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TITLE

Digital Gods
The making of a medical fact for rural diagnostic software

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Short Bio

Dr. Payal Arora is an Assistant Professor in International Communication and Media at Erasmus University in the Netherlands. Her expertise lies in social computing, informatics, new media, ethnography, and international development. Her recent work has been published in several peer-reviewed scholarly journals including *Information Communication and Ethics in Society* (ICES), *International Journal of Cultural Studies* (IJCS), *Education Philosophy and Theory Journal* (EPTJ), *Association for Academic Computing and Education Journal* (AAACE), *International Journal of Education & Development using ICT* and the like. Her upcoming book, Dot Com Mantra: Social Computing in Central Himalayas entails an exploration of social practice with computers and the Net in Almora, India, including the analysis of key ICT initiatives at the ground level. She earned her Doctorate in Language, Literacy and Technology from Columbia University, Teachers College in New York, a Masters degree in International Policy from Harvard University, and a Teaching Certificate from the University of Cambridge. For more details, please check her website: www.payalarora.com

Digital Gods: The making of a medical fact for rural diagnostic software

Abstract

Chronic shortage of doctors in rural India seriously impacts the quality of healthcare available to villagers. In recent years, there has been considerable excitement in digital diagnostics as a possible answer to this situation by allowing non-doctors to diagnose and treat patients. This paper focuses on one such diagnostic tool that has gained serious traction amongst transnational health foundations and State governments alike. Here, the focus is on the customization and localization of this software through a pilot study in Central Himalayas. A baseline survey and extensive interviews are conducted for categorization and population of health data content. This entailed the analyzing of the segmentation and transfer of health information of disease history and symptoms from the patient to the software as well as situating this study in the larger understanding of the healthcare system in this community. In doing so, this paper argues that much of such health information is difficult to categorize and sufficiently vague to provide for confident diagnostics. Further, the data population of the treatment segment is deeply political and socio-cultural. Thereby, this paper problematizes the innate assumption underlying the design of such software- that being that there is one way to diagnose and treat patients based on pure information.

Keywords: medical diagnostics, social computing, digital, information management, quality healthcare, doctors, rural India

Introduction

Doctors are often seen to play God, converting probability into certainty. This is even more so in regions where the dearth of resources and poor training compels medical practitioners to make health decisions based on fragmented information flows. It is no wonder then that medical misdiagnosis is a common fact amongst rural and poor populations, resulting in the worsening of an already desperate situation. Also, sophisticated health management systems, when present, seem at large to serve primarily the purpose of policy making and control. More specifically, in the case of India, there exists an impressive seamless flow of health information

of citizens, from bottom to top, aggregated for government officials. This surveying of health can be attributed to the post-colonial legacy where information has been viewed for the most part as a tool of national surveillance instead of possible tools for reflective learning and change for medical efficacy at *all* levels in the healthcare system.

While no doubt macro-surveillance has its place in healthcare in detecting possible epidemics and health shifts of entire groups and peoples by the State, an equally compelling case can be made for access to medical information at the micro level. Healthcare workers and practitioners can benefit greatly in gaining a bird's eye view of healthcare information of their patients by having the patient's medical histories and socio-environmental trends that could aid them in medical diagnosis and treatment. Responding to such needs, new technologies provide opportunities for new strategies of healthcare. The digitalization of healthcare information has become globally widespread. In India itself, ambitious efforts to digitalize health information is underway.

Currently, there is excitement of extending these tools to allow for better diagnostic accuracy and treatment. This paper focuses on the pioneering and developing of one such diagnostic software, developed by an American medical company, claiming to be one of the most comprehensible medical knowledge management databases and the most effective diagnostic tool in developing countries. It has recently gained serious traction amongst some of the top international healthcare foundations as a key tool for digital diagnostics in developing countries. Its stated unique advantages lie in its intuitively interactive and decision support ability for accurate diagnosis and treatment by non-doctors as well as its customized database for rural diseases. This tool is meant to encompass not just medical information management but also its evaluative capacity of symptoms and other medical information to reach an accurate

diagnosis. In other words, this tool strives to be the answer to the lack of doctors in rural areas in developing countries, allowing a non-physician to diagnose and treat patients.

In particular, this paper delves into the first live pilot testing of this tool in rural India, revealing some critical issues in healthcare information management. More specifically, the focus here is on how medical information is collected and populated as part of the Phase 1 deployment of this software. Problematics of standardization and localization comes to the fore. In doing so, this paper argues for a reevaluation of the claims of digitalization of mass healthcare information for diagnosis and treatment. This is timely as massive investment into such tools is being considered amongst transnational health foundations and State governments worldwide. While there is much potential for this tool as a means to guided learning and upgrading the skills of healthcare workers, such tools continue to be “non” intuitive and possibly dangerous if used by non-physicians.

Socializing (with) the Geeks?

It's not easy to humble technology. For decades, software has been created in the laboratory with little interaction between the users and designers. If at all, users are often beckoned as guinea pigs, testing their adaptability and responsiveness so as to tweak software to suit their needs and abilities (Davis, 1989; Goodhue, 1995). Else, user groups are identified, propelling the creation of particular software products. In recent times, there appears to be a paradigm shift as markets expand cross-culturally and internationally, and users are revealed to be deeply complex and dynamically changing in their needs (von Hippel & Katz, 2002). The age of digital customization seems to have arrived. Users and their contexts appear inseparable.

In the process of knowledge creation, users and their contexts continue to be largely untapped (Rogers, 2003). Knowledge can be characterized as a proportional blend of that which is factual and context-free as well as that which is embedded within the context of the user (Tornatzky & Fleischer, 1990). Or put another way, knowledge creation is the intersection and interplay of “tacit knowledge-that which is personal, context-specific, and difficult to articulate and communicate- and explicit knowledge-that which can be transmitted from one source to another in a systematic manner and that which is relatively objective” (Nambisan, Agarwal, & Tanniru, 1999, p. 369). Thereby, in the production of information technology software, it can be argued that the logic of reasoning employed in the design of software navigation is contingent on users and their contexts. “Intuitiveness” in the usage of information tools can be seen as the degree to which context is translated and manifested in the design of software.

This extends to the understanding of usage of digital information that requires an “interdisciplinary study of the design, uses and consequences of information technologies that takes into account their interaction with institutional and cultural contexts” (Kling, 2007, p. 205). In other words, this “social computing” encourages dialogue between software designers and users across different phases of product development. The design of effective information systems requires an understanding of what constitutes as “better” and “easy” technologies in relation to the user’s context. The confidence in predicting socio-economic outcomes from particular technologies, however well designed, are slowly dissipating; after all, “the analytical failure of technological determinism is one of the interesting and durable findings from social informatics research” (p. 208). Thereby, the interplay of laboratory designed tools with live and targeted environments requires a nuanced and multi-perspective approach. Statistics are

compelled to partner with qualitative means if we are to genuinely investigate techno-social efficacy.

The stakes are raised substantively when it comes to the creation and usage of medical information to guide in digital diagnosis and treatment. Healthcare is essentially an important public good. Here, both public and private interests come to play when involving information technologies with healthcare (Stienstra & Watzke, 2007). There is no doubt however that to diagnose and treat patients with the aid of medical software, it is critical to customize and indigenize medical information with the patient's specific medical symptoms, history and locality. This is no small feat, a challenge which has barely begun to reveal itself. Balancing "special" needs and interpretations of the user with a "universal" design is at the heart of such an endeavor.

E-Governance and Healthcare in India

Healthcare in India is in crisis. The Third National Family Health Survey¹ revealed that 46 percent of all Indian children are malnourished. The infant mortality rate, though improving, is still high and much worse than other developing countries. This is complicated by the fact that less than half of all Indian women receive care after childbirth and only 40 percent give birth in hospitals or medical centers. The percentage of women and children in India who are anemic had increased to 56 percent and 79 percent respectively since the late 1990s. The number of people living with HIV/AIDS in India is estimated to be 5.206 million, the second largest in the world.

Currently, there is broad commitment globally to computerize national healthcare information (Madon, Sundeep, & Sudan, 2007). Part of the Millennium Development Goals², this effort is seen as crucial to manage and deliver improved public healthcare services. In India, such commitments are reflected in the ambitious multi-billion dollar National Rural Health

Mission³ (NRHM) healthcare plan launched by the Government of India in April, 2005, to provide Medicare facilities in villages. However, in spite of significant investments, improvements are slow and intermittent in rural healthcare in India. Shortage of doctors in India is one of the most critical barriers to the expansion and quality of healthcare (Ranjan Roy, 2008); against the requirement for 21,490 doctors, there are only 5,910 specialist doctors available at community health centers across the country, and of the 66,059 nurses and midwives needed for the health centers, only 41,313 appointments have been made.

Sadly, most of India's 6.5 lakh rural villages where two-thirds of the population resides, have few other options but to seek for diagnosis from healthcare providers with less than a high school diploma in hand (Ranjan Roy, 2008). After all, 75% of allopathic practitioners reside in cities, leaving space for a crop of unqualified practitioners to serve the rural public. For example, it was found that amongst rural general practitioners, only 29% knew the exact composition of oral dehydration solution (ORS) for diarrhea, an often fatal yet easily preventable malady amongst the poor, with none knowing the right method to prepare the ORS package (Patil, Somasundaram, & Goyal, 2002, p. 2).

The river never runs dry: Flow of Healthcare information

The cliché, “knowledge is power” is experiencing a new lease of life in this Information Age. Since post-colonial independence from the British in 1947, India has been surveying her population on multiple facets including land tenure, health, education, and employment. Yet, much of this information aggregation has imitated the colonial legacy of hierarchical flow from bottom to top for consolidation, policy making and control of State territories and arenas of interest (Cohn, 1996). On the healthcare front, government officials at the district level serve as

“human computers,” bringing together maternity, fertility, mortality and other medical data sources that come through from the monthly updates from the vast and spread out field staff of nurses, midwives, and healthcare volunteers.

The efficiency and streamlining of such data through its manual system is truly impressive and remarkable. For instance, there are 17 registers maintained at the Auxiliary Nurse station alone (ANM’s office) that is regularly updated. The registers include health information on mothers and their children, administrative funds, monetary incentives for “volunteer” *Asha* health workers, child immunizations, antenatal, measles, primary healthcare center (PHC) reports for their doctors, stock registers, family planning, school children and village health indices.

So as we see, this remarkable bureaucracy is no small feat. That said, little of such information has been historically used for diagnosis and treatment. In the last decade however, the Indian government has partnered with transnational health agencies to monitor and track national healthcare information for preventive and curative measures as well as digitalize such efforts for easier modification and cross-department/ State sharing.

***RightChoice*⁴: A novel medical diagnostic software**

RightChoice is a software suite that is designed especially for the healthcare needs of developing countries. It is pioneered and owned by an American private medical software company, backed by significant venture capital funding. Accurate, customized and rapid diagnosis, portable and accessible medical information and informed public healthcare planning and implementation are their key selling points. It claims to be built around the most powerful and “intuitive” engine; it separates itself from the competition by its inference engine that is stated to be extremely efficient, compact, portable, and runs against very large medical databases

encompassing multiple simultaneous medical specialties. It features a shift in medical informatics from simple data gathering to comprehensive systems management, data interpretation and decision support.

The company states that even a minimally trained healthcare worker in a remote clinic can make an “accurate” diagnosis of common and challenging medical conditions and be guided to give effective treatment and advice. This is accomplished by its offline software-mediated intuitively guided interview process, supported by a medical database customized for the region of use. With each patient encounter for diagnosis and treatment, a fully integrated electronic health record is created and the entire database is able to be compiled centrally for the purpose of healthcare planning for monitoring and program evaluation. Its capabilities are as follows: diagnostics, treatment recommendations (only for those diseases which have been “approved” by the medical community as treatable by non-physicians and stabilization techniques by non-physicians), prevention and education, electronic health records, epidemiological and disease monitoring services (monitoring national health programmes and schemes through alert systems), supervision of healthcare workers (electronic flagging for mistreatment) and reference and treatment guide.

Their knowledgebase is created from a modular format which assumes that each disease can be broken down into a description of findings such as symptoms, physical exam, medical history, and laboratory tests. By incorporating data on how frequent a finding may be in a disease along with the prevalence of the disease in general, the diagnostic software can make a more powerful prediction as to the presence of an individual disease. They claim that they are the only product in its category to be able to run statistical inference in near-real time, producing not only a differential diagnosis but suggestions of related clinical findings. The knowledgebase

itself is being created from a review of specialty text books as well as original medical articles and input from specialty physicians into the database to ensure that every finding has the best data that can be found to substantiate it. When fully developed, it aims to have the most extensive database of medical knowledge available, which is both multilingual and multicultural.

Phase I: Regionalization Plan: Baseline Survey

Positive clinical tests of diagnostic products are not enough to scale and create buy-in, particularly in rural areas in developing countries. The potent combination of new terrain and new technology in healthcare, one of the most important areas of development, comes at a cost. Yet, there are no shortcuts. Live pilot projects are ideal as it allows for cross-learning and product customization within safe boundaries of “trial and error.” The scope of this paper lies in the analysis of the first phase of this project, that being the creation of the baseline survey and population of such content to help understand the major diseases and census information that exist in the specific region of choice. This is meant to serve as a guide to the localization of this diagnostic software that takes into account the social background, living conditions, previous diseases, immunization history, and much more for accuracy in diagnosis and treatment. Thereby, the system is meant to work as follows. When a person, who has already gone through the baseline data entry comes in for medical care, they will have a medical record already present (created from the baseline data). Then the healthcare worker will ask the questions that exist in the software including chief complaints, and all the other information not included in the baseline data to guide her diagnosis. However, as this paper argues, even this seemingly basic first stage of information gathering for product development raises red flags, demanding a reevaluation of the claim of medical software usage for diagnostic and treatment purposes.

Almora: Setting for the Pilot Study

While it is common to associate rural terrain with poverty, Almora, a picturesque district in the Kumaun region, east of the newly created Uttarakhand State in 2000 (previously called Uttaranchal) in India evokes all but that. This land lies between the river Kosi and Suyal and has stood as the cultural and political nodal point of Kumaon for almost four hundred years. Yet, according to the latest 2007 Uttarakhand State Government statistics, 90% of Almora's 632,866 population resides in villages. Males number 294,984 and constitute roughly 47% of the population and females number 337,882 or 53% roughly. The reason for women outnumbering men is due to the high male migration rate of 60% to the neighboring States of Uttar Pradesh and Punjab primarily due to its high rate of unemployment (Sati & Sati, 2000). A majority of the population are Hindus (98%) with the rest being a motley group of Muslims, Sikhs, Christian, and Buddhists. Also, 90% of the population is engaged with subsistence agriculture. Villagers in Almora struggle with certain basics for survival including access to quality healthcare, clean water, electricity, good education, and regular transportation, particularly as households are scattered across this mountainous region. For instance, 55% villagers have to walk more than 5 km to reach the nearest bank in Almora and women spend an average of 4- 6 hours collecting fodder and fuel for their day to day living (Mehta, 1997). Also, 60% of the rural population lives in areas that are more than 5 km from towns where access to most of the markets, hospitals, colleges and other services reside.

Given Uttarakhand is a newly created state, it has made efforts to gain the title of "aspiring leader" in e-readiness⁵ as it actively engages in creating connectivity across its terrain

through a steady supply of computers to high schools, universities, government agencies as well as providing ICT kiosks for access to a host of government services for villagers. Currently in Almora, all government high schools and universities have computers and broadband and wireless services have just come into fruition as of a few years ago. Additionally, initiatives for digitalizing data across government agencies are in motion including the health sector.

Information comes at a cost

The choice of Almora was not random. One of the chief venture capitalists of this software company happened to be of Indian origin and related to a savvy Indian businessman in Almora who was interested in this project. That said, this kind of “doing good” was also a possible lucrative business opportunity for all actors involved: the Almora consultancy, the venture capitalist group, and the medical software company. The researcher here was hired by the Indian consultancy to facilitate the pilot from start to finish. This paper however delves deeply into the initial facet of this pilot study, that which focuses on the surveying and populating of medical data into the system.

The baseline survey was conducted as a random sampling of villagers across four different villages (total pop. = 267). We hired two girls with college degrees and some experience in nursing to help with the fieldwork data collection over a period of two months. Both girls were fluent in Hindi and Pahadi, both languages commonly used in this area. They also had adequate English for such a task and sufficient data entry skills. The researcher accompanied the girls often in fieldwork for quality checks of data collection, as well as for a detailed ethnographic understanding of this region and its people. Fieldwork commenced at eight in the morning and went on till 4pm with lunch breaks in the field. This was a particularly

difficult region to conduct surveys in as houses were spread across the mountains, taking about half an hour to get from one household to another. On average, about twenty minutes was spent in each household. The data was entered into the computer twice a week and at the end of the two months, it was shared with the American medical company.

Simultaneously, interviews with doctors and nurses in this region were conducted regarding their views on this digital intervention. Also, visits were made to all possible places of dissemination and implementation of the diagnostic software: Primary Healthcare Centers (PHCs), Community Health Centers (CHCs), Auxiliary nurse offices (ANM's offices), district hospitals, private practitioners and Ayurvedic centers.

Speaking in survey form?

There are six sections to the baseline survey given by the diagnostic company: Demographics, disease history, childbearing, surgical procedures, immunizations, and habits (See Chart 1). "Demographics" include the individual's personal details such as name, age, gender, address and marital status. "Disease history" categories were drawn from World Health Organization's list of rural diseases in developing countries, thereby including malaria, dengue, leprosy etc. The "Childbearing" segment was designed based on the fact that in developing countries, women's health is deeply tied to maternity patterns and practices. "Surgical procedures" are basic given limited resources and the "Immunization" section includes initial and follow up booster shots for children. Lastly, "Habits" are basically limited to the ingesting of harmful substances such as tobacco, drugs, and snuff.

In our encounters with the villagers, most people would initially claim to not have any ailments. However, in making the "surveying" more in nature of conversation, ailments such as

stomach aches, knee pain, head aches and worms amongst the children would make it to the surface rather quickly. Except for one village, the rest of the villagers were receptive and opened up about their health status. The exception of the one village was due to its recent history with a nearby hospital that promised them medication after surveying them but never came back. While one would expect the demographic section to be rather straightforward, it is worth noting that most villagers did not know their exact age or that of their children. Instead, they spoke in approximations, giving us ranges for their age. This can cause problems, particularly when tracking maternal health and immunization boosters. In fact, the immunization section was completely blank except for reports on measles and tetanus which did not address this section. Besides polio drops, most villagers were unaware of what immunizations were given to their children. Polio drops were easy to remember as it was the only immunization that was orally ingested. That can be remedied easily in the digital medical database if ANM's and Anganwadi's (pre-school teachers) records of immunizations are collated and entered into the system. After all, immunization is a government project administered by ANM's.

That said, one of the most important findings from this survey was on symptomatic reporting for diagnosis and treatment. When we came to the reporting on disease history, 27% of the villagers reported dysentery, followed by hypertension (13%) and then roundworm (10%) (See Chart 2). The statistics in the rest of the categories were negligible. Under the surgical section, besides the 5 vasectomies reported, the rest of the sections came out blank. While the regular categories of this health report for the most part came out "clean," the most astonishing part of this reporting was the complete filling up of the "Other" category in the "Disease History" section. Every single "Other" column was filled up with health issues that did not fit the stated categories. Every villager became a patient.

Some random examples from the 267 reports of villagers under the “Other” column in the “Disease history” section are as follows:

- Hole in the Uterus, doesn't feel hungry, swelling in Intestine, Faint
- Weakness, Faint, Doesn't feel hungry
- Waist pain, Stomach pain,
- Joint pain, Body rash with puss, Faint, Frequent fever
- Body pain, Constipation
- Waist pain, Foot pain, Doesn't feel hungry
- Waist pain, Right arm pain, Migraine, Frequent fever, Burning palm & foot, White dots on chest
- Uterus came out in second delivery (suggested operation), Cough , Stomach pain, Leg pain
- Leg pain, Stomach pain, waist pain, joint pain.
- Frequent vomiting
- Right leg pain, Waist pain, Whole body swelling
- Faint (for 1 year), doesn't feel hungry, back pain, waist pain
- Stomach pain, frequent fever, Chest pain, Cough, Breathing problem, Faint, Eyes pain, Migraine Leg pain, Constipation, Waist pain
- Stomach pain, Waist pain, Migraine, Frequently fever
- Joints pain, Waist pain, Knee pain, Migraine

In fact, having analyzed the “Other” category, the ten most common health complaints are as follows:

1. Waist pain
2. Stomach pain
3. Chronic Body pain
4. Joint pain
5. Eyes swelling and watering and burning
6. Migraines
7. Not feeling hungry
8. Frequent fever
9. Uterus problem
10. Stone problem

In fact, pain seems to be chronic and frequent; a lifestyle companion of the poor in this region. Part of this is due to the fact that in the hills, much of the work is highly laborious; for women, pain comes from their daily strenuous chores of carrying water and wood for miles to working in the fields for hours at a time. Also, given the responsibility of housework and the fact

that many of their male companions have immigrated to the city for work, women take little rest after giving birth. Stories abound; for example, a woman from one of the villages had just had a cesarean at the hospital. After discharge the day after, she walked back to her village which was about four miles from the hospital. In a short while of having reached home, she became very septic and had to be brought back to the hospital again. Males who have stayed behind are often subjected to chronic pain; “my husband has very bad body pain but what can he do, he’s a day laborer so he comes home takes medication and goes to work the next day.” Hunger is also another cause of chronic pain, leading to “habits” such as smoking; says one woman as she minds her children while feeding the cow; “smoking settles down the stomach (*Paet sah jatha hai*).” And so it seems that this “Other” category is inundated with data that is unwieldy and sufficiently vague. “Waist pain” finds itself in company of other similarly confounding descriptions of chronic health problems plaguing the villagers.

The Reign of the Painkiller

Diagnosis without treatment is a wasted endeavor; they are two sides of the same coin. Poverty compels villagers to seek for medical attention primarily in times of emergency. Their most faithful friend is the painkiller. Pharmacists are more sought after in these regions than doctors on a day by day basis. There is little room for remedy of lifestyles: women continue to take care of their children, collect firewood, utilize wood based cooking stoves, work in the fields, collect fodder and fuel, and take care of their cows. Furthermore, there is a general lack of basic awareness of sanitation; as one leading NGO activist states, “to have them use a sanitary napkin is in itself a big deal!” Also, little attention is paid to their health, as they get consumed

with survival; “I didn’t even know I was pregnant until the 5th month” says a 25 year old mother of five.

When sick, almost half the villagers reported that they go to the *JarPhook* or local shaman for healing. Also, we must keep in mind that allopathy is not the only system at play. According to the Chief Medical Officer (CMO), there are 40 State allopathy dispensaries, 51 Ayurvedic treatment centers and 11 homeopathy centers. Yet, given that there is far less regulation with such alternative systems, allopathy continues to be the dominant choice (Bhola, Kumari, & Nidha, 2008). Here, about half the villagers discussed going to private practitioners, mainly *Deenapani*, a private hospital, and some private practitioners in the town. The other common location was the District hospital, but few reported ever visiting the primary or community healthcare centers (Berman, 1998). It seems then that when the painkiller fails, the hospitals take over.

As for treatments, getting drugs can be expensive and cumbersome. While supposedly free, many villagers bought their medications. Sometimes it was a matter of timing as a district hospital doctor reports:

There is a local dispensary out here which provides free medications. Monthly we send in our requests to the head office in Dehradun for quantity of drugs remaining every month and how much supply is needed. But often these meds take time coming here so patients go directly to pharmacists and buy instead.

Or perhaps it is about political deals with pharmaceutical companies that leave local government hospitals with little choice. A hospital staff gives some insight into the system:

The problem is that with treatment drugs, we send requests per month about what we need but the head officer sends us standardized drugs, some of them not useful to us in this area so it will just sit here. Or they get our forms but send us some packaged deals that they made with some pharmaceutical companies because they want to promote their drugs. It’s all contracts here. Sometimes the delay itself makes the drugs useless like some seasonal viruses come but they will send treatments after 6-9 months then there’s

little use or we use expired medication. Either way the patient has to pay for their drugs many times. And even when available, treatment is not “objective” but rather, based on referrals. Often, doctors prescribe medications based on the incentives they get through referrals. In fact, the lucrative part of practicing medicine lies in the commissions through tests and referred medications: ultrasounds, x-rays, and CT scans are the norm (Bhat, 1999). As one private practitioner admits:

This healthcare business is based on referrals. This product [RightChoice] will not work. Doctors recommend other specialists and drugs based on the commissions they get on them. There is a deep tie up with the pharmaceutical industries and other specialists with CT Scans and X-rays...sometimes you will see a doctor recommend at least 10 medicines for he can get a lot of commissions from that.

Sadly, this has created a behavior amongst patients of demanding for tests and drugs as an indicator of good doctoring (Trostle, 1999). As one medical technician remarks, “nowadays everyone wants an ultra sound whether it’s for their waist or neck or head or their back...they don’t understand what it is.” For those who cannot afford to buy medications, they wait for the free prescriptions to come their way. Sometimes, this can be harmful as they can get expired medications and worse, medications that are obsolete but continue to be prescribed. For instance, there were cases of sulphur drug prescription which, as one of the doctors stated, was no longer being prescribed since the 1980s.

This is not to say that government healthcare practitioners are not eager for change. As one senior government doctor remarks:

Why start from below? You should start from above. The government should make sites that are useful for us. See, they should keep information online on all the medications available, the credentials of pharmacists and which drugs are certified and which are not. We also wish we could communicate directly to them our needs and go directly to the seller or drug company. By the time we wait for the government to respond, our patients have bought the drug from elsewhere. Rate tenders, contracts and equipment purchase should all be open for us to see. The Central Drug Licensing Authority should make all

their transactions online so we can be part of it also. Right now I Google if I want to see something. Say I want to refresh myself about an illness or treatment I just Google. But sometimes I go to the website of the government and download forms but it's in pdf form and it doesn't come on this computer. Maybe I'm not doing it right. Also, I want to see the company lists so we can buy directly from companies. Why wait? We can also know medical updates, drug updates its side effects and all that information. We just got this computer about 2 months ago. They just placed it but we haven't used it much. It is in my office now. I'm interested in knowing new things but at my age, my learning is very slow. I call my daughter in Delhi and she tells me mum, it's because you don't have adobe that is why the pdf is not coming up. How do I know what's adobe?

Ten Doctors give you Ten Diagnosis

One physician remarks: “doctors will always appear to be indispensable. You put ten doctors in a room and get them to give a treatment and you will see that nobody will agree with one another. They play God here...why do they want to invite a challenge or test their status?” The idea that a digitalized diagnostic system can come up with a standardized and single treatment goes against how medicine is perceived and practiced across cultures and communities. Besides the obvious tension between allopathy, ayurvedic, homeopathic and other approaches to medicine, there is tension even within allopathic circles. Making a decision based on, for instance, “waist pain, right arm pain, migraine, frequent fever, burning palm & foot, white dots on chest,” as shared earlier by one of the villagers is not an easy task. There is a good chance that three different doctors may come up with three different strategies to address this.

Besides, diagnostics does not happen in isolation but often with the aid of tests. Thereby, even if this tool was to succeed in diagnosing correctly a patient's symptoms by a non-doctor, the patient would still have to seek a doctor for further tests and prescriptions for medication. In other words, the trip to the hospital is inevitable and the need for a doctor is unavoidable.

Conclusion

Digital diagnostics excites for a simple reason – it’s a fresh idea. New perspectives and innovations are needed to counter the growing shortage of doctors in rural areas. Holding back or attracting good doctors to rural areas has not worked. The fact that majority of the Indian population continues to reside in the rural terrain and are subjected to often abysmal standards of healthcare requires an urgency in addressing rural healthcare. This demands a comprehensive outlook that takes into account the current healthcare system of referrals, incentives, user behavior, private and public medicine, alternative medical approaches, current manual data management, government mindset of information usage, access and cost of treatment and lifestyle of the patients. The fact that the manual healthcare data system exists, reflect an understanding of the importance of information. The fact that health information continues to be used as primarily census data and not for learning is a formidable challenge that will require some serious effort at creating buy-in on both ends – the public and the private sector.

RightChoice has successful clinical trials to its name. It can definitely serve as a healthcare data management tool. It can also be an excellent learning tool, allowing healthcare workers, practitioners, and doctors to upgrade their skills and knowledge. It could also offer a valuable second opinion to doctors, helping them in their decision-making process. But so can other tools out there, many of them freely available⁶. *RightChoice*’s unique selling points are its usage amongst non-doctors for diagnosis and treatment and its promised customization of rural diseases and symptoms. As we have seen, usage of such tools by non-physicians such as the healthcare workers is in itself problematic at a legal and political level.

This paper however, is concerned with its customization aspect through localized healthcare information of villagers. Even if usage was possible by a non-doctor, both politically and legally, the very fact that information does not come “clean” or “easy” to fit into set

categories makes this process “non” intuitive. Taking this further, populating the treatment section is deeply political. Even if we are to go beyond the politics of referrals and other systems at work, the notion that there is one way of interpreting “symptomatic” data to lead confidently to a diagnosis is, as we have seen, problematic. Even if this were to be compounded by visual data, this would require a doctor to make the final decision. And lastly, even if it were to succeed in circumventing these issues, the fact that this digital diagnostic tool does not come hand in hand with the actual treatment requires the patient to seek a pharmacist or other medical dispensaries, requiring an added step in this process. Doctors know best, the old adage goes. Digital doctors will have to do better than that.

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Chart 1: Survey Design

Chart 1: SURVEY DESIGN -QUESTIONS FOR MEDICAL DIAGNOSTIC SOFTWARE														
Demographic	Patient ID	Name	Father/Husband's Name	Birthdate	Age	Gender	Marital Status	Address	Village					
	Asthma	Chicken PoxY/N	Measles	Tuberculosis	Malaria	Leprosy	Hepatitis A	Dysentery	Diabetes	Stroke	Hypertension	Heart Attack	Round Dengue worm	Other
Disease History	No. of Pregnancies	# live births	# surviving children	Miscarriage/ Abortion	Type of Delivery H/N/B	Hospital	Cesarean Section	Forceps birth	Control Pill	Birth Control	Tubal Ligation	IUCD/C/O		
	Appendectomy	Cardiac bypass	Angiography	Tonsilectomy	Vasectomy	Other								
Surgical Procedures	Polio1	P2/P3/Pb1 /Pb2	BCG1/BCG 2/BCG3	BCG1/BC Gb2	MMRBooste r1=A/2	DTP1/2/3	er1/2	1/2/	ChickenP					
Immunizations	Tobacco S/C	Paan	Snuff	Alcohol	Supari	Drugs	Other							
Habits														

Chart 2: Survey Results

Villages	No. Patients	Disease history	Childbearing	Surgical Procedures	Immunizations	JarPhook
Village 1	132	CPox = 27/ Dyst=55/ HepA=4/ HyperT=9/ Worms =13/ Asthema=5	Blank	Blank	Tetnus & Measles	67/132
Village 2	30	4dysentery/12=hypertension/ 22=roundworm/ Dyst=12/ Diabetes=4/ HyperT=12/ Asthema=4/ Worms=3	blank	1 vasectomy		13/30
Village 3	65	HyperT=1/ HepA=2/ Dyst=2/ Worms=3	blank	2 vasectomy	Measles	22/65
Village 4	40	HyperT=1/ HepA=2/ Dyst=2/ Worms=3	1-condom use	1 vasectomy	Measles-waist pain	16/40
Total (n)	267					

¹ Third National Family Health Survey, India: http://www.nfhsindia.org/nfhs3_national_report.html

² United Nation’s Millennium Development Goals: <http://www.un.org/millenniumgoals/>

³ National Rural Health Mission Policy, India: http://india.gov.in/citizen/health/national_rural.php

⁴ The name of the medical diagnostic company has been changed in this paper to “RightChoice” for privacy purposes.

⁵ DataQuest. (March 8, 2008). *Inclusive India*: http://dqindia.ciol.com/content/top_stories/2008/108030801.asp

⁶ See Mayo Clinic for example: <http://www.mayoclinic.com/>