

Scoresheet for Tangible Effects of Patient Participation

[Kreindler, S. A., and A. Struthers. 2016. Assessing the organizational impact of patient involvement: a first STEPP. *International Journal of Health Care Quality Assurance* 29:441-453. <https://doi.org/10.1108/IJHCA-01-2015-0013>](#). Reprinted with permission from Sara A. Kreindler.

NOTE

This assessment instrument is included as part of the Assessing Meaningful Community Engagement in Health and Health Care Policies and Programs project. For more information on the project visit <https://nam.edu/programs/value-science-driven-health-care/assessing-meaningful-community-engagement/>, and for more information on the Assessment Instrument Summaries visit <https://nam.edu/introduction-to-assessment-instrument-summaries>.

Scoresheet for Tangible Effects of Patient Participation

The three STEPP items should be scored for each recommendation patients made; in the absence of recommendations, items can be scored for each issue patients raised. Each item is intended to be scored separately, without considering the scores on the other items (unless instructed otherwise in the “please consider” section).

Q1) Magnitude of recommended change *or* issue raised

(How great is the potential impact on patients?)

1 = small

2 = medium

3 = large

To score Magnitude, please consider:

- Whether scoring a recommendation or an issue/problem that patients have raised, consider the extent of its likely impact on patients (i.e., on their health and/or other aspects of their experience) – not the degree of difficulty for the organization.
- Please remember to score the magnitude of the **issue or recommendation that patients raise**, *not* the magnitude of the organization's response (which is scored separately in Q2).

Magnitude = 1 (small)

Issues/recommendations with a *small* impact on patients would include minor inconveniences, quality of "hotel services" in non-residential care settings (unless it is a mental-health care setting and the changes have a clear link to promoting mental health), and information gaps (where these are inconvenient to the patient but do not threaten the overall quality of care). Changes with a small impact might include

- o provision of information (e.g., signage, self-serve educational materials)
- o improvement of hotel services in a non-residential setting (or minor changes in a residential setting)
- o continuation of an existing activity or service with no implication of enhancing or increasing it (*unless* there are plans on the table to discontinue it)

Magnitude = 2 (medium)

Issues/recommendations with a *medium* impact on patients relate to significant aspects of care (e.g., access, quality, safety, patient-centeredness) but would have a moderate rather than profound impact in these areas. Changes with a medium impact might include

- o specific (simple) changes to the care process
- o modest changes to the design/layout of facilities
- o moderate increases in the intensity or hours of service
- o moderate increases in patients' autonomy or potential for engagement
- o pervasive changes to amenities in a residential care setting

Magnitude = 3 (large)

Issues/recommendations with a *large* impact on patients would include serious problems with access, quality, or safety, or the expressed need for totally new types of services. Changes with a large impact might include

- o creation of a new service
- o major changes to facility design/layout, type or intensity of services offered
- o major or comprehensive process changes to improve quality, safety or access

Q2) Organization's Response

(How fully did the organization address the issue?)

-1 = opposed the recommendation or denied the issue

0 = took no position

1 = put the issue/recommendation on the agenda

2 = adopted some of the recommendation / took some action on the issue

3 = *adopted it in entirety / fully addressed the issue*

To score the Organization’s Response, please consider:

- To get a high score, the organization must not only state their agreement with the recommendation but do something to put it into practice. This doesn’t mean that it must be fully implemented, but a clear plan of action must be underway.
- “Organization” here means whoever was targeted by the recommendation. If the recommendation is targeted at someone other than the scoring program/site (e.g., the whole region), you can (a) take the item out of the STEPP calculations for the program/site, or (b) score the program/site on the basis of what they did to advocate for the recommendation being adopted by others.

Organization’s Response = -1 (opposed)

Score -1 if the organization rejected or did the opposite of the recommendation, or denied the issue.

Organization’s Response = 0 (no position)

Score 0 if the organization didn’t take a position (e.g., didn’t do anything about the issue, but might do something in future).

Organization’s Response = 1 (on the agenda)

Score 1 if the organization put the issue/recommendation on the agenda. This could mean they (a) showed interest in the matter, discussing and investigating it further; (b) adopted a change in principle but have taken no steps to carry it out; or (c) took a mix of actions that seem to support and oppose what patients suggested. In most cases, it means the organization took no real action.

Organization’s Response = 2 (partial adoption)

Score 2 if the organization adopted some of the recommendation or (if no formal recommendation exists) took some constructive action on the issue. For a recommendation, score 2 if the organization (a) adopted some components of what patients recommended; (b) adopted a milder or scaled-down version of what patients recommended; or (c) tried to achieve what patients wanted through some other means. If scoring an issue, score 2 if the organization took some concrete action, but less than it could have.

Organization’s Response = 3 (full adoption)

Score 3 if the organization adopted the recommendation in entirety or fully addressed the issue. For a recommendation, score 3 if the organization did exactly (or almost exactly) what patients recommended. If scoring an issue rather than a recommendation, score 3 if the organization did all it reasonably could to address the issue.

Q3) Influence that patient input appears to have had on the organization’s response (Was it one reason why an action was taken? Was it the only reason?)

0 = *none (the decision had already been made)*

1 = *slight*

2 = *moderate*

3 = *high (it was the only or principal reason for the decision)*

To score Influence, please consider:

- In general, try to score Q3 (influence) without considering Q2 (organization’s response). For example, the organization might fully adopt what patients recommended, but patient input might be only one reason for the decision – or not a reason at all.

Influence = 0 (none)

Score “0” if the decision had already been made, or was totally unrelated to the patient involvement activity.

Influence = 1 (slight)

Score “1” if the decision seems to have been made primarily for some other reason(s) (e.g., political pressure, staff committees, past feedback, etc.). Such reasons might have been present all along (e.g., the organization was already strongly considering such a change) or might have arisen after the involvement activity (e.g., Accreditation report). The patient involvement activity may still have had a small influence on the decision, but it was not the main reason for the decision.

Influence = 2 (moderate)

Score “2” if the decision seems to have been partly influenced by the involvement activity. This could mean that the organization was considering the change as an option, but was not certain to adopt it or move forward with it. The involvement activity seems to have been a significant reason for the decision, but it still was not the only reason.

Influence = 3 (high)

Score “3” if the decision seems to have been largely influenced by the involvement activity. This could mean that the organization had not been addressing the issue at all, or had endorsed the opposite of the recommendation. There are no other likely reasons why the decision was made.

How to score Influence if a recommendation was not adopted:

- If the organization *opposed* the recommendation (Q2 = -1), score “0” for influence if this is an unchanged position, or if the organization had no choice (e.g., it was compelled by a new law, emergency situation, etc.). Score “1” if this is a new position that the organization chose to adopt.
- If the organization did nothing about the issue (Q2 = 0), score “0” for influence.
- If the organization put the issue on the agenda (Q2 = 1), you can use your discretion to avoid over-scoring them for influence. (For instance, if patients raised an issue that wasn't very novel or unusual, and the organization responded by discussing it at a regular meeting, there's no need to score higher than "1" for Q3.)

How to score Influence if a recommendation was co-created by patients and staff:

- Score “0” if the matter was brought forward by staff, and was of little interest to patients.
- Score “1” if the proposed change or issue had the support of both patients and staff during the involvement process.
- Score “2” if some staff were initially resistant to the proposed change (/unconcerned about the issue), but changed their minds as a result of patient input.
- Score “3” if all staff initially were initially opposed to the recommendation (/unconcerned about the issue), but changed their minds as a result of patient input.
- **Note:** If recommendations were co-created, both patients and staff members should be involved in scoring Influence. Data on the extent to which staff opinions changed should be collected during or as soon as possible after the involvement activity.

Total Scores

For each recommendation, multiply the item scores to give a total impact score:

$$Q1 * Q2 * Q3 = \text{Total Score}$$

(Remember to multiply the items, not add them.)

Then generate the following composite scores:

- Net Impact (sum of total scores)
- Positive Impact (sum of only positive scores)
- Greatest impact (sum of top three scores)

Also report the number of recommendations in each of the following categories

- adoption with influence (total score > 0)
- adoption without influence ($Q2 > 0$ and $Q3 = 0$)
- rejection ($Q2 = -1$ or 0)

Scoring Examples

1. During a focus group, many patients note that the MS Clinic at Hospital X is difficult to find; there is very little signage. Prior to the focus group, the staff hadn't realized that the clinic was difficult to find. After the focus group, they put up better signage and start sending out maps with the letter containing the patient's appointment date and time.

Magnitude = 1 (small impact on patients)

Organization's Response = 3 (fully addressed the issue)

Influence = 3 (high)

Total = 1 * 3 * 3 = 9

2. In October, the patient advisory council at a primary care practice recommends, "At least twice a week, the clinic should stay open until 7 p.m. instead of 5 p.m." The clinic announces plans to stay open until 7 p.m. on Mondays starting in November. Meeting minutes reveal that the decision was made back in June, and is being implemented on the timeline that was originally planned.

Magnitude = 2 (medium impact on patients)

Organization's Response = 2 (partially adopted the recommendation)

Influence = 0 (none; decision had already been made)

Total = 2 * 2 * 0 = 0

3. A worryingly high number of patients and family have complained about surgical site infections at Hospital Y. Many patients described how their hospital stay was prolonged due to infection, and a few family members reported that their relative had died as a result of their infection. The hospital refers the issue to its patient safety committee, which has not reported back yet. Hospital administrators had already seen data showing the high infection rate at their site, so they probably would have called in the patient safety committee eventually.

Magnitude = 3 (large impact on patients)

Organization's Response = 1 (put the issue on the agenda)

Influence = 1 (slight)

Total = 3 * 1 * 1 = 3

Note: *These examples are entirely hypothetical, and bear no relation to the involvement initiatives in our study.*

Interpretation of Composite Scores

This table offers a guide to interpreting the average of a PII’s top three item scores (“Greatest Impact” divided by 3), drawing a distinction between involvement activities whose impact is direct (patients generate new, specific recommendations) *vs.* indirect (patients contribute to the decision-making process on organizational issues).

Average of Top 3 Scores	If a <i>direct-impact</i> activity, patients have...	If an <i>indirect-impact</i> activity, patients have...
< 6	had little impact on organizational decisions	had little impact on organizational decisions
6	been able to get small changes partially adopted	had a slight influence on medium-sized issues
9	been able to get small changes adopted	had a slight influence on major issues
12	been able to get medium-sized changes partially adopted	had substantive influence on medium-sized issues
15	been able to get small to medium changes adopted	had substantive influence on medium to major issues
18	been able to get medium-sized changes adopted	had substantive influence on major issues
21	been able to get medium to large changes adopted	had full influence on medium to major issues
24+	been able to get large changes adopted	had full influence on major issues