Author's response to reviews

Title: Indivo: a Personally Controlled Health Record for Health Information Exchange and Communication

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Author's response to reviews: see over
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Matt Hodgkinson
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and

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Re: MS: 3385582131513898

Dear Mr. Hodgkinson and Ms. Puebla:

Thank you very much for your review of our manuscript. We have revised according to the reviewer’s comments, remaining cognizant of what is most appropriate to include in a “Software” type manuscript for BMC. We believe that the manuscript is clearer and more useful as a result.

Your suggestion of a reference to the Norwegian forum is quite apropos and you will see Mr. Crawford’s presentation from 2006 on the front page of the link you kindly forwarded! And the project listed in the table as “Access control test application” is in collaboration with our colleagues at the Norwegian University of Science and Technology.”

Please find below a point by point response to the reviewers.

Sincerely,

Kenneth D. Mandl, MD, MPH
Reviewer 1.
"This paper duplicates a lot of things already published in previous papers or can be read from website (www.indivohealth.org)."

***While there have been previous papers written that describe Indivo, the material in this paper is original and largely focused on innovations and approaches devoted since 2003 architectural description. The current paper more specific than previous papers and website and is geared towards the larger use of the software rather than the specific implementation of the software. Naturally, some information about the software must appear on the website making the software available (as encouraged by BioMed Central). We have reviewed and revised to ensure a minimal overlap.

"As an example, figure 1 is identical with a www-page figure."

***As part of a general effort to highlight the unique aspects of the Indivo platform—including the fact that it is, in fact, a platform—we have modified the figure to place more of an emphasis on the Indivo API as a critical component. The figure is now organized around the system’s concepts rather than its specific moving parts.

“For some reason the above web address is not mentioned at all.”

***The website www.indivohealth.org was cited twice in the original manuscript—in reference 5 as well as under the “project homepage” heading.

“Instead of duplication what is already available, I am proposing that the authors will modify this paper and concentrate to the following topics:

- Description of features unique to INDIVO!
- Compararison between INDIVO and some major systems available in the market (there are more than 20, for example MyOscar, HealthSpace, Ericson EMH and Health Hero)"

***We have attempted to focus entirely on features unique to Indivo or products deriving from Indivo. We have added some discussion of Indivo in comparison with other systems. There are actually few directly comparable applications, since most “PHR” applications are integrated databases and user interfaces, rather than API driven platforms. Interestingly, MyOscar is explicitly based on the Indivo architecture and uses the Indivo (formerly called PING) codebase. http://myoscar.org/history. The project listed in the table as “Networked primary care PCHR” was a collaboration with our colleagues at McMaster and led to the MyOscar implementation. MyOscar was referenced in the original manuscript. We have expanded our discussion of it in the revised manuscript.

“Much more clearer description of the business model of INDIVO including the financing model is needed. It is necessary to clearly describe, which kind of records are stored (e.g. original EHRs, copies or records made by the patient) by the INDIVO server. The business model should explain if the INDIVO is only a record banking system or a real service for multisource preservation and distribution of PHRs.”
"We did not believe these were appropriate subjects for a BMC Informatics “Software” paper. Business models for personally controlled health record systems may vary widely and the underlying Indivo architecture is capable of supporting many approaches and – as discussed – many forms of incoming data. But as software, Indivo does not have a “business model” as such – it's an enabling component for a larger model. We are exploring this very important question in a number of contexts as part of our ongoing research agenda in the broad consumer-oriented healthcare technology area.

“The security model should be clarified. The security policy model and its implementation is no not enough understandable now. Writers are speaking about two classes of security policies. Based on ISO and ASTM standards there should be a holistic security policy for the whole service including INDIVO and all connected entities. This model should be defined. As an example, it should be clarified how the data access and data disclose decisions are made (e.g. using rules, access control tables or policy based decision making model)"

"Indivo's dual class (server and individual) approach to access policies is a defining feature of the system. The policy evaluation rules affords maximum control by the record owners over their personal health data within the boundaries set by the system administrators.

"Writers have missused (or misunderstood) the meaning of identity federation (token) term. This should be corrected. If identity federation is really used, the standard/method it is based should be mentioned (e.g. identity token, SAML, attribute certificate)."

"I hope also to know how the communication security and long term preservation security is achieved?"

"It has been explained in this paper, that the INDIVO system is based on open standards, but no standard is mentioned. It is necessary to define which standards are used for document transfer and preservation (e.g. XML, HL7 CDA) as well as for security. I like to know if INDIVO is meeting HIPAA and/or ISO/IEC 27799 security standards?"

"What about audit logs, are them available?"

"The writers have mentioned that the patient-doctor relationship should be secured, but it is not explained how this is realised."
Indivo relies on existing patient-doctor relationships to authenticate patients. If a patient is known to a provider or to an institution, the account may be provisioned. At this stage we do not provide additional security around the authentication process.

“The INDIVO systems has been used for 5 years. Still writers are not presenting any results or impacts. This should be one of the cornerstones of this paper.”

We certainly appreciate the importance of evaluation and are currently engaged in several qualitative evaluations and formal trials of Indivo. A manuscript detailing one such evaluation is under review elsewhere. For this paper, we chose the “Software” article type and attempted to conform to the editorial guidance, “We encourage authors of software applications, tools or algorithm implementations to publish descriptions of their code using the Software article type.” We have, however, added a short reference to some of our ongoing and public health oriented work with Indivo.

Finally the annex including the deployment history of the INDIVO is not needed in this publication.

We thought that this table would be useful for readers, and in fact it does contain references to implementation and considerations raised by Reviewer 1.”

**REVIEWER 2.
Discretionary Revisions (which the author can choose to ignore)

1. please explain...'display a federation token upon request'

**We have clarified this section in response to the Reviewer 1 comment above.

2. what is "presenteeism" is this the opposite of absenteeism?

***Some historical information is available at http://en.wikipedia.org/wiki/Presenteeism

3. I think the first paragraph of conclusions should be a section called "future work".

***We kept to the recommended section headings.

4. I would like to read more about how "coded data" is extracted from the CDA or CCR and put into the database for future processing.

***We added the comment, “Standard coding systems, such as LOINC, may be used when the source data provider supports them.”

5. I would like more infomation on the clinical decision support engine. is there a paper describing this elsewhere?

***This has been briefly described in a submission to the AMIA Fall Symposium and will be detailed in a full separate manuscript.