Continuous Tracking and Analysis of Disease Outbreaks in Rural Areas of Lahore

Identifying Underserved Villages at High Risk for Outbreaks and Discovering Patterns Associated with Disease Incidence

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1. Introduction

This section provides a summary of the work being proposed as part of this project.

1.1 Motivation

A number of statistics related to healthcare in developing countries make for grim reading. In Pakistan, for example, over 250,000 deaths result each year from diarrhoea [1], while another 300,000 can be attributed to diseases such as tuberculosis, measles, whooping cough and pneumonia [2]. The majority of these cases are preventable and even fully curable through inexpensive treatment during the early stages.

Failure to address this situation is often attributed to the lack of monetary and skilled human resources, which limit the ability to provide universal care. For example, the per capita public health expenditure in Pakistan was 16 dollars in 1999; by 2003, that figure had gone down to 13 [3]. These limitations make it critical to use available resources efficiently. Specifically, it becomes increasingly important in the setting of developing countries such as Pakistan to pre-empt disease outbreaks and restrict the spread of disorders in high risk areas before more involved (and potentially unavailable) therapies become necessary. By intensively focussing on such high impact localities comprising the major component of the disease burden, a significant improvement could be achieved.

1.2 Overview

The focus of this project is to explore the use of sophisticated analytical techniques and geographic information systems, coupled with the distribution of new cases recorded at healthcare facilities, to identify sub-communities in rural areas of Lahore that are at high risk for outbreaks. The Ministry of Health in Pakistan, as part of a project in association with USAID, UNICEF, WHO and World Bank, already maintains a national health information database with information from primary healthcare centres. We propose to extend this work through the following innovations:

- Use data from public hospitals to discover “hidden islands,” i.e., identify underserved regions affected by disease where primary healthcare centres do not exist and patients had to visit the nearest city to seek treatment. These cases would not appear in the national health information database, which collects data from primary healthcare facilities. No such facilities exist in underserved regions, and disease outbreaks would therefore not be recorded for these areas. Instead, the disease

numbers for such regions must be backwards-reconstructed by pooling hospitals records together.

- Supplement information about disease incidence in each region with detailed demographic and socioeconomic data collected by other government agencies and with data in geographic information systems (GIS) such as the ones that exist at MIT. This information allows for a means to relate communities and discover similarities that may be useful in pre-empting disease outbreaks and also for understanding factors that play a key role in the occurrence of a disease.
- Promote projects in high-risk sub-communities that might be able to spread awareness of protective mechanisms and simple therapies.

2. Background

2.1 Need and Community Served

Each year, approximately half a million people in Pakistan die as a result of diarrhea, pneumonia, tuberculosis, measles and whooping cough [14]. The majority of these cases are preventable and even fully curable through inexpensive treatment during the early stages. Large physical distances and uninformed resource allocations may be a major factor in whether or not this early treatment is administered. Sixty percent of Pakistanis live in rural communities [13]. Urban hospitals and rural healthcare clinics treat people who come from the surrounding rural areas, but when a community is a significant distance from the nearest healthcare facility, members of that community may only decide to make the trip after they become seriously ill and the disease has progressed beyond the easily and cheaply treatable stages. Even after making such a trip, it is known that the rural health clinics are not always staffed (a serious resource allocation issue) due to non-compliance amongst the staff [8,9].

Our work is intended to eventually benefit all communities which use the currently existing rural and urban healthcare facilities. Those communities which use these facilities but are furthest away will likely experience the largest (positive) change in healthcare accessibility. These rural communities, both near and far from the current healthcare facilities which attempt to serve them, fall into the category of “rural but reachable” communities we hope to eventually benefit.

The scale of the ultimate implementation is large, so we plan first to implement a pilot, with a smaller target community. We hope to collect and analyze data from the city of Lahore, shown in Figure 1, and use this data for the benefit of the Wahga Town area (shown in green on the right of Figure 1), which is predominantly comprised of rural communities that depend on urban healthcare facilities. It is also more readily accessible than some of the other rural areas in the vicinity of Lahore.

While the project initially focuses on rural areas of Lahore, the proposed work has applicability for other parts of Pakistan and, more generally, for developing regions globally. The problem of needing to prioritize healthcare work to target high risk communities in the context of limited resources is common to many other parts of the world and we hope that positive results from our initial work in Lahore will allow us to expand this effort in the future.

2.2 Why Pakistan?

The work described in this proposal is initially planned to be carried out in Pakistan (particularly, in the region outlying Lahore). This decision is motivated by the fact that Pakistan fits the model of a typical developing country reasonably well, with many of the characteristic problems such as insufficient economic and skilled human resources, low levels of literacy and a lack of awareness regarding the treatment of many common diseases. It is the sixth most populous country in the world, which translates to a significant population pressure on available resources. Changes such as increasing the per capita public healthcare expenditure are difficult since they require a much larger allocation of funds than in small countries. Per capita income in Pakistan, for example, is around 700 dollars and this number itself is lower than the per capita public expenditure on healthcare for many countries.

The presence of a large population further gives rise to regions of high population density in cities where disease outbreaks are more severe owing to increased interactions and an inability of infrastructure such as clean water and sewage to keep pace. Complicating the situation further is the fact that almost 60% of the population in Pakistan lives in rural areas [13], which are often hard to reach and where resources such as telephones and electricity are unavailable. Furthermore, the landscape of the country (and the corresponding weather) itself is quite diverse ranging from coastal regions and deserts, to the Himalayas.

From this perspective, improving the healthcare in Pakistan is a particularly challenging proposition. This makes it a system that is particularly well-suited to be studied as the findings are likely to be a superset of the problems encountered in most developing countries.

Two additional factors that are important in motivating the choice of Pakistan are that firstly, the country has recently seen a period of progress on various fronts, and there is an increased focus on healthcare, and secondly, a large number of deaths in Pakistan are currently associated with diseases such as diarrhoea, pneumonia, tuberculosis, measles and whooping cough (approximately half a million each year [14]), which have relatively inexpensive treatments. In many cases, the occurrence of these disorders is compounded by the failure to recognize the illness and to take appropriate steps. In such a setting, it is reasonable to expect that even in a resource-constrained environment, a mechanism for keeping these diseases in check can be discovered and used to make a positive difference.

It is important to point out that while we propose initially carrying out this work as a pilot project in Lahore, it has more widespread applicability. There are a large number or rural communities around the world that likely suffer from similar issues of being underserved, or that would benefit significantly from pre-emptive mechanisms. We therefore believe that all of the ideas described here could be extended to other regions globally following an initial rigorous assessment and understanding of the utility of the proposed approach.

2.3 Current State of Data Collection and Analysis in Pakistan

In the early 1990s, the Ministry of Health in Pakistan started work on the NHMIS project supported by USAID, UNICEF, WHO and the World Bank [6]. This project collects a variety of data from peripheral primary healthcare facilities including disease details and the availability of important resources such as drugs, contraceptives and machinery [7]. Data is collected from each district and the information is passed along to provincial computer centres. The objective of NHMIS is to record information on health events and to

monitor the availability of critical items of first level care facilities. NHIMS also provides information on facility utilization rates, referrals, immunizations, maternal care and family planning. Yet, as reported by the Ministry of Health in [6]:

> "Reports generated by the facility based HMIS receives low priority, monitoring is poor and facility staff look upon HMIS as an additional workload."

A significant component of this problem is described in [6,10] as owing to limited analysis currently being undertaken on the collected data.

3. Innovation and Enhancements

We consider the NHMIS an obvious starting point for our work and propose various innovations to enhance this effort along different dimensions.

3.1 New Sources of Data to Discover Hidden Patterns such as Underserved Regions

Our work builds upon the efforts of NHMIS by proposing the use of information from major public hospitals such as Shalamar Hospital and Gulab Devi Hospital to supplement data collected from primary healthcare facilities in rural areas. We believe this data to be useful for a number of reasons.

Firstly, primary healthcare facilities may consistently miss a significant fraction of the total patients in rural areas suffering from a disease. There are three main scenarios where this might happen:

- Patients commute regularly to the city for work or sale of goods, and prefer urban medical treatment options
- There is an absence of local healthcare facilities, which mandate travel to seek treatment
- The presence of "ghost" clinics [8,9] means that although primary healthcare facilities exist, they do not provide adequate care

These cases mean that in addition to information collected at primary healthcare facilities, it is essential to incorporate statistics from public facilities in the city. Specifically, by pooling together information from public hospitals in the city, it is possible to backwards-reconstruct areas of consistent outbreaks and identify localities that are underserved. To the best of our knowledge, no other public health project in Pakistan currently attempts to do this backwards-reconstruction.

This issue of "ghost" clinics also potentially leads to noise in the NHMIS statistics, since information is collected by the same facilities that are responsible for providing care. The statistics collected may therefore be underrepresented in some cases for monitoring purposes. In these circumstances, we consider data collected from hospitals to be interesting from the perspective of

providing a parallel, independent assessment of disease spread and also from the point of view of allowing for a more complete understanding of the state of medical care if supplemented with NHMIS data.

3.2 Sophisticated Data Analysis Techniques

In addition to extending the current NHMIS work, we also expect our project to provide further motivation for future government efforts to maintain a national health management database. There is limited analysis currently being undertaken on the collected data. This represents an area where the data analysis expertise at MIT and other institutions can be useful, particularly in the area of knowledge discovery on massive datasets. We believe that such analysis will allow us to add further value and demonstrate the usefulness of a system similar to the NHMIS, particularly if discovery of high risk communities can be supplemented with community-based efforts to promote awareness about diseases and protective mechanisms. More details on the proposed work in this area are provided in Section 4.

3.3 Data Fusion across Multiple Sources of Information

We also plan to investigate relating statistics on disease occurrence with socioeconomic parameters in an effort to predict regions where there may be outbreaks of a disease. Initial results of an effort in India to organize a national database with family health surveys [12] indicate that socioeconomic parameters are often strongly correlated with specific diseases. Other programs, such as Pakistan's National Action Plan on Non-communicable Chronic Diseases (NAP-NCD) [16], are surveying socioeconomic indicators to identify risk factors for non-communicable diseases, but they are not also getting data directly from hospitals. Furthermore, their emphasis also seems to be on legislative changes, the formulation of health policy in Pakistan, and the implementation of national health plans, rather than tackling the issue on a lower level by focusing on regional communities. We hope to use both trends in disease occurrence and socioeconomic parameters such as the ones described in [12] to obtain a more sophisticated approach to prediction of outbreaks.

3.4 Pre-emptive Disease Identification

At a higher level, our work attempts to help reduce the latency of dealing with outbreaks. This proceeds along multiple dimensions. Most notably, we hope to use data analysis techniques to discover patterns that can predict imminent disease outbreaks. This includes finding communities that have a certain regularity of disease incidence, or have a profile that matches closely with another community where an outbreak has occurred, or have certain characteristics such as proximity along a propagating disease path that put them at risk. In the presence of NHMIS data regarding the medical equipment available at each rural facility, we could further use this information to assess susceptibility and preparation to meet challenges.

We also hope to expedite response to an existing or imminent outbreak by sharing all our work with other volunteer groups or organizations. In the ideal case, we plan to make all aspects of this project publicly accessible via a web-interface.

The pre-emption of disease outbreaks could also help reduce the cost of managing illnesses. Specifically, better awareness regarding

issues such as vaccination, contraception and practices such as boiling of water and oral rehydration, might help prevent situations where more expensive therapies are necessary. In cases of tuberculosis, a more thorough appreciation of the need to adhere to therapy (and the increased risk of drug-resistant TB to the community if members do not complete treatment) may help reduce the number of cases where expensive chemotherapeutic agents are required. The findings of the World Lung Foundation DOTS Coverage program in Pakistan [17] state that "among [tuberculosis] patients who had defaulted on previous treatment, treatment success was only 58%, mostly as a result of patients defaulting again." Poor adherence to therapy, therefore, is a vital issue to address.

More generally, one of the central ideas behind this work is that predicting disorders helps save resources by allowing more simple fixes.

4. Project Details and Feasibility

The project is divided into three parts.

4.1 Phase I: Interfacing with Data

During the initial phase of the project, we plan to pool together information from public hospitals and the NHMIS system. We consider information in public hospitals to be a natural extension of the data currently collected by the government and propose working with the NHMIS Bureau to record this information for all the hospitals in the Lahore area. Depending on the delays associated with this process, we may also consider collecting the information directly ourselves, although in this case, the proposed work may be scaled to initially focus on information from Shalamar Hospital and Gulab Devi Hospital. This decision is largely for logistical reasons, and from the perspective that positive results of a pilot project may allow for a more compelling case to be made for future work by the government in this area.

The specific disorders for which data will be collected include major respiratory, diarrhoeal and venereal diseases. Information collected will include disease details and the sub-district or neighbourhood where the patient is based (to maintain patient confidentially, we plan to obtain scrubbed data bearing only the geographical location of cases, at the level of a zip code or sub-district).

Associated with the endeavour of collecting geographical distribution of cases is the goal of developing a high-resolution map of communities in the region adjoining Lahore. Information in demographic surveys carried out by the Federal Bureau of Statistics and geographic information systems such as [13] will be used for this purpose, as well as any additional datasets that may be available. If possible, we may also attempt to obtain spheres of influence and communication patterns for each sub-district to determine the extent to which geographically proximal communities interact. Where necessary, we hope to cooperate with local municipal bodies to obtain additional information.

The information gathered during the project may be made publicly available via a web interface for use by other groups interested in studying disease patterns or carrying out relief work. This is contingent upon approval by the Ministry of Health and the hospitals

sharing data with us. Depending on the extent to which this project evolves, the web interface could also be extended to include a backend statistical toolbox that allows for queries to be run on the collected data.

4.2 Phase II: Data Analysis

A follow-up to the process of collecting data is to use this information to identify underserved communities and to discover patterns associated with disease outbreaks.

The discovery of underserved communities will be carried out using different approaches. A first step is to identify regions for which cases are recorded by hospitals, but where no medical facilities exist according to government records. A second approach is to use data from the NHMIS and hospitals to construct a background model for how frequently diseases should occur within geographical superclasses of communities. Anomalies in these trends likely correspond to islands where healthcare facilities are inadequate. A third step extends this idea by using information from NHMIS and hospitals to obtain a model for how frequently patients visit public hospitals once cases have been reported at peripheral primary healthcare facilities. Deviations from a normal range may indicate regions at high risk. The assessment of risk may also be carried out by deriving historical trends for diseases at the level of each community and finding statistical abnormalities. Other possibilities include the examples provided earlier in Section 3.4.

The process of discovering patterns associated with diseases follows from the use automated inference techniques to discover similarities across the socioeconomic parameters collected for each community in the high-resolution map. A considerable literature exists in the area of automated inference, and many of the algorithms described in the literature can be applied to the task of identifying commonalities between different examples. Other techniques in the area of trend detection and automated root-cause analysis may also prove to be useful.

4.3 Phase III: Reporting Findings and Promoting Community-based Efforts

A third component of this project is to communicate findings of underserved regions and communities predicted as being at high risk for diseases to the Ministry of Health and volunteer organizations. Collaborating with these groups, community-based projects could be structured where a representative is selected through an interview process and trained to help promote awareness amongst the group regarding first lines of defence against diseases. In the case of disorders such as tuberculosis (i.e., which are associated with substantial therapies), the community representatives could also play a role in helping motivate greater adherence. The central idea behind this work is to pre-empt diseases and take steps before an outbreak.

4.4 Schedule and Practical Considerations

A rough schedule for the project is as follows. Owing to the nature of this work, specifically the need to coordinate data collection with different institutions, it is possible that certain milestones may be delayed. We do not explicitly budget for these unforeseen circumstances, but provide these dates as a rough idea of the timeline for the proposed work.

Jun '07 – Aug '07	Seek access to NHMIS statistics Coordinate data collection from hospitals Construct map at sub-district level with socio-economic indicators
Sep '07 – Feb '08	Data analysis to identify high risk communities and patterns associated with diseases
Mar '08 – Jun '08	Communicate findings to Ministry of Health and volunteer organizations Coordinate community projects in regions that are at high risk for a disease
Post Jun '08	Track the impact made by community workers and evaluate their performance rigorously

4.5 Community Partners

Our project will be supported locally by the Shalamar Hospital [4], which was established in 1982 as a non-profit institution to cater to low income regions of Lahore. With support from some of the leading members of the business community in Pakistan, Shalamar Hospital is amongst the major healthcare providers in the city of Lahore. It is recognized by both the Pakistan Medical and Dental Council, and the College of Physicians and Surgeons Pakistan. The outpatient department for the hospital is around a thousand patients per day, while the facility has 350 beds for surgical services.

Another partner for our work in Lahore is the Gulab Devi Hospital [5], which was established in 1927 as a centre for treatment for tuberculosis. The hospital has since grown into the leading facility for treatment of respiratory disorders and is the biggest chest hospital in South Asia with 1400 beds. It is recognized by the College of Physicians and Surgeons of Pakistan and provides patients who can show financial need with treatment (including operations) for free.

We plan to use data available at these hospitals to identify communities that are at risk, and also to design community-information projects that can be used to educate villages that are at high risk for diseases regarding simple protective mechanisms and treatment options. Clinicians at both Shalamar Hospital and Gulab Devi Hospital have considerable expertise working with patients from rural areas, and would be an invaluable resource in helping us design a programme that maximally communicates useful information to communities at risk. In addition, Shalamar and Gulab Devi are two of the largest facilities in Lahore and statistics at these hospitals are ideally matched to the work proposed.

We are also in the process of coordinating our efforts with the local government in Lahore, specifically municipal bodies, which may help us implement and sustain community projects. This process is following largely through the personal contacts of some members of our team. We also expect to meet shortly with the Gates Foundation after they expressed a preliminary interest in learning more about our work following an initial exchange. We have also written to the WHO office in Pakistan and are awaiting a response.

We believe that these groups may be able to offer us more advice on possible ways to improve our work, and we would ideally like to benefit from their guidance. In addition, we hope to cooperate with these groups to push for the adoption and incorporation of our work if it demonstrates potential to foster a positive change.

4.6 Supervision

Our work will be supervised at MIT by Professor John Guttag, who served as the head of the MIT Department of Electrical Engineering and Computer Science from 1999 to 2004, and currently leads the Data-Driven Medicine Group at the Computer Science and Artificial Intelligence Laboratory, and by Professor Jonathan Rosen, who teaches in the Harvard-MIT HST Division and is currently the Executive Directory of ITEC Boston University. Both Professor Guttag and Professor Rosen are committed to the goal of improving international healthcare and are currently involved in research projects that involve the use of technology in medicine. Professor Guttag is particularly experienced in the area of analyzing large amounts of data, while Professor Rosen has organized projects in the past to develop low-cost incubators out of easily available automobile parts for use in regions around the world where there is no continuous supply of electricity and his experience of work in a global setting will be useful in shaping the focus of this work.

We are also currently in the process of making contact with disease epidemiology faculty at the BU School of Public Health and the World Health Organization. Initial exchanges on this front have been exceedingly positive.

5. Community Connection and Impact

Initial results of an effort in India to organize a national database with family health surveys [12] has shown promise, i.e., by demonstrating that the availability and better utilization of information can make a significant contribution to social health efforts. We therefore believe that if we are able to carry out our work and demonstrate a similar utility of the analyses we are proposing, it is likely that our effort will be taken further by various groups working on improving healthcare.

In more detail, the government in Pakistan already collects information from peripheral primary health facilities. We see our work as a natural extension of this existing effort. Specifically, after initial conversations with members of the Ministry of Health, we are confident that our work might be incorporated in the long-term into government efforts. Notably, we plan to address two of the existing suggestions by other parts of the medical community in Pakistan, i.e., the need to collect statistics from public hospitals, and the use of more sophisticated analytical techniques. The latter, in particular, appears to be a desired goal of the Ministry of Health itself as suggested on their website [6].

We also believe that the work being proposed can be sustained readily by non-government organizations including hospitals such as Shalamar and Gulab Devi, which are non-profit facilities and stand to benefit from the decreased demands imposed on a fixed set of resources by disease outbreaks. Universities such as the Lahore University of Management Sciences have also demonstrate a commitment to volunteer work of this kind (e.g., the RISEPAK effort [15]) and could be expected to help with this endeavour. Finally, we also believe that volunteer organizations and groups such as the WHO may further find the work being proposed a reasonable

investment of their resources as it will guide many of their existing efforts in a more productive direction, i.e., by pinpointing specific regions where healthcare efforts may be most fruitful. As part of this project, we propose to explore the possibility of developing long-term partnerships with one of these players on the healthcare front in Pakistan.

An associated consideration is that the amount of work needed to sustain the proposed effort will most likely decrease in the future, making it easier to sustain this effort. Specifically, with the advent of patient health record systems, public hospitals will have information about new cases in an electronic format and a system to run statistical inference queries on this information will be fairly inexpensive.

We are confident of being able to form successful partnerships with many of the groups suggested above. Specifically, we have already obtained letters of support from both Shalamar Hospital and Gulab Devi Hospital and are optimistic about their long-term commitment to the project. Some of us also have contacts with members of the Ministry of Health and the government in Pakistan, and we are currently in the process of trying to get government support for our work. One of the members of our team serves on the core project team for the School of Science and Engineering, and we believe that we can obtain both technical help locally as well as student support for the project over a long period of time on this front. Finally, as described earlier, we hope that we might be able to follow up with the Gates Foundation and obtain their guidance and support for how to best help the project be sustained over a long period of time.

6. Open Issues

A number of open issues exist regarding the proposed work, which need to be addressed prior to the start of the project:

- What specific information exists in the NHMIS database?
- What factors restrict public access to the NHMIS database through a web database?
- Does the NHMIS database contain the geographical distribution of new cases recorded at public hospitals?
    - Based on the information in [6,7,10] it does not seem that this is the case, which is one of the major contributions of our work. However, it may be that the government may plan to collect this information in the future, in which case, we would hope to work with them and focus more on the analysis of this alternate stream of information
- What cooperation can government agencies and hospitals extend to support our efforts?
    - As described earlier, initial contact with various groups has been productive. We are currently in the process of exploring further partnerships, and hope that as the project becomes more refined and produces quantifiable results, we will be more successful in this effort.
- Are there analyses that the government or volunteer organizations would find particularly useful?
    - We believe that much of the information that we hope to provide will be useful to the government and volunteer organizations, including the presence of communities that are unable to get care and must travel to hospitals and the risk of disease outbreaks. There may be additional analyses that we have overlooked. As described earlier, we hope to

get in touch with organizations like the WHO and also meet with people in the Ministry of Health to get more feedback on this subject.

In addition to these questions, it would also be helpful to obtain a quantitative assessment of the percent of the population currently living in regions that are underserved either due to the absence of healthcare facilities, or due to non-compliance of healthcare staff. There is significant anecdotal evidence to support the existence of these regions, and while obtaining a precise estimate of the population living in these areas is a challenging proposition (finding these hidden regions represents an important goal of this project) it would help assess the value of the work being undertaken.

7. Budget

The predicted budget for this project is as follows:

Item	**Total Cost**
Data Entry	**$4,800.00**
Services (manual entry of data)	$3,000.00
Transportation of operators to hospitals	$1,800.00
Equipment	**$3,500.00**
Server and Storage	$2,500.00
Software	$500.00
Internet connection	$500.00
Community Representatives	**$800.00**
Nominal incentives to representatives	$500.00
Transportation (for training and back)	$100.00
Stationary and miscellaneous expenses for representatives	$200.00
Other	**$900.00**
Phone calls, transportation by project members etc.	$900.00
Total Amount Requested	**$10,000.00**

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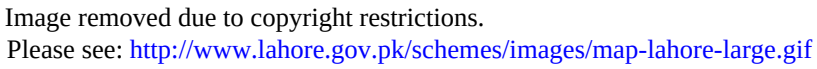

Figure 1: Map of Lahore provided by the city district government.

EC.715 D-Lab: Disseminating Innovations for the Common Good
Spring 2007