Author's response to reviews

Title: High Acceptability for Cell Phone Text Messages to Improve Communication of Laboratory Results with HIV-infected patients in rural Uganda: A cross-sectional survey study

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Author's response to reviews: see over
Response to Reviewers (responses in bold face type)

A. Referee #1
1. It is not clear in this paper the exact type of communications that are being investigated. In the beginning, I interpreted the paper as describing opinions on patient-provider health communications in general, then it was about sending laboratory results, but at the end I think the aim was to suggest to patients with abnormal results that they should return to the clinic. In essence, the message is not truly sending actual lab results, but aims to get the patient to return to clinic. There is a multitude of ways that providers and patients could communicate via SMS, and I think this study refers to only one, which is fine, but it is not really clear from the manuscript. In the interviews, were patients given this as a specific scenario, or were they asked about SMS communications more generally? More detail is required on the specific scenario the researchers envision SMS being used for, if they had one.

This is an excellent point. We have clarified in the introduction and methods that we were querying patients on SMS messages to inform patients about abnormal laboratory results, not the actual results themselves in the text:

We designed the interview to cover four primary domains of health-related communication in our patient population: a) cell phone use practices and literacy, b) satisfaction with and preferences for clinic laboratory result communications, c) privacy and confidentiality issues about health-related communication, and d) acceptability of and preferences for cell phone text messaging to notify patients about abnormal test results.

In a survey of 50 HIV-infected patients in care in rural Uganda with access to cell phones, we found nearly universal acceptability for communications of information about laboratory test results via cell phone text messages.

We also included more information in the background section about our specific goals of the study and use case.

At the Immune Suppression Syndrome (ISS) Clinic in Mbarara, Uganda, clinic staff have been interested in investigating cell phone communication as a means of informing patients about abnormal test results and motivate early return to clinic when appropriate.

2. No data are provided on the study response rate. It is important to know if the study participants differed significantly from the clinic population. This is particularly relevant to mobile phone use and ownership. By including access to a phone as an eligibility criterion, the researchers have biased the findings relating to outcome a) cell phone use. Did they collect data at the time of recruitment on how many people were not enrolled as they did not have a phone? Do they have estimates of phone use for their entire clinic population? If neither of these estimates is available it is a major limitation to the study.
Thank you for this suggestion. We have added the following text to clarify this:

*Four participants were not enrolled due to: lack of cell phone ownership (2), declined consent (1), or did not have the required time available to complete the interview (1).*

We agree that limiting the study enrollment to those with cell phone access affects generalizability of our findings. We did so because the proposed intervention should largely pertain to those have access to cell phones. Our outcomes of interest, including cell phone literacy, use practices and acceptability of a text messaging system to notify patients of abnormal results, have limited relevance in those without cell phone access.

3. There are some areas where I think the discussion could be added to. There were many benefits of SMS to patients which have not been discussed. For example, I found it interesting that several individuals mentioned an improved relationship with their caregiver, and an increased sense of empowerment due to the messages. I would also like to see some suggestions or discussion on how to deal with the anxiety created by receiving negative medical information in an SMS; vice versa there is the potential to alleviate anxiety when patients are sent normal laboratory results.

Thank you again for this insightful point. We have provided further comment on the secondary gains from SMS communication:

*Participants also cited secondary benefits from cellular phone messaging of laboratory result information including improved relationship with clinic staff and providers and decreased transportation costs from less frequent clinic visits.*

We also suggested potential solutions to increased anxiety related to electronic receipt of bad news.

*Another concern expressed by study participants was the potential for anxiety caused by receipt of bad news with electronic messages. All participants expressed interest in the opportunity to call back after receipt of a message and most also expressed interest in a texting option. Other strategies to mitigate anxiety from receipt of bad news include enabling walk in appointments for patients after abnormal test results and using personal voice calls instead of messages for particularly critical results. The strategies should be considered in future use of technologies to communicate health information with patients.*

4. I have two issues with the manuscript title. Firstly, it refers to communications ‘among HIV patients,’ but in reality the paper describes communications between patients and providers.

*Changed it from “among” to “with”*
Secondly, the term ‘health related communications’ is very broad, whereas the paper seems to be limited to suggestions for return appointments based on laboratory results (as discussed above).

Changed it to “laboratory result communication”

5. On page 10, paragraph 2 – what is the meaning of “ABCDEFG”?

ABCDEFG is a coded message that is told to the participant at the time of the blood draw so they are aware that the message indicates an abnormal test result. I indicated this more clearly in the text:

Notwithstanding a preference for specificity, 24 participants (48%) prefer a direct to a pre-specified coded message (example for direct message: “Your laboratory tests are ready, please return to clinic” example of pre-specified coded message: “ABCDEFG”).

6. A paper looking at acceptability of cell phone messages among young people in Uganda has been published very recently. It might be useful to add this to the background – Mitchell et al, 2011, Health Educ Res 26(5) 770-81.

Thank you – This is added.

7. Have there been any other studies, anywhere in the world, investigating the use of SMS for sending HIV laboratory results? I don’t know of any, but I have not searched extensively. If not, this makes this study unique and the authors might want to note that in the introduction.

We included a sentence stating this in the introduction.

8. Of the various uses of SMS described in the 2nd paragraph of the background, most uses are very conceptually different from the aim of this study. The exception is return to care for STI treatment, which is very similar – i.e. send lab results and ask the patient to return. I would recommend focusing a little more on the STI treatment studies.

This is a good suggestion – though there are few studies showing benefit from these interventions, even in developed countries.

9. In the results section, manuscript page 10, the paragraphs describing ‘worries’ and ‘being startled’ are fairly repetitive of previous results.

This is true. We did ask some questions in a fairly repetitive manner in the survey to allow participants multiple options to report concerns and to increase the sensitivity of detecting them.
B. Referree #2

It is unclear why the methods are placed after the results/discussion/conclusions, please move them.

Thank you for this suggestion - we have changed the order of sections.

This research is helpful in deciding methods of intervention that are appropriate in different contexts. There is little acknowledgement of the costs associated for receiving texts in this RLS. Would these costs need to be addressed/compensated by the provider? Please add a point of discussion about costs of texting in this environment.

In Uganda, there is no cost to receipt of SMS messages. The providers would need to pay for the messages (approximately 0.02 – 0.04 USD per message). I have added a sentence on these costs in the conclusion section.

The level of acceptability is pretty surprising considering there is a risk of disclosure. It seemed that qualitatively, you managed to reach a sample of individuals who had already disclosed their status. This may be limited in other settings.

We were also surprised by the level of acceptability. Ultimately, some participants did recognize disclosure as a real risk, but seemed to value the access to health information over this potential risk. We do state in the limitations section that our findings might not be generalizable to other settings.

Language and literacy are high, which is also surprising in this rural sample. There was little discussion on the translation process of the tools. Please add a comment about that process.

The latest Ugandan census results in 2002 reported 76% literacy, notably lower than our estimate of 90%, but this estimate is also out of date. In limiting the study to cell phone owners, we also likely selected a population with literacy levels higher than the general population. This is acknowledged as a limitation. Thank you for the suggestion regarding study tool translations– I have done so in the methods section.

There are interventions that are using cell phones for texting without testing the acceptability with success. I suppose that would infer acceptability. Specifically, these are being done in Kenya and Malawi. Please include those references.

These are included in references 15-17.
3. Referee #3
I only have one comment: While the analysis suggests that concerns about confidentiality and disclosure of HIV status were infrequent, it can also be argued that disclosure can have large negative consequences even if they affect just a small fraction of patients. It would have been nice to see a more detailed discussion about available mechanisms that can address privacy issues that arise from SMS communication.

Thank you for this excellent point. I have added the following text to the conclusion section to address this weakness:

There is a near complete lack of published data and great need to evaluate the acceptability and feasibility of methods to optimize the confidentiality of mobile phone communications including password protected messages, coded messages, direct voice messages, and interactive-voice response formats. We hope to compare comprehension and acceptability of coded messages and use of a PIN code as part of a planned health-communication intervention at the HIV clinic in Mbarara. Finally, while concerns about disclosure were uncommon, disclosure can cause significant social and physical harm. As such, it is important that patients understand and accept these risks prior to sending sensitive SMS information.
4. Referee #4

1. My only main suggestion is that the authors report on who accepted to participate in the study and who did not. Although consecutive patients appear to have been screened, we do not know who refused to participate and therefore cannot assess potential selection bias.

Thank you for this suggestion. Four potential participants were not enrolled (2 did not have access to cell phones, 1 was not interested and 1 did not have time to complete the survey). We have added this information to the results section.

2. I would also like to see a greater discussion/emphasis on the importance of two-way versus one-way communication, since this appeared important to participants.

Thank you – I have added the following paragraph in the discussion:

Another concern expressed by study participants was the potential for anxiety caused by receipt of bad news with electronic messages. All participants expressed interest in the opportunity to call back after receipt of a message and most also expressed interest in a texting option. Other strategies to mitigate anxiety from receipt of bad news include enabling walk in appointments for patients after abnormal test results and using personal voice calls instead of messages for particularly critical results. The strategies should be considered in future use of technologies to communicate health information with patients.

3. The title should be more specific to relaying laboratory information via cell phones.

Thank you – we have changed the title to:

“High Acceptability for Cell Phone Text Messages to Improve Laboratory Result Communication with HIV-infected patients in rural Uganda: A cross-sectional survey study”

4. The definition of “early and later return” is not clear at this point.

Good suggestion – I clarified this point:

When ordering tests with potentially abnormal results, clinicians and/or patients must decide between an early return visit within days to weeks, often at significant cost to the patient, or the standard months-long return with the threat of delaying care.

5. Regarding studies on SMS communications for HIV care, “Although relatively untested” is probably misleading in this context. While this may be true compared to cardiovascular drug trials, some of the highest quality studies for evaluating ART adherence interventions studies, including both behavioural and biologic outcome indicators are available (see recent Lancet ID review, and Cochrane
review). Agreed, more studies are still required.

Yes – I changed that sentence to be more appropriate:

Though more studies are needed, early studies of cell phone use to improve HIV-related communication in resource limited settings have benefits in reducing missed clinic visits and improving medication adherence [15-17].

6. This is a highly disclosed group (98%). How might patients who have not disclosed their HIV status respond?

Only four participants declined participation – please see response to comment 1.

7. The reluctance to use a PIN is very enlightening in terms of usability. Every extra step in the SMS communication chain is a barrier to usage.

Yes – agreed – this is a big challenge!

8. The ‘potential to increase stress’ is a novel finding in terms of patient concerns. This should be further explored.

Thank you – we added the paragraph described in comment 2 above to address this issue.

9. Relationship building with healthworkers is a key finding: “I think this would help me relate better with the doctors, and I would accordingly”.

This is also included in the paragraph in comment 2.

Although consecutive patients were screen for enrolment, what proportion was eligible and who refused? This is important to understand any potential selection bias in this paper. (noted above)

Yes – thank you we have added this to the manuscript – see comment 1 above.