Tool for Implementation and Evaluation of Citizen-user Involvement

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Introduction to the Tool

People who need and use mental health services (citizen-users) have the right to take part in decisions about how services are provided. The Tool for Implementation and Evaluation of Citizen-user Involvement will help mental health organizations to involve people who use services participate in service planning.

We made the tool after interviewing 63 people who used mental health services. They helped us define what it means to participate. They also described what organizations need to do to make it possible for people to participate. We also looked at articles that talked about how people can participate in planning health services. The tool is the result of this work.

How the Tool Can Help

This tool can be used by organizations such as hospitals, health authorities, and community programs. Many things affect decisions about the way the mental system works and how services are provided. The goal of the tool is to help organizations to include people in these decisions in two ways. First, the tool can measure how well they are including people in decisions about services. It also can show them how to improve how they involve people. The tool can be used to improve decisions about a large program, a small service or a health policy. The tool provides a way to encourage more involvement of people who use mental health services in service planning. It tells organizations what has to happen for people to participate. It gives organizations a way to assess how well they are including people in making decisions about services.

Using the Tool

The tool describes what should be done to involve citizen-users and what to assess to find out if organizations are including citizen-users in planning services. It provides a guide to how participation could be assessed. Organizations can think about their own environments and use the tool as a guide to assessing their organization.

The tool has 5 columns. The first three columns show what to look for when assessing if an organization includes people in decisions about services. The last two columns show how to find out if an organization includes people in decisions about services.

The first column includes the dimensions of participation. These are factors that all organizations need to have for people to participate in decisions about services. The next column is called criteria. It tells us what organizations need to do in each of the dimensions. Organizations can see how well they are meeting each of the criteria. The third column is called indicators. Indicators tell us how well organizations meet the criteria. Indicators help us decide the types of questions to ask when evaluating experience and documents. For example, do people say that the criteria are being met? Do written documents state that the criteria are being met? This column gives specific examples of what to look for in people’s responses and in documents to show that the criteria are being met.

The last two columns show how to evaluate if people are participating. The first way to see if people are participating is by talking to people. This is called evaluation of experience. The second way is through evaluation of documents. Both ways of evaluating are important. They tell us how the organization is achieving the criteria defined for good participation practices.
Steps for Using the Tool

The following are the steps to follow to use the tool.

**Step 1**
Look at each dimension (column 1) to see how it fits your organization. Think about how each criterion (column 2) fits within its dimension.

**Step 2**
Review columns 3, 4, and 5. Decide how to evaluate participation in your organization. Write down what you will look for (column 3), who you will ask (column 4) and what documents you will search (column 5) to find out whether the organization is meeting criteria in each dimension.

For example, you may say that you will interview participants to evaluate whether there are diverse participation activities and respectful, flexible and inclusive processes. The criteria and indicators will help you make an interview guide that will help you decide what to ask participants. Questions in an interview guide may look like this:

- What kinds of things are people doing to participate in planning and evaluating services?
- How are decisions made?
- Are participants’ ideas valued, recognized and documented?
- How often are ideas of participants used?
- How are participants given the chance to use their skills?
- To what extent do participants have skills that are similar or different from each other?
- What is it like for the participants to work with the other members of the team?
- What is the leadership like?
- What is it like to attend meetings?
Using the criteria and indicators you will also write down what to look for when evaluating organizational documents. Documents can show you whether policies support diverse participation activities and respectful, flexible and inclusive processes. Examples of what you would look for in documents are statements about whether the organization:

- Believes it is important for people to participate
- Is committed to making decisions with others
- Uses plain language
- Makes sure that information about people is confidential
- Believes that there should be no prejudice or discrimination

**Step 3**  Conduct the evaluations by conducting interviews and reviewing documents.

**Step 4**  Analyze results. Identify areas of strength and weakness. What criteria are being met? Where are there gaps?

**Step 5**  Share the results within the organization.

**Step 6**  Develop and implement an action plan to address gaps.
Terms

**Citizen-user** - The term “citizen-user” identifies people who need mental health services. The term says that people have rights as citizens and experiences of using services in the mental health system.

**Consumer representatives** – These are people who represent consumer and self-help groups.

**Health planners** – These are the people who make decisions about the funding and delivery of programs and services. They work for governments, health authorities and hospitals.

**Non-consumer staff** – These are the people deliver programs and services and do not identify as being consumers of mental health services.

**Policies** – Most organizations have policies. Policies are written statements that guide decisions and actions of organizations. They often describe principles and values of the organization.

**Committee documents** – Most organizations have committees and working groups that address issues about the planning, quality and evaluation of programs and services. These committees have documents including terms of reference, records of meetings and correspondence. Terms of reference describe the purpose of the committee, who should attend, authority, responsibility and how often the committee meets. Records of meetings include agendas and minutes. Correspondence includes letters and e-mails.

**Accreditation documents** – Most health organizations go through an accreditation process. In this process an outside organization rates how well the health organization is doing against many criteria. This is one way that the quality of the services provided by the health organization is evaluated. The health organization has reports and other written material related to this accreditation process.
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<th>Dimension</th>
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| The organization provides opportunities for diverse participation activities. | Citizen-users participate in health service planning in several different ways. | **Look for:**  
• Statements that show participation activities are important to the organization.  
• Statements that show that participation activities occur.  
• Statements that show that citizen-users are asked what types of participation activities should be used.  
• Citizen-users have ways to give input into service planning without being asked or being part of formal committees. | **Ask:**  
Citizen-users  
Consumer representatives  
Health planners  
Non-consumer staff | **Look in:**  
Policies related to participation activities  
Committee documents |
The organization provides opportunities for diverse participation activities.

### Dimension: The organization provides opportunities for diverse participation activities.

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</table>
| Citizen-users are involved at all four stages of health service system planning:  
  - conceptualization  
  - development  
  - implementation  
  - evaluation | Look for:  
  - Documentation of participation activities in each of the four stages. | | Look in:  
  - Committee documents  
  - Health service planning reports. |

Citizen-users discuss ideas and decisions about services with health planners.

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| Look for:  
  - Statements that show citizen-users and others perceive that citizen-users and health planners discuss ideas and decisions. | Ask:  
  - Citizen-users  
  - Health planners  
  - Non-consumer staff | | Look in:  
  - Policies related to participation activities  
  - Accreditation documents  
  - Committee documents |
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| The organization uses respectful, flexible and inclusive processes. | The organization uses plain language when communicating with citizen-users. | **Look for:**  
- Statements that plain language must be used during communication with citizen-users.  
- Proof that an analysis of the reading level of written material has occurred.  
- Statements that show that citizen-users feel that plain language is used during communication and in written material. | Ask:  
Citizen-users | Look in:  
Organizational policies related to participation activities  
Correspondence with participants  
Committee documents |
| The goals of participation activities are agreed to by citizen-users and health planners. | **Look for:**  
- Statements that show that goals of participation activities were agreed to by everyone involved.  
- Whether the type of participation activity allows the level of citizen participation that is expected by citizen-users and health planners. | Ask:  
Citizen-users  
Health planners | Look in:  
Committee documents |
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| The organization uses respectful, flexible and inclusive processes. | Rules about how discussion occurs during participation activities are decided by citizen-users and health planners. | **Look for:**  
- Statements that show that the rules of discussion during participation activities are agreed to by everyone involved. | **Ask:**  
Citizen-users  
Health planners | **Look in:**  
Committee documents |
| Citizen-users believe their opinions are valued by others involved. | **Look for:**  
- Statements that show that citizen-users believe that their opinions are valued. | **Ask:**  
Citizen-users | | |
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<td>The organization uses respectful, flexible and inclusive processes.</td>
<td>The contributions of citizen-users are recognized.</td>
<td><strong>Look for:</strong></td>
<td>‣ Ask: Citizen-users</td>
<td>Look in: Committee documents</td>
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<td>‣ Statements that show citizen-users perceive that their opinions are recognized.</td>
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<td>‣ Documents that acknowledges the importance of the participation of citizen-users.</td>
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<td><strong>Look for:</strong></td>
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<td>‣ Statements that show that the ideas of citizen-users are accurately documented.</td>
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<td>The organization accurately documents the ideas of citizen-users.</td>
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<td><strong>Look for:</strong></td>
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<td>‣ Statements that show that the ideas of citizen-users are accurately documented.</td>
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<td><strong>Ask:</strong> Citizen-users</td>
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<td><strong>Look in:</strong> Committee documents</td>
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| The organization uses respectful, flexible and inclusive processes. | Action that has a positive impact on the health care system is an outcome of participation activities. | **Look for:**  
• Evidence that the information collected during participation activities is included in the development of programs and services. | **Ask:**  
Citizen-users  
Health planners  
Non-consumer staff members  
Consumer Representatives | **Look in:**  
Evaluation reports  
Research reports  
Quality reports  
Management meeting records |
| The organization utilizes the skills of the citizen-users. | **Look for:**  
• Statements that show citizen-users are asked about their skills.  
• Evidence that position descriptions acknowledge varying skills.  
• Statements that citizen-users perceive that their skills are utilized. | **Ask:**  
Citizen-users | **Look in:**  
Committee documents  
Position descriptions |
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| **The organization uses respectful, flexible and inclusive processes.** | All those involved in the participation activities maintain confidentiality of personal information. | **Look for:**  
  - Policies that explicitly state that confidentiality of personal information will be maintained. | **Ask:**  
  - Citizen-users  
  - Health planners  
  - Non-consumer staff | **Look in:**  
  - Policies |
| **A team approach is used throughout the participation activity process.** | Look for:  
  - Policies that affirm the use of a team approach.  
  - Statements that show citizen-users and others perceive that they are part of a team during participation activities.  
  - Standardized assessment of team functioning | **Ask:**  
  - Citizen-users  
  - Health planners  
  - Non-consumer staff members | **Look in:**  
  - Policies |
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| The organization uses respectful, flexible and inclusive processes. | Leadership is effective throughout the participation activities process. | **Look for:**  
• Statements that show citizen-users and others perceive that participation activities have effective leadership.  
• Evidence that shows that there are opportunities for leadership development.  
• Standardized assessment of team functioning | **Ask:**  
Citizen-users  
Health planners  
Non-consumer staff members | **Look in:**  
Leadership training manuals. |
| People with diverse experiences are included. | **Look for:**  
• Evidence that shows that citizen-users have a variety of skills and experiences.  
• Statements that show citizen-users and others perceive that people with diverse experiences are included in the participation activity. | **Ask:**  
Citizen-users  
Health planners  
Non-consumer staff members  
Consumer Representatives | **Look in:**  
Committee documents  
Position descriptions |
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| The organization uses respectful, flexible and inclusive processes.      | Meetings are scheduled taking into consideration citizen-users’ schedules, safety and comfort. | **Look for:**  
  - Evidence that meeting times are negotiated with citizen-users.  
  - Evidence that citizen-users perceive that their schedules and safety are considered when developing meeting times.  
  - Evidence that the environments in which meetings take place are comfortable for citizen-users | **Ask:**  
  Citizen-users                                                | **Look in:** Committee documents                                       |
| The people who run the meetings conduct them in ways that are comfortable for the citizen-users. | **Look for:**  
  - Statements that show citizen-users perceive that meetings are comfortable. | **Ask:**  
  Citizen-users                                                |                      |                                     |
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<td>The organization uses respectful, flexible and inclusive processes.</td>
<td>Processes are free from intimidation, exploitation and discrimination.</td>
<td><strong>Look for:</strong>&lt;br&gt;• Policies denouncing intimidation, exploitation and discrimination in all organizational forums.&lt;br&gt;• Evidence that there are mechanisms for participants to address behaviour perceived as intimidation, exploitation or discrimination.&lt;br&gt;• Evidence that participants are informed of mechanisms to address behaviour perceived as exploitation or discrimination.&lt;br&gt;• Statements that the participation of citizen-users will not impact negatively on the type or amount of health services they can receive from the organization.</td>
<td><strong>Ask:</strong>&lt;br&gt;Citizen-users</td>
<td><strong>Look in:</strong>&lt;br&gt;Policies&lt;br&gt;Orientation packages</td>
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<td>The organization supports citizen-users throughout the participation process.</td>
<td>Citizen-users receive training.</td>
<td>Ask: Citizen-users</td>
<td>Look in: Policies</td>
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<td><strong>Look for:</strong></td>
<td>Health planners</td>
<td>Look in: Records of training programs</td>
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<td>• Evidence that training is offered and attended by citizen-users.</td>
<td>Non-consumer staff members</td>
<td>Evaluation of training programs</td>
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<td>Citizen-users have sufficient information to fully participate.</td>
<td><strong>Look for:</strong></td>
<td>Ask: Citizen-users</td>
<td>Look in: Committee documents</td>
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<td>• Proof that citizen-users are provided with orientation packages prior to the participation activity.</td>
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<td>Orientation packages</td>
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<td>• Written acknowledgement of the need to keep citizen-users informed.</td>
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<td>Training modules</td>
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<td>• Evidence that shows there are processes in place to keep citizen-users informed.</td>
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<td>• Statements that show citizen-users perceive that they have sufficient information to participate.</td>
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| The organization supports citizen-users throughout the participation process. | Information provided to citizen-users is provided in a way that is understandable and useable. | **Look for:**  
- Written acknowledgement that the organization needs to provide information in a way that is understandable.  
- Statements that show citizen-users perceive that they understand the information provided to them.  
- Statements that show citizen-users perceive that they can use the information provided to them.  
- Statements that show that the ways that information is provided to citizen-users is evaluated. | **Ask:**  
Citizen-users | **Look in:**  
Policies |
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<td>The organization supports citizen-users throughout the participation process.</td>
<td>Citizen-users receive encouragement and guidance from staff and management.</td>
<td>Look for:</td>
<td>Ask:</td>
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<td>• Statements that show citizen-users perceive that they receive encouragement and guidance.</td>
<td>Citizen-users</td>
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<td>• Written expectations that staff and managers will provide encouragement and guidance to citizen-users.</td>
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<td>Citizen-users receive resources and supports for advocacy and self-advocacy.</td>
<td>Citizen-users</td>
<td>Look for:</td>
<td>Ask:</td>
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<td>• Training modules that include advocacy and self-advocacy.</td>
<td>Citizen-users</td>
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<td>• Statements that show citizen-users are given information about the resources and supports for advocacy.</td>
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<td>• Money is available to help new and existing advocacy groups to participate.</td>
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| The organization supports citizen-users throughout the participation process. | Citizen-users are remunerated for their participation. | **Look for:**  
  - Ways that remuneration for time and transportation is offered to participants | **Ask:**  
  Citizen-users  
  Consumer representatives | **Look in:**  
  Policies  
  Budgets |
| | A budget is provided for participation activities. | **Look for:**  
  - An allocated budget for participation activities. | | **Look in:**  
  Policies  
  Budgets  
  Annual reports |
| The organization promotes citizen-user participation in the decision making process. | Citizen-user participants have similar characteristics to the population impacted by planning decisions. | **Look for:**  
  - A policy that supports representativeness.  
  - Ways that the demographic characteristics of the population impacted by planning decisions are documented.  
  - Statements that show that citizen-users and others perceive that participants are representative of the population. | **Ask:**  
  Citizen-users  
  Consumer representatives  
  Health planners  
  Non-consumer staff members | **Look in:**  
  Policies  
  Documentation of the demographic characteristics of the population impacted by decisions |
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| The organization promotes citizen-user participation in the decision making process. | The interests of the population impacted by planning decisions are represented in participation activities. | **Look for:**  
- Ways that interests are discovered and documented.  
- Statements that show citizen-users and others perceive that the interests of the affected population are represented. | **Ask:**  
Citizen-users  
Consumer Representatives  
Health planners  
Non-consumer staff members | **Look in:**  
Planning documents |
| There are multiple ways that people are informed about opportunities for participation. | **Look for:**  
- Ways that information about opportunities for participation is provided through word of mouth, public service announcements and posters in community locations.  
- Statements that show that plans are made for changes to the membership of committees and planning groups so that opportunities are available for more citizen-users. |  | **Look in:**  
Records of recruitment |
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| The organization clearly connects citizen-user participation to the decisions it makes. | The organization clearly describes and shares information with citizen-users and other stakeholders about the impact of participation activities on health system planning. | **Look for:**  
• Statements that show there is a clear plan for sharing information about decision making.  
• Ways that organizations use participation activities to make decisions.  
• Ways that organizations tell participants, citizen-users and other stakeholders how they used participation activities to make decisions.  
• Ways that organizations tell the public at large about the outcomes of their participation activities. | Ask:  
Citizen-users  
Consumer representatives | **Look in:**  
Evaluation reports  
Committee documents  
Organizational records including management meeting records, board minutes, and annual reports  
Public news releases and media reports |
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| The organization clearly connects citizen-user participation to the decisions it makes. | Responsibility for using the results of participation activities is clearly defined. | **Look for:**  
- Statements that show job descriptions describe responsibility for creating, conducting and evaluating participation activities.  
- Statements that show that accountability for linking participation activities to decisions is identified in position descriptions of key decision makers. | | **Look in:**  
Position descriptions  
Performance appraisal forms |
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| The organization clearly connects citizen-user participation to the decisions it makes. | The organization evaluates participation activities. | **Look for:**  
- Evidence that resources are allocated for evaluation of participation activities.  
- Evidence that evaluation is done by someone who is not part of the participation activity or decision making.  
- Evidence that evaluation reports on the outcomes of participation activities are completed.  
- Policies that describe the goals, objectives and expected outcomes of participation activities.  
- Policies that mandate a review of participation activities on a regular basis. | **Ask:**  
Citizen-users  
Health planners | **Look in:**  
Committee documents  
Organizational records including management meeting records and Board minutes  
Policies |
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| The organization clearly connects citizen-user participation to the decisions it makes. | The organization continues effective participation activities.          | **Look for:**  
- Plans to continue effective participation activities.  
- Plans to modify ineffective participation activities.  
- Plans for new participants to become involved in effective participation activities over time. |                          | **Look in:**  
Committee records  
Organizational records including management meeting records and Board minutes  
Policies |
Bibliography


