Health 2.0 and User Driven Healthcare:
A Work in Progress

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Anemia is a leading cause of mortality and mortality in the developing world (Tolentino & Friedman, 2007). Myshkin Ingawale (Biosense Technologies, 2012), an engineer, and his team devised a technology ToucHb which estimates the hemoglobin in a non-invasive manner, thereby creating a diagnostic aid which could potentially reduce the number of deaths occurring in rural areas due to undiagnosed Anemia (Baker, 2012).

Myshkin Ingawales's story brought forth a realization in me that engineers have an important role in helping out in rural areas that often lack basic medical facilities.

While organising TEDx Eastern MetropolitanBypass which was a TEDx (TED, 2012a) event around the webcast of TEDxChange (TED, 2012b), our team had to decide on a theme for our TEDx event and we created our theme around "technologies for a healthier world." We started out studying the existing scenario in rural and sub-urban/urban regions and we noted that even if technology is available, there is a dearth of skilled personnel. At our TEDx event, Kaustav Bera's team demonstrated User-Driven Healthcare UDHC. One of the obvious questions around this presentation was, "Will the impact of such an approach to health care be extensive?"

Surprisingly it appeared from the presentation that in spite of a lack of skilled personnel for operating healthcare systems, technology may bridge the void that isolates the people living in rural regions from accessing good healthcare technology.

THE RESPONSIBILITY OF TECHNOLOGY

The primary goal of technology is to make life easier and for that the technology itself has to be user-friendly. Hence, if we focus on making user-friendly technologies, they could even be used by a six year old! Low availability of quality health diagnosis facilities will turn out to be driving force for usage of collaborative systems

We propose a very simple idea similar to the One laptop per child project which aims to empower children by providing them with "low-cost, low-power connected laptops" and involving them in active learning, we could provide low cost tablets to social workers in rural areas, who will in turn collect health data from care-seekers and send them online to a 'user driven' healthcare UDHC network, thereby engaging the community in address-

ing its own healthcare needs (One Laptop per Child Project, 2012). Since mobile network and telecommunication services are available in rural areas, Internet can be accessed via GPRS. At present, in the pilot phase, social workers use conventional computers to send across the information, however hand-held devices would greatly increase the outreach and coverage of the UDHC services.

IMPLEMENTATION

As the Montreal Gazette reported in April 2012, several walk-in clinics Montreal have started sparing patients endless waits by sending a text or an automated voice message when it's almost their turn to see the doctor.

"The patients gain back their freedom. They don't have to wait for four or five hours in a waiting room full of sick people," Sara Michaels, the manager of one clinic, told the newspaper. "Instead, they can take a number, and then they can go out and do their groceries or whatever, and the system will alert them to come back," she added.

In urban and sub-urban India, UDHC can help solve the existing bottleneck condition of rising care-seeker to care-giver ratios. A Sample scenario:

A person 'A' visits doctor 'X' who refers her to doctor 'Y,' who in turn refers her to doctor 'Z.'

Along with that goes the long idle times spent at each clinic, waiting for her turn. Very often, professionals neglect health-checkups for the above reason.

Instead the care-seeker can simply send her issue to the healthcare network of a thousand health professionals(or care-givers), where the network of caregivers unanimously decide the next step in diagnosis and can refer doctor 'Z' directly. Because the whole issue is discussed in a network powered by the Internet, the care-seeker 'A' could even be provided an appointment at Doctor Z, directly!

Even better, the diagnosis can be done online. The care-seeker could be asked to upload medical test results and the network of care-givers would diagnose the problem and solution.

All the above takes place while the person 'A' remains occupied with his professional life!

There is an opportunity in bringing about a paradigm shift in the healthcare system by using technology to conserve resources such as both time and costs. In addition, by providing a secondary tier of structured support, user driven websites provide users with a supplementary decision-making aid which is essential in this era of information overload.

THE URGENT NEED OF HEALTH 2.0 FOR THE YOUTH

Man is least himself when he talks in his own person. Give him a mask and he will tell you the truth -Oscar Wilde

A common scenario prevalent among the urban youth is substance abuse (illegal drugs/alcohol, etc.), engaging in promiscuous behavior, accidents, mental health issues and other psychosocial issues (Chown et al., 2008).

For example, take the challenges faced by a adolescent drug-addict. Firstly, the purchase of drugs is illegal. Hence, those who consume will be hesitant in discussing details about the procurement and use of the drugs. Things get worse when adverse health effects start cropping up. Not many have the courage and perseverance to seek professional help and/or to get themselves rehabilitated. Some wisely decide to consult a physician but foolishly hide the significant details. This leads to incorrect diagnosis. Addressing such health concerns, especially in developing nations where indulging in many of the aforementioned practices is still considered as taboo, would require creating a platform where the youth can communicate their problem without fear of censure.

The previous problem can be solved by getting the care-seekers post their problems and health history online in a dedicated portal where anonymity will be assured.

HEALTH 2.0: A SIBLING OF WEB 2.0?

Health 2.0 can be considered a conglomerate of web 2.0, mash up technology and healthcare.

The main characteristics of mashups are combination, visualization, and aggregation. It is important to make existing data more useful, moreover for personal and professional use. To be able to permanently access the data of other services, mashups are generally client applications or hosted online (Wikipedia, 2012).

ReCaptcha and Wikipedia can be considered a benchmark for massive online collaboration.

ReCaptcha helps in digitalization of books as well as in the obvious use of preventing spam.

Wikipedia on the other hand is a collaboratively built encyclopedia.

Health 2.0 (utilizing web 2.0) is a subset of User Driven healthcare in the sense that User Driven health care comprises Web 1.0, Web 2.0 and other versions of the web in evolution. Figure 1 presents a schematic depiction of the major differences between email based web 1.0 and collaborative web 2.0. In a User Driven Healthcare network, Care-seekers

adding problems and care-givers contributing solutions augmented by Web2.0 can turn the system into a massive encyclopedia of health issues and their corresponding solutions. The massive encyclopedia will have the potential and intelligence to predict what a care-seeker might need. However, care would be taken to strike a balance between algorithm prediction and a medical practitioner's consultation. A medical practitioner might not be able to suggest similar cases from a database of a thousand cases, but an intelligent algorithm will come handy here.

UDHC usage growth is expected to be exponential because higher the usage of the system, stronger the knowledge base grows (UDHC, 2012). The latter shall act as a feedback to the system that may further increase its usage.

TARGET USER GROUPS

The user groups comprise of individuals who are the stakeholders of the healthcare system. Health is a universal right – therefore the users range from patients (both educated and illiterate) to healthcare professionals (physicians, nurses, social workers, allied health profession-

Figure 1. A visual comparison of the traditional email system and a collaborative system (wiki)
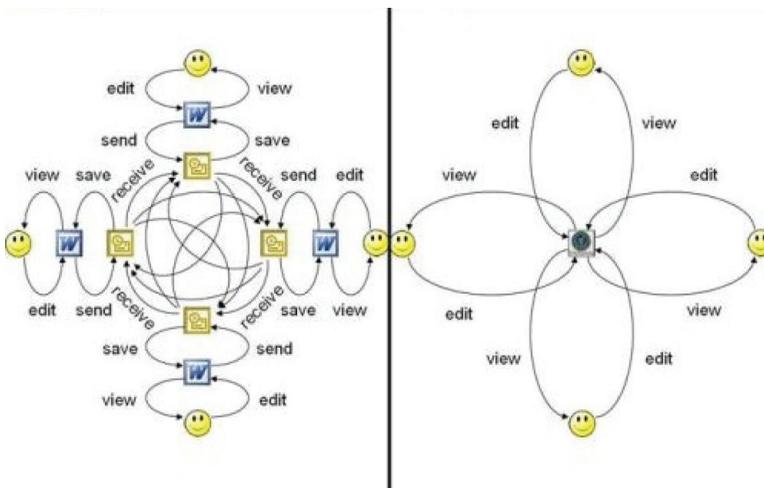
als etc) to students (medical and paramedical), secondary care-givers (such as family members of the patients) and policy makers. Therefore a collaborative interface would need to be simple enough for the lay user to navigate and at the same time, comprehensive enough to provide them various modes of expression (textual, pictographic, voice/video recordings) etc.

User-Driven Health Care – An Overview of Our Implementation in Progress

The technology is a web-based application. Average-power computers (economy/low cost tablets) can be used to access the internet to use the collaborative system we've been working on.

The web-based solution allows care-seekers and social workers to upload care-seeker health issue narratives in the form of rich text supported by images (Figure 2). The interface is being developed in a way so that one can navigate through all the cases in a simulated desktop environment, keeping in mind that there will be users of varying proficiency levels.

The web application being developed has 3 primary display interfaces: INPUT, PROCESS, OUTPUT. The PROCESS is where the hidden-layer discussion takes place. We are developing and designing the application in such a way that the necessity for the user to leave the current page/tab is minimal. The INPUT page displays the care-seeker inputs or narratives. The Process page displays the patient inputs and archived discussions. The OUTPUT page displays the care-seeker inputs and solutions. Another piece of information common to all the pages are the 'list of health cases' (health cases are also referred to as care-seeker inputs).

Initially we failed to accommodate the following in the same visual scope in our website.

1. List of health cases.
2. Details of the selected health case from the list of health cases.

Hence, the initial design a shown in Figure 3 was replaced by the new design as shown in Figure 4 and Figure 5.

From the perspective of data, we are aware that initially the application will not have much

Figure 2. Uploading interface for care-seekers

*Figure 3. The initial interface to browse the health cases*
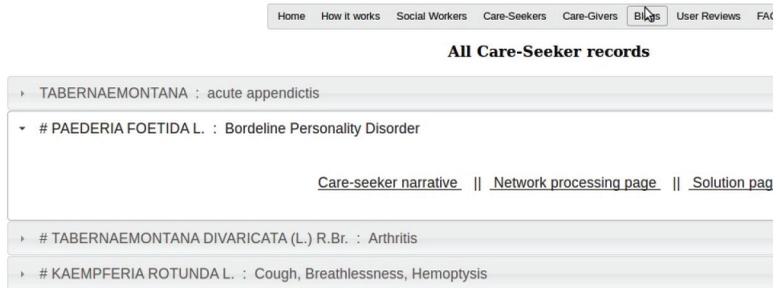
Figure 4. The INPUT page
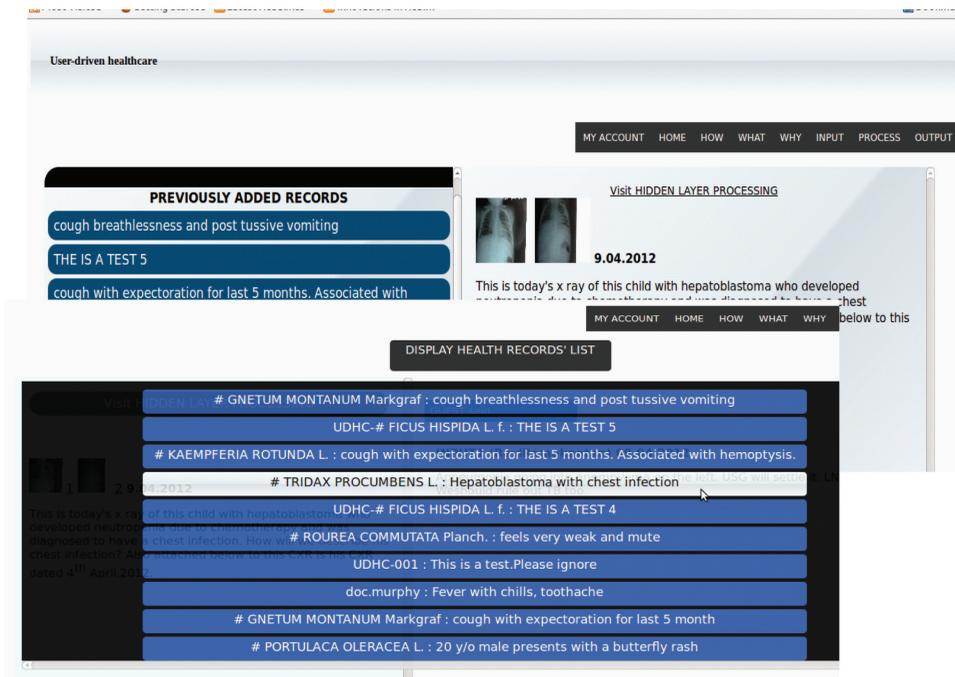
health data. The collaborative platform will be harnessed by health enthusiasts or common people to learn from previously uploaded cases. To do this we have partnered with BMJ to provide us metadata of their health cases (Figure 6), using which we can redirect UDHC users as soon as they upload their health case to the UDHC website such that they can immediately visualize similar health cases in the BMJ Case Reports web-site.

A prediction engine is used that takes the uploaded health case as input and generates links to similar health cases from BMJ Case reports (BMJ, 2012) as output. The prediction engine is implemented as an isolated web-service (along with a dedicated database server for storing indices used in the prediction). This will help in care-givers or health narrative uploaders to go through similar health cases that have been encountered by others. This

Figure 5. The list of health cases are hidden and the health case details and archived discussions are visible in the PROCESS page

Figure 6. The metadata feed from BMJ

prediction engine will run on a separate server to make sure that the overheads due to computation of health case similarity are not borne by the server hosting the UDHC application.

This serves two purposes. Psychologically it helps the care-seeker feel better, by making her realize she is not alone and that a health case similar to hers has been discussed

Figure 7. Sign in access to health information
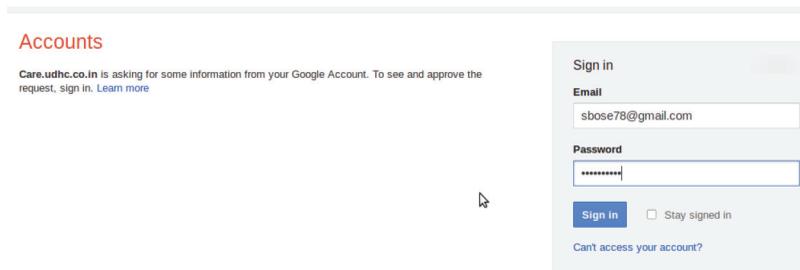
before. Technically, it helps the care-seekers learn more about the possible solutions to their health problem.

In order to ensure patient confidentiality, we ensure that care seekers do not use their own names,, instead they are assigned a botanical name. For other users, a separate registration is not required - one would be asked to login using their Google (Google Developers, 2012) or Yahoo (2012) account (Figure 7).

CONCLUSION

In the current era of Health 2.0, the web interface is a powerful tool which bridges across geographical, economic, socio-cultural and intellectual divides to connect various user groups together. While some schools of thought might view this as a depersonalization of medical care – telemedicine could those in resource-poor areas get access to medical expertise which might not be available to them otherwise.

There are barriers to be addressed and ironed out before such a system is implemented such as patient privacy issues, the identification and accurate triaging of health concerns over a web interface, technological challenges, overcoming linguistic diversity and communication barriers, training ground personnel etc. However by engaging the community in the healthcare system via user driven networks, the stakeholders in the system can collaboratively work towards proactive solutions which ad-

dress the deficits and defects which plaque the infrastructure (Kazley et al., 2012).

The scope and widespread application of user driven networks would depend upon the active participation of the individual user groups as well as the redressal of the barriers which preclude its adaptation. The malleability of such networks, largely due to the omnipresent web interface, allows them to be developed in a parallel manner at the local and global levels.

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Shoubhik Bose, a Computer Engineer, working in Accenture, is an independent researcher in the field of collaborative healthcare technologies. He organised a TEDx conference in Kolkata with a team of Engineering students in April 2012 as part of a global dialogue on UN MDGs. He is a passionate software developer working with algorithms, web and cloud-based technologies and social applications. He has co-authored a paper on "Service Crawling the Cloud" as part of his research in cloud crawling. He blogs and enjoys programming autonomous robots. Apart from his current on-going work on web-based User-driven healthcare solution, he is currently working on integrated healthcare and social media applications for developing solutions to socio-health issues, voluntarily with a diverse team of technologists at Mission Arogya.