

Developing Patient-Centered Outcomes

Paul Cook

Once you have started to measure the process, you have already begun to improve it. – Edward Deming

Measurement is improvement. – Donald Berwick

Choosing the right outcome matters. In the private sector, the saying is that “you get what you pay for.” In the public sector, the parallel rule is that “you get what you measure.” In both cases the thing that you incentivize is the thing you tend to get more of. So, in health care if you measure the wrong outcome you get more of it but it doesn’t necessarily help. For instance, I study medication adherence. Just taking a medication that might not work is not a patient-centered outcome; treatment success is.

Aim statements must match outcome measures. Because you get what you measure, a project’s aim statement must match its primary outcome. If I say that my project is important because it will prevent adverse events connected to patients falling out of treatment, but my main outcome measure is patient satisfaction with care, it’s possible that satisfied patients could still have adverse events. There *might* be a causal link between these variables, but the burden is on the project leader to convince others of that.

The outcome measure is the one unchanging component of QI or evaluation. In research projects the one constant is the intervention. That’s the “internal validity” of the study, which researchers maintain via manuals, treatment fidelity measures, etc. But in QI the *measure* is the one constant, and the interventions are whatever might work. These can change, so if the first intervention fails, your project isn’t done; go back and do another PDSA cycle. But if your goal changes, you have a different project.

Patient-centered outcomes differentiate QI or evaluation from research. Part of the definition of QI is that the patient is expected to directly benefit from the activities. Direct benefit to the patient means that there has to be a patient-centered outcome; process measures might benefit the health care professional or the organization instead. In evaluation, the central question is whether a program has *value*, so the connection to patient outcomes may be more distant. But if health care organizations exist to improve health, the ultimate value of a program also has to be defined eventually in terms of its benefit to patients. Without a patient-centered outcome, QI/evaluation can creep over into research.

Patient-centered outcomes help projects succeed over time. New projects often start strong but fade gradually. The problem is that health care is in a state of perpetual change, and what seems today like a self-evident example of good patient care is tomorrow going to seem like a burden to the organization’s bottom line, a programming headache for the EHR vendor, or a non-interest to the new department head. What keeps a project on the front burner is Vicki Erickson’s motto: “we’re saving lives.”

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Patient-centered outcome measures can be hard to implement, for three major reasons: First, health care providers are like most professionals in that we focus mainly on the rules of our guild and what our peers think of us. What our peers tend to notice is our process, so we too focus on actions rather than results. Outcomes require looking at things from the patient's point of view, and often are delayed in time, so they tend to be hidden from us. Second, we like process measures because they feel more controllable. I can determine what *I do*, but what *happens to my patient* as a result seems out of my hands, especially if my patient has any say in the matter. That uncertainty can be uncomfortable. Finally, patient-centered outcomes are simply more difficult to operationalize. They often aren't captured in the EHR. They may require asking direct questions of the patient, using new surveys, or looking at data over the long term. But we should not give up on measuring the right outcome just because it's difficult. We should instead persevere, and teach our organizations the importance of using patient-centered outcomes, if we want to be the kind of leaders who "boldly transform health together."



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Worksheet for Patient-Centered Outcomes

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Aim statements for QI or questions for program evaluation should be SMART goals, that is:

SPECIFIC – is the outcome concrete enough to know whether or not you have achieved it? This includes being able to specify where the project took place, who was involved in making changes, what they did, and what they were trying to accomplish. QI and evaluation are *not generalizable*. The details of where, when, and how they were done, by whom and for whom, will limit any conclusions from their results.

The context for this study is ...

MEASURABLE – the data used to gauge the program’s success should also be concrete and quantifiable, with a specified numerator and denominator. The measure should be described in enough detail that someone else could look at the same information, replicate your math, and come to the same result.

The measure for this study is ... for patients who ...

ATTAINABLE – what’s the current (baseline) result on the outcome measure, and is there room for any improvement? Even if we would like the final result to be at 100%, can we really get there from here in the time available? Is our goal too modest, and can we stretch ourselves to do a little better instead?

The measure is currently at ... and by the end of the study our goal is to get it to ...

RELEVANT – is the outcome patient-centered? In other words, does it matter to the *patient*, rather than to the provider, the funder, the health care system, society at large, etc. All of those interests are also relevant, but patients don’t often care about them. What does the patient want to get out of the health care interaction? (note: sometimes I see “realistic” here, but that’s the same as attainable in my mind).

The outcome measure is important to patients because ... and important to the organization because ...



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TIME-FRAMED – by when do you expect to see an improvement? Is that long enough to achieve a change? Or is it too far out to really make a difference? Would it be possible to get results sooner? How often can you collect data and report it back to the organization (e.g., quarterly, monthly, weekly)?

Data will be collected with a frequency of... and we expect to see these measurements change by...