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Making health data maps: a case study of a community/ university research collaboration

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Abstract

This paper presents the main findings from a collaborative community/university research project in Canada. The goal of the project was to improve access to community health information, and in so doing, enhance our knowledge of the development of community health information resources and community/university collaboration. The project built on a rich history of community/university collaboration in Southeast Toronto (SETO), and employed an interdisciplinary applied research and action design. Specific project objectives were to: (1) develop via active community/university collaboration a geographic information system (GIS) for ready access to routinely collected health data, and to study logistical, conceptual and technical problems encountered during system development; and (2) to document and analyze issues that can emerge in the process of community/university research collaboration. System development involved iteration through community user assessment of need, development or refinement of the GIS, and assessment of the GIS by community users. Collaborative process assessment entailed analysis of archival material, interviews with investigators and participant observation. Over the course of the project, a system was successfully developed, and favorably assessed by users. System development problems fell into four main areas: maintaining user involvement in system development, understanding and integrating data, bringing disparate data sources together, and making use of assembled data. Major themes emerging from the community/university collaborative research process included separate community and university cultures, time as an important issue for all involved, and the impact of uncertainty and ambiguity on the collaborative process. © 2002 Elsevier Science Ltd. All rights reserved.

Keywords: Community health; Research collaboration; Community/university partnership; Interdisciplinary; Geographic information systems; Medical informatics; Canada

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Introduction

This paper presents and discusses the findings of a community/university collaborative research project to develop accessible and relevant health data maps for a sub-area of a major Canadian city. In a larger sense, the impetus for the project behind this paper came from two trends in community health research in Canada throughout the 1980s and 1990s: (1) the increasing involvement of community stakeholders in the joint design, conduct and dissemination of research concerning local health problems; and, (2) attempts to bridge narrow academic disciplinary perspectives by fostering truly *transdisciplinary* investigation (Rosenfield, 1992; Health Canada, 1997; World Health Organization, 1997). The project grew from this context, and was fostered by a deeply held conviction, shared by both the community and university partners participating in this project, that a better job of understanding and acting on the 'upstream causes' of ill health *at the population level* (McKinlay, 1979), could be done through *partnering*, and *integrating* the diverse perspectives and resources represented in the project. This type of community/university research collaboration represents an emerging research paradigm (Kuhn, 1970) which itself requires further investigation.

The overall goal of the project was to improve access to community health information, and in so doing, enhance our knowledge of the development of community health information resources, and community/university collaboration. Under this broad goal, we had two specific objectives. The first was to develop and iteratively refine via active community/university collaboration a geographic information system (GIS) for ready access to routinely collected community health data, and to study logistical, conceptual and technical problems encountered during system development. Our second objective was to document and analyze issues that can emerge in the process of community/university research collaboration and to discuss their implications for other such research partnerships. The purpose of this paper is to present an overview of the findings from the project. These findings relate to the two objectives of the project, namely the empirical research outcomes related to the construction of the novel community health GIS, and the results of the qualitative examination of the collaboration between community and university partners in developing the system. More detailed analyses of each of the two components of this project are the subject of future papers.

Immediately following this introduction, we describe the evolution of the community/university collaboration underlying this project. Then, following a brief review of relevant literature, we present the methods used for collaborative system development and assessment of the collaborative process. In order to maintain continuity

within each objective of the project, findings are presented and discussed together for system development, then for the collaborative process. Finally, we conclude by outlining the relevancy of our findings and making recommendations for future work.

Background

Because events prior to the initiation of most collaborative community-based projects have the potential to shape the nature, and influence the success of what subsequently develops (Altman, 1995; Hodgson & Abbasi, 1995; Guldan, 1996), we start with a brief project history. This project represents a unique community/university partnership. The community partners in this project were all members of the Southeast Toronto (SETO) coalition; a coalition of health agencies, social services and residents of a discrete geographical area of the larger city of Toronto. SETO was formed in 1989 to strengthen agency collaboration and community involvement in identifying and responding to the health needs of residents. The university partners included academics from several Departments across four Faculties at the University of Toronto—Arts and Science (Geography and Planning), Architecture, Medicine (Public Health Sciences) and Social Work.

The downtown Toronto community served by SETO members has, by Canadian standards, a high prevalence of low income, unemployment, single parent families, teen births, and elevated mortality rates from a variety of causes. In addition, certain groups face barriers to accessing health care information and services, and to involvement in decision-making. SETO also has a long history of community mobilization. For example, Toronto's first legal clinic was established in the area, and many other services were established as a result of the residents' commitment and ability to take action. Accessible community health information has been an interest of SETO since its inception. For example, one coalition partner, the Toronto Public Health Department, designed a series of neighborhood profiles for use by local agencies. SETO partners had also explored the use of maps for health assessment and service planning, and were interested in further investigating the potential of this method of representing health information.

From an academic perspective, this project arose out of a deliberate effort on the part of the University of Toronto to facilitate a collaborative applied research initiative, which was to focus on the basic determinants of urban health, employ interdisciplinary teams, and involve local community organizations as active partners. This three-year initiative began in 1994 and was led by a newly appointed 'Provostial Advisor on Population Health.' The first steps were a series of ad hoc meetings of academics interested in such research collaboration,

together with members of SETO. The project that ultimately received funding was a direct outcome of these initial meetings.

In the years leading up to the funded project, SETO partners identified two issues of specific interest—respiratory health, and the need for accessible and relevant community health information. In 1995, a team of co-investigators including SETO members and researchers from the University of Toronto prepared and submitted to a national public sector funding agency an initial research proposal to collaboratively develop health data maps which would be accessible and useful to SETO members. This initial proposal was rejected and, in 1996, SETO and the University of Toronto Research Office provided the ‘health data mapping project’ team with ‘seed’ funding to conduct an exploratory investigation into the nature and extent of respiratory illness in this area of the city. The results of this preliminary investigation indicated that rates of hospital admissions for respiratory illness were greater than expected. While the limited information available did not allow for a thorough examination of the determinants and status of community respiratory health status, it did confirm that both respiratory health and access to a greater breadth and depth of health information were priorities for SETO members. At the same time as this exploratory study was being carried out, the project team continued to revise the more extensive research proposal, which was re-submitted in September 1996. This submission was successful and funding was received for a two-year project that began in September 1997.

Relevant literature

Information and collaboration are both fundamental to community health. The importance of each is stressed by various perspectives on community health, including Health Promotion (World Health Organization, 1986, 1988, 1997), Population Health (Evans, Barer, & Marmor, 1994; Frank, 1995), and Health for All (World Health Organization, 1998; Zoellner & Lessof, 1998). It has been suggested that information and information systems can facilitate examination of health determinants, monitoring of health outcomes, and empowerment of communities (Evans et al., 1994; Lorenzi, Riley, Blyth, Southon, & Dixon, 1997; Zoellner & Lessof, 1998). Similarly, a role has been identified for collaboration within and between academic, government and non-governmental organization sectors to further community health research and action (World Health Organization, 1997; Zoellner & Lessof, 1998). Despite an understanding of the importance of information and collaboration in community health, gaps exist in our knowledge, particularly in terms of practical issues associated with both health information (Berndt, Hevner, & Studnicki, 1998; Mettee, Martin, & Williams,

1998; Zoellner & Lessof, 1998) and research collaboration (Altman, 1995; Baum, Santich, Craig, & Murray, 1996; Guldan, 1996).

Community health applications of GIS and information systems

GIS are potentially powerful resources for community health for many reasons including their ability to integrate data from disparate sources, and their inherent mapping functions. A well-developed GIS has the potential to provide ready access to a wealth of health data, but design considerations for GIS in a community health context are largely unknown. Experience with applications of GIS to health issues has increased considerably over the last decade, but in vast majority of cases, GIS has been applied to time-limited etiological research as opposed to ongoing efforts in health planning, promotion and protection. GIS are now frequently used for health research in a variety of areas including communicable diseases (Becker, Glass, Brathwaite, & Zenilman, 1998), cardiovascular diseases (Scott, Temovsky, Lawrence, Gudaitis, & Lowell, 1998), alcohol (Midford et al., 1998) and drug use (Latkin, Glass, & Duncan, 1998), animal disease control (McGinn, Cowen, & Wray, 1996), and chronic respiratory diseases (Hales, Lewis, Slater, Crane, & Pearce, 1998). Recent reviews of the use of GIS for research in epidemiology (Anonymous, 1996; Clarke, McLafferty, & Tempalski, 1996), tropical diseases (Openshaw, 1996) and environmental health (Dunn & Kingham, 1996; Vine, Degnan, & Hanchette, 1997) reveal an evolving understanding of the benefits and drawbacks of applying a GIS to etiological health research. There is also a growing trend towards using GIS for disease surveillance (Devasundaram, Rohn, Dwyer, & Israel, 1998) and health services research (Bullen, Moon, & Jones, 1996; Scott et al., 1998).

These examples describe a range of GIS applications in a health context, but they all apply a GIS to a single research or surveillance issue over a limited period. The relatively infrequent use of GIS to facilitate ongoing community health planning and promotion may be due to the problems encountered in identifying, acquiring and integrating a wide range of georeferenced data relevant to community health (Twigg, 1990; Marrett, Theis, Baker, & Whittick, 1998). However, if these difficulties can be overcome, experience suggests that GIS (van Oers, 1993) and information systems in general (Roos, 1995; Roos et al., 1999), can make use of existing data sources to support decision-making and problem solving in community health planning, service delivery, and health promotion. Given the limited experience in developing systems for ongoing community health use, it is important to identify the logistical, conceptual and technical issues encountered in system development in this context.

Collaborative community/University research

While there is a considerable body of literature describing community/university research partnerships, and/or the outcomes of these research collaborations, relatively little research has examined the actual process of collaborative research. The few studies that do exist have noted that as organizations and individuals are brought together to form research partnerships, differences in their organizational/institutional cultures become apparent. These differences relate to issues of power, expertise, and control and are exacerbated by communication problems and discrepancies in resources (Bickel & Hatstrup, 1991; Peterson, 1993; Gilling, 1994; Somekh, 1994; Barnsley, 1995; Cottrell, Lord, Martin, & Prentice, 1996; Gondolf, Yllo, & Campbell, 1997; Rovegno & Bandhauer, 1998). Some studies have also identified that different bases of knowledge, ways of behaving, thinking, acting, and talking all contribute to difficulties in communication. Differing views about the nature and purpose of the research, methods for studying a particular issue and the use—including the political use—of the research findings tended to further complicate the collaboration (Bogo et al., 1992; Nyden & Wiewel, 1992; Peterson, 1993; Boutilier & Mason, 1994; Gilling, 1994; Cottrell et al., 1996; Gondolf et al., 1997).

Time, in terms of both the time required to carry out the research and the different time orientations of partner organizations, tends to complicate collaborative research efforts (Bickel & Hatstrup, 1991; Nyden & Wiewel, 1992; Galinsky, Turnbull, Meglin, & Wilner, 1993; McFarland, DiBlasio, & Belcher, 1993; Boutilier & Mason, 1994; Gilling, 1994; Bevilacqua, Morris, & Pumariega, 1996; Corse, Hirschinger, & Caldwell, 1996; Lundy, Rippey-Massat, Smith, & Bhasin, 1996; McWilliam, Desai, & Greig, 1997; Rovegno & Bandhauer, 1998). In addition, it has been recognized that an intensive time commitment is required to develop mutual understanding and effective working relationships (Bevilacqua et al., 1996). It has also been reported that the necessary slower pace of the collaborative research may result in feelings of dissatisfaction on the part of some researchers (McWilliam et al., 1997).

Several studies have reported that each of the partners involved in collaborative research perceive particular risks and threats in entering into participatory research partnerships. Community partners tend to see potential conflicts between service provision and research demands (Stiffman, Feldman, Evans, & Orme, 1984; Corse et al., 1996; Lundy et al., 1996; Gondolf et al., 1997), while university partners tend to see the collaboration as posing threats to research rigor, control over the research process (Stiffman et al., 1984; Galinsky et al., 1993; Lundy et al., 1996) and constraints on publication opportunities.

In summary, while the existing literature provides broad descriptions of issues in collaborative research,

there has been, to date, no rich, detailed study of the process of collaboration between the partners as they work together on a joint research project. The project discussed here sought, in part, to address this gap in the research on collaborative research.

Methodology

Execution of the project was realized through two project teams, each containing both community and university partners and supported by a research associate. Community partners included front-line workers as well as senior administrators, while university partners represented tenured and non-tenured faculty (including department chairs and a senior academic administrator), university staff and graduate students. One team facilitated the development of the GIS, and the other team oversaw an ethnographic study of the collaborative process. A steering committee composed of researchers drawn from both teams directed the overall implementation of the project. In presenting the methods, we first describe system characteristics. We then present the methods for system development, followed by the methods for the assessment of the collaborative process.

System development

The GIS was implemented on a PC platform using standard software for mapping (MapInfo Professional 5.0, MapInfo Corporation, Troy, NY), data storage (Excel 97, Microsoft Corporation, Redmond, WA), and storage of data set descriptions (Word 97, Microsoft Corporation, Redmond, WA). Only the graphical user interface required extensive customization, using the MapBasic programming language (MapInfo Corporation, Troy, NY). Through three different levels of custom interface (Fig. 1) users could view pre-made maps; create, overlay and analyze custom maps through series of prompts from the system (i.e. a 'wizard'); or, access the full functionality of MapInfo for more complex map creation and analysis. An example of a sample map created for the first level of the interface is shown in Fig. 2. All levels of the interface allowed access to metadata as brief overview 'pop-up' screens and through links to detailed metadata files. Users could also store maps they had constructed, and print maps using a color printer. Table 1 lists a range of data describing the determinants and manifestations of respiratory health that were included in the GIS.

System development followed a collaborative, interdisciplinary action research design (Boog, Coenen, Keune, & Lammerts, 1996). This approach drew upon theory and methods encapsulated in standard models of information system development (Checkland & Holwell,

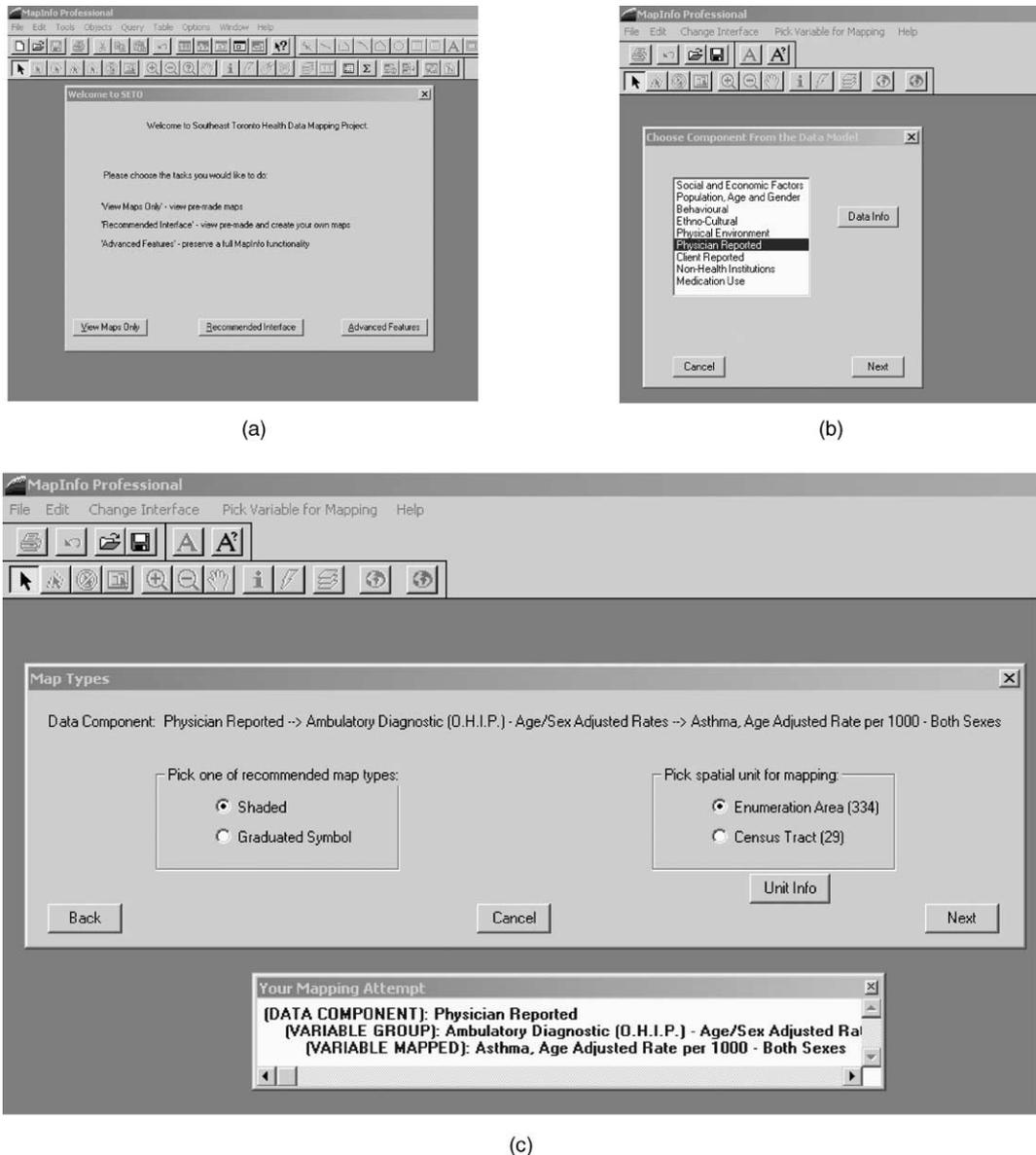


Fig. 1. Screenshots of the customized user interface. (a) Initial screen following logon. Three levels of interface are suited to different levels of user skill. ‘View Maps Only’ accesses a selection of pre-made maps, ‘Advanced Features’ provides full access to MapInfo. (b) First screen of intermediate interface. The user selects a data model component for mapping (‘Physician Reported’). Note that the interface is now simplified, and that metadata is accessible by clicking ‘Data Info’. (c) Intermediate interface after selecting a data model component, a variable group and a specific variable to map. The user is now prompted for a map type and a spatial resolution. The users’ path through the data model is shown at the top of the ‘Map Types’ window, and in the ‘Your Mapping Attempt’ window. Note that available map types are constrained by the type of variable (i.e., the user is mapping a rate, so the ‘dot density’ map type is not available), and that more information about spatial resolution can be accessed by clicking on ‘Unit Info’.

1998), with a particular focus on participatory design (Sjoberg & Timpka, 1998) and GIS development methods (Becker et al., 1995). Broadly summarized, system development involved iterating through: determination of community partner needs and abilities (Fig. 3, a–d); development or refinement of the informa-

tion system (Fig. 3, e–i); and, assessment of the system by community partners (Fig. 3, j). In the following paragraphs, we comment on the most notable steps in a single iteration through the development cycle.

In an initial step (Fig. 3, a), university and community partners developed a ‘conceptual’ data model. The

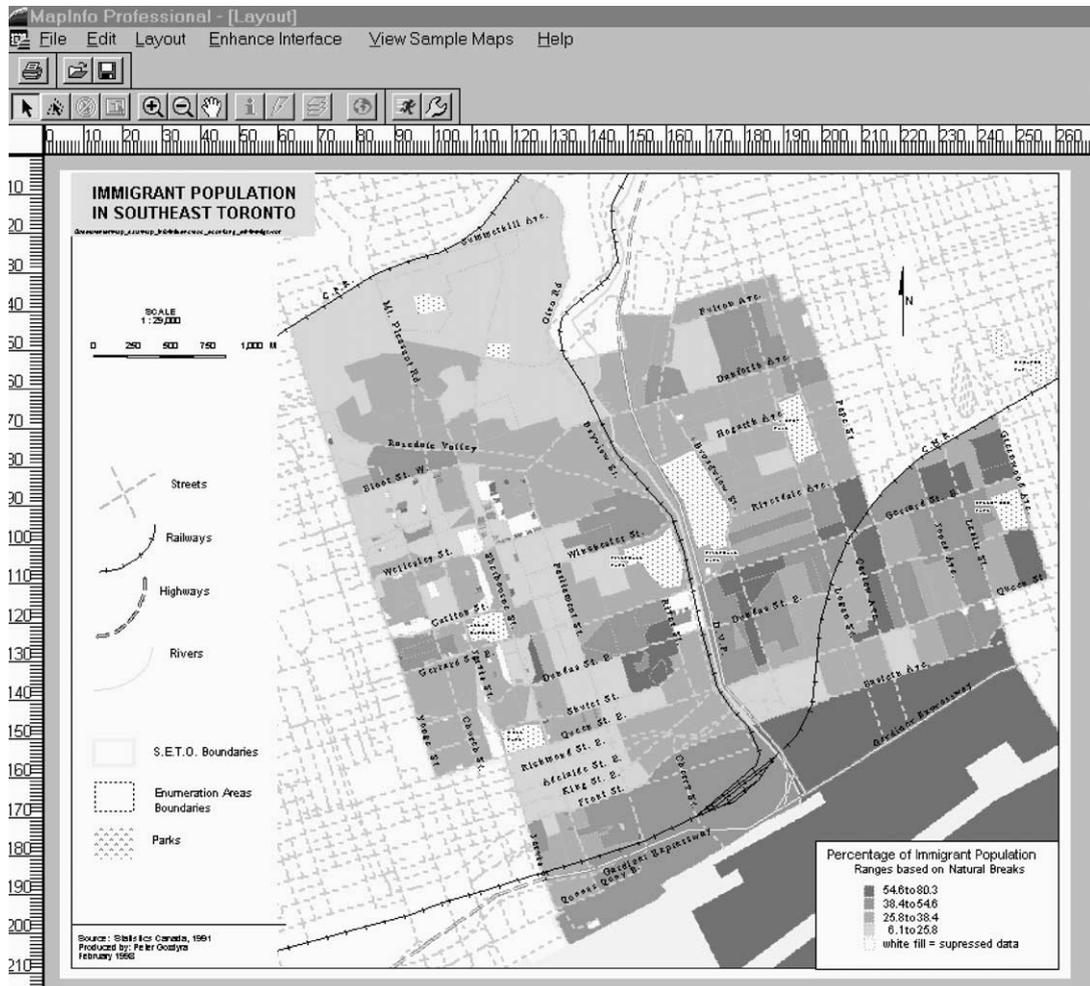


Fig. 2. Sample map created for the 'view maps only' interface.

purpose of this model was to facilitate data integration and enable discussion of respiratory health concepts among participants from different backgrounds. We developed the data model by discussing and modifying a determinants of health model (Evans & Stoddart, 1990; Frank, 1995). A determinants of health model was used as the basis for our data model as the determinants of health model explicitly acknowledges the influence that non-medical determinants (e.g. income, occupation, environment) have on population health status, qualitatively relates these determinants to health outcomes, and has been used successfully as the basis for other population health information systems (Roos et al., 1995). The resulting conceptual data model was consistent with theories of population health (Evans & Stoddart, 1990; Frank, 1995) and respiratory health (Rosen, 1999; Stone, 2000; Valacer, 2000), while still being straightforward enough for use in a community setting.

The next steps involved identifying, evaluating, and acquiring potentially relevant data sets (Fig. 3b–d). For lack of other available mechanisms, investigators relied upon previously existent or informal contacts to identify relevant data for the project. Separate conditions were negotiated with each data holder to allow data set access and transfer. Once data were acquired, they were integrated into the GIS using our data model and the spatial unit of the enumeration area (EA—a census sampling area with a median population of 400 in SETO) to relate data sets to one another (Fig. 3, Step f). Base maps of EA boundaries were constructed in MapInfo (version 5.0, MapInfo Corporation, Troy, NY) and ARC/INFO (version 7.1, Environmental Systems Research Institute, Redlands, CA) formats to provide lattices for the integration and display of data. Georeferenced data sets were translated into MapInfo tables and stored in a directory structure reflecting the conceptual data model.

Table 1
Data contained in geographic information system

Data acquired	Organization data acquired from
<i>Data describing determinants of respiratory health</i>	
Census, cartographic files	Statistics Canada
Land use, traffic volume	City of Toronto
Air monitoring and emissions	Environment Canada
Air monitoring	Ontario Ministry of the Environment
Consumer spending patterns	Compusearch
<i>Data describing outcomes of respiratory health</i>	
Hospital separations	Canadian Institute for Health Information
Ambulatory physician visits and procedures	Ontario Health Insurance Plan
Prescription drug sales	IMS

On the basis of user comments, the system was limited to three map types that were most easily interpreted (i.e. shaded or choropleth maps, dot density maps and graduated symbol maps). Map creation was limited by data type to ensure appropriate depiction for a given data type (e.g. counts could be mapped as dot density or graduated symbol, but not choropleth or shaded maps). A graphical user interface was designed to allow users with varying levels of skill to access metadata and view or create maps in a manner suited to their skills (Fig. 3, i). The iterative nature of the overall project design and the close involvement of users in system design drew upon both user-centered and rapid prototyping/iterative design methods (Patel & Kushniruk, 1997).

Community partner needs and abilities continually directed the development of the information system through a series of four university based workshops, and on-site testing at community partner locations (Fig. 3, j—workshops summarized in Table 2). At post workshop briefings, investigators discussed their observations and user comments, and developed action plans for making necessary modifications to the system. At the on-site trials, system users completed a questionnaire with 11 questions addressing user skill (2), data content (3), system interface (4), and system utility (3). The main questions addressing system interface, data content, and system utility are shown in Table 3. Completed questionnaires were analyzed by calculating summary statistics for responses to questions on a Likert scale, and by identifying themes in responses to open questions. Following each of the first three workshops and the on-site trial, we initiated another iteration through the system development cycle.

Collaborative process

Ethnographic research seeks answers to questions about the culture and behaviors of groups or commu-

nities and attempts to understand these from the insider's point of view (Spradley, 1980; Denzin & Lincoln, 1994; Creswell, 1997). The research activities for the collaborative component of the project followed standard ethnographic research methodology. Specifically, this component was framed as a qualitative case study (Yin, 1985, 1993) and utilized three different data sources: (1) project archival materials; (2) two sets of interviews spaced one year apart, with each of the co-investigators; and, (3) participant observer notes taken during the various interactions of the two sets of partners.

The project archives included minutes of meetings, memos, and other written materials that had been produced during the three-year period prior to the funded project start-up in September 1997. Initially, these archival materials were reviewed to create a project chronology and to determine key moments in the life of the project. They were then subjected to a standard content analysis to generate recurring themes that were used to inform the subsequent in-depth interviews with the co-investigators.

After the collaborative process sub-team developed an interview guide, in-depth interviews were conducted with each of the co-investigators at two different points during the funded project. Interviews focused on the interviewee's history of involvement with the project, experiences of working with the other partners and perceptions of facilitators and barriers to collaboration. Each of the interviews lasted from one and a half to two hours and all interviews were tape recorded and transcribed. Interview data was then coded using the QSR NUD*IST program (version 4.0, Sage Publications Software, Thousand Oaks, CA). After the first set of interviews was coded, the preliminary coding report was presented to all co-investigators as a validity check. The collaborative process sub-team then met to consider the themes

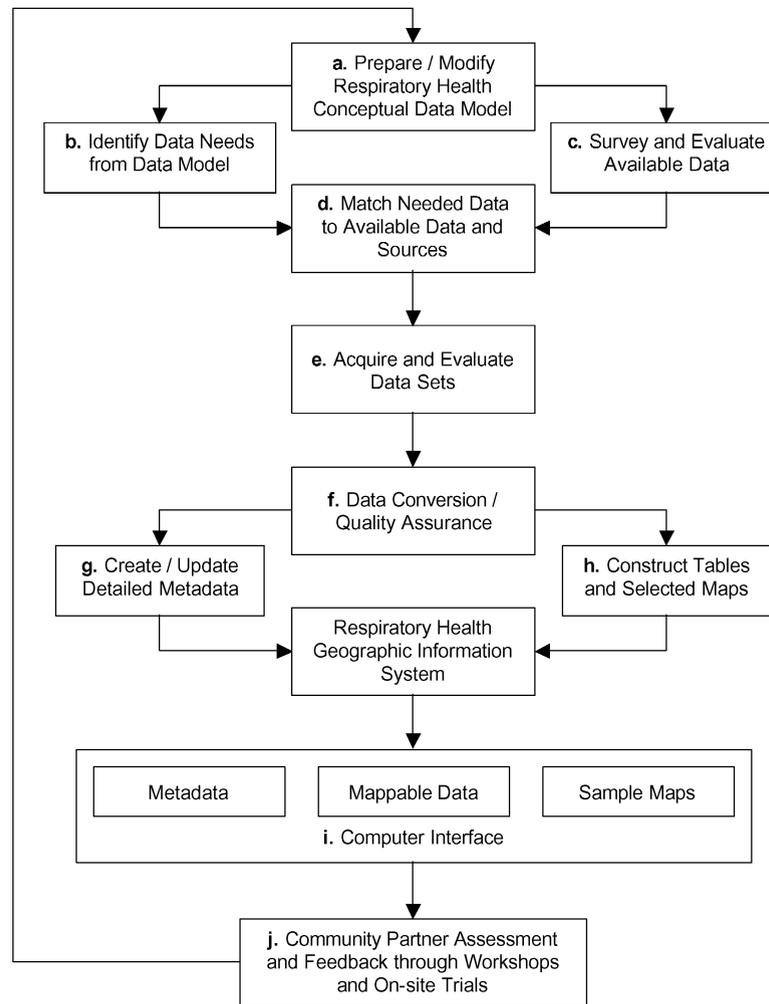


Fig. 3. Overview of iterative system development process (adapted from (Becker et al., 1995)).

that were emerging from this preliminary coding and based on these emergent themes all transcripts were recoded in order to develop a thematic analysis. The second set of interviews, one year later, was an opportunity to confirm the validity of the thematic analysis, to probe for new or different themes and to check for disconfirming evidence.

Over the course of the project, the research associate for the collaborative process sub-team observed interactions between the co-investigators at regularly scheduled meetings of the steering committee, research team meetings, and during the four workshops held for the community partners. Detailed field notes of these meetings and post-meeting reflections were kept in a journal that were later coded and integrated with the other data sources.

Results and discussion

System development

The project developed a GIS, to integrate and provide access to routinely collected data relevant to the determinants and manifestations of respiratory health in SETO. A survey was given during the on-site trials to elicit user opinions of data content, the interface and the utility of the GIS. Eight users completed the questionnaire while testing the system at five community partner sites. The four female and four male respondents were all in positions that required frequent use of computers to manipulate health data (e.g. Health Promoter, Health Information Analyst, Research Manager). In addition, some (three) regularly used mapping

Table 2
Community partner assessment and feedback during system development

Event		Month of project ^a	Aim	Organization
Workshop	1	2	Introduce project to potential system users at partner organizations; gather initial user input on system requirements	Half-day session in meeting room, presentation by research team; open discussion of system requirements
	2	10	Community partner assessment of information system; feedback to research team on aspects of system to refine in next iteration of system development cycle	Hands-on half-day workshops in university computer laboratory; users worked on simulated scenarios (developed with community partners); co-investigators gathered opinions on system content and interface
	3	16		
On-site testing		20		Two-week period of on-site system use by community partners at community organizations; initial training session and ongoing support; feedback gathered via questionnaire
Workshop	4	24	Present initial results to system users; discuss future directions	Half-day session in meeting room, presentation by research team; open discussion of future directions

^aProject duration was 24 months.

and statistical software, and the majority (five) regularly used database software. As Table 3 shows, users found that the intermediate level interface was easy to use, and felt that the system in general was useful (average response of 3.3 for both questions on scale from 0 to 4). Users also thought that the types of data and types of maps were relevant (average responses 2.9 and 2.8, respectively), but there was less satisfaction with the level of detail in the available data (average response 2.4). Users commented that it would be helpful to have more recent data, data for neighboring areas (to support comparisons), and specific data sets not already included in the system (e.g. cancer, communicable diseases). When questioned about what activities that the GIS could facilitate nearly all users (seven) indicated it was useful for describing the community, many (six) thought it was useful for health advocacy and planning, and some (five) thought that it would be useful for health services and disease etiology research. Only half the respondents (four) indicated that the system would be useful for delivery of health services. Specific comments made about the utility of the system included: 'It is useful to see trends in the patient population within a service area,' and 'The system provides a way of presenting information that is easy for an audience to understand.'

We take the results of our use assessment as evidence of 'proof of concept' for this type of system from design and use perspectives. There are, however, some qualifications that should be noted. First, our assessment results are based on a small sample of relatively proficient computer users who routinely handle health data. Users with different skill levels may view the system differently. Also, although none of the questionnaire respondents were investigators in the study or authors of this paper, they were all members of organizations that were strong proponents of the project. Knowledge of this organizational commitment may have led respondents to view the system favorably.

Although, it was not a main objective of the study, demonstrating the utility of such a system adds important context to our main objective of identifying problems encountered in system development. Table 4 summarizes the main issues encountered in system development, and the solutions employed to address each issue. In some cases, solutions were definitive, but for the most part, they merely provided an interim means of addressing a problem so that system development could continue. In the following paragraphs, we present our findings and discuss the issues in light of the work of others.

Table 3
Questionnaire responses ($n = 8$) for main questions

Area	Question	Average ^a	Max	Min
Usability	Overall, how easy/difficult was it to use the mapping program?	3.3	4	2
Data	How relevant are the types of data in the mapping program to your work?	2.9	4	0
	How appropriate is the level of detail of the data in the mapping program to your work?	2.4	3	2
	How relevant are the types of maps produced by the mapping program to your work?	2.8	4	2
General system	Overall, if you had access to a similar mapping program in the future, how useful would it be for your work?	3.3	4	2

^a Responses were given according to a five point Likert scale, with a maximum value of 4, and a minimum of 0.

Table 4
Issues encountered and 'solutions' employed in system development process

Aspect of development process	Major issue encountered	'Solutions' employed to address issue
Maintaining user involvement	Difficult to maintain involvement of community partners	Used hands-on development workshops and on-site system pilots. Included community partners on technical development team
Understanding and integrating data	Differing conceptions of respiratory health among participants	Jointly developed data model through discussion between academic and community partners
Bringing disparate data together	Data sets organized by different geographical units	Used data model and a common high resolution geographical unit for linkage
	No means to systematically locate data	Used informal research networks. Approached branches of government
Making use of assembled data	Unclear legal and administrative grounds for sharing data	Negotiated separate conditions of use for each data set and confirmed data would be used for research
	Limited and inconsistent descriptions of existing data (i.e. metadata)	Adopted standard metadata model to represent available descriptions in an organized manner
	Potential for data display to be misleading	Limited available map types and constrained map types by data types. Provided access to metadata during map making and display
	Range of user skill and needs	Developed user interface with different levels to match classes of skill level

The challenge of maintaining user involvement

A number of authors have suggested that early and continued involvement of users in system development is important, if not essential (Lorenzi et al., 1997; Checkland & Holwell, 1998; Gremy, Fessler, & Bonnin, 1999). Our experience in this project supports the position, as we found that user input strongly influenced design decisions, and the resulting system appeared to meet user needs. However, we found it difficult to maintain

consistent user involvement in system development, and co-ordinating user involvement required considerably more resources than we had estimated at the outset of the project. We encountered these difficulties despite the strong interest of the community partner agencies in the project. Enabling factors for involving users appeared to be the iterative development process, direct involvement of users in the development team, and on-site system evaluation at community partner locations. The diffi-

culty we encountered may be partly attributable to 'local' issues such as the ongoing restructuring of the provincial health system. In general though, developing a system across a number of organizations in a community is a logistically complex undertaking. Given the problems encountered in maintaining user involvement in system development within a single organization (Lorenzi et al., 1997; Checkland & Holwell, 1998), it is not surprising that user involvement was problematic in a community setting. Results from the ethnographic component of this study suggest that issues such as separate cultures, time, and uncertainty may hamper collaborative system development.

Understanding and integrating data—data model development

As information systems increase in prevalence and complexity, models of the relationships between data elements are becoming increasingly important. Data models, more correctly called 'ontologies', explicitly define how concepts (i.e. variables) within data sources relate to each other. In a sense they are explicit 'mental models' or 'conceptual models', which facilitate integration of data by information systems (Davidson, Overton, & Buneman, 1995) and support a common understanding of data by people (Chandrasekaran & Josephson, 1999). In our project, we found that university researchers from different disciplines and community partner representatives tended to use different vocabularies and concepts to describe respiratory health. The 'conceptual' data model developed by participants over a number of meetings was successful in facilitating a common dialogue about respiratory health and enabling access to data. The model also facilitated data integration around the common geographical unit of the enumeration area (EA).

Bringing disparate data together—data identification, description and acquisition

Despite the declared benefits of combining population health data from different sources (Office of Health and the Information Highway, 1998; Stead, Miller, Musen, & Hersh, 2000), information systems that address community health needs in an ongoing manner are the exception (van Oers, 1993; Roos et al., 1995; Berndt et al., 1998), with most systems addressing specific research issues (Linger, Burstein, Zaslavsky, Aitken, & Crofts, 1998). In attempting to bring disparate data sources together, we encountered a number of issues in identifying, describing and acquiring data sets that could hinder the successful development of community health information systems. The issues encountered can be stated succinctly as a lack of directories for locating existing data (Ramroop & Pascoe, 1999), generally poor descriptions (i.e. metadata) for existing data (O'Dwyer & Burton, 1998), and non-standard encoding of data.

Some of these issues have been noted in other settings (Twigg, 1990; Marrett et al., 1998; Mettee et al., 1998; O'Dwyer & Burton, 1998). World Wide Web accessible directories of data would greatly facilitate identifying data sources, and there are efforts underway to develop these in some countries (Office of National Health Surveillance, 1999). Considerable effort has been directed at vocabularies and data standards in clinical medicine (Cimino, 1998; McDonald, Marc Overhage, Dexter, Takesue, & Suico, 1998), but progress in community health has been slow (Godden, Pollock, & Pheby, 2000), despite development of standard health data models by some countries (Australian Institute of Health and Welfare, 1995; Partnership for Health Informatics and Telematics, 1999). The importance of these issues must be acknowledged within public and community health, and concrete steps taken to address them.

Another issue we routinely encountered in our attempts to acquire data sets was a concern over data 'ownership' and/or privacy. Many data holders did not have an established protocol for access to their data, or a clearly identified person with the authority to release data. In the absence of these, data holders were reluctant to release data, and acquisition of some data required a considerable amount of discussion and follow-up. Negotiations to obtain data centered on the research nature of the project, and in some instances, co-investigators bartered expert consulting services for data. The difficulties encountered in acquiring data indicate that privacy concerns present a serious obstacle to system development.

Making use of assembled data—data depiction and the user interface

Access to information is clearly important to enable individuals and communities to address health issues (World Health Organization, 1986), but once accessed, individuals must be able to make use of the data. The ability to make use of assembled data is influenced by many factors, including how the system depicts the data, and the skill and knowledge of the system user. Early in the project, it was apparent that a range of data depiction options (i.e. from pre-made maps to a full-function GIS) would be necessary to meet the variable needs of different end-users. The complex nature of the data, and the heterogeneity in user skill and knowledge both demanded consideration when designing data depictions to facilitate *appropriate* interpretation. Data manipulations, limitation of map type by data characteristics, and provision of access to metadata partially addressed this issue. However, it must be acknowledged that visual depiction of complex demographic, health care utilization, consumer, and environmental information is challenging (Tufte, 1997). This is especially the case when combining data from disparate sources and

working across disciplinary boundaries. We attempted to minimize the potential for misinterpretation of data by providing descriptions of data sets and by constraining how data types could be depicted (Byrom & Pascoe, 1999).

The range of user skill and knowledge was partially addressed by developing a graphical user interface with a number of different 'levels', each supporting a different level of users with different degrees of skill and knowledge. Problems from an interface design perspective included incorporation of a variety of visualization methods (e.g. tables, text, maps) into a single interface, and the need to constantly change the interface to accommodate a refined understanding of user needs and changes in the underlying data structure. Standard software engineering methods, such as design models and modular programming, helped to address these problems. In general, users of community health information systems will nearly always have variable skills and organizational contexts (Medyckyj-Scott, 1993), and this will influence system requirements (Bowker & Star, 1999). Creation of multiple levels of user interface, as done in this study, is one possible approach to this problem of variable user characteristics. Another approach is to use artificial intelligence, as employed in decision support systems, to facilitate user control of information visualization (Shahar & Musen, 1996; Andrienko & Andrienko, 1999).

To summarize, the GIS we developed for access to routinely collected community health information was favorably assessed by a small group of users, and a number of issues were encountered in system development. Our findings appear to be generalizable to other settings as many of the issues have been encountered elsewhere. However, they have not all been previously described in a community health context. These issues have specific implications for practical system development, health information policy, and health informatics research. We address these implications in our conclusions, but in general the issues we encountered will hinder a community's ability to make effective use of existing community health information. Until these issues are addressed, it will be difficult for communities to realize the potential health benefit of enhanced information technology, and increasing volumes of available data

Collaborative process

Initial analysis of the archival material resulted in the development of a project 'life history' and our first significant finding. Although a large group of potential community and university research partners initially met for the purpose of developing a funding proposal to support their research work, it was in fact, several years before any major research funding was granted. In spite

of this, a smaller group kept meeting for three years with only a small amount of 'seed money' to maintain motivation and momentum. This suggests that for this small core group of co-investigators (community and university), commitment to the idea of community/university collaboration was significant enough to maintain their involvement for an extended period of time in the absence of major funding. In addition, to the timely injection of the small amount of 'seed funding', archival materials indicated that the vision and leadership of one of the university partners was crucial in sustaining continuing commitment. This key partner initiated the project as part of a mandated role within the university: to develop an urban life and health research focus that was to be accomplished through an interdisciplinary, collaborative, university alliance with local community health organizations. Indeed, interview data revealed that this person's leadership style facilitated a forum for open dialogue, for the exploration of ideas and for the development of mutual respect. This set in motion a process for working together across many disciplinary and institutional boundaries both within the university (e.g., Arts and Science, Medicine) as well as between the university and the community.

The archival materials, as well as the interviews, also indicated that the history of the project was punctuated by several 'key events' such as an early unsuccessful research presentation to the community, rejection of the first grant proposal and a project retreat held during the preparation of the second round of funding applications. While all the co-investigators acknowledged the awarding of major funding as a significant event in the life of the project, these earlier events were noted as almost equally significant.

The findings from the archival materials contributed to the development of the interview guide and provided an historical reference point for the co-investigators. Analysis of the interviews and field notes revealed several issues that shaped and influenced the collaborative process and partnership that developed during the course of this project. These issues resolved into three major themes: separate cultures, time and uncertainty/ambiguity.

Separate cultures

A key realization for all of the participants in this study was that the partners were situated within and, therefore, familiar with two very distinct cultures, with attendant differences in expectations, values, outcomes, reward systems and work styles. Real understanding about these differences was slow to develop and early misunderstandings had tangible impacts upon the partnership.

For the community partners, tension developed from the competing demands of everyday life in overburdened, often underfunded, service delivery agencies.

Meetings were difficult to schedule and were variably attended, as front-line practice and management often intruded upon the research activities. There were difficulties too in learning to work with the academic partners. A community partner noted:

One of the challenges has been to work with academics. Academics have individual agendas and they are to publish and to develop their own pieces of research and they're not used to working in groups—and they also compete. They are always competing with each other on vocabulary and knowledge so it is not always easy working together.

For the university partners, there was enormous professional tension and individual anxiety in participating in a long-term project with uncertain academic reward, product or output, particularly for the untenured university partners. Feeling unsupported by academic culture, which places more value on individual rather than collaborative research, university partners also believed their concerns were not well understood by their community partners. One academic partner noted:

I'm learning about the distance between myself and some of the community people. I remember I was once at a conference and somebody said to me 'I know where an ivory tower is, I just didn't know they were so high and that we couldn't see each other.' ... You begin to realise the gap in domains of knowledge between the community and university.

Sub-themes within the 'separate cultures' category included issues around language, trust and power. *Language* refers to those issues that arose from different understandings about specific words (such as 'community', 'author'), as well as those that arose from different knowledge bases and ways of understanding the world. It is important to note that these differences occurred as frequently between university partners from different academic disciplines as between university and community partners. *Trust* developed slowly over time, as each co-investigator came to recognize the strengths, commitment and knowledge of the other co-investigators and as the group worked to resolve conflicts and make joint decisions. Both partners equally noted the importance of this aspect of the collaboration:

The hardest challenge has been developing the trust and respect and the ability to convert my head space into what might be more in alignment with what other people were bringing to the table. (Academic partner)

Relationships have developed as we've moved through these three years. And it's getting to know each other, relating and learning to trust each other. (Community partner)

Issues of *power* were seen to derive from differences in status, resources, skills, and personal commitment to the project. Real differences in the perception of the sources of power became apparent.

It's interesting what threatens people and what makes them react and so on, and I think it is a little bit a question of power because we're all there to do the work anyway. I think we all know that but there's still this sort of dance that happens around the table.

Some of the university partners felt the community partners held enormous power, as it appeared that they alone determined the focus of the research project and approved the research agenda. For their part, some of the community partners felt overwhelmed by the apparently resource-rich academy and felt they had to repeatedly argue for the place of the community partners in the research process.

Time

Time was a recurring theme for all the partners. Most of the co-investigators had not anticipated the length of time required for the collaborative research process itself. Individual partners had ambivalent feelings about the time they had devoted to this project, expressing frustration at its seemingly slow progress. Nonetheless, they acknowledged how much they had learned from the exchange of ideas that developed while spending time 'around the table' with the other research partners. This is expressed by one of the co-investigators:

In my view this is high risk. It's very burdensome in terms of the time commitment, energy commitments—painful time. You get hurt feelings, people upset. But it's very rich. The experience is very rich you know. You get more '*ahas!*' for a thousand hours.

Time was thus both a difficulty for individuals and an asset to the collaborative project as a whole. There was frustration on the part of individuals at the long lead-time in developing the partnership, determining the research agenda, applying for funding, and undertaking the actual research and development of the health data maps. However, most of the partners concurred that the lengthy lead-time allowed the relationships to become well established, supported the development of trust in those relationships, created an environment where knowledge could be shared, and finally contributed to the emergence of genuinely collaborative working relationships, which, ultimately, resulted in the production of a useful, useable respiratory health GIS.

Uncertainty and ambiguity

One of the major findings of this component of the project was that in spite of clear project goals and

objectives, the collaborative process itself engendered considerable uncertainty and ambiguity. Many of the co-investigators indicated that learning to accept and work with the uncertainty and ambiguity about where the project was ‘going’ as it developed and unfolded was the most difficult aspect of participating in this collaboration. As one partner described it:

This was an evolving thing, as these things are. It (develops) out of these messy processes...and it’s always amazing what a kind of stew it is when everyone sort of tosses things in and does their best.

At the same time, most co-investigators indicated that this was also the most important part of their personal knowledge development. For some, uncertainty and ambiguity were *essential* to the shared experience of exploration, debate, and reflection that characterized this project, and indeed as one partner described ‘it was precisely this uncertainty and ambiguity that created the space for us to ask critical questions’.

To be sure, uncertainty and ambiguity also caused individuals to feel anxious about the project’s direction, their own roles and time commitment. Some co-investigators suggested that a clearer direction would have helped them to feel more comfortable, while others suggested that had there been more clearly defined roles and project expectations from the beginning, the process could have been accelerated. However, upon probing, most of the co-investigators recognized that it had taken substantial time for the partners to develop fundamental trust in each other’s motivations, competence, reliability and integrity—which they saw as essential to the ultimate success of the project—and doubted whether accelerating the research process would have allowed the same levels of trust to develop.

The findings of the collaborative process component of this study confirm the findings of earlier studies about the issues involved in community/university research collaborations. Firstly, key people and key events appear to be important in maintaining the life and momentum of collaborative projects. Leadership style, small amounts of ‘seed funding’ and the willingness to learn from failures all appear to be significant features in successful collaborations.

Secondly, community and university partners are situated within very different institutional/organization cultures that have different expectations and priorities regarding research and which place very different demands and expectations on the individual partners.

Thirdly, time is a major issue, both the long lead-time required to establish good working relationships and the amount of individual time devoted to the project. Lead and individual time are clearly related, as it takes time for research partners to learn each other’s language, priorities, demands and expectations, which

are shaped to a great extent by the particular institutional location of each of the partners. Indeed, most of the co-investigators in the present study indicated that their own knowledge development, in terms of learning each other’s language and ways of viewing the world, was one of the unanticipated rewards of collaboration.

Finally, this project has revealed an important issue not reported in earlier studies and which we believe to be at the core of community/university research collaboration: the indeterminate nature of the research process and its outcomes. As indicated by the analysis of interview data, this uncertainty and ambiguity was difficult for all the partners. However, those who had continued with the project from the early pre-funding years through to the completion of the funded project acknowledged that this uncertainty and ambiguity was an essential part of learning to trust each other and work together. As indicated by this study, successful community/university research collaboration demands from all partners a patience with and tolerance for the uncertainty and ambiguity of a *necessarily* emergent research process.

The issues associated with community/university research collaboration, as demonstrated by this study, should be regarded, in themselves, as neither positive nor negative; they are neither barriers, nor facilitators. Rather, these issues represent challenges which, by the way in which they are met, have the potential to shape the emergent collaborative process in particular ways, presenting opportunities for moving a project towards its overall goal, which in the case of the present project was to produce useful, useable health data maps. Each of these themes represent an opportunity for any community/university research collaboration for resolution or non-resolution, for developing understanding or not, for compromise or for acknowledging where compromise cannot be obtained.

Conclusions

In the interest of facilitating both the development of community health information systems and successful community/university research collaborations, we make some recommendations based on our experience. Action must occur on a number of fronts, and recommendations are therefore directed to a variety of sectors. To enable development of community health information systems, we make three recommendations. First, *developers of community health information systems* should recognize the effort required to maintain user involvement in the design process, and plan accordingly. Design methodologies can be used to facilitate user involvement, and ultimately, addressing the recommendations we make about collaborative research should enhance collaboration between system developers and users.

Second, *governmental and non-governmental data creators and holders* should take steps to improve population health data accessibility and usability. In addition, action should be taken to improve data documentation (i.e. metadata), create data directories, develop data standards, and enhance compliance with existing standards. A wide range of stakeholders in society must collectively address the issues of privacy and stewardship of population health data. Third, *health informatics research* should explore methods to optimize the use of assembled population health data. Methods to allow visualization and analysis of data from a variety of sources across space and time must be developed and evaluated.

In terms of facilitating community/university research collaboration, both partners must recognize that, while working together offers considerable benefits, it also requires considerable time and effort. First, *funders* of community/university research collaborations need to recognize that building and maintaining successful collaborations, distinct from the research itself, takes time and effort, and can be logistically demanding. The inherent complexities in a collaborative project require a principal investigator with the ability and skills to provide leadership in maintaining the research focus without undermining a participatory process. Allowance of sufficient time is essential for the collaboration to develop, and for periodic reflection on the project's progress. Resources should be made available to provide for a dedicated project facilitator in addition to the usual research assistants, and to facilitate community partner participation. Second, *community partners* engaged in collaborative research with universities should see themselves as equal partners, in part, by making an organizational commitment to research. This includes supporting staff involved in research and advocating with funding agencies for research resources. Third, if *universities* are serious about fostering community/university research partnerships, they should acknowledge its importance by developing structures within the university system that support such collaboration including, inter alia, the following: a designated long-term position within the university hierarchy charged with facilitating community/university research collaborations; mechanisms for rewarding faculty involvement in collaborative research; and strategies to provide tangible acknowledgment of the contribution of community partners to research.

Community/university research collaboration is a relatively new research paradigm that has recently become a major strategic theme of health funding agencies in Canada and elsewhere. At the same time, technological developments are making possible new and innovative ways of representing complex health data and information that can be extremely useful to community-based health organizations for health planning and advocacy. This project has sought to articulate

and clarify some of the issues involved in both of these important new developments in health research.

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