Reviewer's report

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

**Version:** 1  **Date:** 20 September 2009

**Reviewer:** Keith McInnes

**Reviewer's report:**

[Most of the suggestions are discretionary -- I would strongly encourage a table that summarizes basic data about all 16 health centers; I would also encourage more description of what % of clinics used the HDCC registry software, and what kind of training was provided during the Collaborative in how to set up, populate, and sustain useful registries. Also a bit more discussion of what appears to be anomalous registry results (Fig 2) would be helpful.]

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

This paper examines the quality of data in cancer registries of 16 community health centers taking part in a quality improvement collaborative (the Health Disparities Cancer Collaborative). As the authors mention in the conclusion, they have provided an “unvarnished” experience with the Health Disparities Collaborative. With that in mind I think they could provide some more details regarding the process by which health centers were directed/encouraged to create registries, e.g. what training did they receive, what percent used the HDCC software, what kind of staff person was in charge of the registry at the health centers, and where were data posted each month.

The manuscript brings an important “inside” look at the process of disease registries which are a common feature of quality improvement collaboratives. The design and methods are solid, and the discussion is thorough with useful lessons for quality improvement methods and evaluation. It is very well written.

**Background:**

P 5: “half of physician organizations” -- consider “physician office practices” instead (I thought of physicians unions first, but I don’t think that was meant).

P5: Good point to examine completeness of data across health centers over time: in some collaboratives registries start out very small (e.g. 10-20 patients) and as they are added to, the results can vary greatly (which seems to be the case here too).

**Methods:**

What percent used the HDCC software for the registry? Were any analyses done looking at completeness of data and improvements, comparing the centers that
used the HDCC software to those that did not.

Results:

I would find an introductory table helpful that describes the 16 CHCs participating, e.g. basic statistics on number of patients (e.g. mean, range, standard deviation), number of doctors, number of nurses, geographic location, whether have an EHR, used the HDCC software or not, number of months reporting registry data, etc.

P7. How many of the 16 centers used the HDCC registry software? For those that didn’t what systems were used?

P8. the process of entering patients into the registry has substantial potential for bias, i.e. those more active patients (seen in one of the months of the collaborative) would be more likely to be entered into the registry than patients who had not been seen in some time. Also the more active patients would be more likely to have the screenings and follow-ups, assuming that those were issues covered in the collaborative sessions.

P10, last line – “25%” should be “24%”, according to Table 2.

P11, For Figures 1, 2, and 3, it would be helpful to know how many centers were involved. Since all three figures are just for breast cancer, the sum of the numbers of CHCs represented in Fig 1, 2, and 3 would equal to 16—if I’ve understood the numbers correctly.

Discussion

Important finding that selection bias threatens the validity of general inferences drawn from the overall collaborative. This points out one of the challenges of evaluating collaboratives – i.e. having good quality data of processes and outcomes, and secondly having comparison clinics. As is pointed out later, there were no comparison clinics, so it is not clear that even the improvements in proportion of patients screened can be attributed to the collaborative, and not to other trends going on in community health care centers at the time.

The discussion is good in that it draws out the implications, and limitations of these data, e.g. health organizations may be hesitant to report data unless they are favorable.

Also very interesting and important point about the importance of collecting data not just at individual community health care centers, because of care and services that are provided at specialty referral practices. This points to the large gap in the US health care system in which data for individual patients who receive care from different health care organizations usually are poorly linked.

P16. In the third line from the bottom, I think the authors mean Figure 2 (not Figure 3) where there is a late, rapid increase in eligible population.

P17: I agree that it is challenging to define the denominator population, and that
many clinics do not have disease registries. The authors have done a nice job of raising some of the inconsistencies – however one point they don’t raise is that this is probably a new process for many of the clinics. They may have gotten a brief “lesson” about disease registries during one of the three collaborative sessions, but it may have been insufficient for them to be proficient and accurate. They are likely to make mistakes at first, and thus I think there may be a lot of “noise” in the first year of data. I think Figure 2 exemplifies this with the dramatic shifts in every category – number screened, eligible population, and proportion screened. (see comments below about Figure 2).

P17: “.data entry burden for large screening populations...” It would be helpful to describe in the “Collaborative Intervention” section how much training was given in disease registries, and something about what the HDCC software was like – e.g. based upon an existing software like Excel or completely homegrown? Had it been used in other settings? Etc.

Figures:
It would be helpful to add in the legend/title the number of centers to which each figure applies. If I understand Figures 1, 2, and 3, in total, they sum to the 16 centers.

Figure 2: there is a striking anomaly in the May to October period – large drop in number eligible and number screened. What might explain this? Could this be due to one large center (with large number of patients) where the procedures for keeping the registry changed for some reason?

Author Contributions:
In the second sentence one author, ST, is listed twice – I’m assuming this is a typo.

Additional File 2:
I would consider including this in the main paper, or at least the screening mammography data. Again, this shows the “messiness” of use of registries and new data monitoring procedures for community health centers. For example the drop of 497 patients eligible for screening mammography. This was probably a center where they misunderstood the processes and criterion that were outlined in the collaborative, and maybe through one of the phone conferences or in a one-on-one with collaborative faculty learned that their methods were different from the other programs – and thus this adjustment was made.

I think it also would suggest, and the authors might consider adding this to the discussion, that if collaboratives are thinking of using these kind of data as an evaluation tool of how well the collaborative is working, then more effort is needed to bring all the clinics up to speed. This has been advocated before in other articles, but it bears repeating. Collaboratives often have a heterogeneous group of clinics – from different regions, different sizes, different approaches to care. Getting them all to use similar registry and reporting procedures can be quite challenging.
Level of interest: An article of importance in its field

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