Reviewer's report

Title: The Health Disparities Cancer Collaborative: a case study of practice registry measurement in a quality improvement collaborative

Version: 1 Date: 1 January 2009

Reviewer: Ellie Grossman

Reviewer's report:

Overall, this paper provides a useful real-world description of the use of patient-registry data for quality-improvement work – specifically, related to cancer screening – and the strengths and weaknesses of registry data for these purposes. As detailed below, it would benefit from inclusion of more details relating to registry data collection, verification, and maintenance.

Major Compulsory Revisions

1. More information about the completeness of the registry would be quite useful in understanding its utility as a measurement tool. It sounds like each center had to enter into the registry all patients who had been seen in a three-year time period before the HDCC; do the authors know how long it took them to do this, and do they have any validation of the completeness of this data entry? Were these patients entered in chronological order, or was there some sorting/prioritizing of those with significant medical problems, abnormal screening tests, or other characteristic? If the calculation of screening rates was based on who had happened to be entered in the registry by a particular point in time, the pattern and completeness of this data entry could matter a lot.

a. Given that much of the data required for entry into the registry depended on reports from outside institutions (e.g. mammogram reports), what was the workflow such that these data were entered into the registry on an ongoing basis? And again, any validation of completeness?

2. The delineation of the three patterns of change in numbers and proportions of patients screened is a useful framework, and provides a good model for reporting of results in future studies of population screening efforts. However, it would be interesting to see if there were any center-specific patterns in these changes – i.e. if one center had a particular pattern of change for breast cancer screening, was it the same for the other 2 types of screening as well? Do patterns of change in all 3 types of screening tend to track together at each individual center? What do these patterns mean about particular QI strengths/weaknesses/strategies at the site level?

Minor Essential Revisions

1. Can the authors tell us more about these 16 health centers? Are they typical of health centers around the country? How were they selected to participate in the HDCC?
2. Given that the aim is in part a real-world description of how practice registries work, some more information about time/staff needed for data entry and registry maintenance (and how these resources were funded) would be useful. How many centers used the HDCC-provided registry software, and what did those that did something else do? How many of the centers had an electronic medical record (EMR) or other electronic patient accounts system – and did these automatically flow into the HDCC patient registry?

3. Do Figures 1, 2, and 3 show data for just breast cancer screening, or for all 3 screening types? The text on p.11 where the figures are referred to made me expect that the figures would show the patterns for all 3 types.

Discretionary Revisions / Comments

1. Page 6 could benefit from a little more detail about what these “local teams” looked like and how much staff time/effort/$ was allocated to these efforts.

2. The concept described in analysis #3 (page 9-10) – i.e. looking at both the n and the % of pts screened, as well as the size of the target population - is practical and useful. Clearly, when investigating the drivers of quality change (or lack of change) at individual institutions, one needs to keep all of these items in mind. There may be merits for particular situations/institutions to choosing one indicator over another as a benchmark to publicize, and these choices should be made consciously and carefully.

3. One aspect of the data presented in Table 2, in addition to the main point discussed in the text (i.e. detectable change), is the disturbingly low rate of timely treatment after cancer diagnoses. I understand this chart to say that for the 31 women diagnosed with breast cancer, only 2 received initial treatment within 90 days of diagnosis; similarly slow follow-up seems the case for CIN2/3 and colon polyps/cancer. Can the authors comment on the lack of timely treatment?

4. On pages 13-15, the authors’ third explanation for lack of data on the more ‘distal’ events in the cancer screening process seems the most plausible. I would assume that mammography and colonoscopy do not occur on-site at these health centers, and it may often be difficult for centers to receive initial test results – let alone information on the follow-up of abnormal tests. I might have expected more data available in the registry for Pap smears and colposcopies, as I would imagine that many of these are performed on-site at the centers. Do the authors have information on how many of the centers offered these services on-site, and if data quality/completeness varied accordingly?

5. I would agree that for comprehensive accountability (p.15) we need health-system change and integration across sites – any specific thoughts as to how to make this happen? Are ‘patient-centered homes’ with resources available for coordination the answer? If the authors have any information about particularly successful health centers in the HDCC, that could be interesting to present, even in an anecdotal form.
6. I would also agree with the authors’ comments on pages 16-17 re: dangers of an unreliable denominator. Until facilities are equipped with comprehensive EMRs, the burden of maintaining a patient registry to track large-population tasks like cancer screening seems overwhelming and likely to fail (be inaccurate/incomplete) due to limited resources. The HDCC is probably the best-case scenario, given that these were probably particularly motivated centers with special attention from national organizations.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.