Evaluating Anonymous Social Networking for HIV Patients with Social Prototypes

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ABSTRACT

Socialization is an important conduit of information, and particularly so in developing countries. Ironically, People Living with HIV/ AIDS (PLHA) avoid socialisation among themselves as well as among others because of stigma. We describe a unique Anonymous Social Networking (ASN) product for PLHA called "Sangam" that uses an Interactive Voice Response System (IVRS). We evaluated our design by simulating the interaction of the proposed social networking system among the PLHA by using simple tools such as phones and computers. We call this method "Social Prototyping". This method allowed us to gauge the response PLHA might have with such a system and also helped us evolve the design. It also enabled us to deeply involve the PLHA, designing *WITH* the people, rather than FOR the people. We found the method simple yet effective. And yet, it gave rise to interesting questions to investigate in future.

Keywords: HIV/ AIDS, Anonymous social networking, Interactive Voice Response Systems, social prototypes.

1. INTRODUCTION

HIV / AIDS affects 0.5% of the world population or about 33.3 million people. [1] A large majority of this population resides in developing countries. For example, South Africa accounts for 5.6 million PLHA, while India accounts for about 2.4 to 3 million PLHA [1].

Socialisation is usually an effective medium for the flow of information within a community, and particularly so in developing countries, where localized authenticated information may not be available. However, life as a PLHA is hard. Despite legislations, PLHA have been stigmatized, discriminated against and deprived of basic human rights in the society, workplace, families, and even in some hospitals. PLHA are looked upon as immoral people who deserve their status because of their careless and deviant behaviour. PLHA are left with no choice but to accept this as a way of life, and many try to cut themselves off from the society.

In recent times new opportunities are available in developing countries in terms of mobile phones. India has seen a three-fold increase in the number of mobile phone users, with 267.54 million in 2009 to about 900 million in 2012, covering more than 85% of the population [2]. On the other hand internet users still stand at 100 million in 2012 as compared to 45.3 million in 2009 and reaches on 9% of the population [3]. Worldwide there are about 2.26 billion internet users as compared to 6 billion phone users, showing clearly that internet penetration is far less as compared to mobile phones, especially in the developing nations. Considering that a majority of users in developing countries are likely to have low levels of literacy and technology exposure, a voice based ICT solution using phones offers potential to reach out to a large number of people.

The question we explore in this paper is whether it is possible to help PLHA get engaged in a social network with other PLHA anonymously over the phone, where they can freely share their experiences, and get information and support. We evaluated our concepts by creating what we call "social prototypes".

These prototypes helped us engage the PLHA in the design process, generated a deeper understanding of the possible social dynamics that could emerge amongst the PLHA, and ultimately guided us to create a better design.

In the next section, we enumerate the background issues related to HIV and discuss the need for socialisation amongst PLHA and review the relevant prior work and establish the objectives of our work. Based on our understanding of the context from literature as well as first-hand interviews with PLHA, counsellors and doctors, we conceptualized the features of an initial design of an anonymous social network that could be delivered over an IVRS. This initial design is discussed in section 3. We evaluated this initial design by constructing two social prototypes, which is discussed in section 4. Section 5 discusses the findings from the social prototypes and its implications.

2. BACKGROUND

The Human Immunodeficiency Virus (HIV) spreads through exchange of infected body fluids, mainly during unprotected sexual intercourse, during blood transfusions, by using an infected syringe needle, or from a mother to her baby. HIV attacks the immune system of the infected person. The reason HIV is feared and stigmatized much is that once infected, as of now, there is no way to completely eliminate the virus from the body of the patient. The treatment of HIV consists of Antiretroviral

Therapy (ART), a set of drugs that work by interrupting the process of viral replication. Once a patient is stabilized on an ART regimen, his viral load reduces and immunity improves gradually. In this way, ART has managed to convert HIV from a "virtual death sentence" to a "chronic manageable disease" [4].

However, the virus can build resistance to ART, particularly if the adherence to ART is poor. Several lines of ART drugs have been developed, but the first regimen has the "best chance for a simple regimen with long-term treatment success." [5]. Hence, it is highly desirable that once a patient is initiated and stabilized on ART, he should take his pills regularly. PLHA are counselled about potential side effects and the importance of adherence before initiation on ART.

In the Indian context, some counsellors have faced problems in making PLHAs from rural regions take HIV seriously, and improve adherence to ART.

"For them it is just a like a prolonged fever, they do not understand the ill effects of not adhering to medicines" [Senior Counsellor, Personal Communication]. Recent studies from India report that while many efforts are being made to provide information and support to PLHA by government and non-government bodies, a lot more still needs to be done [6]. Digital technologies have a significant potential in the current context. Technology could be used to speed up clinical operations, to help PLHA maintain health records, to plan their finances better, to support counselling efforts, to help PLHA be more adherent, and in developing a conceptual understanding of HIV and its treatment [6].

There have been several efforts to use technology, both computers as well as mobile phones in HIV treatment, particularly in resource-rich countries. [7] [8] [9] [10]. However, mixed opinions were expressed about the potential of technology interventions in developing countries, mainly due to cost apprehensions [11]. As phone penetration improved though, authors have become more optimistic. Two pilot experiments in Uganda and Kenya report that using phones for communication between PLHA, primary health workers, and the clinic staff improved adherence and gave a feeling to the PLHA that "someone cares" [12]. Project Masiluleke in South Africa reports increased calls to the HIV helpline after they sent SMSs to a large number of people [13]. Cell Life uses mobile phones for mobile data collection, and sending messages for HIV prevention, positive living, linkages to clinics, text counselling, and supporting ART in South Africa [14]. TAMA is an IVRS based product that gives reminders at pill times, provides remedies for common symptoms and provides health tips to PLHA in India [15]. A phone-based broadcasting system for urban sex workers in Bangalore provides broadcast information such as microfinance reminders, medical test reminders or advertisements about computer training camps [16].

In parallel, there have been other community-based issues that are being dealt with the use of ICTs, like AIR (Advancement through Interactive Radio) was introduced to address the empowerment issues of women in Sub-Saharan Africa [17]. In India, Gram Vaani is another step towards development of community, and empowering people by using interactive radios through phones [18]. It enables people to communicate by leaving and receiving messages about issues in Jharkhand, also giving information and bringing awareness to the community.

2.1 Social Networking among PLHA

While most technology interventions for PLHA discussed above do consider socio-cultural aspects and deal with issues such as trust, power distance and emotional support, there have been no efforts to put together a technology-mediated system for peer-to-peer social networking among PLHA. Given the stigma and social taboos associated with HIV, and given that many in the targeted user group are less educated, financially deprived, and from a vulnerable section of the society, it would indeed be challenging to put together such a system and earn trust in it from the PLHA.

PLHA in India socialize little, for several reasons [6]. For example, PLHA face difficulty in locating a good HIV clinic because it is an embarrassing question to ask an acquaintance. Some PLHA avoid social functions to maintain ART times. Others avoid it because socialisation often involves expenses, and PLHA have a higher than usual financial stress. Depression, fear, stigma, discrimination, and 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.

The closest part of the society to an individual is his family. Family support in all its forms, economic, emotional, as well as practical (such as pill-time reminders), helps a lot in any illness, and particularly in HIV. Those PLHA who have managed to disclose to their family members and earn their support benefit a lot. When family members support and care for them, PLHA eventually accept their new way of life and deal with their condition with hope and confidence. On the other hand, disclosure (both planned and accidental) has led to breaking up of families, and this is what PLHA seem to fear the most and postpone disclosure [6].

Fear of disownment and denial, prevents many people from disclosing to their family. Fighting the illness alone leads to depression, isolation, and adverse effects on their health. It results in lack of planning, creates obstacles in the treatment and may put the family members at risk of HIV infection.

PLHA can potentially benefit a lot from socialisation. In developing countries, and particularly in India, socialisation is an important way by which information flows in the society. People make several decisions in

their life by asking someone else in their social network. Be it mundane day-to-day activities such as way-finding, a critical financial decision such as buying a house, or something that could affect one's life such as selecting a spouse, one's social network of family, relatives and friends plays a crucial role.

PLHA do have a lot to share amongst themselves, and someone in a similar situation as oneself is perhaps the most convincing source of information. Some PLHA use simple, yet interesting changes to their lifestyle for improving ART adherence or to integrate it in their lives [6]. On the other hand, sex workers choose to ignore simple tips such as carrying condoms along with them due to fear of accidental disclosure (either of their HIV status or their profession itself) [19].

Informal socialisation among PLHA seems to be happening in some contexts where it is possible to overcome the stigma with the assurance of anonymity. Those who are new to the ART medication find the advice from experienced PLHA invaluable and the most believable [6].

There have been several efforts to bring PLHA together as a community. In some cities in India, formal positive networks of PLHA and support groups exist. Through their local HIV clinics or ART centres there are face to face community gatherings every month where PLHA are free to share their thoughts and opinions in the presence of a moderator. Relevant topics are chosen for every meeting, and discussions are conducted by a moderator. This connects PLHA with people like them, which eases their burden and encourages them to interact. "When I share my problems with another PLHA I know I am not fighting HIV alone" [PLHA, Personal Communication]. The activities of these networks seem to be growing and their members benefiting [6].

Unfortunately, the reach of such face- to-face socialisation is limited and many PLHA cannot and do not socialize in this manner. The fear of disclosure is too strong and the PLHA are unable to overcome it. For People Living with HIV, this may be manifested in feelings of shame, self-blame, and worthlessness, which, combined with feelings of being isolated from society, can lead to depression, self-imposed withdrawal and even suicidal feelings. [20] They lose out on information relevant to HIV like timely advice, treatment and many other services. "An unchallenged culture of silence can only exacerbate the AIDS epidemics and increases confusion, denial and stigma" [21].

2.2 The Objective
Anonymous socialisation can potentially benefit PLHA by enabling them to interact with peers to exchange information and the much needed emotional support. The objective of this research is to explore the potential of such "anonymous socialisation" and to understand the design requirements and the constraints under which such a system would operate.

3. INITIAL DESIGN OF SANGAM
We conducted interviews with 4 PLHA, 4 counsellors and 11 doctors in Mumbai. The initial interviews were conducted in MDACS (Mumbai District AIDS Control Society) where we interacted with 2 PLHA and 4 counsellors. The PLHA were a concordant (both HIV positive) couple with no children. The husband was on ART since ten years and his wife was still a non-ART PLHA. We also visited a private HIV clinic and conducted interviews with both ART and non- Art PLHA, men and women. The Doctors we interviewed included HIV specialists, TB and lung specialists, a gynaecologist, general physicians, a dentist, two psychiatrists and a clinical psychologist.

Doctors reported that 'trust' is one thing that lacks within the HIV community at various levels. For instance, a person who gets himself checked for HIV and turns out to be positive, gets himself rechecked at another clinic, not once but several times. Out of fear of the society, many people go to other cities to get themselves tested.

HIV specialists had very diverse points of view. While some felt their patients are happy and are not in denial or isolation, few feel socialization lacks in most HIV communities and they do look forward to communicate and share their feelings. An HIV specialist told us that one of his patients was in denial for more than 16 years and he could still not make her accept that she is a victim of HIV, which he believes can be handled well by a PLHA who has been through the same situation in the past.

3.1 Goals, Opportunities and Constraints
Based on our understanding of the context of the socialisation and information needs of the PLHA from literature and interviews, we identified the most important goals, opportunities and constraints for our system. Potentially a socialisation product can help the flow of right information to the right person. It should not propagate myths or misunderstandings. Information needs to be authenticated and trustworthy.

We identified two main constraints for our system. Firstly, there is a need for the PLHA to retain anonymity and avoid accidental, unwanted disclosure in his / her social circles, including family, friends, neighbours and employers. Secondly, we did not want our system to be a forum for online dating or matchmaking. Coincidentally, these two constraints seem to be against the very nature of typical social networks in other contexts.

3.2 Interactive Radio
We propose an 'Interactive Radio' (fig. 1) that will work as a social network on phones. We call this system "Sangam".
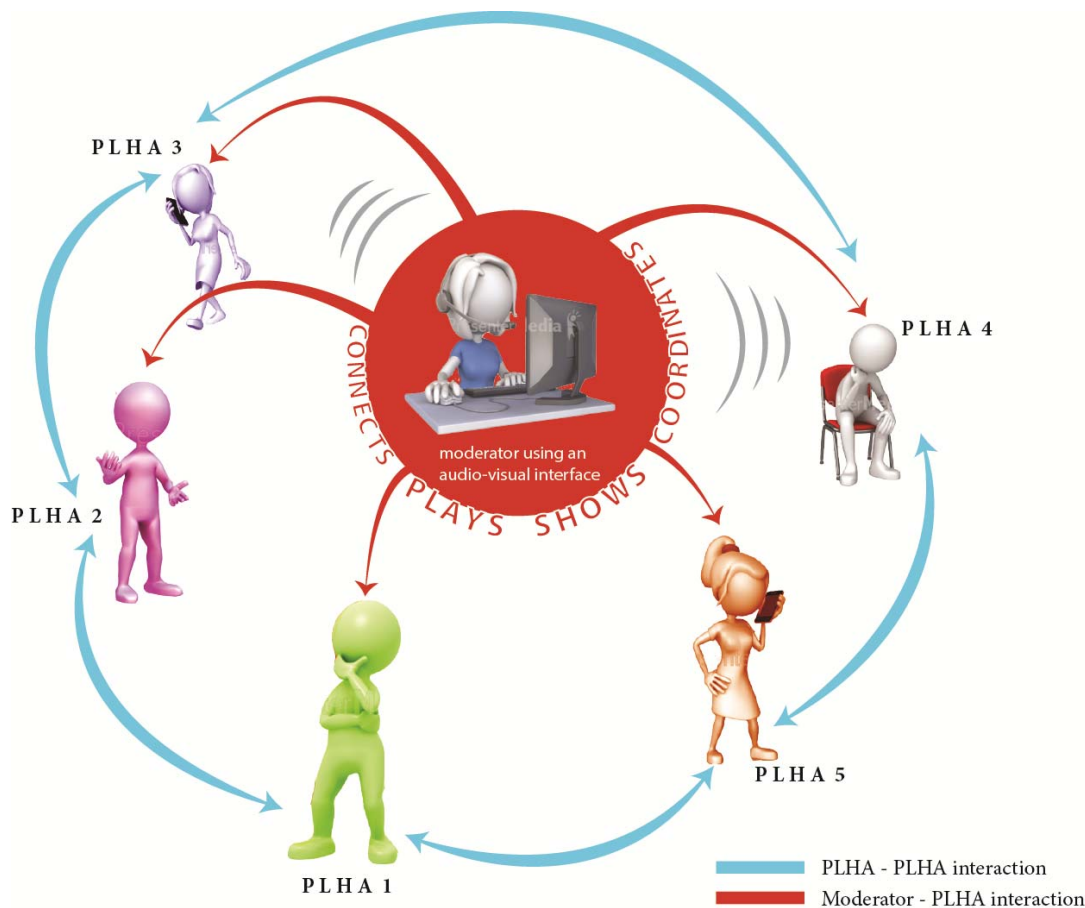
Fig 1. Structure of Sangam; Moderator uses an audio- visual interface to connect PLHA. The PLHA listen to the radio programs over the phone and can get connected to other PLHA by a conference call.

Radio is a familiar concept even amongst low literate groups. However, a radio is a broadcast medium and can be heard only as per a pre-determined schedule. Further, running a 24x7 radio channel may require extensive budget, and an "HIV radio channel" may be too big a step to begin with.

With an interactive radio we aim at providing the users with shows that could either be live or pre-recorded, that the PLHA can listen to in their free time. The concept could be deployed using an IVRS, which is accessible from even the most basic phones. An interactive radio need not have content 24 hours of the day – just an hour of programming for each day would be more than enough to sustain interest among the small community of PLHA. It is a platform where they can interact with other PLHA, post questions, receive answers, get regular personalized updates based on specific needs, and get connected to other HIV networks.

As shown in fig. 1, the radio will have a moderator who will act as the central link to connect PLHAs with each other. He / she co-ordinates discussions, answers queries and ensures a degree of moderation and authentication of information. In addition to the voice channel, the moderator also has a visual interface to control the flow of the session. The moderator could be a counsellor, a social worker, outreach worker, a senior PLHA, or any other person with sufficient knowledge and understanding of HIV.

The following kinds of information could be potentially handled over an interactive radio.

Helpline and directory: It directs and guides PLHA with contact information about HIV clinics, ART centres, counsellors, drop- in centres, NGOs, camps and events.

Financial advice: It assists PLHA to find organizations or individuals to give them financial support for their treatment.

Disclosure to family: It advises and helps PLHA in disclosure to family. It advises family members to help and support a PLHA.

Employment: It helps PLHA get information about their rights, get legal aid, in case of discrimination at work, and find alternative opportunities for employment.

Medical and lifestyle: It hives information about lifestyle improvement and home remedies or common problems.

Nutrition: It provides professional diet and nutrition information localized for each community.

Children: It discusses issues about PLHA couples planning to have children, or about bringing up children in a PLHA family.

3.3 Expert Shows

We consolidated these services with different kind of programs to be given to our callers. We framed few program categories into which these services will be segregated: Expert shows, Chat room, Offline Question and Answer Sessions.

Each day, a topic would be selected and an expert (such as a HIV specialist Doctor, a counsellor, a nutritionist or a legal expert) will be invited to give advice and tips to callers. The session would be conducted by a moderator, who would initiate the discussion by asking a series of questions of common interest. Information would be provided in a conversational manner.

The PLHA may listen to the expert show live. During the show, the moderator can view the list of PLHA who have tuned in to the show. During the show, the PLHA would also have an opportunity to ask questions. To do so, the PLHA should "raise a hand" by pressing a key on the number pad. The moderator is able to see who has raised his hand, and since how long. At an appropriate time, the moderator can put a PLHA online to post his or her questions to the expert. Without such an explicit permission from the moderator, the PLHA cannot just blurt out his question. Once such a discussion is going on between a PLHA and the expert, at her discretion, the moderator may add other PLHA to the same discussion. For example she may announce, "If you want to ask a related question or join in the current discussion, press 4. If you want to ask another question, press 5."

It is possible that the moderator may not be able to take all questions from all the PLHA during a show. However, at the end of the show, each PLHA will have an opportunity to post his / her questions. The moderator would go through the questions, identify common questions among these and post them to the expert in the next part of the show. Often, questions need follow-up questions from the expert before these can be answered. The moderator could invite specific PLHA for the next show and make sure that they are available. The PLHA can also listen to the pre-recorded expert show off-line. Again, they will have an opportunity to ask questions at the end of the session.

After the show, if more than one PLHA has similar queries or suggestions related to queries, the moderator may choose to connect them to each other through a conference call. Their conversation may or may not be aired, depending on the wishes of the PLHA.
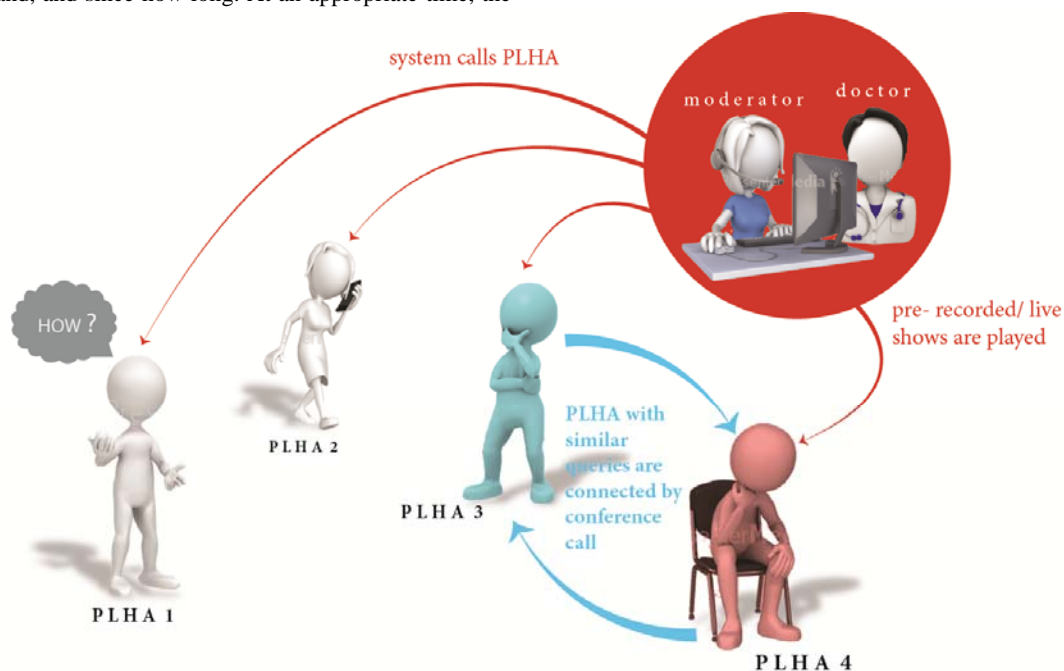
Fig 2. Expert show; Pre-recorded or live programs are played to the listeners and queries are answered by the expert and moderator online. PLHA with similar queries/ concerns are connected through conference call for further interactions.
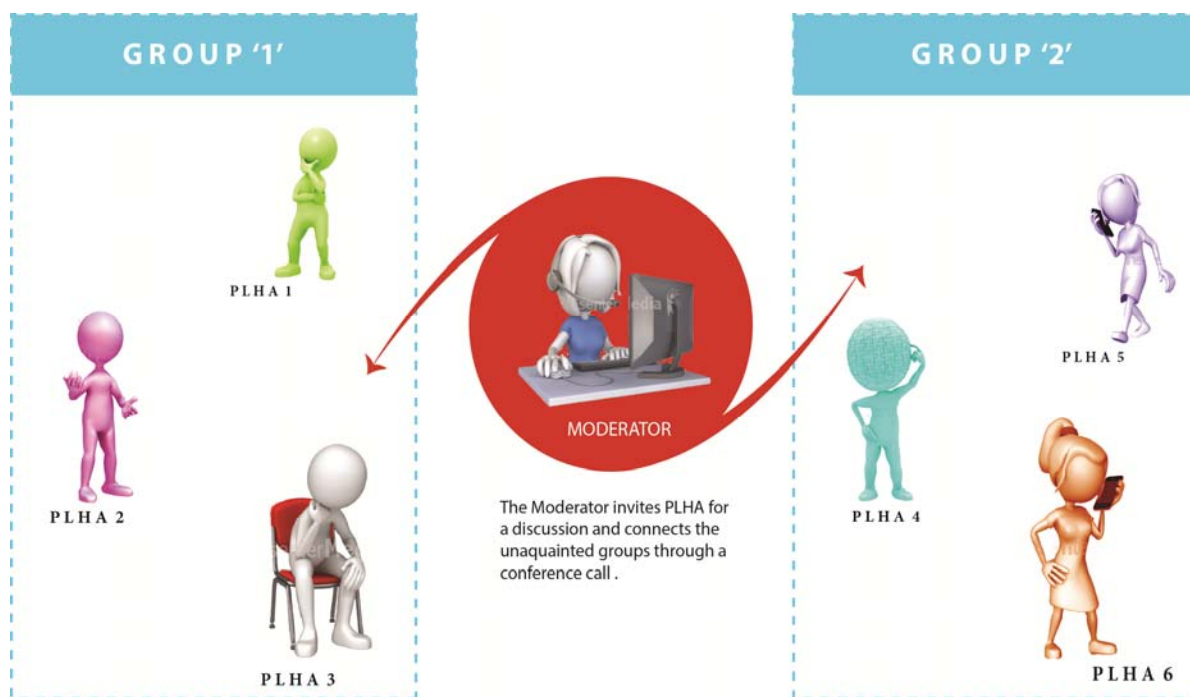
Fig 3. Chat room; The moderator connects two groups of PLHA or more (unacquainted) and invites them to a discussion on any HIV related topic. Open discussions are encouraged to induce interactions and confidentiality is maintained throughout the sessions.

3.4 Chat Room

While an expert show is a discussion with an expert, a Chat Room (on air) is where a discussion happens among a group of like- minded people. In this program, many PLHA come together at a time and have a conference call to discuss a topic of mutual interest. During the interviews, it was observed that PLHA love listening to stories of other PLHA and also to share their own experiences. Hearing about others' experiences and knowing that they are not alone in their struggle reduces mental stress and motivates them. The aim of this program is to have dynamic peer-to-peer interaction that will lead to sharing of experiences and knowledge among the PLHA.

Before a chat room is assembled, a like-minded group of 8-10 people is constituted. This would be done either by the HIV clinic, an NGO, or a positive network where the PLHA has signed up. Constituting a like-minded group that will interact and support each other can be a challenging task in the context of a diverse country such as India, as it requires the matching of not only demographic elements such as language, age, and experience with HIV and ART, but also social aspects such as gender, attitude, education and income group. A group too diverse may not gel together and may not produce the desired socialisation.

The group is assigned a moderator and is assigned a mutually convenient time when the group would get together in the chat session. (for example, on each Monday, at 7 pm). At the appointed time, the moderator will call the PLHA and invite them to the chat session.

The topic for every chat session will be pre-determined, but occasionally, there would open sessions as well.

The moderator may start the session by asking a few basic questions to trigger the conversation. The moderator could narrate a related real-life story that may be inspiring or thought provoking. Next the moderator may invite comments or suggestions from others or ask them to narrate a similar incident in their own life. At the end, the moderator could summarize the lessons learnt during the session. This would be followed by announcements if any, including the topic of the next session.

During the interaction the identity of the caller will be kept confidential. They may be identified by a code or by a pseudo name.

Maintaining decorum in a chat session is critical. At the same time it is important to trigger spontaneous conversation. In real life discussions, members take many visual cues from each other to decide upon turn-taking. But in a voice-only medium this is a challenge as visual feedback is absent. Social structure within the group also determines who gets a preference to speak at what time during the conversation. However, since the group is otherwise anonymous, social stature may play a smaller role, at least in the beginning when the group is new. Therefore turn-taking is a difficult task. On the other hand, enforcing too strict a protocol on turn-taking would not lead to a spontaneous chat session.

To overcome this challenge, a moderation strategy different from the expert show is used in the chat room.

By default, each participant is allowed to speak. The participants will be instructed in the beginning of the session about turn-taking. During the session, if two people start saying something simultaneously, and neither of them withdraws in an acceptable while, the moderator may temporarily mute one of them at her discretion. A particular audio beep would be played for only that person at such time, giving feedback to the person that he or she has been muted. When the moderator would want to encourage a particular person to speak, the moderator may either indicate so verbally or could use another targeted beep.

3.5 Offline Questions Answer Sessions

A third mode of interaction was off-line interaction. Any questions that are left unanswered at the end of an expert show, or any other questions that may require disclosure of personal data could be answered in the off-line mode. The advantage in an offline conversation is that it can be conducted in a controlled manner. This is also useful if the expert needs to refer to some information that is not available during the show.

The moderator's interface shows a list of such pending questions. She would hear the question and may choose to give the answer herself or may ask the question by calling up an expert. This answer will be recorded (Figure 4). The recorded answer will be initially accessible only to the PLHA who asked the question. After he gets the answer, the user has the option to make the question and the answer public (within the system) or to leave it private.

If the question and answer are marked public, the moderator will categorize the question and the answer appropriately. At times, she may also consolidate similar questions, and if required re-record such questions. She may also insert "links" to other related material within the system (such as an expert show). All PLHA have the option to browse publicly archived questions and answers by category.

4. THE SOCIAL PROTOTYPE

While there could be multiple ways to evaluate a new product, it is clear that a typical usability evaluation that tests whether users are able to use the product, how much time they take to complete tasks, or how many errors do they make while doing so, would fall short of actually evaluating the design intent behind Sangam.

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 sign up for using Sangam? Would they be willing to speak? Would they share their personal stories? Would they ask relevant questions? Are the types of controls planned for the moderator appropriate and adequate? The key question we ask is: "How can we get data about realistic social responses without actually constructing such a system?" Further, only to an extent can one visualize all the scenarios of how a social network might work. A social product needs to evolve along with its community. So what could be the future directions in which Sangam could evolve?

Considering our limitations and in response to these questions, we chose to create what we call as a "social prototype". *We define a social prototype as a prototype that is deployed as close to the actual social context as possible in order to gain insights about the effect that the product may have on socialisation.* We evaluated this concept amongst a group of HIV positive migrants living in Mumbai.
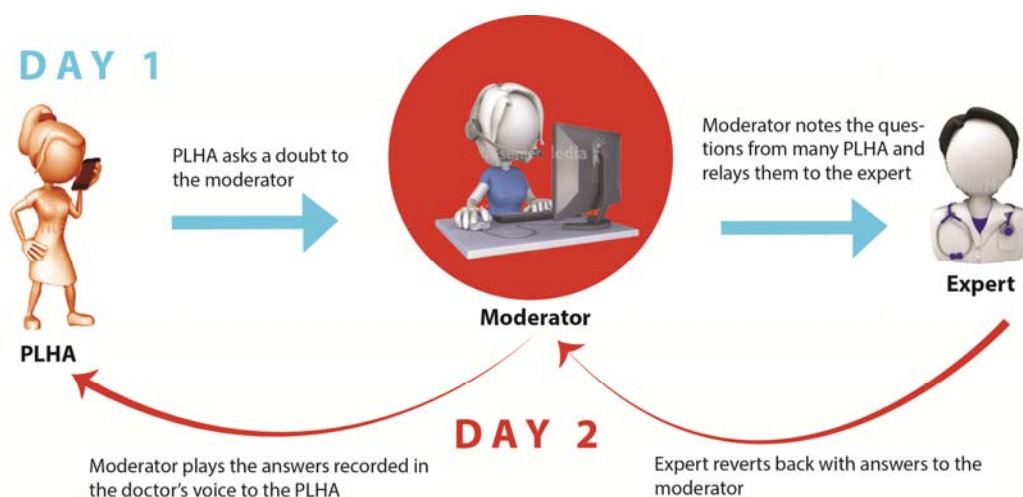

Fig 4. Offline Question and Answer session; If a PLHA does not get an opportunity to speak to an expert on air, or if there is a confidential matter to be discussed, he/ she can leave a message with the moderator which is then directed to the expert to be attended to. The PLHA is given the answer at a later period by the moderator and the cycle can continue for further discussion.

4.1 Expert Show and Offline Q and A

This social prototype was an experiment to understand how an offline conversation might perform in a real life situation with relatively less tech-savvy PLHA. This prototype was carried out across a period of four days. We used conference calling to implement our idea of multiple people participating in a live session.

We collaborated with experts, including a nutritionist, a HIV counsellor and social worker and a HIV doctor to create relevant scripts for the content of a nutrition-based programme.

We scripted four nutrition-based modules:

- General tips
- Nutrition for pregnancy
- Quick Bites
- Frequently asked questions

Each module was designed in a manner that were in a conversational format (between the expert and the moderator) rather than a one way lecture or advice by the expert, which may become saturating for the listener. Information given in a conversation would be more engaging and casual in approach. The duration of all the modules was 4-7 minutes each.

The most interesting program of all was Quick Bites. Since we were targeting this prototype to PLHAs residing in Mumbai, we assumed that they are running very busy lives and often tend to neglect their food habits and health in the process. Quick Bites is a program which aims at providing our listeners with quick recipes that take very less time for preparation but are nutritious at the same time. We also considered that our target belongs to the low-income strata of the society, and worked out the ingredients that will be used by them on a daily basis, are inexpensive, and easily available in the market. Each of these programs were translated from English to Hindi, and then recorded in the voices of the moderator and the nutritionist.

The first experiment was done with an existing positive network – a group of 10 male PLHA and 4 women PLHA who were migrants to Mumbai (group A). Being an exploratory method for evaluation of the social network, we considered involving PLHA who were acquainted with each other during the initial stages of the prototype. (Later prototypes involve unacquainted group interactions that would test the effects of total anonymity amongst PLHA.) These participants belonged to the lower income group, the men usually working as watchmen or cooks and waiters in small restaurants. The women are either housewives or work as part-time maid servants in the nearby localities. Some of the users were co-located and joined the session on a shared phone on speaker phone, while some joined individually. All participants in this experiment knew each other.

We tried to imitate the system as it would work in a real life scenario. The recorded programs were played from the moderator's end, and the PLHA were in their respective places (either at work or at home). They were called one by one and put on a conference call. One of the pre-recorded modules of health tips were played to them for about 7 minutes. After that, the moderator asked if they could comprehend the content of the program.

They all agreed and said that it was very relevant to them. Some of them were hesitant to speak initially, while one or two of them promptly started asking questions. For example, one of them (P) asked about when and how ART is started for PLHA. The questions were recorded and the PLHA were assured that they would be answered the following day.

The questions were relayed to the doctor and we recorded the answers in his voice. The next day we called each PLHA and played the answer given by the Doctor. The PLHA P had a further query regarding ART itself – asking how he should take the ART pills and how could he remember it easily. We repeated the process and gave him the answer the following day.

After hearing the answer, P wished to ask the doctor another question. He wanted to know if it was OK for him and his wife to conceive a child. To this, the Doctor replied that as this matter was sensitive and complicated, and P should discuss the matter personally with the doctor. P was not completely satisfied to hear this response.

To see how this session might work in a different context with a different set of people we played these health tips to a group of three women who are HIV positive, of which only one of them was on ART for more than 4 years. On listening to the health tips Group B was contended with the program and did not have any questions or suggestions.

4.2 Chat session

To understand how people unknown to each other might interact in a live session over the phone, we conducted our second social prototype. Here we chose 7 people from the earlier two groups as participants. We chose 'Quick Bites' as it could be of common interest to both groups and would probably trigger a conversation.

The moderator called people from both the groups. To start with, the moderator asked each of them to introduce themselves. Most PLHA used their (real) first names to introduce themselves. During the recruitment, a particular PLHA was concerned about revealing his identity. He was assured that he need not reveal his real name or identity. However, during the prototype session, he voluntarily introduced himself with his real first name.

The moderator began by asking simple questions about their routine and food habits. Each participant shared their lifestyle and food habits in brief. The moderator then asked them if they would like to listen to some quick recipes that could help them in their daily routine and played the quick bites program (of about 4.5 minutes).

After the program, the PLHA had mixed feedback. The women from the Group B were happy with the tips and they were ready to experiment with the recipes. Some of the male migrants from Group A said that though these were good tips, they felt it was not possible to try the recipes given the conditions they live in. One of them (Q) said that 'he stays in a rental house with many other people and so he does not get to cook anything for himself'.

To this, a woman R (from Group B) gave some additional tips that he could use despite his problems. She suggested that he could make a mixture of multiple *dals* (pulses) once a week, dissolve one tablespoon of the mixture in milk and have it at any time of the day. He can get the mixture ground in a local grinding shop (*chakki*) and store it, this would save a lot of his time and it is nutritious at the same time.

R seemed to be a person knowledgeable about HIV because she was constantly interacting with peer PLHA being a part-time outreach worker. So, PLHA P asked the moderator if he could ask R the same question that he had asked the doctor earlier. The moderator encouraged the PLHA to discuss the matter, though it was off-topic. P then asked R about his desire to have children. R asked him about his and his wife's health status. The conversation continued for about fifteen minutes and R told P that they can plan a child if R's wife's CD4 count is above 500, but she should get herself checked before trying to conceive. P was satisfied with R's suggestions.

The PLHA Q who had earlier spoken about food habits, wished to share something more. He said that he has been HIV positive for five years now and he had not disclosed his status to his family. He gave reasons like 'they would get very emotional' and 'there is still not enough knowledge about this disease in his native place' and also that he 'had no idea how to tell it to anyone in the family'.

In the group B, there was an outreach worker T, who also does counselling for the HIV community. She started to converse with Q and told him the importance of disclosure to his family. She explained that disclosure to the family would give him both emotional and financial support. She gave him ideas about how he could disclose to his family. She enquired about who was the closest to him from his family and then advised him to first make him / her understand his situation. If that person is mature, open minded and trusts him, then he / she could help by supporting him and telling about his HIV status to the family. This way, Q realized the importance of disclosure

and was very happy to have shared his thoughts. He mentioned that it was the first time he had openly talked about his problems as he hesitates to discuss it with his friends who are not HIV positive.

5. DISCUSSION

Although it was identified in prior work that there is a need for socialisation, the social prototype re-established the importance for anonymous social interaction amongst PLHA. Peer learning and informal learning has always been very effective and that is clearly seen in these three experiments. PLHA seem to trust and value advice given by other PLHA, sometimes more than the specialists who treat them. The safe environment of Sangam gave the PLHA the assurance and freedom to openly discuss their problems and concerns. During the recruitment, some PLHA were concerned about their identity, if they would have to give their name to be able to use the system. On learning that it is voice based and that they can access it from anywhere, they were pleased and it helped them to be more active participants during the experiments.

By design, all activities in Sangam were moderated. Moderation has several advantages. It ensures that only authenticated information flows within the social network. It reduces the usability barriers by putting human in the loop as the moderator does the technical tasks [refer my paper Mobile Phones and Economic Sustainability - Perspectives from India]. It gives a credible "face" to the network, encourages participation and maintains decorum during the discussion while allowing for anonymity.

From one point of view, moderation could be considered a constraint that limits scalability of Sangam. Moderation is dependent on availability of trained personnel. As the social network becomes larger, moderation may become correspondingly more difficult. However, Sangam could be seen as a more feasible alternative to the face-to-face socialisation being currently attempted through positive networks. Sangam could seed social networking, and if the activities of such a network grow, more experience PLHA could possibly take over from professional moderators.

The real-time cost of implementing such a system in practice would be justified by the fact that a PLHA would have to give more time and effort to a face-to-face interaction than a phone interaction. The cost of a phone conversation would be a lot less than having to physically relocate to interact with another PLHA. Moreover, India having the cheapest airtime costs, it may not be perceived as a problem to have phone interactions occasionally. Also, it would be a step forward for PLHA from being completely isolated individuals of the society to being more active yet 'anonymous' participants in socializing within their community, at the least.

5.1 Problems faced

For many of the users, talking to multiple people at the same time was an unfamiliar concept. Given the medium of phones and conference calling, there were difficulties faced due to the environment they were located in, but with the progress of the prototyping sessions, the PLHA adapted themselves by choosing to be in more comfortable and noiseless areas and thus co- operated.

Since it is a voice based system it was a bit difficult to keep track of the people who were present in the conversation. The moderator had to keep calling out to each of them to be sure of their presence. Also in this case the moderator was familiar with the PLHAs she was interacting with, but in a real life scenario there will be a need to change names to maintain confidentiality. It will take time to adapt to a pseudo identity and respond.

During online conversations, chat sessions are prolonged and it is also difficult to maintain decorum. If there are a large number of people participating, it will become all the more challenging for the moderator to keep track and give turns. In online conversations the discussions became too detailed and time consuming, which may not be feasible in real life settings.

5.2 Expert and Lay, Offline and Online

At times, an expert might hesitate to give an answer in a social forum perhaps because he "knows too much", and knows particularly that there might be many exceptions to a rule. An expert's opinions would always be taken as absolute, unquestioned truth. On the other hand, a lay person would be willing to give the most common answer which would satisfy a peer. The person who asked the question is perhaps only interested in the common answer, so that he can decide whether it is worth perusing the matter with an expert later.

In case of the PLHA P who had enquired about whether he could have a child, the doctor had refused to answer online as it is a sensitive subject and should be discussed after understanding the history of the PLHA in detail, which perhaps the doctor thought was too much to go into in an online forum. The doctor's response was indeed very appropriate, because any concrete answer from a doctor in the context of one PLHA could be possibly misinterpreted by another PLHA. However, the answer did not satisfy P, and being curious, he consulted another PLHA R during the chat session. While R answered the specific question with the most common answer – that yes it is possible for a HIV positive couple to have a non-HIV positive baby under some conditions, fortunately, R was knowledgeable enough to point out that the answer could vary from case to case, and P should really consult the doctor before making a final decision. P was more satisfied with R's answer than that of the doctor's though both suggested the same action.

R had two specific advantages over the doctor. Firstly, R was in a live chat with P, and could ask many follow up questions to R. The doctor was communicating with P in an offline mode, and hence asking too many follow-up questions was not easy offline. Secondly, in a sense, R had the advantage over the doctor that that she was not an expert and was not perceived to be one. Thus, she had the freedom to pass on the most common answer and yet did not have the liability that her answer would be taken as an absolute truth.

This points out that the 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 propelling PLHA to join in and discuss things that they always wanted to, but had not done for years.

These experiments also re-emphasize the role of the moderator in social interaction. Fortunately, R gave a reasonably accurate answer and followed it up with the caveat that P must consult the doctor before trying to conceive. Had R not done so, it would have been the duty of the moderator to do so. These experiments clearly indicate that it is not advisable to have un- moderated peer to peer interaction in such contexts, as the effects of wrong information circulating among the vulnerable population would be very harmful.

5.3 Information Overload

Information is best if it is given and taken in small amounts. Pre-recorded content was particularly perceived to be long in the audio medium. While we played the health tips for little more than seven minutes, some of the participants found the program duration to be long, and could not concentrate towards the end of it. Similarly, when the quick recipes were played (four and a half minutes) some participants reported to have got an overview but did not remember the tips in detail.

It is our sense now that we can avoid information overload if we can provide audio information in nuggets of shorter duration. Tips can be segregated and given one by one or two each day. Closely related subjects can have two tips played together, so that people are able to correlate and remember them better.

The chat sessions are informal and interactive, and hence people may be able to retain more. Thus the duration can be slightly longer depending on the subject of discussion.

In our session, the moderator already knew each PLHA personally and could use her relationship to ask specific questions to individuals in the group. But in real systems, this will not be the case and it may not be possible to call out each person to give them a chance to speak during a

discussion, especially if the number of participants is large.

An alternative method for this problem would be to have an audio response from the system to the caller. With the visual interface, the moderator can see all the PLHA and may indicate to a particular participant that he could speak next. Such an instruction (or an audio beep) could be played only to that listener. The listeners may be instructed in the beginning of the session about this method of taking turns. Similarly, the moderator can block out person from his end, if he/ she is disturbing the decorum of any discussion. The moderator may also have the right to discontinue a conversation and continue it later, in case of time constraints or misbehaviour issues.

6. CONCLUSION

We conceptualised Sangam as an anonymous social networking platform over IVRS for PLHA. We evaluated our concepts with the help of experimental social prototypes.

These experiments reaffirmed the importance of socializing amongst PLHA. The findings help in understanding the requirements of such a system better. The intervention of such a networking platform needs refinement at multiple levels. The content of the radio programs need to be well 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 interaction and not become a one way communication. For the PLHA to be confident and have trust in the system, we should assure them of their confidentiality and anonymity and yet address their needs at a personal level. The system should be simple, customizable and very adaptable to the user, considering that there are a large number of non tech- savvy mobile phone users. It should engage the PLHA strategically using interactive programs, timely advice and updates. This will not only instil a feeling of involvement but also encourage each PLHA to participate and share his / her insights.

Being a voice based system, there is a possibility of people recognizing voices. However it may not be as critical as physical accidental disclosure. An alternative method to deal with this issue is to have voice modulation/ filtering in the IVRS that can help avoid such situations.

There are lessons to be learnt in terms of social prototyping as well. Our experiments teach us that indeed it is possible to put together high fidelity social prototypes using simple, off-the- shelf tools. Social prototypes can help us quickly try out innovative social networking ideas with minimal investments. Such prototypes will help us evaluate the design ideas for their effectiveness in a challenging social setting. The insights learnt from such prototypes helped us quickly understand which ideas

worked, which failed, what the risks are, and how Sangam could be evolved in future.

Future work includes redesigning the social system after taking into account the lessons learnt from the experiments. It will explore more specific social parameters such as age, looks, identity and how these can affect face-to-face and voice-only interactions. It will be interesting to observe how social barriers can be overcome with the help of a voice- based system. This will be followed up by developing a robust product that could be deployed in the field in collaboration with positive networks, NGOs and HIV clinics.

7. Acknowledgements

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