

The RESPECT study: a feasibility randomised controlled trial of a sexual health promotion intervention for people with serious mental illness in community mental health services in the UK Hughes E, Mitchell N, Gascoyne S et al BMC Public Health. 2020; 20: 1736. doi: 10.1186/s12889-020-09661

| | Treating sleep problems in young people at ultra-high-risk of psychosis: study protocol for a single-blind parallel group randomised controlled |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | feasibility trial (SleepWell) Waite F, Kabir T, Johns L et al. BMJ Open. 2020;10(11):e045235. 2020 doi: 10.1136/bmjopen-2020-045235 |
| | Routine measurement of satisfaction with life and treatment aspects in mental health patients – the DIALOG scale in East London Moslet F, Priebe S & Bird V BMC Health Serv Res. 2020; 20: 1020. doi: 10.1186/s12913-020-05840-z |
| Publication 5: PROMS in CMHTs | Blenkiron P & Goldsmith L. Patient Reported Outcomes Measures in Community Mental Health Teams: Pragmatic Evaluation of PHQ-9, GAD-7 and SWEMWBS. <i>BJPsych Bulletin</i> Oct 2019; 43(5): 221-227. PMID: 30898178 Cambridge University Press. |
| Weblinks | http://dx.doi.org/10.1192/bjb.2019.20 HTML BJPBulletin@rcpsych.ac.uk https://www.cambridge.org/core/services/aopcambridge-core/content/view/5FAF009C0F29680A80E9F092A7973586/S2056469419000202a.pdf_Open Access. |
| Туре | Original Clinical Research |
| PB Involvement | PB designed the study, led the clinical implementation and data collection, analysed the data, led the writing of the published paper and disseminated results to peers |
| Outcomes (PROMs) Evaluated | Initial & 3-month follow measures, using the PHQ-9 (9-item scale assessing ICD-10 depressive symptoms across 4 ordinal response scales, plus functional impairment), the GAD-7 (7 items recording anxiety symptoms, 4 response scales) and the SWEMWBS (a 7 item tool to assess global wellbeing with 5 response categories). Separate factor analysis for: self-harm risk, problem solving ability and ability to function. Professionals' questionnaire recorded care setting, diagnosis & Mental Health Cluster ('Payment by Results'). |
| Participants/Setting | 245 service users aged over 18 referred to specialist mental health services (CMHT & Psychiatry), York & North Yorkshire, UK |
| Abstract | Aims and Method: We evaluated routine use, acceptability and response rates for the Patient Health Questionnaire, Generalised Anxiety Disorder Scale and Short Warwick Edinburgh Mental Well Being Scale within adult community mental health teams. Measures were repeated 3 months later. Professionals recorded the setting, refusal rates and cluster diagnosis. Results: 245 service users completed 674 measures, demonstrating good initial return rates (81%), excellent scale completion (98-99%) and infrequent refusal/unsuitability (11%). Only 32 (13%) returned follow up measures. Significant improvements occurred in functioning (p=0.01), PHQ-9 (p=0.02) and GAD-7 (p=0.003) scores (Cohen's d = 0.52-0.77) but not in SWEMWBS (p=0.91). Supercluster A had higher initial PHQ-9 &GAD-7 (p<0.001) and lower SWEMWBS scores (p=0.003) than Supercluster |
| | B. Supercluster C revealed the greatest functional impairment (p=0.003). Clinical Implications: PHQ-9 and GAD-7 appear acceptable as patient reported outcome measures in CMHTs. SWEMWBS seems insensitive to change. National outcome programmes should ensure good follow up rates. |
| 1 | |

Dissemination & Impact

- Oral presentations by PB: LYPFT Research Forum 2016, Weetwood Hall Leeds, LYPFT, BPH Governance & Audit Group 2016, and TEWV Research Day, Durham University 2017.
- Poster presentations by PB: RCPsych International Congress, London 2016 and BABCP Conference, Glasgow 2018 http://rcpsych.tfi.ipostersessions.com/default.aspx?s=visitor
- Strategic links and discussions with TEWV Outcomes re utility of SWEMWBS v ReQoL as future preferred PROM

Comments

Linked Article:

Blenkiron P and Goldsmith L. Patient Reported Outcome Measures in Community Mental Health Services: Patient Centred or Pipe dream? Pragmatic evaluation of the usefulness and acceptability of SWEMWBS, PHQ-9 and GAD-7. Innovation Magazine, LYPFT Research & Development Newsletter, p15, July 2016

TEWV NHS Trust e-Bulletin 9.4.19 Paul Blenkiron, consultant, Huntington House, York. Congratulations on your recent publication in BJPsych Bulletin





http://intouch/News/Pages/Congratulations.aspx.

Citations

Updated 10/2023

(Pubmed & Google Scholar) Most recent, English Language Boulton AJ, Tyner CE, Choi SW et al. Linking the GAD-7 and PHQ-9 to the TBI-QOL Anxiety and Depression Item Banks. 2019, 34(5):353-363 J Head Trauma Rehabil 10.1097/HTR.00000000000529.

Fenfen Wan G, Zheng M, & Zhang D. How to deal with the negative psychological impact of COVID-19 for people who pay attention to anxiety and depression. Precision Clinical Medicine, Jun 2020, 3(3), p161. doi.org/10.1093/pcmedi/pbaa023

Niculescu, I, Twinkle A and Iaboni, A. Screening for depression in older adults with cognitive impairment in the homecare setting: a systematic review. Aging & Mental Health, 2020, p. 1.

Ge F, Zhang D, Wu L, Mu H. Predicting Psychological State Among Chinese Undergraduate Students in the COVID-19 Epidemic: A Longitudinal Study Using a Machine Learning. Neuropsychiatric Disease and Treatment, 2020, 16, p. 2111. doi.org/10.2147/NDT.S262004

Wang Y, Ge F, Zhang J, Zhang W. Heterogeneity in the co-occurrence of depression and anxiety symptoms among youth survivors: A longitudinal study using latent profile analysis. Early Intervention in Psychiatry, 4 Jan 2021. doi.org/10.1111/eip.13101

Marnn, Htoo H, Zin PMM et al. COVID-19 Pandemic Impact on Public Distress, Economy and Education of Bago Division in Myanmar. Technium Soc. Sci. 2021 10.1136/bmjopen-2018-027250

<u>I Niculescu</u>, <u>T Arora</u>, <u>A Iaboni</u>. <u>Screening for depression in older adults with cognitive impairment in the homecare setting: a systematic review</u> - Aging & mental health, 2021 - Taylor & Francis

SG Echevarria, R Peterson. College students' experiences of dating app facilitated sexual violence and associations with mental health symptoms and well-being - The Journal of Sex, 2022 - Taylor & Francis

VJ Lucas, S Burke, A Selby <u>The effectiveness of cognitive behavioural therapy for patients with concurrent hand and psychological disorders</u>. Journal of Hand Surgery, 2023 - journals.sagepub.com

<u>P Łakuta</u>, D Krankowska...<u>Enhancing well-being and alleviating depressive symptoms in people with HIV/AIDS: An intervention based on if—then plans with self-affirming cognitions</u>, Health and Wellbeing, 2022 - Wiley Online Library.

Shevlin, Mark, Butter, Sarah, McBride, Orla, Murphy, Jamie, Gibson-Miller, Jilly, Hartman, Todd K, Levita, Liat, Mason, Liam, Martinez, Anton P, McKay, Ryan et al (show 17 more authors) (2022) Measuremen t invariance of the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder scale (GAD-7) across four European countries during the COVID-19 pandemic. BMC Psychiatry, 22 (1),154.

| Publication 6: Depression Scales | Lynch S, Clarkson P, Blenkiron P, Fraser J. Scale based protocols for the detection and management of depression. <i>Primary Care Psychiatry</i> 2002; 8(3): 77-84. |
|-------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Weblinks | https://doi.org/10.1185/135525702125001506 https://www.research.manchester.ac.uk/portal/en/publications/scalebased-protocols-for-the-detection-and-management-of-depression(094f8a90-24c7-4f5d-93d0-f9666b37101f).html |
| Туре | Review and Discussion Paper |
| PB Involvement | Co-author |
| Outcomes (PROMs) Evaluated | PROMS for depression: BDI, HADS, BDS: Evidence base, strengths and limitations of the approach. |
| Participants/Setting | Adults presenting in primary care with mental health problems |
| Abstract Dissemination, | Despite evidence for the potential effectiveness of self-rating scales in the detection and management of depressive illness in primary care, they have not been as widely adopted as has been hoped. This may reflect views on their clinical utility when administered in isolation as opposed to being incorporated into a management protocol. More elaborate and sophisticated methods of improving the detection and management of depressive illness in primary care are available, such as educational programmes and management protocols based on clinical practice guidelines and computerized packages. However, these methods are either expensive or may have variable take up, as primary health care staff may not always find it possible to attend training programmes. Hence, there is increasing interest in the use of more widely accessible and possibly briefer approaches to this problem. One potential avenue that deserves further attention is the use of very brief protocols which have self-rated scales as a central part. This approach is discussed in this paper and work in progress with a new self-rating scale for depression, the Brief Depression Scale, is used for illustrating this approach. Lynch, S., Curran, S., Montgomery, S., Fairhurst, D., Clarkson, P., Suresh, R., & Edwards, R. (2000). The Brief Depression Scale - Reliability |
| & Impact | and validity of a new self-rating depression scale. <i>Primary Care Psychiatry</i> , <i>6</i> (3), 111-118. Lynch S, Clarkson P. Fairhurst D, Edwards R, Suresh R, Curran S (2002) A comparative study of two scoring methods for screening for |
| | depression with the Brief Depression Scale Primary Care Psychiatry, 8:2:73 -6 |

| Citations | Peveler R, Carson A, Rodin G: Clinical Review - ABC of Psychological Medicine: Depression in medical patients. <i>BMJ</i> 2002; 325 doi: https://doi.org/10.1136/bmj.325.7356.149 |
|---------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | Lynch, S (2014): Does depression screening improve depression outcomes in primary care? BMJ; 348 doi: https://doi.org/10.1136/bmj.g1253 |
| Publication 7: NICE Learning Resource | Blenkiron P, Byng R, Chew-Graham C, Goldberg D, Ivbijaro G, Nipah R, D, Rathod S, Shafran R. NICE: Common Mental Health Problems: Clinical Case Scenarios for Primary Care. A learning & development resource to support the NICE guideline CG123 (Common Mental Health Disorders: Identification & Pathways to Care). <i>National Institute for Health and Clinical Excellence</i> , 2012. |
| Weblink | https://www.nice.org.uk/guidance/cg123/resources/clinical-case-scenarios-pdf-version-pdf-181726381 |
| Туре | Support tool for implementation of linked NICE Guideline. Educational resource for use in a group or individual setting. |
| PB Involvement | Co-Author: NICE Fellow 2011-2014: One of 10 nationally appointed ambassadors for evidence-based guideline implementation. Core member of NICE Common Mental Health Disorder Advisory Group 2011-2013. PB wrote Chapter 7: Psychoeducation and Active Monitoring pp 49-56, with focussing on PROMS and assessing outcomes in practice linked to a case study with anxiety and depression. Co-contributor to other parts of resource which highlights use of PROMS (see pp71-73 and glossary p74). |
| Outcomes (PROMs) Evaluated | PROMS with supporting evidence base including PHQ-9, GAD-7, HAD Scale and Distress Thermometer Tool. |
| Participants/Setting | 'Enables participants to apply the stepped care model in routine practice when managing patients with depression, anxiety and other common mental health conditions'. |
| Abstract | 'These eight clinical case scenarios have been developed to improve the identification, assessment and treatment of common mental health problems. They illustrate how the recommendations from 'Common mental health disorders: identification and pathways to care' (www.nice.org.uk/guidance/CG123) can be applied to the care of people presenting in primary care. Each scenario has been written by a different contributor with experience in this field, and includes details of the person's initial presentation, their case history and their GP's summary of the situation after consultation. |
| | Decisions about diagnosis and management are then examined using a question and answer approach. Hyperlinks to the relevant recommendations from the NICE guideline are included after the answer. The clinical case scenarios are available in two formats: this PDF version and a slide set that can be used for groups. You will need to refer to the NICE clinical guideline to help you decide what steps you would need to follow to diagnose and manage each case. |
| Dissemination & Comments | See NICE Website – 'Learning into Practice'. Incorporated into 'NICE pathways' www.nice.org.uk |

| | Kendrick T & Pilling S. Common mental health disorders – identification and pathways to care NICE clinical guideline. <u>Br J Gen Pract.</u> 2012 Jan; 62(594): 47–49. doi: 10.3399/bjgp12X616481 PMID: 22520681 |
|--|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|--|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

| SSIP HYMS Poster & Paper | Ransom S & Blenkiron P: Mental Health Outcome Measures: A clinical review and descriptive survey of psychiatrists' current practical project, HYMS, 2018. (Not currently a peer reviewed publication). |
|-------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| (Unpublished) Weblinks | https://www.hyma.co.uk/modicing/gurrigulum/ggip |
| weblinks | https://www.hyms.ac.uk/medicine/curriculum/ssip |
| Туре | E-questionnaire NHS Service Evaluation, Phase 2 Student Scholarship & Special Interest Programme, Hull York Medical School |
| PB Involvement | PB acted as mentor and supervisor for the project design and facilitated data collection. Sam Ransom, year 3 medical student, created the questionnaire, analysed the results and wrote the SSIP paper and poster. |
| Outcomes (PROMs) Evaluated | Frequency of use and perceived comparative clinical utility of mental health measures: PROMS: PHQ-9, GAD-7, SWEMWBS, ReQoL-10. Comparison with PREMS (Family & Friends Q), CROMS: dementia (MMSE, MOCHA), alcohol (CAGE, AUDIT) and mandated NHS Service Measures: HoNOS, Mental Health Clustering Tool. |
| Participants/Setting | 210 psychiatrists of all grades from Foundation Doctor to Consultant, working within TEWV NHS Foundation Trust, UK. |
| Abstract | Background: An outcome measure (OM) is a tool that can be used to measure how effective an intervention is on a patient over time. They can also be used to assess how well a service is performing and identify what areas need improvement. A 2011 government white paper 'No Health without Mental Health' strongly advocated their use in clinical practice. Objectives: 1) To ascertain which rating scales and OM are used by NHS psychiatrists |
| | 2) To describe attitudes towards and perceived usefulness of these measures3) To describe any differences according to grade, gender or subspecialty |
| | Methods: I designed a 7-item questionnaire on Qualtrics based on the themes identified in discussion with my clinical supervisor and a literature review. The questionnaire was piloted then sent to all psychiatrists from foundation doctor to consultant in the TEWV |

trust. Data was analysed using excel, using non-parametric tests, including Spearman's rank correlation coefficient. Themes and responses to qualitative data were collated.

Results:

The response rate was 62/210 (29.5%). The most common factors affecting use of outcome measures were reported as perceived clinical usefulness, followed by properties of the tool itself (eg short, easy to use), whether use of the tool was mandatory (eg clustering) and professional factors such as peer pressure. Clustering tools and cognitive screens were the most frequently used OM with 44% using them at least once a month. PHQ-9 and ReQol were the least frequently used with only 16% and 4% respectively. There was no statistically significant relationship between the most frequently used OM and the OM deemed most useful $\rho(-0.21)$.

There was no statistically significant relationship between which OM were used frequently by juniors compared to consultants $\rho(0.37)$, men compared to women $\rho(0.60)$ or between general adult psychiatrists and other specialities $\rho(0.35)$. On assessing which OM they found useful there was a statistically significant relationship between juniors and consultants $\rho(0.83)$, men and woman $\rho(0.8)$ and general adult and other specialities $\rho(0.88)$. Cognitive screens were found to be the most useful, with 69% finding them to be useful or very useful. Clustering tools were found to be the least useful with 60% finding them not at all useful. Fig 1 (see poster) shows the relationship between outcomes frequently used and outcomes found to be useful. Fig 2 shows the factors that affect OM usage.

51% of respondents made additional comments. The most commonly occurring themes about OM was about the time they take up (24%) and a belief that OM shouldn't be used as an alternative to clinical judgement (14%).

Conclusions

A recent Cochrane review concluded that there is inadequate evidence that using outcome measures leads to improved outcomes but cited the need for higher quality research. In this study, despite a statistically significant relationship between respondent subgroups about which OM they found useful, this did not relate to how frequently they are used. This supports the idea that there are a range of factors other than clinical utility that determine why respondents use outcome measures in daily practice.