

Health Data Mapping in Southeast Toronto: A Collaborative Project

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Abstract

Health data maps and geographic information systems (GIS) are significant resources for health planning and health services delivery, particularly at the local level. The ability to visualize the spatial distribution of health status determinants and indicators can be a powerful resource for mobilizing community action to improve the health of residents. Currently, health data maps and other GIS applications tend to be highly technical and specialized, and are therefore of limited use to community members and organizations providing community-based health services. Developing relevant, accessible, and usable GIS and health data maps for communities and local agencies is an important step toward enabling individuals and communities to improve their health and increase their control over it. This collaborative interdisciplinary project harnesses the energies and skills of community and university partners in the joint design and critical assessment of a relevant and accessible GIS targeted toward respiratory health in an urban community. A respiratory health data model is used to identify appropriate existing data sources and a comprehensive metadata model facilitates assessment of data sources. Community and university partners are collaborating to design and assess the GIS through a series of hands-on workshops. Qualitative methods are employed to examine the nature and effectiveness of the collaborative process. This project has identified, and is attempting to address, a number of technical and collaborative issues. Technical issues include integrating disparate datasets and developing appropriate methods of data depiction for varying levels of users. Collaborative issues include overcoming substantial diversity of user needs, capacities, and perceptions. Lessons learned from this project are applicable to other projects involving health information system design and university-community collaboration.

Keywords: information system design, collaborative research, community health

Introduction

Health data maps and geographic information systems (GIS) are significant resources for health planning and health services delivery, particularly at the local level. More specifically, the ability to visualize the spatial distribution (e.g., by neighborhood or city block) of health status indicators and other health-related information (such as air

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quality as modeled from traffic and air flow patterns) can be a powerful resource for mobilizing community action to improve the health of residents.

Currently, health data maps and other GIS applications tend to be highly technical and specialized, and are therefore of limited use to community members and organizations providing community-based health services. Developing GIS and health data maps that are relevant, accessible, and useable for communities and local agencies is an important step in realizing the goal of “enabling individuals and communities to increase control over and to improve their health,” to cite the 1986 Ottawa Charter for Health Promotion (1).

Background

To develop health data maps and other GIS applications that are relevant, accessible, and useable, it is crucial to work closely with potential user groups in the community. The project described here has evolved from a collaboration between members of the Southeast Toronto Organization (SETO), Toronto, Canada.¹ SETO is a consortium of community members and community agencies providing health and social services in southeast Toronto—a diverse urban area with a population of 120,000.

Before the initiation of the current project, the SETO partners made a number of advances through collaboration. Through multi-faceted community consultation, respiratory health (especially asthma and related conditions) was identified as an area of focus for this project. Further groundwork was laid for this project by exploring the availability and nature of routinely collected health data potentially suitable for mapping; testing the feasibility and utility of developing health data maps (including the sponsorship of a community workshop to test preliminary “health maps” in a mixed audience of professional, scientific, and lay project stakeholders); and development of a project agenda that meets the requirements of all SETO partners.

Objectives

The entire project is based on the premise that the information resource being developed is more likely to be useful for community members and community health agencies if it is designed, from the start, in collaboration with these end-users. In this project, in addition to creating a GIS, SETO seeks to provide an analysis of the development process. The project’s objectives, therefore, address the product and process of the collaboration between these partners.

Product

The first goal of this project is to produce an interactive, online GIS that is developed and iteratively refined through active collaboration between SETO partners. The GIS will integrate a wide range of routinely collected information relevant to the determinants and manifestations of respiratory health (particularly asthma and related chronic/recurrent conditions) in the population of southeast Toronto. A fundamental

¹ SETO partners include: Toronto Department of Public Health, Central Neighbourhood House, South Riverdale Community Health Centre, Regent Park Community Health Centre, community residents, University of Toronto, Wellesley Hospital, Central Hospital, St Michael’s Hospital.

aspect of the GIS is that it will allow users to access information in a range of formats from collaboratively pre-designed maps to raw data.

Process

The second goal is to document the conceptual, group-process, and logistical/technical problems in the collaborative development of such a GIS for community use, and to describe the solutions found by the project for these problems.

Knowledge Development and Synthesis

The third goal for this project is to analyze and report on potentially generalizable lessons learned concerning both the technical process of GIS development and the social process of collaborating on such a task. In essence, the project seeks to identify factors potentially affecting the success of any collaborative applied research aimed at solving local health problems.

Implementation of Project

Project implementation was preceded by consultation with each SETO member organization to assess their needs and expectations of the project, as well as their current data processing and analysis capability in terms of both hardware/software and personnel. Following the needs assessment, project implementation involves four iterations through two steps: GIS development, then joint critical assessment of the GIS with community-based users.

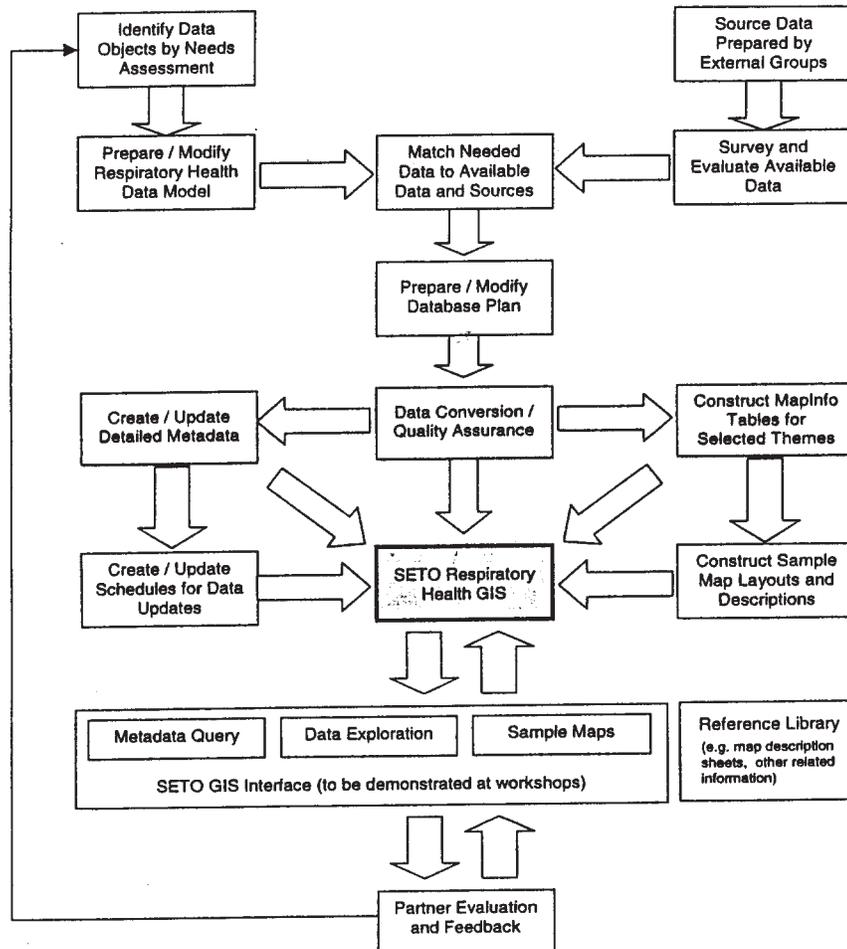
Dividing tasks between a technical team and a collaborative process team facilitates the project implementation. In each iteration, the technical team assesses the needs and capacities of various prospective users among SETO partners, assesses data sources, and produces iterations of GIS prototypes. A user group made up of representatives from SETO member organizations provides feedback on these GIS prototypes. The collaborative process assessment team then analyzes the user group's responses to the prototypes, as well as the technical team's response to that feedback, as obtained through a series of participatory evaluative workshops.

GIS Development

Figure 1 illustrates the iterative process used to develop the respiratory health GIS. This process involves developing data models and assessing candidate data sources, then designing and producing the GIS. The technical team develops a respiratory health data model (Figure 2) to facilitate identification and assessment of candidate data sources. This model attempts to describe the relationship between determinants and indicators of respiratory health.

Criteria for evaluating candidate data sources were developed from a comprehensive metadata model developed for the project. The criteria include the following aspects of a data source: quality, completeness, relevance, ease of integration, potential for misinterpretation, and cost (if any).

The needs assessment discovered a wide range of capabilities among the SETO partners. This finding suggests that the GIS should accommodate this range of capabilities. The technical team therefore decided to base the GIS upon user-friendly, PC-based



Modified from the Department of Geography, University of Buffalo GIS Development Guide. Volume II – Survey of Available Data. <http://www.geog.buffalo.edu/ngia/sara/foursurv.htm>

Figure 1 Data flow diagram for iterative design, production, and assessment of SETO respiratory health GIS.

software including MapInfo (MapInfo Corporation, Troy, NY) and Microsoft Excel, and to devise a system of layered access within the GIS.

The system of layered access provides access to information at varying levels of complexity. Users interested in more complex information can access raw data in Excel format or MapInfo tables. Such users can then create maps or perform other analyses with these data. Users interested in a less complex presentation can access collaboratively pre-designed maps (i.e., MapInfo layouts) and basic analyses. Two examples of pre-designed maps are shown in Figure 3.

So far, the technical team has faced a number of challenges in developing the GIS. These include integrating data sources of varying quality, scale, and “ownership”;

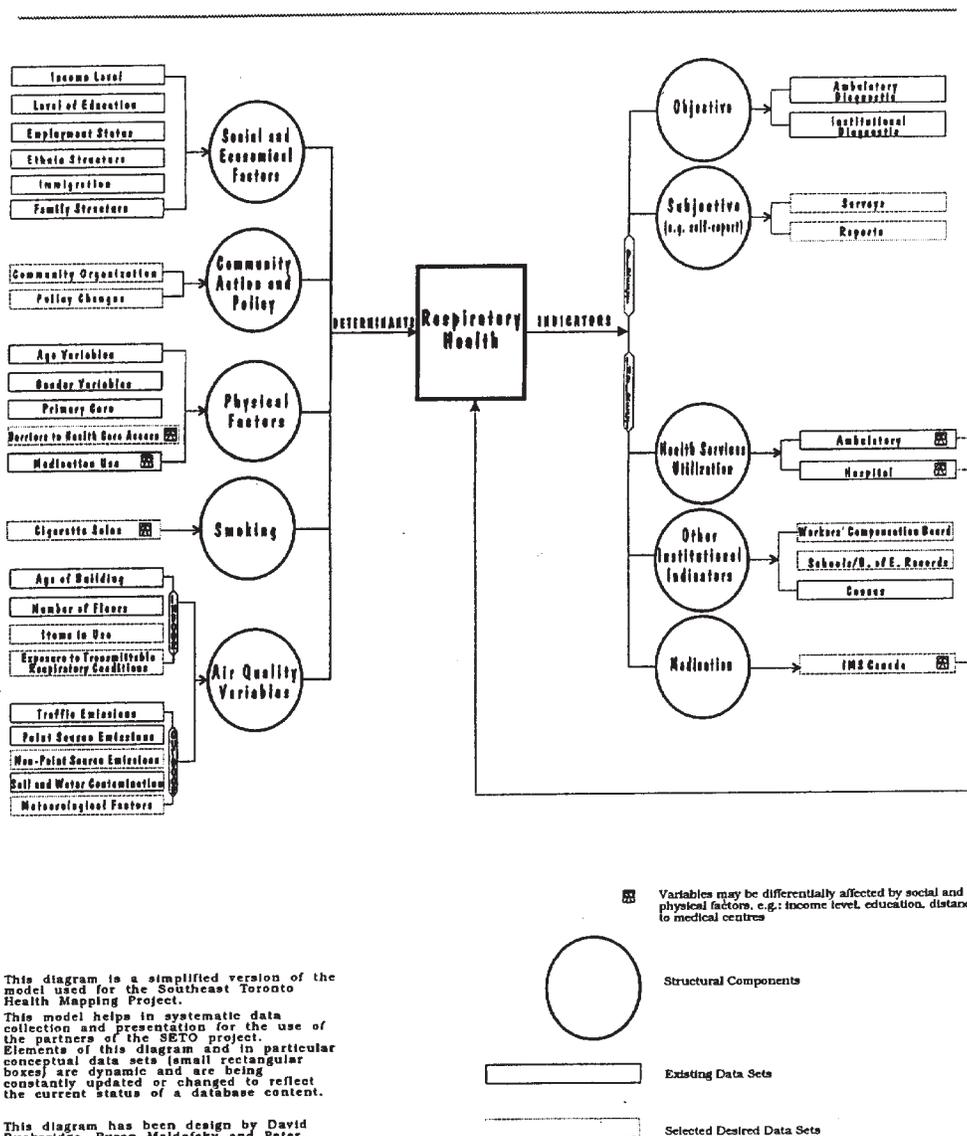


Figure 2 Respiratory health data model.

substantial diversity of user needs, capacities, and perspectives; and the need for data depictions that achieve the essential compromises between various stakeholders' concerns. Depicting qualitative data and integrating them with quantitative data present unique challenges.

Joint GIS Assessment

A joint assessment of the GIS product is conducted through a series of participatory evaluative workshops involving all the project's collaborators. These workshops

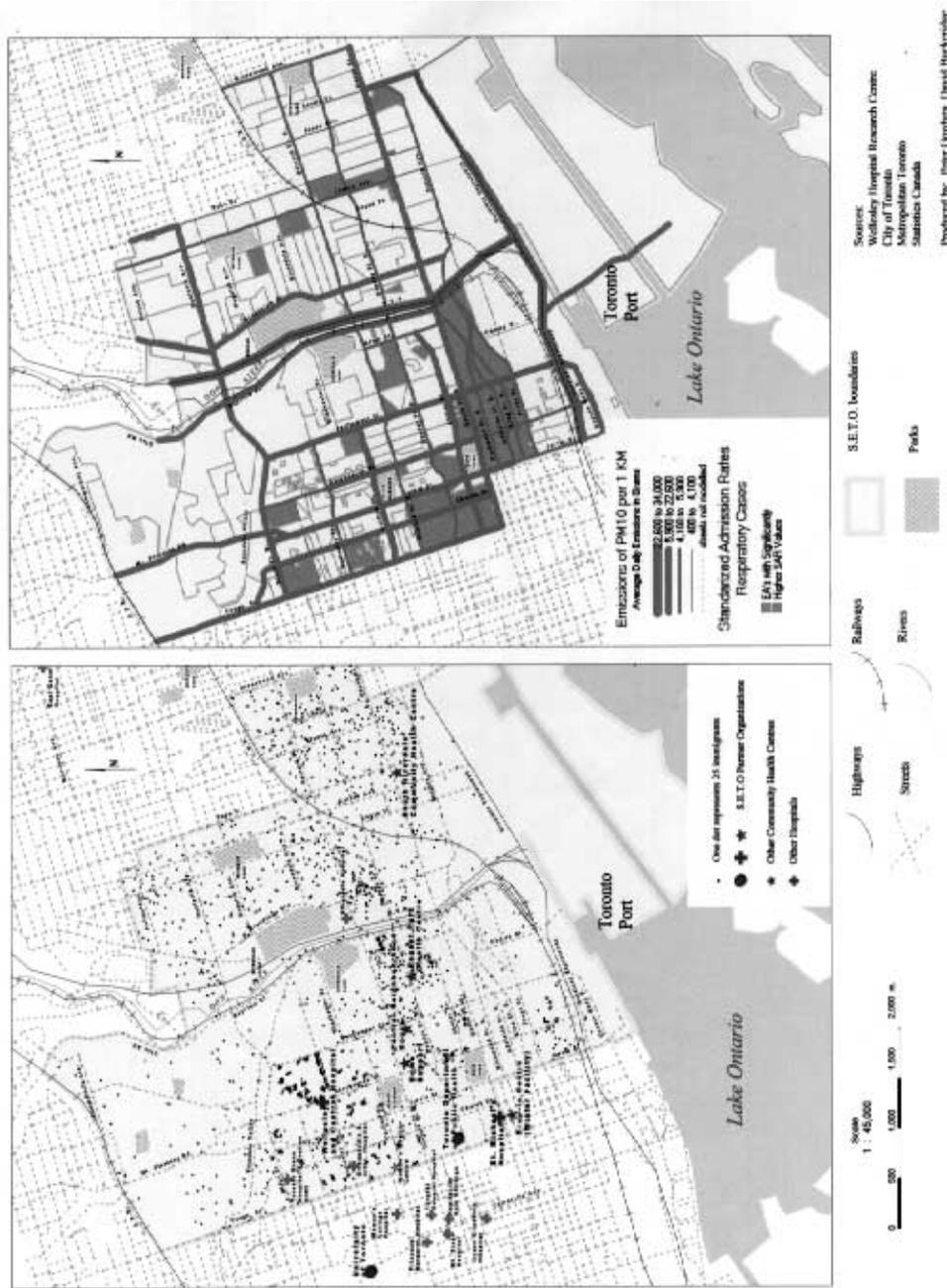


Figure 3 Pre-designed maps, Southeast Toronto Health Mapping Project.

provide feedback to the technical team. They also serve to meet the project's third objective, to assess what factors facilitate or impede collaborative projects of this kind.

The development schedule calls for the technical team to produce, at four points in the project's course, working versions of the GIS for presentation to the user group in day-long workshops. These workshops provide opportunities for hands-on, interactive demonstration and use of the prototype GIS. Feedback from the user group about the quality, relevance, and usability of the GIS is provided to the technical team, which attempts to address the issues raised by revising the GIS for the next iterative loop (i.e., the next workshop) in the collaborative development process.

Immediately following each workshop, the collaborative process assessment team conducts separate focus group debriefing sessions with the technical team and the user group to determine issues of collaboration that arose in the course of the workshop. The sessions are taped and transcribed for qualitative data analysis. Transcripts of the focus group sessions are subjected to a content analysis according to standard qualitative methods. The results of preliminary analysis are presented to a combined meeting of the technical team and the user group and for respondent validation and for discussion. The emerging themes from each set of focus groups are to be carried forward until after the last workshop, at which point the themes will be used to develop a coding scheme that will be applied to transcripts of all focus group sessions.

Discussion of Important Issues

Focus on Public Health Problem Identified by the Community

Community members, community agencies, and researchers have identified respiratory health as an important public health problem in southeast Toronto. Concern among community members in one area of southeast Toronto led to the establishment of an indoor air quality committee some years ago. This committee has held regular workshops and educational events for the surrounding neighborhoods, including participatory theatre performances. In another ethno-culturally diverse area of southeast Toronto, a citizen committee associated with a community health center has conducted a survey of symptoms and other aspects of asthma and its prevention. This survey was prompted by the perception that many new Canadians in southeast Toronto were experiencing respiratory conditions for the first time. Community agencies in southeast Toronto have also worked on the problem of respiratory health for some time in an attempt to achieve a shift in resources from treatment to prevention, including removal of inequities in distribution of risk conditions and access to high-quality care. Finally, epidemiological research done in southeast Toronto has shown a twofold elevated risk of hospital admission for respiratory problems in Regent Park (an area of public housing in southeast Toronto), after controlling for potential confounders.

Community Involvement

Community involvement has always been an essential aspect of this project. As described above, initiatives in the area of respiratory health from concerned community members stimulated the development of this project. Multi-faceted community consultation served to identify health maps and GIS as potentially useful tools for facilitating ongoing activities by community members and community agencies. Furthermore, in

addition to providing definition and scope for the project, community involvement continues to shape the project through the collaborative workshops that are at the heart of the project.

Examination of the Collaborative Process

A decision was made at an early point in project design to examine the effectiveness of the collaborative process rather than the project outcome. This approach was taken because, despite the current enthusiasm for collaborative research, there are virtually no studies that are convincing about the benefits and challenges of this kind of collaboration, or that document and analyze the factors that facilitate or impede collaborative efforts. Collaborative research of this nature requires that people from different backgrounds and institutional cultures, with different demands, incentives, and practices, work together. In so doing, they must overcome conceptual, communication, organizational, and technical differences and challenges. In addition, issues of power and the legitimacy of certain kinds of knowledge arise. In collaborative research, all participants are challenged to ask critical questions about the approaches they take, as well as about the nature, relevance, and efficacy of their respective practices.

Potential to Replicate Project

One of the objectives of this project is to report on potentially generalizable lessons learned concerning both the technical process of GIS development and the social process of collaboration in this task. These lessons should help others to replicate the technical portion of this project. Furthermore, the use of existing datasets, a PC platform, and user-friendly software has kept the cost and expertise required to implement this project to a minimum.

References

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