

# **Metrics and Evaluation Tools for Patient Engagement in Healthcare Organization- and System-Level Decision-Making: A Systematic Review**

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Systematic Review

## Metrics and Evaluation Tools for Patient Engagement in Healthcare Organization- and System-Level Decision-Making: A Systematic Review

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- Background
- Systematic Review Methods
- Results
  - Taxonomy of Metrics
- Practice, Policy and Research Implications
- Next Steps



The background features a large, faint shield-shaped emblem on the left side. Inside the shield, there is a stylized flame at the top and a globe with latitude and longitude lines below it. A horizontal, semi-transparent light-colored band spans across the middle of the image, containing the word "Background" in a white, serif font.

# Background

# Background

Patient engagement in the design and implementation of healthcare services has been globally recognized as essential to healthcare since the 1978 Declaration of Alma-Ata, with increased attention recently (e.g., in the USA, via PFACs or Medicare ACOs).

There is a greater need for formal evaluation of engagement and yet little agreement on how to do it.



# Background

Aim: a systematic review of metrics to evaluate patient, public, consumer and community (P2C2) engagement in organization-, community-, and system-level healthcare decision-making.

Our objectives: (1) to create a taxonomy of possible P2C2 engagement evaluation metrics using an inductive qualitative analysis of the literature and

(2) to compare existing P2C2 engagement evaluation tools against this taxonomy.



# Background

We defined P2C2 engagement as a continuous systematic effort to incorporate the needs, values, and preferences of the P2C2 engagement participants into decision-making.

In those activities, P2C2 engagement participants are involved as stakeholder representatives of their constituents, rather than as individuals.

This review focuses on engagement in organization-, community-, and system-level healthcare decision-making as distinct from patient engagement in their individual personal medical decisions.





# Systematic Review Methods



# Methods

Publications available in English

from January 1, 1962 through April 20, 2015

in 5 databases: PubMed, Embase, Sociological Abstracts, PsycINFO, and EconLit.

Cross-references from the full-text screening.

Gray literature publications via a similar search strategy of the 32 targeted websites of relevant national and international organizations.

This SR was included on May 7, 2015 in the International Prospective Register of Systematic Reviews (PROSPERO), CRD42015020317.



# Methods

3,953 references

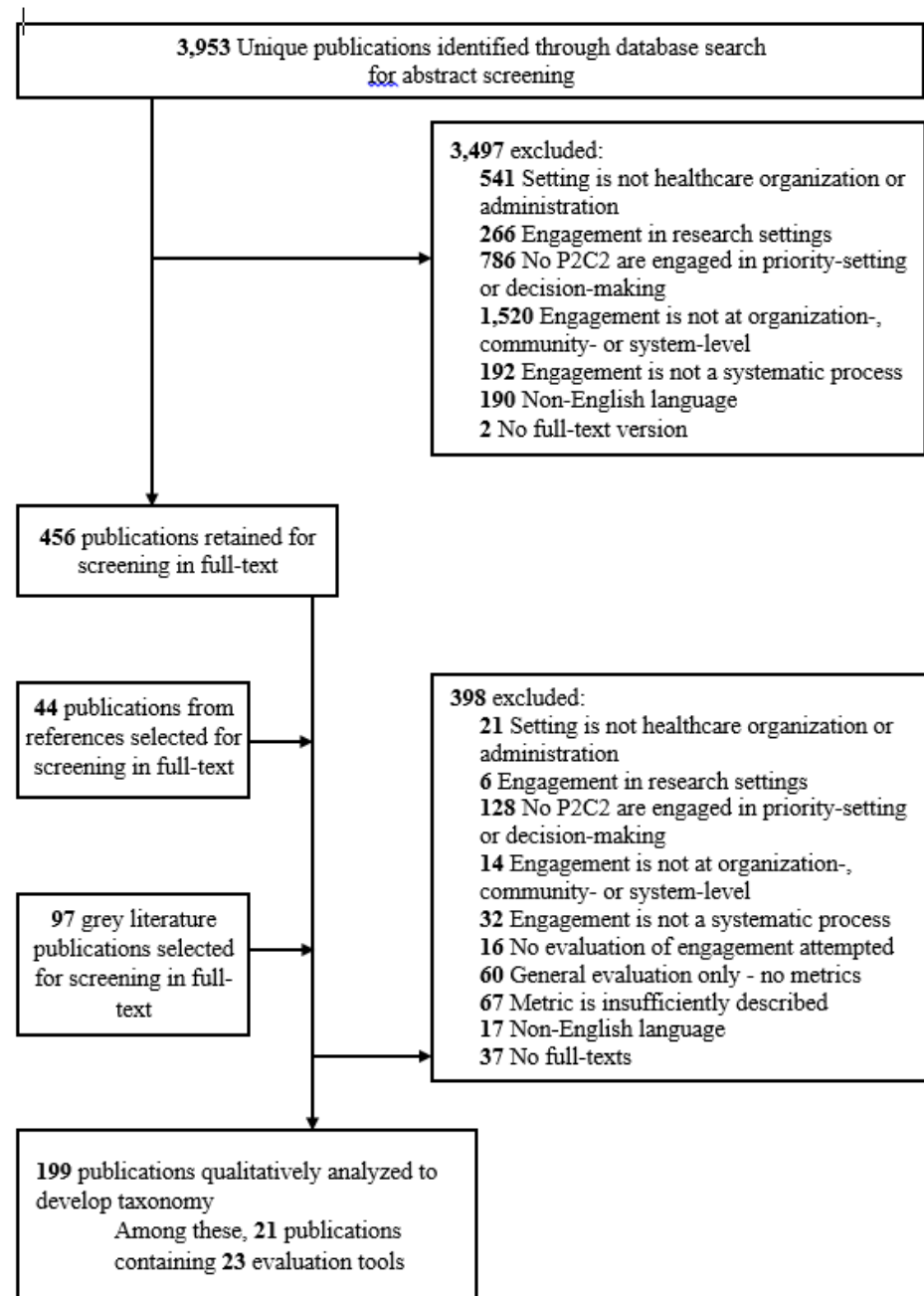
Full-text

456 + 44 + 97

Resulted in:

199 for Taxonomy

23 Tools



# Methods

Two-reviewer independent screening.

Disagreement was resolved involving the third reviewer.

199 publications were independently annotated for the presence of evaluation metrics via an editing style of qualitative content analysis.

Inductively applied a descriptive annotation (or “code”) of what the evaluation metric intended to measure.

Thematic analysis was used to combine and group similarly themed annotations into one list.

Using the accepted distinction between process and outcome metrics the list was reorganized into Taxonomy of (44 +72=116) possible metrics, grouping thematically-related metrics into domains and subdomains.



# Methods

We defined a tool as a questionnaire, survey, or other evaluative device that a healthcare organization or system could be used with no or minimal modification to evaluate P2C2 engagement efforts.

A second qualitative analysis of the included 23 evaluation tools was conducted using NVivo Plus.

Each tool's questions or survey items were coded according to Taxonomy: (1) into the process or outcome category; (2) into the metric subdomain, and (3) as a specific metric within that subdomain. If a question or item was non-specific, it was coded only into the broader category or subdomain.

Items could be coded more than once, and coding frequencies of a metric per tool were tracked.

Assessment of quality of studies reporting the metrics or tools were not applicable.



The background features a large, faint, light-orange graphic on the left side. It consists of a stylized globe with latitude and longitude lines, and a flame or torch-like shape above it. A horizontal, semi-transparent light-orange band runs across the middle of the slide, containing the word "Results" in white, bold, serif font.

# Results

# Results

## Summary of the Big Table

23 identified tools were published 1973-2015.

12 in USA, 3 in Canada, 3 in UK, 2 in Nepal, and the rest once: Djibouti, Honduras, South Africa, Tanzania, Ireland or New Zealand.

13 tools used mixed method evaluation, 6 only quantitative evaluation and 1 qualitative evaluation.

The evaluation was filled out by P2C2 representatives in 1 tool, by organization leaders in 7 tools, by **both** representatives and leaders in 9 tools, and by external evaluators in 6 tools.

The tools were used in diverse settings, from individual hospitals to health systems and programs.



# Results: Taxonomy

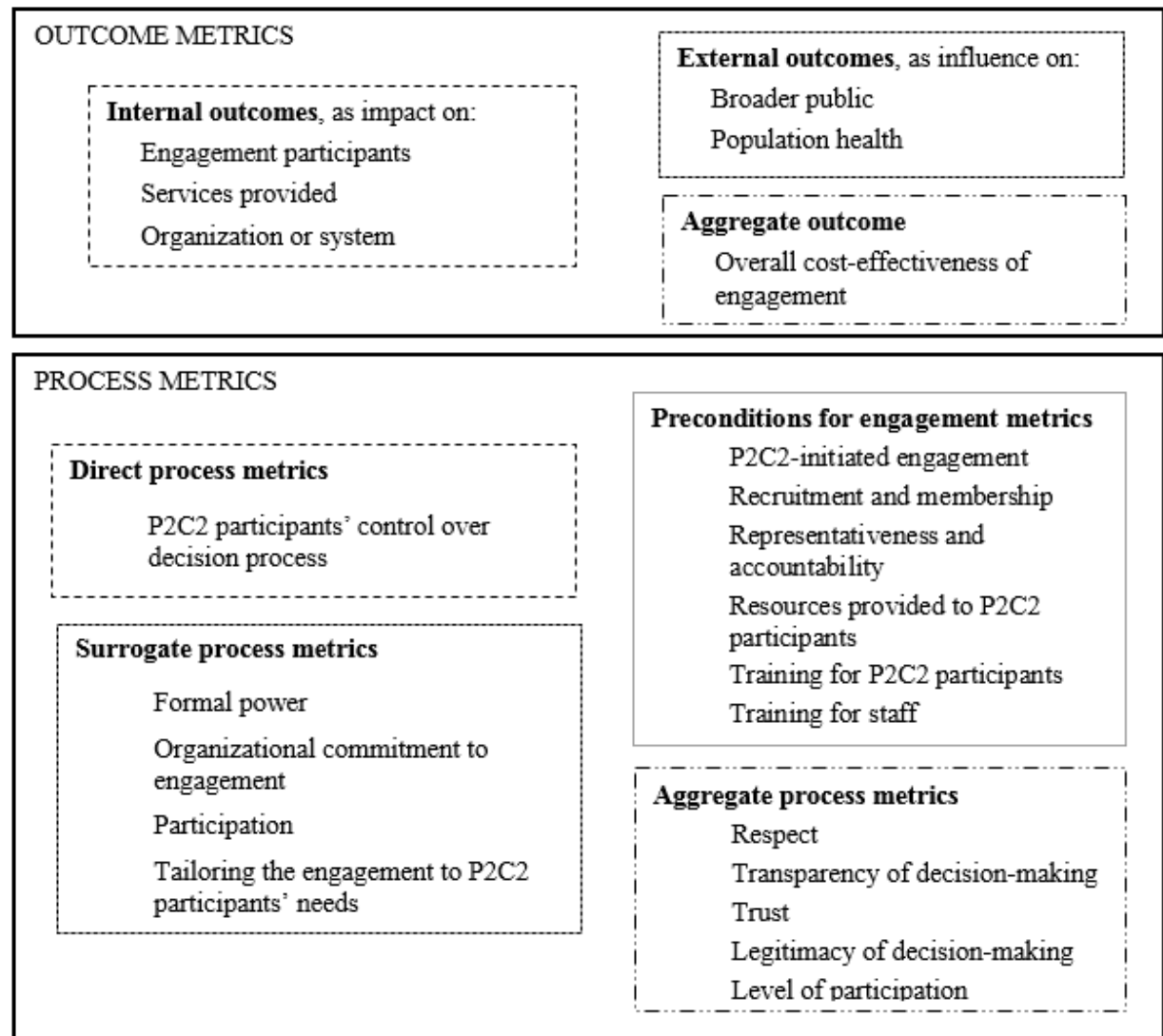


Figure 2. **Taxonomy of metrics: metrics categories, domains and subdomains**  
For the full taxonomy with listed metrics forming each subdomain, please refer to Online Supplementary Material 4



# Results: Taxonomy

## 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 (e.g., 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 (e.g., making annual report available to the public)  
 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 (e.g., to new locations)

### 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

44 metrics

3 domains

6 subdomains

Internal: most relevant to, and evaluated within, a healthcare system.

External: most relevant beyond the system and requiring evaluation outside the system.



# Results: Taxonomy

72 metrics

Domains of Process Metrics

4 domains

‘Direct process metrics’ describe the degree of real control that P2C2 participants have over the decision-making process.

16 subdomains

‘Surrogate process metrics’ describe formal attributes of the process, e.g., hold formal positions, veto power, are financially independent, **attendance**, or organizational commitment.

‘Preconditions for engagement metrics’: recruitment process, resources, training, P2C2 participants’ representativeness and accountability.

‘Aggregate process metrics’ evaluate cross-domain aspects, e.g., Trust or rungs of Arnstein’s “ladder of participation” (manipulation to information to partnership to citizen control).



## 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 (i.e., 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 (i.e., a measure of the amount or intensity of debate during meetings)†††
- Equality of participation among P2C2 participants
- Attendance of engagement participants
- Attendance of P2C2 participants who are minorities
- Regularity of meetings
- P2C2 participants' readiness and attitudes towards engagement
- Substitution of P2C2 participants among attendees

#### Tailoring the engagement to participants (needs or beliefs)

- Cultural beliefs and practices
- Individual mental health needs
- Individual health needs

### 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 (i.e., no conflict of interest)
- Time or terms mandate for membership
- Literacy of P2C2 participants (i.e., ability to read and write)

#### Representativeness and accountability

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

#### Resources provided to P2C2 participants

- Accommodations (i.e., 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
- Unbiased, jargon-free information on which to make decisions

#### 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

### Aggregate Process Metrics

#### Respect (i.e., engagement participants are treated respectfully / not intimidated)†††††

#### Transparency of the decision-making process

#### Trust††††††

#### Legitimacy of decision-making

#### Level or ladder of participation (e.g., Information, Consultation, Delegation, Partnership)

# Results

## Summary of another Big Table

Among 23 tools, 13 included at least one question or item coded as an outcome of P2C2 engagement.

While Taxonomy contains 44 outcome metrics, only 22 of these were identified in at least one tool.

Internal outcomes were more frequently coded than external outcomes.

Individual tools varied in their coverage of outcome metrics: from 1 to 32 coding instances.

6 tools included 4 or more instances of coded outcome metrics and all 6 were designed to be filled out by both leaders and P2C2 representatives.



# Results

## Summary of another Big Table - 2

All 23 tools included at least 1 question or item coded as a process metric of P2C2 engagement.

56 of the 72 process metrics described in Taxonomy were present in at least one tool.

Direct process metrics evaluating P2C2 control over decision process were identified in every tool. However, surrogate process metrics and metrics of preconditions for engagement were the most frequent.

Individual tools varied in their coverage of process metrics, ranging from covering 3 metric subdomains just once to 41 instances within all 6 subdomains.

7 tools included 15 or more process metrics; 5 of them were designed to be filled out by both leaders and P2C2 representatives and the remaining by the leaders only.





# **Practice, Policy and Research Implications**

# Practice, Policy and Research Implications

## Recapitulation

A comprehensive Taxonomy of 116 possible engagement metrics grouped into distinct domains and subdomains.

23 tools that could be used to evaluate P2C2 engagement were identified.

There was no perfect tool: they varied in their coverage of Taxonomy, in the method used (ie, qualitative vs. quantitative) and intended evaluators (leaders, P2C2 representatives, or both, or only external experts).

Parts of Taxonomy were absent from all tools.



# Practice, Policy and Research Implications

It might be suggested **what** may be the essential components of evaluation and how to advance evaluation. These suggestions (Figure next slide) are tailored to a health care system level of maturity for P2C2 engagement.

- Endeavor to progress from basic maturity, (ready to involve P2C2 participants) to fully maturity (significant experience with P2C2 engagement).
- Any evaluation must solicit the P2C2 perspective on engagement.
- Relative emphasis on different process and outcome metrics changes, e.g., shift away from surrogate measures of P2C2 participants control over decision-making toward direct control measures; be more attentive to external outcomes.
- Consider using external evaluators, who could yield additional insights into the P2C2 engagement process.



# Practice, Policy and Research Implications

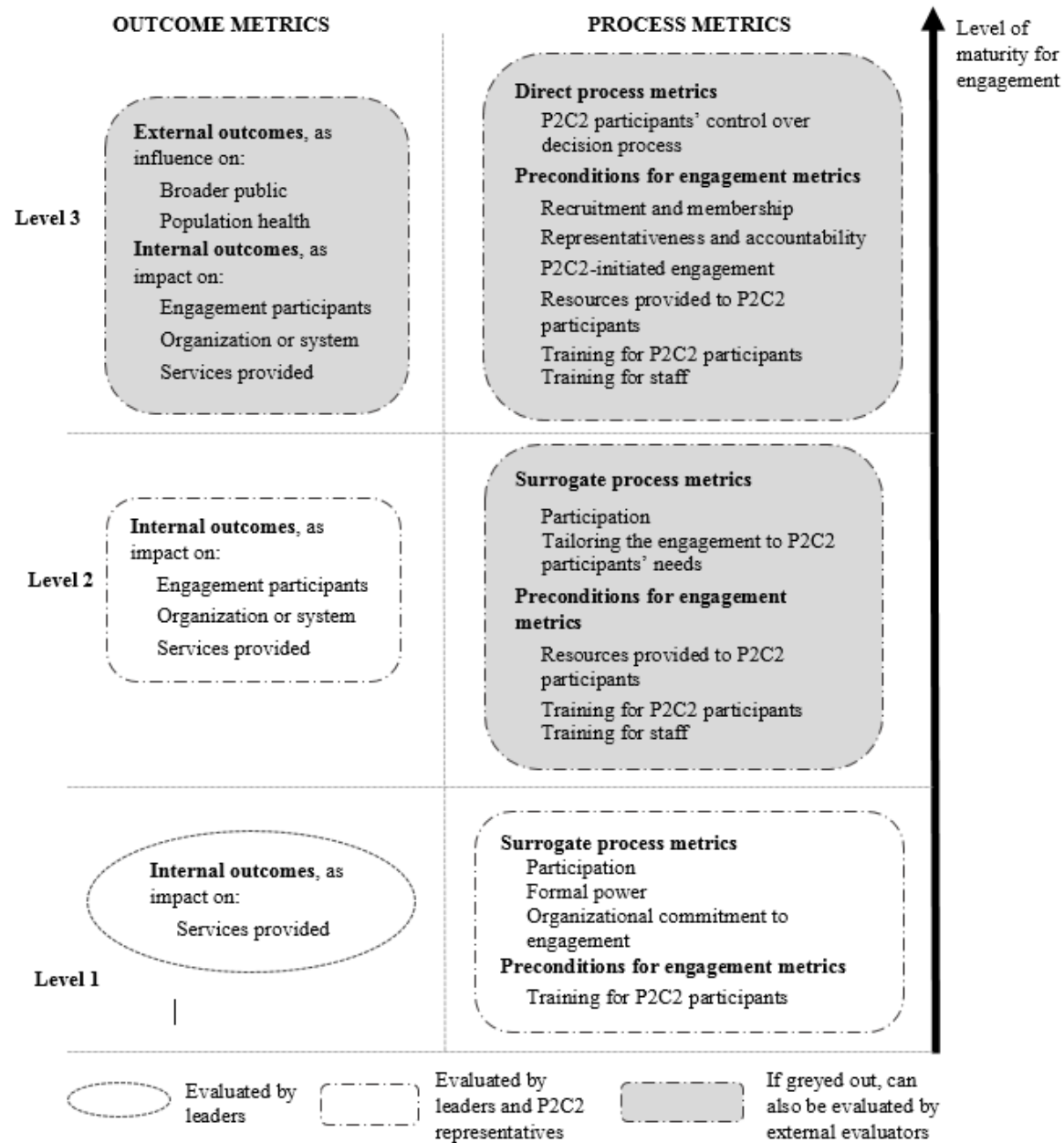


Figure 3. Proposed metric subdomains for evaluating patient, consumer, public and community (P2C2) engagement according to system- or organizational maturity for engagement





# Practice, Policy and Research Implications

Additional research to better understand the validity and reliability of tools and metrics in different contexts.

A consensus-building process to identify and disseminate core metrics. Our taxonomy provides a starting point for that process, which itself must include P2C2 participants. Comparative evaluation of the metrics (e.g., to find the best way to measure representativeness) and the use of those metrics for comparative evaluation of different methods of engagement (e.g., single representatives versus patient councils).

New tools may be needed in order to capture parts of the taxonomy not currently represented in existing tools.



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# Next Steps

# Next Steps

AHRQ (1K08HS023684-01, PI – Matt DeCamp)

[Done] Interviews with ACO beneficiary representatives and ACO leaders from 17 Medicare ACOs about their P2C2 practice.

- “You get out what you put in.”

[Done] A survey of 3,061 Johns Hopkins ACO Medicare beneficiaries (quantitative + qualitative) about their views, including Importance of P2C2 representation and factors considered regarding P2C2 representation.

- Patients think P2C2 representation matters, and may increase trust in health systems.

[In-progress] Focus group with Johns Hopkins ACO Medicare beneficiaries to gain richer insights into patients' views of P2C2 engagement.



**Questions?**

**Thank You!**





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# Methods: Extra

## PubMed:

1. "Consumer Participation"[Mesh]  
2. "Patient Participation"[Mesh]  
3. "Patient Advocacy"[Mesh]  
4. "public involvement"[Tiab], "public engagement"[Tiab], "public participation"[Tiab], "public perspective"[Tiab], "public perspectives"[Tiab], "public representation"[Tiab], "public collaboration"[Tiab], "social involvement"[Tiab], "social engagement"[Tiab], "social participation"[Tiab], "social perspective"[Tiab], "social perspectives"[Tiab], "social representation"[Tiab], "social collaboration"[Tiab], "community involvement"[Tiab], "community engagement"[Tiab], "community participation"[Tiab], "community perspective"[Tiab], "community perspectives"[Tiab], "community representation"[Tiab], "community collaboration"[Tiab], "citizen involvement"[Tiab], "citizen engagement"[Tiab], "citizen participation"[Tiab], "citizen perspective"[Tiab], "citizen perspectives"[Tiab], "citizen's participation"[Tiab], "citizen's perspective"[Tiab], "civic involvement"[Tiab], "civic engagement"[Tiab], "civic participation"[Tiab], "civic representation"[Tiab], "stakeholder involvement"[Tiab], "stakeholder engagement"[Tiab], "stakeholder participation"[Tiab], "stakeholder perspective"[Tiab], "stakeholder perspectives"[Tiab], "stakeholder representation"[Tiab], "stakeholder collaboration"[Tiab], "stakeholder's perspective"[Tiab], "family involvement"[Tiab], "family engagement"[Tiab], "family participation"[Tiab], "family perspective"[Tiab], "family perspectives"[Tiab], "family representation"[Tiab], "family's involvement"[Tiab], "family's participation"[Tiab], "family's perspective"[Tiab], "family's perspectives"[Tiab], "user involvement"[Tiab], "user engagement"[Tiab], "user participation"[Tiab], "user perspective"[Tiab], "user perspectives"[Tiab], "user representation"[Tiab], "user collaboration"[Tiab], "user's participation"[Tiab], "user's perspective"[Tiab], "user's perspectives"[Tiab], "client involvement"[Tiab], "client engagement"[Tiab], "client participation"[Tiab], "client perspective"[Tiab], "client perspectives"[Tiab], "client representation"[Tiab], "client collaboration"[Tiab], "client's involvement"[Tiab], "client's engagement"[Tiab], "client's participation"[Tiab], "client's perspective"[Tiab], "client's perspectives"[Tiab], "patient involvement"[Tiab], "patient engagement"[Tiab], "patient participation"[Tiab], "patient perspective"[Tiab], "patient perspectives"[Tiab], "patient representation"[Tiab], "patient collaboration"[Tiab], "patient's involvement"[Tiab], "patient's engagement"[Tiab], "patient's participation"[Tiab], "patient's perspective"[Tiab], "patient's perspectives"[Tiab], "patient's representation"[Tiab], "patients' perspective"[Tiab], "patients' perspectives"[Tiab], "consumer involvement"[Tiab], "consumer engagement"[Tiab], "consumer participation"[Tiab], "consumer perspective"[Tiab], "consumer perspectives"[Tiab], "consumer representation"[Tiab], "consumer collaboration"[Tiab], "consumer's involvement"[Tiab], "consumer's participation"[Tiab], "consumer's perspective"[Tiab], "customer involvement"[Tiab], "customer engagement"[Tiab], "customer participation"[Tiab], "customer perspective"[Tiab], "customer's perspective"[Tiab], "patient advocacy"[Tiab], "patient advocate"[Tiab], "patient advocates"[Tiab], "patient's advocate"[Tiab], "patient's advocates"[Tiab], "consumer advocacy"[Tiab], "consumer advocate"[Tiab], "consumer advocates"[Tiab], "community advocacy"[Tiab], "community advocate"[Tiab], "community advocates"[Tiab], "public advocacy"[Tiab], "public advocate"[Tiab], "public advocates"[Tiab], "social advocacy"[Tiab], "citizen advocacy"[Tiab], "citizen advocates"[Tiab], "family advocacy"[Tiab], "family advocate"[Tiab], "family advocates"[Tiab], "client advocacy"[Tiab], "client advocate"[Tiab], "client advocates"[Tiab]

Terms and controlled vocabulary 1-4 were combined with the 'OR' operator, forming **Block I**.

5. "Decision Making, Organizational"[Mesh]  
6. "Decision Making"[Mesh]  
7. "Policy Making"[Mesh]  
8. "Clinical Governance"[Mesh]  
9. "Advisory Committees"[Mesh]  
10. "Governing Board"[Mesh]  
11. "advisory board"[Tiab], "advisory boards"[Tiab], "advisory committee"[Tiab], "advisory committees"[Tiab], "advisory subcommittee"[Tiab], "governing board"[Tiab], "governing boards"[Tiab], "governing committee"[Tiab], "governing committees"[Tiab], "hospital board"[Tiab], "hospital boards"[Tiab], "board of trustees"[Tiab], "hospital committee"[Tiab], "hospital committees"[Tiab], "advisory council"[Tiab], "advisory councils"[Tiab], "advisory panel"[Tiab], "advisory panels"[Tiab], "citizen panel"[Tiab], "citizen panels"[Tiab], "patient panel"[Tiab], "patient panels"[Tiab], "governance"[Tiab], "priority setting"[Tiab], "decision making"[Tiab], "decision maker"[Tiab], "decision makers"[Tiab], "policy maker"[Tiab], "policy makers"[Tiab], "policy making"[Tiab], "health care policy"[Tiab], "health care policies"[Tiab], "healthcare policy"[Tiab], "healthcare policies"[Tiab], "deliberative"[Tiab], "deliberation"[Tiab], "deliberations"[Tiab], "partnership"[Tiab], "partnerships"[Tiab], "partnering"[Tiab]

Terms and controlled vocabulary 5-11 were combined with the 'OR' operator, forming **Block II**.

12. "Health Care Rationing"[Mesh]  
13. "Health Priorities"[Mesh]  
14. "Health Care Sector"[Mesh]  
15. "Health Planning"[Mesh]  
16. "Accountable Care Organizations"[Mesh]  
17. "health system"[Tiab], "health systems"[Tiab], "medical system"[Tiab], "medical systems"[Tiab], "health care system"[Tiab], "health care systems"[Tiab], "healthcare system"[Tiab], "healthcare systems"[Tiab], "health system"[Tiab], "health systems"[Tiab], "health organization"[Tiab], "health organizations"[Tiab], "healthcare organization"[Tiab], "healthcare organizations"[Tiab], "health care organization"[Tiab], "health care organizations"[Tiab], "medical organization"[Tiab], "medical organizations"[Tiab], "health sector"[Tiab], "health care sector"[Tiab], "healthcare sector"[Tiab], "medical sector"[Tiab], "accountable care organization"[Tiab], "accountable care organizations"[Tiab], "health care priority"[Tiab], "health care priorities"[Tiab], "healthcare priority"[Tiab], "healthcare priorities"[Tiab], "health priority"[Tiab], "health priorities"[Tiab], "hospital priority"[Tiab], "hospital priorities"[Tiab], "health care planning"[Tiab], "healthcare planning"[Tiab], "hospital planning"[Tiab], "health planning"[Tiab], "health facility planning"[Tiab], "health care rationing"[Tiab], "healthcare rationing"[Tiab], "health care distribution"[Tiab], "healthcare distribution"[Tiab], "health care administration"[Tiab], "healthcare administration"[Tiab], "hospital administration"[Tiab], "health facility administration"[Tiab], "medical administration"[Tiab], "health care resources"[Tiab], "healthcare resources"[Tiab], "hospital resources"[Tiab], "health facility resources"[Tiab], "medical resources"[Tiab], "health care delivery"[Tiab], "healthcare delivery"[Tiab], "health care decision"[Tiab], "health care decisions"[Tiab], "healthcare decision"[Tiab], "healthcare decisions"[Tiab], "medical decision"[Tiab], "medical decisions"[Tiab], "hospital decision"[Tiab], "hospital decisions"[Tiab]

Terms and controlled vocabulary 12-17 were combined with the 'OR' operator, forming **Block III**.

**Block I**, **Block II**, and **Block III** were combined using the 'AND' operator.

# Methods: Extra

## Online Supplemental Material 2. Gray literature sources

Websites of the following organizations:

- AcademyHealth (USA)
- Agency for Healthcare Research and Quality (USA)
- America's Health Insurance Plans (USA)
- American Hospital Association (USA)
- American Institutes for Research (USA)
- Australian Institute of Health and Welfare (Australia)
- Canadian Policy Research Networks (Canada)
- Centers for Medicare & Medicaid Services (USA)
- Consumer Federation of America (USA)
- Dartmouth Institute (USA)
- European Patients Forum (International)
- Food and Drug Administration (USA)
- Health Canada (Canada)
- Healthcare Information and Management Systems Society (USA)
- Institute for Health Metrics and Evaluation (USA)
- Institute for Healthcare Improvement (USA)
- Institute for Patient- and Family-Centered Care (USA)
- Institute On Governance (Canada)
- Kellogg Foundation (USA)
- Ministry of Health (New Zealand)
- National Association of County & City Health Officials (USA)
- National Committee for Quality Assurance (USA)
- National Health Service (UK)
- National Institute for Health and Care Excellence (UK)
- National Partnership for Women & Families (USA)
- Organisation for Economic Co-operation and Development (International)
- Patient and Family Advisory Councils (USA)
- Patient-Centered Outcomes Research Institute (USA)
- Robert Wood Johnson Foundation (USA)
- Royal Pharmaceutical Society (UK)
- Scottish National Health Service (UK)
- World Health Organization (International)



# Results: Extra, Big Table 1-Part 1

Table 1. Listing of Identified Evaluation Tools and their Basic Characteristics

Tool N	Tool name (if applicable), authors	Country	Year	Setting	Method of Evaluation	Brief Description	Who Fills Out Evaluation
1.	<a href="#">Metsch and Veney</a> . <sup>33</sup>	United States	1973	Individual hospital	Quantitative	Scoring tool for meeting minutes that assigns weighted categories of interaction for each consumer recommendation.	External evaluators
2.	<a href="#">Steckler and Dawson</a> . <sup>34</sup>	United States	1978	Health Systems Agency	Quantitative	38 questions in five items/indices and interview data. Adapted from <sup>i-iv</sup> .	Leaders and P2C2 representatives
3.	<a href="#">Rifkin, Muller &amp; Bichmann</a> . <sup>35</sup>	Nepal	1988	Healthcare program	Quantitative	Qualitative data scored 1 to 5 in five dimensions using a ranking table.	External evaluators
	<a href="#">Schmidt and Rifkin</a> . <sup>36</sup>	Tanzania	1996	Healthcare program	Quantitative	Same tools as #3 applied in a different country.	External evaluators
4.	Consumer Participation Questionnaire. <a href="#">Kent and Read</a> . <sup>37</sup>	New Zealand	1998	Mental health services	Mixed method	Yes/No, Likert scale, and discrete choice items.	Leaders
5.	<a href="#">El Ansari &amp; Phillips</a> . <sup>38</sup>	South Africa	2001	Healthcare program	Quantitative	7-point Likert scale covering eight dimensions. Derived from sources evaluating engagement outside healthcare.	Leaders and P2C2 representatives
6.	Partnership self-assessment survey. <a href="#">Shortell et al</a> . <sup>39</sup>	United States	2002	Diverse	Quantitative	5-point Likert scale items. Four components are measured using 1-5 items.	Leaders and P2C2 representatives
7.	<a href="#">Halliday, Asthana &amp; Richardson</a> . <sup>40</sup>	UK	2004	Diverse	Mixed method	4-point Likert scale (covering nine dimensions) and open-ended questions. Derived from <sup>v-vi</sup> .	Leaders and P2C2 representatives
8.	<a href="#">Jarrett and Patient Involvement Unit</a> . <sup>41</sup>	UK	2004	Guideline development group	Mixed method	5-point Likert scale and interview questions in open-ended fashion, both evaluating the same aspects.	Leaders and P2C2 representatives
9.	A Hospital Self-Assessment Inventory. Institute for Family-Centered Care. <sup>42</sup>	United States	2004	Individual hospital	Mixed method	5-point Likert scale, and 3-point rating system and open-ended notes.	Leaders and P2C2 representatives
10.	Well Connected. South, Fairfax and Green. <sup>43</sup>	UK	2005	Healthcare program	Quantitative	10-point scale covering six dimensions based on three general scoring criteria. Drawn from tool #3 and <sup>vi-viii</sup> .	Leaders and P2C2 representatives
11.	<a href="#">Grant</a> . <sup>44</sup>	Canada	2007	Mental health services	Mixed method	Yes/No questions, Likert scale questions, and multiple choice items. Modified by adding questions to tool #4.	Leaders
12.	Evaluation Form. Health and Social Care Regulatory Forum. <sup>45</sup>	Ireland	2009	Diverse	Mixed method	5-point Likert and open-ended questions. Derived from <sup>ix</sup> .	Leaders





# Results: Extra, Big Table 1-Part 2

Tool N	Tool name (if applicable), authors	Country	Year	Setting	Method of Evaluation	Brief Description	Who Fills Out Evaluation
13.	Draper, Hewitt & Rifkin. <sup>46</sup>	Djibouti, Honduras, and Nepal	2010	Healthcare program	Quantitative	5-point scale scoring five factors (tool provides example descriptions for 1-, 3- and 5-point scores). Modified #3, by replacing two domains.	External evaluators
14.	PFAC Annual Report Template. Consumer Health Quality Council HCFA, Massachusetts. <sup>47</sup>	United States	2012	Individual hospital	Qualitative	Open-ended items and multiple-choice questions.	Leaders
15.	Consumer Health Quality Council Review Instrument for 2011 Reports. Consumer Health Quality Council HCFA, Massachusetts. <sup>47</sup>	United States	2012	Individual hospital	Mixed method	Open-ended, multiple choice and Yes/No questions.	External evaluators
16.	National Institute for Children's Health Quality. <sup>48</sup>	United States	2012	Diverse	Mixed method	3-point Likert scale questions with "free-text" field and a set of 5-point Likert scale questions. Derived from <i>Essential Allies</i> <sup>25</sup> .	Leaders
17.	HCFA Recommended 2013 PFAC Annual Report Template HCFA, Massachusetts. <sup>49</sup>	United States	2014	Individual hospital	Mixed method	Multiple-choice and open-ended questions	Leaders and P2C2 representatives
18.	HCFA 2013 PFAC Report Review Tool. HCFA, Massachusetts. <sup>49</sup>	United States	2014	Individual hospital	Mixed method	Open-ended, multiple choice and Yes/No questions.	External evaluators
19.	PFAC Council Evaluation. Brigham and Women's Hospital Center for Patients and Families. <sup>50</sup>	United States	2014	Individual hospital	Mixed method	5-point Likert scale and open-ended questions.	Leaders and P2C2 representatives
20.	PPEET, Participant questionnaire, v. 1.0. Abelson and PPEET Research-Practice Collaborative. <sup>51</sup>	Canada	2015	Diverse	Mixed method	5-point Likert scale plus open-ended questions.	P2C2 representatives
21.	PPEET, Organization questionnaire, v. 1.0. Abelson and PPEET Research-Practice Collaborative. <sup>51</sup>	Canada	2015	Diverse	Mixed method	5-point Likert scale plus open-ended questions.	Leaders
22.	CCP evaluation framework. CCP Steering Committee. <sup>52</sup>	United States	2015	Medicaid Managed Care	Quantitative	Review of program websites and documents with Yes/No checkboxes.	External evaluators
23.	National ACO Patient Activation and Engagement Survey. Shortell et al. <sup>53</sup>	United States	2015	ACO	Quantitative	1 to 9 Likert scale and Yes/No items. Part of the National Survey of ACOs.	Leaders

□



# Results: Extra, Big Table 2-Part 1

Table 2. Coding Frequencies of Outcome Metrics in the Taxonomy per Evaluation Tool

Metric	Tool Number (see Table 1)												
	2 <sup>34</sup>	3 <sup>35,36</sup>	5 <sup>38</sup>	6 <sup>39</sup>	7 <sup>40</sup>	8 <sup>41</sup>	9 <sup>42</sup>	12 <sup>45</sup>	14 <sup>47</sup>	17 <sup>49</sup>	19 <sup>50</sup>	20 <sup>51</sup>	21 <sup>51</sup>
<b>* Outcome metric</b>	√	√	√√	√√√	√	√√	√	√	√	√	√√	√√	√√
<b>** Impact on engagement participants'</b>			√√	√√	√	√					√√	√√	
Knowledge			√	√							√	√	
Skills			√	√									
Empowerment			√								√		
Satisfaction			√	√							√	√	
Trust					√							√	
<b>** Impact on services provided</b>			√	√					√	√			√
Efficiency and cost-effectiveness of services				√									
Service availability			√	√									
Services quality and safety				√					√	√			
Services responsiveness to needs				√									
Utilization of services				√									
<b>** Impact on organization or system</b>			√√	√√√		√		√					√√
Accountability of organization to P2C2 served				√									
Staff views on engagement						√							√
Formal (written) organization or system policies						√							
Explicit change to organization or system process of decision-making													√
Additional connections or partnerships with other groups or organizations			√	√									√
Funding and resources availability			√	√									
Visibility of organization				√									
<b>** Influence on broader public's</b>			√										√
Awareness or knowledge of health issues			√										
Support of the organization or system			√										√
<b>** Influence on population health</b>		√	√	√									
Level of health inequalities		√											
Population health status				√									
<b>Aggregate outcome: Overall cost-effectiveness of engagement</b>				√									
Filled out by: External Evaluator		E											
Leader***	L		L	L	L	L	L	L	L	L	L		L
P2C2 representative***	R		R	R	R	R	R			R	R	R	

P2C2 - patient, public, consumer and community

KEY: √ 1-3 instances, √√ 4-14 instances, √√√ 15 or more instances of coding



# Results: Extra, Big Table 2-Part 2

Online Supplemental Material 5. Table 3. Coding Frequencies of Process Metrics in the Taxonomy per Evaluation Tool (Full version)

Metric	Tool (for number correspondence, see Table 1)																						
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
<b>* Process metric</b>	√√	√√	√√	√√	√√	√√√	√√	√√√	√√√	√	√√	√√√	√	√√√	√√	√√	√√√	√√	√√√	√√	√√	√√	√
<b>** P2C2 participants control over decision process:</b>	√	√√	√	√	√	√	√√	√√√	√√√	√	√	√√	√	√	√	√	√√	√	√	√√	√√	√	√
Agenda setting and time allocation	√												√	√			√	√					
Roles in decision-making are defined						√√	√							√		√	√	√					√
Independence in decision-making													√										
Involvement since first stage of decision process									√			√	√									√	
Involvement throughout types of decision activities	√		√	√		√			√√√	√	√√	√	√	√√		√	√	√				√	√
Involvement throughout 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)			√																				
<b>** Formal power</b>			√	√					√	√	√		√	√	√	√	√	√					
Financial independence of P2C2 participants										√			√										
P2C2 participants hold formal positions within the organizational hierarchy			√								√		√	√	√		√	√					
Statement of formal self-governance by P2C2 participants			√										√				√						
<b>** Organizational commitment to engagement</b>		√√		√	√	√√	√	√	√√	√		√√				√√		√				√√	
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									√			√											

# Results: Extra, Big Table 2-Part 3

Metric	Tool (for number correspondence, see Table 1)																						
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Organization or system rewards staff participation in engagement									√														
Staff readiness and attitudes towards engagement		√		√	√			√	√	√						√						√	
Staff have formal job responsibilities related to engagement																						√	
<b>** Participation:</b>		√√			√	√√	√		√	√			√	√	√		√		√				√
Activeness of participation													√										√
Equality of participation (among P2C2 participants)		√			√	√							√						√	√			
Attendance of engagement participants														√									
Regularity of meetings									√					√	√		√		√				
P2C2 participants' readiness and attitudes towards engagement		√			√	√	√																
<b>** Tailoring the engagement to P2C2 participants</b>																	√						
Cultural beliefs and practices																	√						
<b>P2C2-initiated engagement</b>		√																					
<b>** Recruitment and membership:</b>			√										√	√√	√	√	√	√			√	√	
Method of recruitment			√										√	√		√	√	√			√	√	
Number of P2C2 members and P2C2 versus non-P2C2 participant ratio														√	√		√	√					
Time or terms mandate for membership														√									
<b>** Representativeness and accountability:</b>		√	√		√						√		√	√		√	√	√		√	√		
Constituent representativeness and accountability		√	√										√			√					√		
Democratic representativeness		√											√										
Diversity representativeness			√		√						√					√					√	√	
<b>** Resources provided to P2C2 participants</b>	√√		√		√	√√		√√	√	√		√	√	√√		√	√√	√	√√	√√	√√	√√	√



# Results: Extra, Big Table 2-Part 4

Metric	Tool (for number correspondence, see Table 1)																						
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Childcare														√	√	√	√		√	√			
Financial support					√	√							√	√	√	√	√				√		
Meals and refreshments																		√			√		
Transportation and parking						√								√	√	√	√		√	√			
Translation support																		√			√		
Meeting place tailored to P2C2 participants																		√			√		
Meeting time tailored to P2C2 participants																			√		√		
Support from other P2C2 participants								√						√	√	√					√		
Support for disseminating results of the engagement					√					√		√		√		√	√				√√	√	
Staff support of P2C2 involvement in engagement	√					√		√√	√				√	√	√	√	√		√		√		
Use of a broader P2C2 needs and strengths assessment to support P2C2 representatives in their decision-making			√																				
Feedback from P2C2 complaints																							√
Unbiased, jargon-free information on which to make decisions	√												√	√			√	√		√			
<b>** Training (for P2C2 participants)</b>								√√					√	√	√	√	√	√	√				
Presence of training													√		√	√							
Quality of training								√√						√	√								
Scope of training														√	√			√					
<b>** Training (for staff)</b>									√	√		√				√						√	
Quality of training																						√	
<b>Aggregate process</b>																							
<b>Respect</b>						√										√				√			
<b>Transparency of the decision-making process</b>																				√	√	√	√
<b>Trust</b>							√													√			
<b>Level of participation</b>													√										√
Filled out by: External Evaluator	E		E										E		E			E				E	
Leader***		L		L	L	L	L	L	L	L	L	L		L	L	L	L		L		L		L
P2C2 representative***		R			R	R	R	R	R	R	R	R					R		R	R			

P2C2 - patient, public, consumer and community

KEY: √ 1-3 instances, √√ 4-14 instances, √√√ 15 or more instances of coding

