

Common Measures for Mental Health Science Laying the Foundations June 2020

Dr Greg Farber (National Institute of Mental Health), Professor Miranda Wolpert (Wellcome Trust)
and Dr Danielle Kemmer (International Alliance Mental Health Research Funders)

Background

Following the 2019 International Alliance of Mental Health Research Funders (IAMHRF) meeting in London, a data harmonization working group was established and is chaired by Greg Farber. The overall goal of the group is to recommend a common set of data collection measures with the goal of allowing data measured from many different research participants in many locations to be easily combined for subsequent data analysis.

The IAMHRF group focused initially on demographic measures that could be adopted by mental health researchers working in many different countries. The first draft of those measures is now out to consultation. The consultation closes October 15th 2020 <http://iamhrf.org/demographics-common-measures>. **We encourage all funders and their research communities to take part in this consultation.**

Over the same timeframe, discussions took place between the Wellcome Trust and the National Institute of Mental Health (NIMH) around measures that they could jointly agree as required to be used by those they funded. Recognizing the complexity of the task, they decided to agree to a minimum set focused on measures of outcome for anxiety and depression. Appendix 1 below lists the measures that have been agreed. All funders that commit to require those they fund to use at least 4 of these measures are invited to join the Common Measures in Mental Health Science Governance Board (CMB).

The CMB will hold its first meeting (to be held virtually) on 29th October 2020. **We encourage all funders to consider joining the NIMH and Wellcome as founding members on this board.** The IAMHRF will have a place on the board to represent the views and input of those not yet ready to join themselves and will provide the secretariat for this work. Only members of the IAMHRF network are eligible to join the CMB. If you are interested in joining the board, please contact Danielle Kemmer dkemmer@grahamboeckhfoundation.org

Common Measures in Mental Health Science Governance Board (CMB)

The Common Measures in Mental Health Science Governance Board (CMB) will consist of all those funders who commit to require 4 or more of the *Common Measures for Collecting Mental Health Data*.

Currently, each of the funding organizations has the ability to either require, encourage, or suggest that their funded researchers use a common set of data collection measures. To join the CMB, the funder must agree to include some element of requirements within a 2-year timeframe but can also join if they simply strongly recommend 4 or more measures to their research community as a first step. The CMB recommends funders continue to encourage researchers to use any other measures they wish in addition to the common set. Individual funders retain the right to waive the requirement for specific grants or funding programs at their discretion.

Current founding members are:

- NIMH
- Wellcome Trust

The IAMHRF will have a place on this board to provide the secretariat and bring in the views of a wider range of funders. Publishers may join CMB meetings as observers, as appropriate, but will not be voting members.

The chair of CMB will be chosen from within its membership.

The CMB will convene at least twice a year and their task is to agree on what measures are required by the researchers whom they fund. The list of required measures will be refreshed every 2 years in order to allow those being funded not to be inundated with changes in measures. Though suggestions may be made more frequently, they will not be mandated in between formal updates. The CMB will be supported and advised by an advisory group.

Common Measures Advisory group (CMA)

The CMB founders recognize they will need to update the suggested measures on a regular basis. To do this, they will need to receive input on how the initial recommended measures are working and may want to consider additional measures. An advisory group will be created from January 2021 to offer recommendations to the funders. The projects that this group will be charged to work on will be set by the CMB.

- The CMA will be authorized by the CMB to work on particular questions as determined relevant by the CMB. The CMB will select and define topics for the CMA to consider and report back to the CMB.
 - The CMA will be required to share their views with the CMB.
 - CMB members are able to join as observers at all CMA meetings.
 - It is likely that one of the initial tasks for the CMA will be to consider whether any of the demographic measures put out for comment by the IAMHRF working group should be added at the next update of required measures.
- Each funder may recommend 2-3 advisors for membership in the CMA. Candidates will be accepted by a majority vote of the CMB.
- Members of the CMA will bring expertise from the following areas:
 - Clinical research in mental health
 - Psychometrics
 - Lived experience
 - Broader informatics expertise outside of mental health
- Appointment to the CMA will be for two years and will be renewable.
- Meetings will be held as needed and payment will be made to CMA members for participating in the meetings by the CMB.
- It is expected that many meetings will use videoconferencing. Non-CMA members may be invited to participate in some discussions to provide expertise as needed.
- Input will be funded with support from CMB members.

Appendix 1

To be part of the CMB, funders must commit to require at least four of the following for relevant funded projects within the next 2 years

- 1) Age (for either adults or youth)
- 2) Sex at Birth (for either adults or youth)
- 4) WHODAS 2.0 – 12 item (for adults)
- 5) PHQ-9 (for adults)*
- 6) GAD-7 (for adults)*
- 7) RCADS-25 (for youth)*

*In exceptional circumstances when these measures are not feasible due to length, funders may agree to the use of shorter versions eg PHQ-2, GAD-2, RCADS-10.

Note: the requirement is that these be collected and stored at level of individual questions (as well as any scale summation) to allow item-level analysis in the future, as relevant.