

Information Sheet and Informed Consent Form for Organizations Collaborating on Research Study Piloting Mental Health Quality Indicators Using the Ontario Common Assessment of Need

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CMHA Toronto is undertaking a research study exploring the feasibility of developing mental health quality indicators for community mental health services using the Ontario Common Assessment of Need (OCAN). Your organization is being invited to participate as a collaborator in this research study. Before you provide consent for your organization to participate in this study, it is important that you read and understand the following description of the study, so you can make an informed decision about taking part.

Purpose of the Research

This community-based research study is being conducted to explore the feasibility of developing mental health quality indicators to measure service outcomes of community mental health services using OCAN data and to identify common data quality issues found in these data. The study will pilot various quality indicators and assess the strengths and limitations of these indicators to support measurement of outcomes related to quality improvement initiatives as well as organizational and sector performance.

What Collaboration Entails

If you choose to collaborate in this study, we will ask you to send a volunteer representative for your organization to participate on a Research Advisory Committee (RAC) for the study. Members of the RAC would meet approximately semi-annually and would provide feedback on pilot quality indicators developed from OCAN data. OCAN data for your organization, along with OCAN data from other organizations, from 2017 through to 2024 would be used to create and pilot these quality indicators. You would receive reports that include outcome measures for your organization and other organizations participating in the study as well as outcomes measured at the sector level. You would also receive data quality reports for your organization's OCAN data which will include information about the completeness and consistency of your OCAN data. We will be seeking input and feedback from the RAC members about the specific format of these reports. RAC members would also help identify possible measures to be developed from the OCAN data.

In order to collaborate on this study, your organization would need to be collecting data for the Full or Self OCANs for one or more of the following functional centres:

- Assertive community treatment
- Intensive case management
- Early psychosis intervention
- Support within housing

Other functional centres may be included to explore possible quality indicators based on the feedback of the RAC.

O CAN data used for this study would be obtained from the Integrated Assessment Reader, a data repository, through three Health Information Network Providers. These data would have all directly identifying information such as names, dates of birth, addresses, health card numbers removed prior to transfer to CMHA Toronto. Permission for access and use of these data for this study were provided by Integrated Assessment Record Advisory Committee and the Integrated Assessment Record Privacy, Security and Data Subcommittee which provide oversight of the use of data collected in the Integrated Assessment Reader (including O CAN data). The Health Information Network Providers are permitted pursuant to agent agreements with community mental health agencies on whose behalf they store O CAN data to transfer O CAN data for the purpose of research with the permission of Integrated Assessment Record Advisory Committee and the Privacy, Security and Data Subcommittee. This research has also been approved by the University of Toronto Research Ethics Board (Protocol #24130).

Anticipated Risk/Inconveniences and Potential Benefits

Although the data used for the study will be stripped of directly identifying information and the risk of re-identification is very low, it is conceivable that specific service users could be identified on the basis of indirect identifiers such as place of residence (e.g. municipality) in combination with unique personal characteristics. To mitigate this risk, data will only be reported in aggregate and counts of less than five will be suppressed or data categories will be combined and aggregated.

There is also a potential for risk to reputation for organizations that appear to have poorer program outcomes when comparing outcomes across collaborating organizations. To mitigate this risk, outcomes will not be explicitly associated with specific organizations. Rather organizations will be labelled as Organization #1, Organization #2 etc. in reports and presentations. In addition, in presentations and within outcome reports to organizations, a caution will be included noting that all measures are developmental and for the purpose of a research study to identify the strengths and limitations of measures and should not be used to assess the relative performance of specific organizations or the group of organizations participating in the study.

The potential benefits of this research is that it support future quality improvement initiatives of individual organizations collaborating in the project by providing MHQIs and a measurement framework to measure progress on quality improvement projects. The findings may also serve to inform the work of the Ontario Health's Mental Health and Addictions Centre of Excellence in its efforts to develop performance indicators and a performance measurement framework for the community mental health and addictions sector.

Costs and Reimbursements

There will be no cost to your organizations for participating as a collaborator in this study.

Participation and Withdrawal

Your organization's participation as a collaborator in this study is entirely voluntarily. You can choose not to participate or end your involvement with the study and this will not have any influence on your relationship with the research team or their affiliated organizations. If you decide to withdraw from the study, you can request that your data not be included any time prior to completion of final analyses which is anticipated to be concluded by June 30, 2025. If you choose to withdraw your data, it will be excluded from this study and deleted. You can also choose not to have your organization named as a collaborator in any publications or presentations of findings. If you wish to withdraw your organization's involvement

and/or prefer to not have your organization named in any publications/presentations as a collaborator, you can contact Frank Sirotych at fsirotych@cmhato.org or 416-789-6874.

Confidentiality

No identifying information (e.g. name, date of birth) of service users will be collected and the results of analyses will be presented in summary form to protect the privacy of service users. Only members of the research team, the IT manager at CMHA Toronto and representatives from the University of Toronto's Human Research Ethics Program (HREP) will have access to these data. HREP representatives may access study data to ensure that the required laws and guidelines are followed and HREP representatives are bound by the same confidentiality as members of the research team.

Data collected for the study will be destroyed once the study and associated publications are complete.

Use of Data

The information gathered in this project may be used in agency or journal publications or presentations intended to share learnings. The findings from this research may also be used to inform the work of the Mental Health and Addictions Centre for Excellence in its development of performance measures for the community mental health sector. We will provide members of the Research Advisory Committee with a summary of the findings.

This research study may be reviewed for quality assurance to make sure that the required laws and guidelines are followed. If chosen, (a) representative(s) of the Human Research Ethics Program (HREP) may access study-related data and/or consent materials as part of the review.

Contact

If you have any questions about this project, you may contact Frank Sirotych, Director of Data Analytics, Research and Evaluation, at fsirotych@cmhato.org or 416-789-6974. If you have questions about your rights as a collaborator in the study, you may contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Consent

I have reviewed each page of the information sheet and agree that:

- The project has been explained to me and all my questions have been answered.
- I understand the expectation of participating as a collaborator in the study.
- I understand the potential risks and benefits.
- I understand that the participation of my organization is completely voluntary and that we are free to withdraw participation at any time and this will not have affect my relationship with the researchers or their affiliated organizations.
- I have the authority within my organization to provide permission for our organization's participation.
- I authorize the use of our OCAN data as described in the information sheet.
- I agree that my organization can participate in this study as described in the information sheet.

Name of Person Providing Consent: _____

Position of Person Providing Consent: _____

Signature of Person Providing Consent: _____