**Appendix A:** Scoring Instruction and References for EMPOWER Measures

1. **MISSING ITEMS**

Unless otherwise specified, all derived totals and domain scales will be subject to the 50% or more rule. That is if there are 50% or more items reported then the remainder will be imputed using within-person-mean imputation.

Where an item is imputed within a domain this will also be used if there should be a total score. However the 50% rule will still be upheld for that total score.

1. **RESEARCHER INTERVIEW**

**Relapse**

* There are 7 relapse characteristics.
  + state of the service user: Add up A-D
  + health provision needed: Add up E-G
  + The total sum is just the severity score.
* Type of relapse is related to remission score, this is entered into eCRF by researchers.
* Relapse itself is established from the Date of Onset

**PANSS**

Scoring Instruction- this may differ to a similarly named measure:

* Using Five-Factor Model- total up scores from each of the five factors.

\*There are 5 domains/factors: P, N, D, E, ED

Responses: 1=Absent 2= minimal 3= mild 4=moderate 5=moderate severe 6=severe 7=extreme

***P: 6 items***

1 Delusions

2 Hallucinatory Behaviour

3 Unusual Thought Content

4 Suspiciousness Persecution

5 Grandiosity

6 Somatic Concern

***N: 7 items***

7 Lack Of Spontaneity

8 Blunted Affect

9 Emotional Withdrawal

10 Social Withdrawal

11 Motor Retardation

12 Poor Rapport

13 Social Avoidance

***D: 9 items***

14 Stereotyped Thinking

15 Poor Attention

16 Disorientation

17 Disorganisation

18 Difficulty In Abstraction

19 Mannerisms

20 Lack Of Judgement

21 Disturbance Of Volition

22 Preoccupation

***E: 4 item****s*

23 Poor Impulse Control

24 Excitement

25 Hostility

26 Uncooperativeness

***ED: 4 items***

27 Anxiety

28 Depression

29 Guilt

30 Tension

**PLUS a Total Score of these domains**

Reference:

* van der Gaag, M. Cuijpers. A, Hoffman, T., Remijsen, M,. Hijman, R. de Haan, L. van Meijel, B. van Harten, P. Valmaggia, L. de Hert, M. Wiersma, D., The five-factor model of the Positive and Negative Syndrome Scale I: Confirmatory factor analysis fails to confirm 25 published five-factor solutions, *Schizophrenia Research*, Volume 85, Issues 1–3, 2006, Pages 273-279, ISSN 0920-9964, https://doi.org/10.1016/j.schres.2006.04.001.

**PSP**

Scoring Instruction: None needed

* Total score is given

Reference:

* Morosini PL, Magliano L, Brambilla L, Ugolini S, Pioli R. (2000) Development, reliability and acceptability of a new version of the DSM-IV Social and Occupational Functioning Assessment Scale (SOFAS) to assess routine social funtioning. *Acta Psychiatrica Scandinavica*; 101(4):323-329.

**Calgary**

Scoring Instruction:

\*All items are scored 0- 3 ( 0=Absent 1=mild 2=moderate 3=severe)

***Items:*** *Depression Hopelessness Self-Depreciation Guilty-Ideas Pathological-Guilt Morning-Depression Early-Wakening Suicide Observed-Depression*

* Add up all scores

Reference:

* Addington D, Addington J, Schissel B. (1990) A depression rating scale for schizophrenics. *Schizophrenia Research*; 3(4):247-251.

**TLFB**

Scoring Instruction: use directly from eCRF.

* Use in last 28 dyas of alcohol cannabis, other drug
* Total number of days drinking, heavy drinking, using cannabis, number of days using other drug is inputted into eCRF.

Reference:

* Sobell, L.C. & Sobell, M.B. (2000). Alcohol Timeline Followback (TFLB). In American Psychiatric Association (Ed.), *Handbook of Psychiatric Measures* (pp. 477-479).

1. **PARTICIPANT SELF-REPORT (Service user- all time point)**

**FEASIBILITY**

* Not to be scored. Each item separately

**PCS (actually PCM)**

Scoring Instruction:

* Individual scores for each item.
* Inputted into eCRF.
* 1 (not at all ) to 10 (very critical indeed)
* vars are: (CriticalTowardsPerson CriticalTowardsMyself WarmTowardsPerson WarmTowardsMyself SupportedByPerson)

References:

* Hooley, J. M. (Unpublished scale). Perceived Criticism Measure. Department of Psychology, Harvard University. Cambridge, Massachusetts.
* Dianne L. Chambless, Kimberly D. Blake (2009) Construct Validity of the Perceived Criticism Measure, *Behaviour Therapy*, 40(2), 155-163,

**GSE**

Scoring Instruction:

vars are: 10 items

(TryHard OpposesMe StickToAims UnexpectedEvents UnforeseenSituations

NecessaryEffort CopingAbilities SeveralSolutions ThinkOfSolution HandleWhatever)

* Each Item scored as: 1 (not at all true) to 4 (exactly true),
* Use Total sum all responses for final score. Ranging from 10-40.
* No reverse scoring.

Reference:

* Schwarzer R & Jerusalem M. (1995). Generalized self-efficacy scale. In J Weinman, S Wright, & M Johnston. Measures in health psychology: A user’s portfolio. Causal and control beliefs. Windsor, England: *NFER-NELSON*: 35-37

**FoRSe**

Scoring Instruction:

* Items are split into 3 subscales with no reverse scoring. (Intrusiveness, Awareness and Relapse)

|  |  |
| --- | --- |
| **Domain** | **Questions** |
| Intrusiveness | 4,5,9,10,12,15,20 |
| Awareness | 3,13,14,16,17,18,19,21,22 |
| Relapse | 1,2,6,7,8,11,23 |

* Scoring: Do not agree=1, Agree Slightly= 2, Agree Moderately= 3, Agree Very Much= 4
* Sum scores for each subscale and for the total score (sum of all items).

Reference:

* Gumley, A & Macbeth, A & D. Reilly, J & O'Grady, M & White, R & Mcleod, H & Schwannauer, M & Power, K. (2014). Fear of recurrence: Results of a randomized trial of relapse detection in schizophrenia. *British Journal of Clinical Psychology*. 54. 10.1111/bjc.12060.

**MARS**

Scoring Instruction:

* 10 items all Yes= 1, No= 0.
* Report Total score (0-10), with a higher score indicating a better adherence to medication.

Reference:

* K Thompson, J Kulkarni, A.A Sergejew (2000), Reliability and validity of a new Medication Adherence Rating Scale (MARS) for the psychoses, *Schizophrenia Research*, 42(3), 241-247, ISSN 0920-9964,

**SAS**

Scoring Instruction:

* Six subscales- Listening, Consistency, Ending, Safety, Talking and Comfort.
* Listening items: 1,7,13,19
* Consistency items: 2,8,14,20
* Ending items: 3,9,15,21,25
* Safety items: 4,10,16,22
* Talking items: 5,11,17,23
* Comfort items: 6,12,18,24
* Coding for positive items is 1 (Not at all) through to 4 (Always); Negative items were reverse scored 4 (Not at all Always) through to 1 (Always)
* Negative items are: 3,7,8,10,11,12,15,15,19,20,22,25

Reference:

* I. Goodwin, G. Holmes, R. Cochrane, O. Mason, (2003) **The ability of adult mental health services to meet clients' attachment needs: The development and implementation of the Service Attachment Questionnaire,** *Psychology and Psychotherapy: Theory, Research and Practice*, 76 (2), pp. 145-161, [10.1348/147608303765951186](https://doi.org/10.1348/147608303765951186)

**QPR**

Scoring Instruction:

* Each item is scored Disagree Strongly = 0 through to Agree Strongly = 4
* Total score range is 0 – 60
* Sum scores, no reverse scoring
* Total score calculated by eCRF.

Nb this is a 15 item questionnaire and so there are no sub-scales

Reference:

* Neil ST, Kilbride M, Pitt L, Welford M, Nothard S, Sellwood W, et al. (2009) The Questionnaire about the Process of Recovery (QPR): A research instrument developed in collaboration with service users. *Psychosis*; 1, 145-155.

**PBIQ-R**

Scoring Instruction:

* Strongly disagree =1, Disagree =2, Agree =3, Strongly Agree =4
* Items 3,8,20 and 28 are reverse scored

The items in brackets are not utilised in this study. The rest are retained and should be used to calculate sub scale scores as indicated below.

* Control over illness: (2),**7,9,11**,**25**
* Shame: (3),(10),**15**,**17**,**27,29**
* Entrapment: (1),(5),**12**,**21**,**22**,**26**
* Loss: 4,**6**,(8),**16**,**19**,**23**,(28)
* Social Marginalisation: **13**,**14**,**18**,(20),**24**
* Sum items for each score.

Reference:

* Birchwood, M., Jackson, C., Brunet, K., Holden, J., & Barton, K. (2012). Personal beliefs about illness questionnaire-revised (PBIQ-R): Reliability and validation in a first episode sample. *British Journal of Clinical Psychology,* *51*, 448–458

**HADS**

Scoring Instruction: The usual form is used here

* Two domains: Anxiety and Depression.
* Scores for each domain is calculated in eCRF.

Reference:

* Zigmond AS, Snaith RP. (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*; 67, 361–370.

**PAM**

Scoring Instruction:

* Each item is scored on a scale of 0 to 3.
* NB!! Reversed scored items are already in eCRF.
* Two domains:
  + Attachment avoidance (1,2,4,8,9,11,13,16)
  + Attachment anxiety (3,5,6,7,10,12,14,15)
* Total scores calculated for each domain by averaging individual items scores.
* Higher scores reflect higher levels of anxiety and avoidance.
* High overall score reflects a general insecure attachment style.

Reference:

* Berry K, Wearden A, Barrowclough C, Liversidge T. (2006) Attachment styles, interpersonal relationships and psychotic phenomena in a non‐clinical student sample. *Pers Individ Dif,* 41, 707–718.

**uMARS**

(Asked at follow-up, only for service users in EMPOWER arm only of the study). All items individually. Note there are 4 questions about feasibility of using the app in addition to the 12 normal uMARS items on the App acceptability/

1. **CARE CO-ORDINATOR**

**FEASIBILITY**

* Not to be scored. – similar to above

**SES**

Scoring Instruction:

* 4 subscales (Availability, Collaboration, Help Seeking and Treatment Adherence)
* Not at all or rarely= 0, Sometime= 1, Often= 2 and Most of the time= 3.

|  |  |
| --- | --- |
| **Domain** | **Questions** |
| Availability | 1,2,3 |
| Collaboration | 4,5,6 |
| Help Seeking | 7,8,9,10 |
| Treatment Adherence | 11,12,13,14 |

* Sum scores for each item.
* Total Score range from 0-42.
* Higher scores indicate lower engagement with services.

Reference:

* **Tait L, Birchwood M, Trower P (2002) A new scale (SES) to measure engagement with community mental health services.**Journal of Mental Health**, 11(2), 191-198.**

1. **CARER**

**FEASIBILITY**

* Not to be scored – similar to above

**PCS (actually PCM)**

Scoring Instruction:

* Individual scores for each item.
* Inputted into eCRF.

Reference:

* As above

**IEQ**

Scoring Instruction:

* Each item is scored on a scale of Never = 0 to Almost Always = 4
* There is no total score
* 4subscales
* Tension (1-9), Supervision (10-15), Worrying (16-21), Urging (22-29)
* Items not included in subscales: 30-33
* Items 15 and 21 are repeat questions of item 1 and 9. This was not the original intention and so for scoring 15 and 21 are instead replaced by direct copies of the original 1 and 9. Since then items 1 (15) and 9 (21) are used in more than one subscale the total score must be computed from the separate 27 items and not just by adding up the four subscales.

**Nb: in the case of missing values for items 1 and 9 – since these potentially could be imputed in more than one domain, the average imputed value will be used.**

Reference:

* Van Wijngaarden, B., Schene, A., Koeter, M., Vázquez-Barquero, J., Knudsen, H., Lasalvia, A., & McCrone, P. (2000). Caregiving in schizophrenia: Development, internal consistency and reliability of the Involvement Evaluation Questionnaire – European Version: EPSILON Study 4. *British Journal of Psychiatry,* *177*(S39), S21-S27. doi:10.1192/bjp.177.39.s21

1. **HEALTH ECONOMICS *- Not initially derived by statistics team – may verify***

**Resource Use Questionnaire**

**EQ-5D-5L: for both service user and Carer**

Scoring Instruction:

* No= 1, Slight= 2, Moderate= 3, Severe= 4 and Extreme/Unable= 5
* Value for overall health is entered into eCRF.

Reference:

* Devlin NJ, Shah KK, Feng Y, Mulhern B, van Hout B. (2018) Valuing health-related quality of life: An EQ-5D-5L value set for England. *Health Economics*, 27(1), 7-22.
* Hernandez-Alava M, Pudney S. (2018) eq5dmap: A command for mapping between EQ-5D-3L and EQ-5D-5L. *Stata Journal*,18(2), 395-415.

**AqoL-8D**

Scoring Instruction:

* **Might not have to be scored by CHaRT as a Health Economic measure.**

Reference:

* Richardson J, Sinha K, Iezzi A, Khan MA. (2014) Modelling utility weights for the Assessment of Quality of Life (AQoL)-8D*. Quality of Life Research*, 23(8),2395-404.

**CarerQOL**

* Positive items (1 and 6) are scored as No= 0, Some= 1 and A lot= 2
* Negative items (2,3,4,5 and 7) are scored as No= 2, Some= 1 and A lot= 2
* Summing the values for the seven dimensions, a score of 0 translates into the worst informal care situation (a lot of problems and no support or fulfilment); the higher the score, the better the care situation.
* Item 8 ‘how happy do you feel at the moment?’ is a value of 0-10 and is entered into eCRF.

Reference:

* Hoefman RJ, van Exel NJA, Looren de Jong S, Redekop WK, Brouwer WBF. (2011) A new test of the construct validity of the CarerQol instrument: measuring the impact of informal care giving. *Quality of Life Research*, 20(6), 875-87.

**Health Services Use : carer**

* Data is entered into eCRF

**Informal Care: Carer**

* Data is entered in eCRF, no scoring required.