

Evaluating Anonymous Social Networking for PLHA with Social Prototypes

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1. OBJECTIVE

Socialisation is an important conduit of information and particularly so in developing countries. However, People Living with HIV / AIDS (PLHA) tend to socialize less among themselves as well as among others because of stigma [1]. Some PLHA avoid social functions because such functions disturb their ART (Antiretroviral Therapy) schedules. Others avoid it because socialisation often involves expenses. Depression, fear, discrimination, loss of pride and respect are other reasons. Lack of socialisation gives PLHA a feeling of being all alone in the hardest time of their life.

PLHA can potentially benefit a lot from socialisation. PLHA do have a lot to share amongst themselves and consider that other PLHA are trusted sources of information. However the fear of disclosure is too strong and many PLHA avoid face-to-face socialisation.

The current electronic social networking products are primarily designed to help users reach out to their existing social networks and to find new friends and contacts. These are quite unsuitable for the needs of PLHA. In any case, in developing countries, and particularly among the less educated, such electronic social networks do not exist.

We describe a unique Anonymous Social Networking (ASN) product concept for PLHA called *Sangam* that connects to its users through an Interactive Voice Response System (IVRS). We expect that ASN can potentially benefit PLHA by enabling them to interact with peers to exchange information and the much needed emotional support. The objective of this paper is to explore the potential of such anonymous socialisation among PLHA and to understand the design requirements and the

constraints under which such a system would operate.

2. THE DESIGN

We identified two main constraints for Sangam. Firstly, PLHA need to maintain anonymity and avoid accidental / unwanted disclosure. Secondly we did not want Sangam to be a forum for online dating or matchmaking, as this might help the virus.

We conceptualised an “Interactive Radio” that works as an ASN on phones. Radio is a familiar concept even amongst the less educated people. However, a radio is a broadcast medium and can be heard only as per a pre-determined schedule. With an interactive radio, we aim at providing the users with the shows that could either be live or pre-recorded. The PLHA can actively participate in a live show or can listen to a pre-recorded show in their free time.

Through Sangam, PLHA can interact with the other PLHA, post questions, receive answers, get regular personalised updates based on specific needs, and get connected to other HIV networks. Shows on Sangam are moderated to ensure accuracy of information.

For the PLHA, Sangam is deployed using an IVRS, which is accessible even from a basic phone. The moderator has a web-based interface to moderate the discussion. During the show, the moderator may invite other PLHA to this discussion, by announcing “If you want to ask a related question or join this conversation, press 5”. The PLHA can then “raise his hand” by pressing 5 on his phone. On the web-based interface, the moderator can see who has raised his hand and can give an opportunity to one or more PLHA to come live on the show at an appropriate time.

Sangam provides several kinds of information. It acts as a helpline and a directory and direct PLHA with information about HIV clinics, ART centres, counsellors, drop-in centres, NGOs, camps and events. It provides financial advice and helps support their treatment. It advises PLHA in disclosure to family and also advises family members in supporting the PLHA. It helps them find employment, advises about lifestyle improvement, nutrition and home remedies. It helps parents with HIV positive children to manage their regimens.

On Sangam, the information can be provided in different formats. We envisaged three formats: **expert show, chat room, and offline questions and answers.**

During the **expert show**, an expert (such as an HIV specialist, Doctor, a counsellor, a nutritionist or a legal expert) is invited to give advice and tips to callers on a particular topic. The moderator initiates the discussion by asking a series of questions of common interest. Information is provided in a conversational manner. At

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appropriate time, the moderator invites other PLHA to join in and ask questions and discuss with the expert.

The **chat room** allows for free flow of discussion among the PLHA. In this show, many PLHA come together at a pre-determined time and have a conference call to discuss a topic of mutual interest. The aim is to have a dynamic peer-to-peer interaction that will lead to sharing of experiences and knowledge amongst PLHA. The moderator introduces the topic and helps trigger discussions.

Questions that go unanswered in any show may either be taken up in follow up sessions, or could be answered by an expert offline. All such questions and answers are recorded and the PLHA can access them as an **offline questions and answers**.

3. THE SOCIAL PROTOTYPE

To evaluate the design intent of a product meant for social networking, it is vital to understand how it works in real life. Will Sangam promote socialisation among a community as vulnerable as the PLHA? Would the PLHA be willing to speak? Would they share their personal stories? The key question we ask is: *“How can we get data about realistic social responses without actually constructing such a system?”*

To answer these questions we chose to create what we call as a “social prototype”. A social prototype is a prototype that is deployed as close to the actual social context as possible to gain insights about the effects the product may have on socialisation.

While prototyping the expert show, we intended to understand how an offline conversation might perform in a real life situation with relatively less tech savvy PLHA. We used conference calls to deploy this prototype. We collaborated with three experts – a nutritionist, an HIV counsellor and social worker and an HIV doctor to create relevant scripts for the content of a nutrition-based programme. Four modules were created – **general tips on nutrition, nutrition for pregnancy, quick bites, and FAQs**. Each module was designed in a conversational manner and not as a pedantic lecture.

Next, we tried to imitate the system as it would work in real life. The PLHA were located in their respective places (either at work or home). They were called one by one and put on a conference call. The recorded programs were played from the moderator’s phone. After listening to the program some PLHA had questions, which were recorded by the moderator and then played back to the experts. The next day the answers were recorded in the experts’ voice and played back to the PLHA. This experiment was carried over across four days to test the functionality of such an offline conversation and involvement of the PLHA. The PLHA responded positively and adapted to the system with the progress of the prototype.

To understand how PLHA unknown to each other might interact in a live “chat room” session over the phone, we devised another social prototype. Two groups of PLHA – migrant men (GROUP A) and a group of women PLHA (GROUP B) were invited for this session. The topic was nutrition. The moderator introduced the PLHA to each other without naming anyone. However, most PLHA willingly introduced themselves by their first name. A conversation was triggered by asking simple questions about their food habits and lifestyle. A program with simple, quick yet nutritious recipes played back. It was hoped that as the topic is of common interest to both groups, it might trigger a conversation.

While the women found the tips very apt for daily usage, a PLHA (P) a migrant man found it yet difficult to implement it in his daily routine as he shared a rented house with many others. This problem triggered a conversation. Another PLHA (R) from group B suggested some solutions addressing P’s problems. P was satisfied, and wanted to ask some more questions to R which was off topic, but the moderator encouraged him to continue. So P asked R about his desire to have children. R then asked him about his and his wife’s health status. The conversation continues for about fifteen minutes and R told P that they can have a child if P’s wife’s CD4 count is above 500, but she should get herself checked before she conceives. P was satisfied with R’s answers.

This shows that even less educated PLHA are open to such interactions, which are not happening otherwise, even in existing positive networks. The anonymity offered by the system, the freedom to not be seen, the freedom to not speak if one wishes, and the freedom to disconnect at any time seems to be encouraging PLHA to discuss things they always wanted to, but had not done for years. These experiments reemphasise the role of the moderator, and indicate that it is not advisable to have un-moderated interaction in such contexts, as the effects of propagating wrong information will be harmful.

4. CONCLUSION

These experiments reaffirmed the importance of socializing amongst PLHA. The intervention of the ASN platform needs refinement at multiple levels. The content of the radio programs need to be scripted keeping in mind that there should not be information overload. It should be relevant and localized in terms of language, resources and the socio cultural environment of the target groups. It should induce social interaction and not become a one-way communication. This will make the PLHA feel involved and encourage them to share his/her feelings.

ASN can build confidence among the PLHA as it promises confidentiality and yet allows for socialisation. In such a context, a moderated discussion is essential, as it ensures accuracy of information and generates trust.

Social prototyping is a useful method used to evaluate novel social systems. In our case, it helped us to quickly try out innovative social networking ideas with minimal investments. It helped us gauge effectiveness of ideas in a challenging social setting.

Future work includes redesigning the social system after taking into account the lessons learnt from the experiments, followed by developing a robust product that could be deployed in the field in collaboration with social networks, NGOs and HIV clinics.

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