**Supplementary file 4.** Taxonomy of metrics of patient, public, consumer and community (P2C2) engagement in healthcare system-, community-, and organization-level decision-making

<table>
<thead>
<tr>
<th>Internal Outcomes, as measured by impact on:</th>
<th>External Outcomes, as measured by influence on:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement participants’ (patients, staff, others)</td>
<td>Broader public’s (outside the organization or system)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Capacity for future involvement in the organization by the community</td>
</tr>
<tr>
<td>Skills</td>
<td>Level of control over decisions made by the organization or system</td>
</tr>
<tr>
<td>Views</td>
<td>Awareness or knowledge of health issues</td>
</tr>
<tr>
<td>Confidence or self-esteem</td>
<td>Support of the organization or system</td>
</tr>
<tr>
<td>Empowerment*</td>
<td>Involvement as part of social change outside the organization****</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Stigmatization of others</td>
</tr>
<tr>
<td>Sense of ownership</td>
<td>Population health</td>
</tr>
<tr>
<td>Trust**</td>
<td>Population health status</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services provided (by the healthcare organization or system)</th>
<th>Organization or system (eg, resources, policies, procedures, staff)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Efficiency and cost-effectiveness of services</td>
<td>Additional potential connections or partnerships with other groups or organizations</td>
</tr>
<tr>
<td>Number of complaints on services</td>
<td>Diversity of funding sources</td>
</tr>
<tr>
<td>Service availability</td>
<td>Funding and resources availability</td>
</tr>
<tr>
<td>Services quality and safety</td>
<td>Visibility of organization</td>
</tr>
<tr>
<td>Services responsiveness to needs (including needs of subpopulations)</td>
<td>Accountability of organization to the P2C2 served***</td>
</tr>
<tr>
<td>Sustainability of the services</td>
<td>Staff views on engagement</td>
</tr>
<tr>
<td>User experiences with services</td>
<td>Staff satisfaction</td>
</tr>
<tr>
<td>Utilization of services</td>
<td>Informal (unwritten) organization or system procedures</td>
</tr>
<tr>
<td></td>
<td>Formal (written) organization or system policies</td>
</tr>
<tr>
<td></td>
<td>Redesign of staff roles</td>
</tr>
<tr>
<td></td>
<td>Staff recruitment</td>
</tr>
<tr>
<td></td>
<td>Staff training</td>
</tr>
<tr>
<td></td>
<td>Explicit change to organization or system process of decision-making</td>
</tr>
<tr>
<td></td>
<td>Presence of racism in system</td>
</tr>
<tr>
<td></td>
<td>Level of public reporting (eg, making annual report available to the public)</td>
</tr>
</tbody>
</table>

| Aggregate Outcome: | Overall cost-effectiveness of engagement |
| Number of local employment positions supported by organization |
| Organizational ability to adapt to operating environment |
| Sustainability of the engagement initiative |
| Scale of engagement program by organization (eg, to new locations) |

### PROCESS METRICS

#### Direct Process Metrics
- P2C2 participants control over decision process
  - Agenda setting and time allocation
  - Roles in decision-making are defined
  - Independence in decision-making (ie, no organization or system constraints on decisions)†
  - Involvement since first stage of decision process
  - Involvement throughout types of decision activities
  - Involvement throughout the stages of decision process
  - Perceived influence on decision-making process
  - Involvement in finalizing decisions
  - Control over the meeting minutes
  - Assurance of follow-up commitment / translation into action
  - Evaluation of the decision-making process
  - Revision process (for changing decisions or handling complaints)

#### Surrogate Process Metrics
- Financial independence of P2C2 participants
- P2C2 participants hold formal positions within the organizational hierarchy
- P2C2 participants are protected from organization retaliation
- Statement of formal self-governance by P2C2 participants
- P2C2 participants have veto power in decision-making

#### Organizational commitment to engagement
- Formal declaration of support by the organization or system
- Formal expression of commitment by organization or system leadership
- Organization has a paid position(s) dedicated to engagement
- Organization or system rewards staff participation in engagement
- Staff readiness and attitudes towards engagement
- Staff have formal job responsibilities related to engagement

#### Preconditions for Engagement Metrics
- P2C2-initiated engagement (in contrast with mandated)
- Recruitment and Membership
  - Consistency of membership (turnover)
  - Method of recruitment
  - Number of P2C2 members and P2C2 versus non-P2C2 participant ratio
  - Participants’ neutrality (ie, no conflict of interest)
  - Time or terms mandate for membership
  - Literacy of P2C2 participants (ie, ability to read and write)

#### Representativeness and accountability
- Constituent representativeness and accountability (ie, represent values, needs, etc. of the relevant constituency and are accountable to that constituency)
- Democratic representativeness (ie, elected via a democratic procedure by a broader community)
- Representative legitimacy (non-democratic)††††
- Diversity representativeness (ie, minority, vulnerable or marginalized groups are represented)

#### Resources provided to P2C2 participants
- Accommodations (ie, lodging)
- Childcare
- Financial support
- Meals and refreshments
- Transportation and parking
- Translation support
- Meeting facilitator
- Meeting place tailored to P2C2 participants
- Meeting time tailored to P2C2 participants
- Support from other P2C2 participants
- Support from patient advocacy groups or organizations
- Support for disseminating results of the engagement
- Feedback from P2C2 complaints
- Use of a broader P2C2 needs and strengths assessment to support P2C2 representatives in their decision-making

#### Training for P2C2 participants
- Presence of training
- Quality of training
- Scope of training
- Training provided is independent of the organization or system

#### Training for staff
- Presence of training
- Quality of Training
Clarifying examples:

* An example of an item measuring empowerment: “I learn things from the PFAC [Patient and Family Advisory Council] meetings that help me understand how to help the hospital change and improve.”

** An example of an item measuring trust: “As a result of my participation in this activity, I have greater trust in [administering organization to insert relevant term, eg, providers, PPE [Public and patient engagement] staff, organization as a whole, health system, personal competency].”

*** An example of metric description of accountability of organization to P2C2 served: “Public had a role in ensuring that communities were protected and concerns heard when dealing with poor performance. They felt the type of involvement needed was for someone to oversee the process and feedback to the community, thus ensuring that problems were dealt with openly and ensuring greater accountability. Decisions are scrutinized by a member of the public who ensures the concerns and values of either the wider community (acting as a citizen) or the specific community (acting as an advocate) are examined and professionals held to account.”

**** An example of metric description of involvement as part of social change outside the organization: “Participation was not just a tool for recognising their right to involvement. Their goal was structural change. Service-user participation, though flawed, offered opportunities to take part in society and was therefore a starting point. However, the end to which service users aspired was social justice.”

† An example of an item description measuring independence of decision-making: “the community defines priorities and manages the program.”

†† An example of metric description of activeness of participation: “Do consumer members take the lead in raising issues? Are they aggressive in seeking answers to problems? Do they follow up? Are they apathetic?”

††† An example of metric description of debate intensity: the Debate Intensity variable “captured a qualitative aspect,” “specifically the extent to which disagreements were passionate, deep, or intense.” Researcher analyzed “the amount of words spoken, the emotional intensity implied by different words” and “the extent to which perspectives expressed by one person were agreed to or disputed by another.”

†††† An example of metric description of representative legitimacy (non-democratic): “professionals ascribed a certain degree of representative legitimacy to involved users, on the basis of their laity (vis-a`-vis clinical expertise) and their patienthood.”
An example of an item measuring respect (ie, engagement participants are treated respectfully / not intimidated): “Respondents were asked how often they felt intimidated by consumer board members and provider board members. Response categories were “all of the time,” “most of the time,” “some of the time,” and “never.”

An example of metric description of trust: “Trust is one party’s willingness to be vulnerable to another based on the belief that the latter party is competent, open, concerned and reliable. Probably the key condition for trust in the process is public and stakeholder acceptance of the policy substance that is produced by the process.”

References (for online supplemental material 4)