A Picture Speaks For a Thousand Numbers: Allowing the Community to Examine Available Health Data Through User Friendly Mapping Software

Piotr Gozdyra[1], Richard Glazier[2] & Byron Moldofsky[1]

[1]Cartography Office, Department of Geography
University of Toronto. Toronto, Canada
Phone: +416 978-3378 Fax: +416 946-3886
Email: gozdyra@geog.utoronto.ca, byron@geog.utoronto.ca

[2]Department of Family and Community Medicine
St. Michael's Hospital Inner City Health Research Unit
Phone: +416 864-6060 ext. 2574 Fax: +416 864-5485
Email: glazier@whri.on.ca

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ABSTRACT

In the recent years respiratory health has become one of the most burning concerns for many health professionals in large urban centres including Toronto, Canada. Increasing levels of air pollution, polarized socioeconomic status among inner city dwellers and various levels of health service provision are only a few of many factors that are assumed to have a strong impact on respiratory health. These facts are usually well known to researchers, physicians and other experts in the area of public health. However, groups and individuals that could apply this knowledge in the domain of public advocacy and health promotion often lack such information. An additional difficulty arises from the fact that most of the patient data in Canada is confidential, hence access to it is limited to a narrow group of health professional and academics. This paper describes a successful pilot project bringing health information to several community organizations and hospitals in the form of a mappable spatial database. The use of GIS tools and display of relevant data on maps proved to be a successful method of communicating health information and, at the same time, provided means to overcome the strict limits placed upon the release of patient data in a numeric format. An extensive examination of available data and mapping techniques was undertaken by a group of academics, community members and health service providers to objectively represent spatial phenomena that determine and indicate the status of public health in Southeast Toronto. The product of this teamwork has been delivered to groups and individuals engaged in health promotion at the local community level. The database and the custom mapping software received a complimentary welcome at various locations where it was utilized.

***Keywords and phrases*:** respiratory health, GIS, mapping of health variables, multi-institutional collaboration, community participation, public advocacy, health policy.

1.0 INTRODUCTION

The purpose of this paper is to present the design and outcomes of the Health Data Mapping Project (HDMP): A Community-University Collaboration, which is a spin-off project of an almost a decade long inter-institutional collaboration process governed by the South East Toronto Project (SETO). Participating researchers represent such fields as epidemiology, geography, statistics, public health and urban planning and are affiliated with several institutions and organizations including University of Toronto, The City of Toronto Department of Public Health, community health centres, hospitals and health research units.

The objectives of the HDMP are twofold: (a) build and disseminate a comprehensive database reflecting the state of respiratory health among residents of Southeast Toronto and (b) study community-university collaboration in developing the health database. This study focussed on respiratory health, as an area of special concern to community groups within the study region of 120,000 people. However, the study's primary purpose was as a pilot project to learn general lessons about using collaborative methods to build a geographic info system around any health issues, in any area. Sharing of data with community activists and local hospitals serves the purpose of improving the level of understanding of health patterns at a large spatial scale, which in turn helps in the designing of better-fit health policies and service delivery.

One of the unique attributes of this project is its innovative approach to multi-institutional collaboration and health data disclosure. From among a few similar efforts the Rotterdam Local Health Information System (REBUS) initiated in the late 1980's should be mentioned first. The aim of this project is very similar to HDMP objectives – monitoring of health patterns at the neighbourhood level, contributing to the development of local health policies and disseminating of study findings to local health agencies and governments (Oers, 1993). Another example comes from the Midtown Neighborhood Association in Pima County (MNAPC), Arizona. In 1987, MNAPC launched the Midtown Neighborhood Mapping Project, which focused its efforts on collecting demographic, land use and socioeconomic data in order to create a thorough portrait of the studied neigbourhoods. Its findings were used by residents and authorities for advocacy and planning (Anonymous, 1998).

In the following sections of this article emphasis are placed on the design, implementation and evaluation of the technical component of the project. The collaboration study element will be described to a lesser extent due to the nature of this colloquium. Section 2.x describes the theoretical framework of the project while section 3.x focuses on the implementation stage. In section 4.x project's findings and evaluation of its products is discussed. Brief conclusions are found in section 5.0.

2.0 PROJECT'S DESIGN

The HDMP was initiated by a group of researchers and health activists that formed the steering committee and its two working sub-groups: (1) collaborative team and (2) technical team. The latter had adopted the task of creating an interactive geographical information system that would be later used by the Project's partner institutions. Different information needs of these partners were used to construct a preliminary framework for the project's design.

2.1 Conceptual Data Model

In order to establish a methodological framework to be used throughout the lifetime of the project a conceptual data model was developed. The model illustrates some basic concepts in respiratory health by displaying its major data components and relationships among them. Each of these components is essentially a grouping of variables that, in its full version, is further subdivided into smaller groupings and into single variables on the lowest level (see Figure 1). Following the project's method of cyclic revisions and improvements, the Conceptual Data Model underwent several changes to reflect new ideas and data acquisitions.

2.1.1 Design of the conceptual model

The project's conceptual framework was a relatively complex issue. The diverse expertise of the participants and their different expectations regarding the focus of the project needed to be merged into a consistent methodological plan that could satisfy all parties. In order to address this the technical subgroup developed an initial draft of the conceptual data model during several introductory meetings. This framework played a central role in a number of methodological and technical areas of the project such as (1) illustrating the epidemiological relationships between respiratory health and its determinants and indicators, (2) organizing the data collection

and integration efforts, (3) assisting users in navigating through the database and finding information, (4) supporting the design of the custom mapping interface.

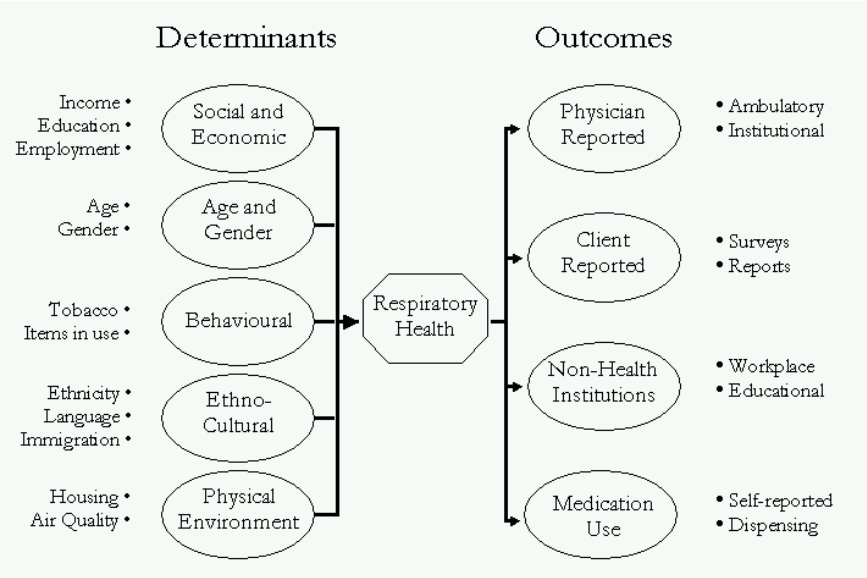

Figure 1: Project's Conceptual Data Model (simplified version)

The general two-sided flowing structure of the data model was adapted from several public health studies that frequently surround the disease component by ecological and individual factors of a deterministic or indicative nature (Evans, 1995). The selection of components at the different levels of the model is a reflection of relevant epidemiological theory, physical and human characteristics of the study area, diverse interests of the project's partners and data availability. The conceptual data model has been recently used by two other health and GIS-related Canadian projects intending to utilize some of the findings and methods developed by the HDMP.

2.2 Project's technical elements

Once the conceptual model was in place the design of the database began. In order to apply the stated strategy of making this geographical information system easily accessible to an audience with a wide range of skills the following technical decisions were made: (1) the project should use windows-based personal computers, (2) raw and mappable data, metadata and other project-relevant information should be organized into a directory structure that reflected the conceptual data model, (3) popular software packages should be used to accommodate less advanced computer users.

2.2.1 Database access and directory structure

Several community partners are faced with computer hardware and software insufficiencies that do not allow them to fully utilize either the health database or the custom mapping interface. For this reason a university-based computer network has been chosen for hosting of the project's digital outcomes. A computer lab has been offered to all partners who wish to use it. The directory structure within which all data has been stored reflects the conceptual data model. Any user equipped with a hardcopy of the full version of the conceptual model can easily find its way around almost 200 MB of data, description files, on-line tutorials and other contents of the database.

2.2.2 Utilization of popular software

Two software platforms, each with different functionality, have been utilized: (1) MS Office 97, (2) MapInfo 5.0. MS Office was found to be very useful for storing and displaying text and numeric data while MapInfo is used for storing, manipulating and displaying spatially referenced data. The use of MS Office internal links helped to connect relevant files making the exploration of the database more efficient.

To illustrate the usefulness of this tool the following example shows possible file connections obtainable with the click of a mouse:

raw data file <-> data dictionary file <-> data evaluation file <-> metadata file

MapInfo was found to be the most user-friendly mapping package. This was an important consideration, as most of the Project's partners have no prior experience in making maps or manipulating of spatial databases.

3.0 PROJECT'S IMPLEMENTATION

The execution of the designed plan has been the most time consuming part of the project. Three stages of this phase can be clearly distinguished: (1) data identification and acquisition, (2) data evaluation and integration into a database and (3) cartographic display of data using GIS tools. In addition, four GIS and health-oriented workshops and a series of evaluations and tests of project's outputs at partners' locations were conducted throughout the course of the study.

3.1 Data collection – sources and obstacles

Identification of the relevant data sets and their potential sources was the first step of the project's implementation stage. Some of the data came directly from the project's investigators. Examples of such variables are the hospital and outpatient records, which equipped the collection with a very valuable set of outcome-type variables. A second important data source is Statistics Canada from which most of the socioeconomic determinant variables have been acquired. The rest of the data came from various commercial and non-commercial institutions such as marketing firms and municipal or federal governments. The table below lists the most important data sets and their sources:

Data set:	**Source:**
Hospital Discharge, O.H.I.P. records	Canadian Institute for Health Information, Ontario Health Insurance Plan
Socioeconomic Profile Statistics	Statistics Canada
Consumer Spending Potential	Compusearch, Canada
Medication Purchases	IMS, Canada
Land Use	Municipal government
Point sources of (air pollutants) emissions	Environment Canada, Ontario Ministry of Environment
Exposure to traffic emissions	City of Toronto, Ontario Ministry of Environment

Only in a few isolated cases was the data acquisition process trivial. In most instances one or more of the following obstacles have been encountered: (1) long bureaucratic procedure of data release, (2) lack of data release protocols, (3) disordered organization of source databases, (4) high cost, (5) data confidentiality, (6) spatial or temporal incompatibility, (7) incompatible format, (8) incompleteness, (9) lack of geographic attributes. Despite such difficulties the project has managed to establish a fairly comprehensive health database.

3.1.1 Unique character of epidemiological data and its mapping

The health data created several sources of possible confusion for those utilizing the maps and these needed to be clarified. First, the users' attention needed to be drawn to the distinction between count data and rates, since both could be mapped using similar formats. Count data, for example number of people seen by a doctor for asthma in a certain location, are most useful for those planning services since they can see where the population's need for services lies. Users were encouraged to employ dot maps for counts, thus representing the distribution and density of service use in a meaningful way. Rates, which reflect both the counts (numerator) and the population (denominator), are most useful for examining reasons or causes. For example, finding high rates of asthma in some locations but not others may lead to further investigations into air pollution or allergens. Users were limited to the use of chloropleth or proportional symbol maps for rates, so that high and low rate areas could be easily distinguished. Randomness of a dot placement on density maps and the use of rate variables on other types of maps allowed overcoming the constraint of the health data confidentiality. One additional possible source of confusion was also addressed. The rates, which were mapped, reflected areas with different age and sex structures. This situation could lead to erroneous conclusions since older populations are expected to have more health problems and increased problems seen on the maps could be due to age alone. For

this reason, we used indirect age-sex adjustment to control for these effects, allowing us to map rates that would have prevailed if all areas shared the same age-sex structure.

3.2 Database – creation, updates and evaluations

The gathering and integrating of data of a substantially diverse nature required cautious planning and thorough quality evaluation. Acquired data was compiled and placed into the appropriate sections of the directory structure. Each data set was then described in a metadata file. A selection of variables was documented in the form of hardcopy sample maps. The full HDMP database construction and evaluation process has been summarized in Figure 2.

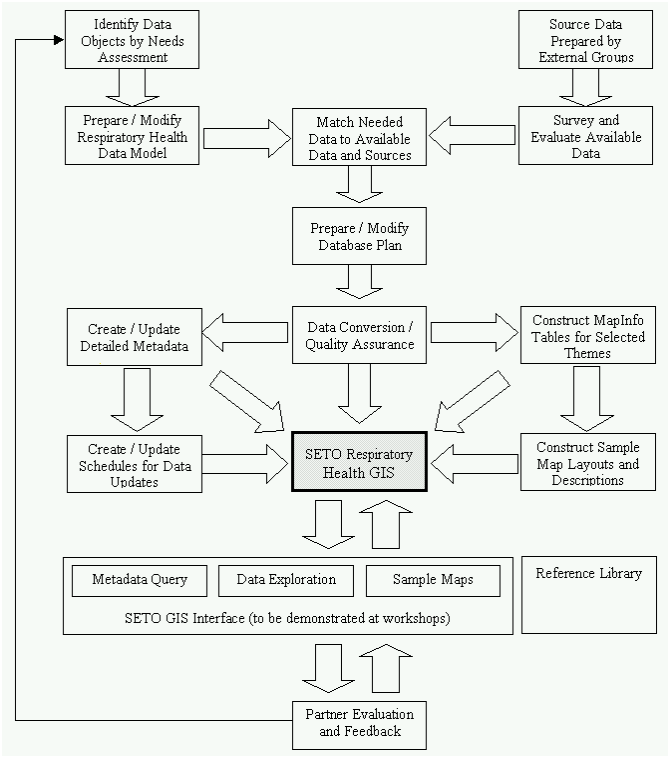

Figure 2: Data Flow Diagram for Iterative Design, Production and Assessment of HDMP Respiratory Health Geographical Information System. Modified from the Department of Geography, University of Buffalo, 1998.

3.3 Application of cartographic and GIS tools for communicating of the gathered information

The four main motives for applying GIS and mapping tools by the HDMP are: (1) supplying of an alternative way of examining data sets that are normally accessible in tabular formats only, (2) allowing for a visual examination of possible spatial patterns of respiratory conditions, (3) overcoming of the data release limitations that are placed upon patient records in a numeric format, (4) introduction of user-friendly mapping utilities to the community. Guided by these intentions the project's technical team faced a challenging process of choosing, designing and creating a reliable mapping application that would best illustrate the health issues of study area. Given the nature of data, a number of cartographic preferences have been defined. Combination of the GIS and mapping choices formed the guidelines for designing of the custom geographic information system.

3.3.1 Main cartographic considerations

Most of the staff members of community and health institutions for whom the project prepared the spatial database have limited experience in the interpretation of maps and virtually no experience in map creation. This situation limits the usefulness of the information system and brings the risk of incorrect mapping techniques being applied by non-expert users. To alleviate this problem some basic cartographic concepts and the pitfalls of mapping were presented during the university-based workshops. The system addresses these problems in two ways: by providing "read-only" sample maps which model recommended methods and solutions, and by

introducing a customised "recommended" mapping interface, described in section. 3.3.2. The interface limits the map-creation options of the users to encourage cartographically sound practices.

Mapping at appropriate scales
The use of detailed census units (Enumeration Areas) as the standard mapping unit results in a large variation in the size of polygons mapped. Small polygons in congested areas and much larger ones around the periphery pose a common cartographic problem. In the interactive environment, this can be partially overcome by zooming in for a closer look, and this was encouraged. However, for overall visualization of data in the study area, and for hard copy map output, the problem is significant. The tendency is to underestimate the significance of small areas, as their visual weight is low. To address this on the sample maps, an enlarged inset map of the most congested area was incorporated into the standard map layout. For users' independent mapping, the scale issue was addressed by encouraging types of data representation least likely to be subject to scale-related problems.

Mapping using appropriate data representation
As shortly mentioned earlier, the data representation methods available were choropleth mapping, proportional symbol mapping, and dot distribution mapping. The most common fault by inexperienced users is the use of choropleth shading to represent absolute numbers. Therefore, in the customized interface, choropleth mapping was enabled only for rate or density data variables. Dot distribution maps were encouraged as most appropriate for showing count data. The use of proportional symbols was enabled and encouraged for representation of either rates or counts. Correct scaling of these symbols was also suggested by the methods used on the sample maps, and by the incorporation of appropriate methods (linear scaling for bar symbols, areal scaling for circles and squares) within the customized interface.

Mapping using appropriate colours and symbolisation
In all three methods of representing data, the overall impression communicated by the map can be skewed by inappropriate use of colour or symbols. For choropleth shading, visually relating higher values to darker shades of a single hue is usually most successful for the depiction of quantitative values. The shape of the geometric figure used for proportional symbols mapping is critical - irregular shapes which add visual noise and are difficult to relate to areal units should be avoided. For dot distribution mapping, the choice of dot size, colour, and dot unit value is basic to the visual clarity and usefulness of the display.

Mapping using appropriate layering techniques
Two factors make for appropriate data "layering" on a map. The first is a well-designed, unobstructive base map on which to reference data layers. Thus in the customised map interface, a standard representation of base data was supplied as the foundation on which to superimpose data layers. The second is using appropriate representation methods for successive data layers. In the sample maps and workshops it was suggested that plotting dot distributions overlaid on choropleth maps was the most effective way to explore comparisons of different data sets that are mapped together.

Other factors
Other cartographic issues such as legend design, data classification, and general rules of map interpretation were also addressed in the partners' workshops. Despite these precautions it is important to consider that creating and interpreting maps is a new method of health data analysis for many institutions involved in the project, and therefore some mapping errors and misinterpretations are still possible.

3.3.2 Need for custom mapping interface

Upon the completion of the first hands-on workshop it became evident that the MapInfo software in its full format poses more challenges to the non-expert users than was initially anticipated. They found it difficult to master the spatial concepts and the use of software tools representing them. At that point the technical team made the decision to offer a more user-friendly interface, which was subsequently developed using MapBasic programming language. Its main goal was to simplify the mapping process for the non-expert GIS users allowing them to focus on data exploration and development of useful concepts rather than resolving software questions.

The overall envisioning of the interface was a crucial part of the customization of the mapping process. All members of the technical team met on numerous occasions exchanging ideas and making refinements to the tools that will be available to future software users. Collaboration with community members, cartography/GIS experts, epidemiologists and other specialists proved to be a very effective way of designing of tools that will be

able to address needs of different users. This interactive process engaged many concerns that would normally be overlooked if only programmers and GIS specialists were responsible for designing the software.

Three levels of interface complexity
One of the first decisions made was to ensure that software users with different skills or expectations would be able find the appropriate tools. Three levels of interface complexity were integrated to meet this objective:

- Viewing pre-made maps - this level is the simplest of all three and requires no GIS or mapping experience. After the launching of MapInfo the user is presented with a list of sample maps related to the scope of the project. No manipulation of these maps is possible, except for printing and saving them into the user's home directory. This level can be also used by advanced users to view the examples of more complex map layouts that can be produced using a full functionality of MapInfo.
- Recommended interface - the option gives access to the project's mappable database taking the user through several interactive steps that result in creating of a simple thematic map of the chosen variable. One data set can be mapped in each iteration but the user can repeat the process overlaying new thematic maps or producing them side-by-side for comparisons. Each variable has a set of pre-defined mapping options, such as map type, range of symbol sizes or colour palettes. Such constraints were necessary to ensure that users with less advanced cartographic skills will not choose incorrect mapping techniques. Selected metadata and descriptions of more advanced cartographic concepts have been also embedded into this level.

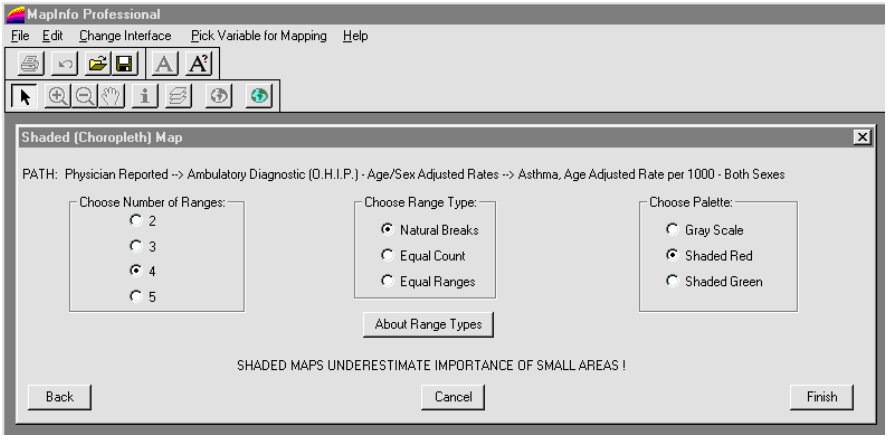

Figure 3: Recommend interface custom dialog showing sets of pre-defied choropleth mapping options for a user- chosen variable.

- Advanced features - full functionality of MapInfo accompanied by the recommended tools. This level is reserved for more experienced GIS users. It offers a full range of mapping options maintaining access to project's database in both numeric and mappable formats. To ensure confidentiality of the data sets the access to this level is protected by an additional password available for project-affiliated researchers.

Flexibility vs. simplicity
A common computer tools design issue of searching for the right balance between flexibility and simplicity of the applications has been encountered. Supplying more options in the recommended interface, such as possibility of modifications of elements of a created map was assumed to be useful for the user, but at the same time such elasticity was resulting in a greater complexity of the custom dialogs. Hence, it has been decided that the recommended interface will offer an easy, well-guided mapping process that can be repeated effortlessly by the user, and any output modifying and data querying options will be available at the advanced level. This solution has been evaluated and approved by the users of the application.

Upgrades and updates
The project's custom interfaces have been designed to serve a well-defined group of users with a pool of carefully chosen data sets. The question of sustainability of HDMP's outputs has been raised by the partners nevertheless. Due to a number of complex issues such as data ownership or availability of technical support after

the project's completion date no further arrangements facilitating updates of the database and software have been made. However, foreseeing this kind of uncertainty the technical team has placed a special attention to the tasks of database creation and the programming of custom interface, so the future developers of these products will not have too many difficulties in understanding and improving the already existing resources.

4.0 LESSONS LEARNED

The Health Data Mapping Project can be considered as innovative in the Canadian setting. The results of this pilot project deliver helpful pointers to future undertakings of a similar nature. Two categories of conclusions relate to (1) the project's goals and achievements in the dissemination of health information and (2) overall findings concerning collaboration. While the former was a set of tasks designed and implemented by the project's personnel and affiliates, the latter depended mainly upon the willingness for cooperation among partner and non-partner institutions.

4.1 Evaluation of the project's output

This evaluation process was conducted in two different ways. First, between June of 1998 and January of 1999 several university-based workshops took place. Among approximately 20 attendees were health specialists and activists from the project's partner and non-partner institutions. The first workshop was organized in a form of a presentation while during the subsequent ones participants had an opportunity to learn and practice their mapping skills using the health database and interface developed by the technical team. Each of these hands-on workshops was preceded by a short cartographic training session and concluded by a 'questions and answers' period during which participants had a chance to communicate their approval or dissatisfaction based on the tested GIS. Secondly, between February and May of 1999 five system testing sessions took place at partners' locations. Two community health centres, two hospital research units and the Department of Public Health of a Toronto municipal government were visited. At each of these locations the technical group set up appropriate computer hardware and software allowing the staff to have a continuous access to the project's health GIS for a period of two to three weeks. The hardware-software-data system was accompanied by a hard copy manual that included such sections as a confidentiality agreement, user guide for the custom mapping interface, full list of mappable variables, example-based mapping exercises, sample maps and evaluation questionnaire. It is unknown exactly how many users tested the system but is estimated that this number ranged from as few as two to as many as ten or more at each site depending on the institution. Eight people completed the evaluation questionnaire, which emphasized issues of meeting partners' mapping/data needs and suitability of the custom GIS.

4.1.1 Meeting community's information and mapping needs.

Based upon partners' feedback a clear message has been identified – mapping of health information is useful for all institutions and individuals that were invited to this collaboration. In the case of one of the community health centres the reception of project's mapping product was so favourable that its staff members have asked for permanent access to the software and data upon completion of the project. In general, the ability to map the phenomena, which were earlier unknown or known only intuitively, has been highly valued by all partners. Being able to produce maps permits them to discover spatial patterns and examine the geographic relationship between supply and demand for health services. In response to the evaluation questionnaire most users found the spatial data content 'relevant' or 'very relevant' with one person marking the option 'not relevant'. All respondents found the level of mappable data 'appropriate' or 'somewhat appropriate'. Several user comments suggested that the regular maintenance and updating of this health database would be useful for their work purposes. Some remarks were also made about extending the range of health variables to other conditions such as rabies and cancer.

4.1.2 Database and custom mapping interface

To some surprise the MapInfo segment of the database was given considerably more attention by the users than the text and numeric data components. This outcome probably reflects the fact that the community members are interested in a graphic display of data as opposed to tabulations. This finding confirmed the initial concern of placing significant attention on the quality of mappable data and to making correct choices of mapping techniques. The feedback received during university-based workshops was reflected by the improvements in the database contents and applications developed by the technical team. The on-site testing of this improved system brought a range of reviews focusing on the straightforwardness of the custom interface and clarity of available mapping techniques. All respondents found the custom interface 'easy' or 'very easy' to use. They also agreed that the maps that can be produced range from 'somewhat -' to 'very relevant' for the operations of the visited

institution. A variety of other more technical responses were also received providing useful information for possible future developments of this or other similar health information systems.

Although the study area is Southeast Toronto the following suggestions communicated by the system users can be easily extended to other projects of a similar nature:

- Community activists are most interested in a wide range of up-to-date variables of a health and socioeconomic nature. Other interesting data sets should describe local environmental conditions such as indoor and outdoor air quality, housing stock, homelessness and gender and age-specific issues.
- Although specific users may be mainly interested in neighbourhood level phenomena, the database should cover a larger spatial extent, preferably the whole city in which the neighbourhood is located. This enlarged area can be used for comparison purposes.
- Metadata and straightforward descriptions of mapping tools should be easily accessible to users with limited GIS skills.
- On-going technical support should be available to all users of the database.

4.2 Benefits and obstacle of an inter-institutional collaboration

Collaboration with over fifteen partner and non-partner institutions has been an essential component of the HDMP. Some differences in this cooperation pattern between the partner and non-partner institutions have been clearly detectable.

4.2.1 Cooperation with partner institutions

Partner organizations and individuals supplied a majority of expertise and portions of data necessary for the completion of this project. The management and stability of this cooperation often proved to be a difficult task. The main obstacle was a lack of time that could be assigned by some institutions to meetings and workshops organized by the project. Another, more complex and difficult to deal with barrier was a sporadic underestimation of the potential gains from such teamwork. To a large extent a lack of experience in utilizing spatial databases and maps can be blamed for this. However, the overall collaboration among partner institutions involved in this project must be summarized as successful and productive.

4.2.2 Cooperation with non-partner institutions

Many non-partner institutions have been approached during the lifetime of this project mainly for the purpose of data acquisition. One important lesson has been learnt from these contacts – it is often very difficult to find the right people who are willing to offer an extra time from their schedule to the work that is not related to their daily tasks. Consequently, the chances of the timely achievement of goals of such cooperation are much greater if the key people in the approached institutions can be defined and approached. Previous contacts should also be used whenever possible.

4.3 Future steps

All users of the project's GIS expressed their interest in seeing this product being further developed and possibly utilized on a permanent basis at their institutions. The two main problems that should be addressed during the revision of the system for possible future uses are improving the ways of disclosing health data variables without violating confidentiality constraints, and the development of easier-to-access mapping applications. The first of these goals leads to solving of a potentially complex cartographic question of how an average user interprets health-related maps and which of the preferred mapping techniques should be applied in the given set of applications. The question of dissemination of health information and unconstrained accessibility to mapping tools directs the future efforts towards Internet-based mapping applications. Both of these problems will be included in the new study that has been recently initiated under the umbrella of GEOIDE – an extended network of geomatics research and research-supporting organizations in Canada.

5.0 CONCLUSIONS

The HDMP has addressed a number of public health-related issues during its two-year life span. The project's innovative character encompassed a fairly broad definition of initial goals that have been later refined and reflected in the project's outputs. The defining and completion of project's goals was achieved through the collaboration of several institutions that served as a source of diverse expertise and expectations. The main technical outcome is a comprehensive respiratory health-related spatial information system and the custom

mapping interface for its mining and analysis. A substantial amount of work has been also committed into the development of methodological concepts linked to gathering, compiling, integration and display of health and health-related information. An equally important research outcome accomplished by the project but less emphasized in this paper was the study of the collaboration process. The knowledge of how to effectively communicate with other individuals and institutions often strengthens the likelihood of a successful completion of research efforts that require such diverse inputs.

The HDMP has produced a whole range of recommendations on how to address the issues of multi-institutional collaboration, development and maintenance of health GIS, data mapping, software interface design and others. The relatively short time length of this project has not allowed for some more complex analysis and applications however, most of these shortcomings have been recognized and some of them will be confronted in the new study that has been initiated in the summer of 1999.

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