Author’s response to reviews

Title: Establishing spatially-enabled health registry systems using implicit spatial data pools: Case study – Uganda

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Author’s response to reviews:

We are happy that you found our research interesting. We are also very thankful for the insightful comments that we believe have improved the paper substantially. Please find below our answer to the reviewers. The manuscript has been revised and hopefully satisfies the comments.

Shaun Grannis (Reviewer 1)

Comment 1
Using a case study format, the authors describe two prototype approaches for capturing and integrating geospatial information with clinical data. The first approach creatively involves leveraging pre-existing geospatial data generated by Uganda's National Water and Sewerage Corporation (NWSC), which geocodes the location of residential water meters and can be linked to individual patients. Patients need only bring in their water meter number. The second approach allows an individual to select their residential location using a Maps Application. The user selects where they live on a map, and Geocodes are returned.

The value of adding geospatial data to clinical registry data is clear. The key hypothesis of the paper is that asking the patients to report their household NWSC meter numbers along with other personal details upon hospital admission will supply uniquely identifying spatial information. (p. 6, last paragraph)

The approaches described for capturing geocode data are creative; the mapping application seems to have interesting potential. I have a few questions, which I believe the authors should address prior to publication.
Response
Thank you for your positive review of our manuscript and for the very insightful comments that we believe has significantly improved the paper.

Comment 2
First, the manuscript does not make clear the degree to which this prototype has been deployed and evaluated. The authors should clarify whether they are describing a design-only, or whether the system has been developed, tested, and implemented. If the manuscript simply describes a proposed design (but not implemented), then its impact is reduced.

Response
We apologize for not being clear. What we presented in the paper is not only a proposed design. The system has been implemented. It has also been presented to the experts and ministry officials. They have welcomed the creative idea and solution. However, it has not been implemented by the Ugandan Ministry of Health yet.

Changes
Section 2.2, lines 173 – 177

Comment 3
Second, they should comment on the degree to which the geocoded water meter approach is generalizable to other countries. Do other countries geocode their water meters? If so, then this represents a generalizable approach. If not, the authors should acknowledge such as a limitation, and describe what aspects of the water meter approach could be generalized to other countries in the absence of geocoded water meters.

Response
Yes, some countries have geocoded utility meters, while others are in the process of acquiring them. Within East Africa, utility provision has been semi-privatized hence meters are georeferenced in order to trace homes where to deposit the monthly invoices. Therefore, our system can be generalized and extended to these settings allowing for spatially referencing patient records.

Changes
A text regarding generalization has been added to the discussion (line 252 – 255).
A text regarding limitation in generalization added to the discussion (line 279 – 291)

Comment 4
Third, I would encourage the authors to comment on how willingly they think patients will identify their home location (is it viewed as an invasion of privacy?), and also how adding geospatial identification to the patient registration workflow will affect registration efficiency. How much would such a system slow registration, which is typically a high-volume high-throughput process.

Response
In many European countries, like Sweden, patients’ location (home location) must be registered in the system. According to the law, all patients’ diagnosis records must be linked to the social security number and home location of the patients. This can also be the case for Uganda. Another issue that may arise is relevant to the security of information and to which extent (e.g. considering privacy and ethical issues) this information can be used and distributed. This needs laws and legislation to clarify the cases.
As you mentioned, the privacy and confidentiality issues do exist and need to be resolved by introducing proper laws in Uganda. For example, aggregated data can be analyzed and distributed, not data at the individual level. Therefore, there is a need for both legislative and systematic solutions to fully address these issues. We added a description to the text to highlight these practical (none technical) issues and their solutions.

Concerning registration efficiency, the provision of a water meter number alongside other patient details should not affect the registration efficiency. However, in instances where one has no meter number, the use of navigation services may slow down the registration process. But we cannot skip this stage. We believe that with experience the efficiency of medical personnel would improve over time.

Changes
Willingness to identify their home location, as well as privacy and confidentiality issues: The last paragraph of the discussion, line 288 to 291.
Slowing down of registration process was added as a limitation of the system, especially where one has no meter number and the navigation option has to be used (line 279–284).

Comment 5
Finally, while the manuscript is well-written and the benefits of a successful implementation of such technology are apparent, the degree to which this work substantially contributes to the body of medical informatics knowledge is not clear due to the lack of clarity regarding generalizability and maturity of the implementation. If limited in generalizability and deployment, I would advocate this work be re-positioned as a conference abstract or poster.

Response
A prototype system has been implemented and seriously discussed with officials at the Ministry of Health in Uganda. So from an implementation perspective, we confirm the existence of a prototype system. However, real deployment of the system is a national project that should be decided by policy-makers at the Ministry of Health. The level of implementation of the system was highlighted in the text. The contribution of the system to health informatics was explained. We also discussed the generalization of such approach to other countries.

Changes
-A paragraph discussing the level of implementation of the system in Uganda is added to the end of section 2.2, line 173 – 177.
-The contribution of the system
-A paragraph discussing the contribution of the system to health informatics has been added in the discussion (line 270 – 274)
-A text highlighting the contribution has also been added in the conclusion (line 298 - 300)
-A highlight has been added in the introduction (line 90 – 92)
-A highlight has been added in the abstract
-We have addressed the generalization aspects (line 252 – 255)

John David Halamka (Reviewer 2)

Comment 1
A well written paper about a well-conceived prototype and case study.

Response
Thank you for your positive review of our manuscript and for your thoughtful comment that we believe
has substantially improved the paper.

Comment 2
There is only one question that I had based on Gates Foundation work done in Africa. How do you identify the patient to avoid the problem of having duplicate entries in the database? Name/Gender/Date of birth match does not work well in Africa. Maybe consider biometrics?

Response
In Uganda and in most East African countries, every citizen is required to register for a National Identity card. This comes with a unique number (National Identity Number – NIN) that has been added as an extra field to the database. This will allow for unique identification of persons. NIN is similar to Social Security Number in US and Personal Number in Sweden.

Changes
- We added an extra field the system to save the patient’s NIN in the system. The field is shown in the updated figures of the user interfaces of the system.
- The required descriptions were added to the text (line 183 – 184).