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

OUTCOME METRICS

Internal Outcomes, as measured by **impact on**:

Engagement participants' (patients, staff, others)
- Knowledge
- Skills
- Views
- Confidence or self-esteem
- Empowerment*
- Satisfaction
- Sense of ownership
- Trust**

Services provided (by the healthcare organization or system)
- Efficiency and cost-effectiveness of services
- Number of complaints on services
- Service availability
- Services quality and safety
- Services responsiveness to needs (including needs of subpopulations)
- Sustainability of the services
- User experiences with services
- Utilization of services

Organization or system (eg, resources, policies, procedures, staff)
- Additional potential connections or partnerships with other groups or organizations
- Diversity of funding sources
- Funding and resources availability
- Visibility of organization
- Accountability of organization to the P2C2 served***
- Staff views on engagement
- Staff satisfaction
- Informal (unwritten) organization or system procedures
- Formal (written) organization or system policies
- Redesign of staff roles
- Staff recruitment
- Staff training
- Explicit change to organization or system process of decision-making
- Presence of racism in system
- Level of public reporting (eg, making annual report available to the public)

External Outcomes, as measured by **influence on:**

Broader public's (outside the organization or system)
- Capacity for future involvement in the organization by the community
- Level of control over decisions made by the organization or system
- Awareness or knowledge of health issues
- Support of the organization or system
- Involvement as part of social change outside the organization****
- Stigmatization of others

Population health
- Population health status
- Level of health inequalities

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

Formal power

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

Participation

Activeness of participation††
Debate intensity (ie, a measure of the amount or intensity of debate during meetings)†††
Equality of participation among P2C2 participants
Attendance of engagement participants

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
Staff support of P2C2 involvement in 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 (in content or financing)

Training for staff

Presence of training
Quality of Training

Attendance of P2C2 participants who are minorities	Unbiased, jargon-free information on which to make decisions
Regularity of meetings	**Aggregate Process Metrics**
P2C2 participants' readiness and attitudes towards engagement	Respect (ie, engagement participants are treated respectfully / not intimidated)†††††
Substitution of P2C2 participants among attendees	Transparency of the decision-making process
Tailoring the engagement to participants (needs or beliefs)	Trust††††††
Cultural beliefs and practices	Legitimacy of decision-making
Individual mental health needs	Level or ladder of participation (eg, Information, Consultation, Delegation, Partnership)
Individual health needs	

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."[1]

** 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]."[2]

*** 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."[3]

**** 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."[4]

† An example of an item description measuring independence of decision-making: "the community defines priorities and manages the program."[5]

†† 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?"[6]

††† 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."[7]

†††† 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-à -vis clinical expertise) and their patienthood."[8]

††††† 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.""[9]

†††††† 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."[10]

References (for online supplemental material 4)

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