Evaluation of the Rapid Risk Factor Surveillance System

Final Report

Revised

May 15, 2000

Prepared by

Paula J Stewart MD, FRCPC

Paul Sales MBA

Community Health Consulting

Table of Contents

Background

From June to October 1999, the Durham region of Ontario implemented a pilot project for a Rapid Risk Factor Surveillance System (RRFSS). The project was supported by a partnership that included:

- the Durham Regional Health Department
- the Public Health Branch, Ontario Ministry of Health
- Cancer Care Ontario
- the Laboratory Centre for Disease Control (LCDC), Health Canada.

The latter three organizations provided funding to support the data collection and evaluation of the project. The Canadian Coalition on Cancer Surveillance provided personnel support to assist in its development, and all partners contributed time and expertise.

The impetus for the project came from the need for ongoing and timely risk factor data that could be used for program planning and evaluation at either the local, provincial or national level. At the time of the study initiation, Health Canada's National Population Health Survey (NPHS), a longitudinal survey of 17,000 adults conducted every two years, was the only ongoing source of data on risk factors. It is designed "to relate health outcomes to health determinants for each sampled individual"[1] and to see how these outcomes change over time. The survey collects data through telephone and in-person interviews. The data becomes available for use one to two years after it is collected. The NPHS provides national and provincial level data. Some provinces have contributed extra resources to enlarge the sample size so that regional estimates could be made. In 1996-97, for example, Ontario supplemented the national survey with additional funding to provide regional level data.

The NPHS was designed as a longitudinal study to look at causal relations over time. However, it does not collect data at frequent enough intervals, nor with sufficient sample size at the provincial or local level to be useful to policy makers. To expect the NPHS to fill the needs of a surveillance system is, therefore, unreasonable.

A recent analysis by the Laboratory Centre for Disease Control (LCDC) concluded that an additional survey system designed specifically for risk factor surveillance, such as the American Behavioural Risk Factor Surveillance System (BRFSS), would complement the NPHS. The BRFSS collects time series data via monthly telephone surveys at the state level. (A description of the BRFSS can be found in Appendix A.)

---

[1] MacNeill I B, Umphrey G J. Concept Paper on Canadian Health Surveys and Risk Factor Surveillance. LCDC, Health Canada, 1997

From a statistical perspective, a surveillance system that samples at frequent time points and on a continuous basis at the provincial or local level has several advantages[2].

- The data are more suited for detecting temporal changes.
- Seasonality components can be examined, both for their own sake and to "de-seasonalize" the monitoring of temporal trends
- The collection of data is carried out at frequent enough intervals that the effect of a program can be tracked over time. This is particularly valuable when the effect occurs quickly.
- The data can be aggregated flexibly to make before-and-after comparisons when a new program is initiated or when other potential impacts occur.
- Statistical procedures analogous to quality control techniques would allow a fast response to statistically significant changes over time.
- The data can be aggregated in different ways to look at demographic and regional breakdowns, or rolled up to produce national statistics.

The BRFSS model as implemented in the RRFSS pilot project could provide the basis for a surveillance system that includes all three levels of public health decision-making in Canada. Data collected at the level of regional public health departments could be collated by provincial/territorial Ministries of Health who review it for trends across the province or territory. This information could then be sent to the Laboratory Centre for Disease Control (LCDC), who could study the national scene and make recommendations for policies regarding prevention and control measures.

---

[2] MacNeill I B, Umphrey G J. Concept Paper on Canadian Health Surveys and Risk Factor Surveillance. LCDC, Health Canada, 1997.

Purpose of the RRFSS Pilot Project and Its Evaluation

The purpose of the RRFSS pilot project was to develop and implement a model for a Rapid Risk Factor Surveillance System that would provide timely, regional level data for planning and evaluating a wide variety of health issues. The information obtained would be useful for assessing the feasibility and usefulness of this methodology for a provincial and national risk factor surveillance system. While the content was important and the goal was to maximize its potential, the primary purpose of the project was to pilot the process of a surveillance system.

The specific objectives were to assess the feasibility of a rapid risk factor surveillance system and evaluate the process, based on the following criteria:

- Rapid, timely use at the local level
- Flexibility and adaptability (allowing for different options)
- Ability to meet time frames
- Representativeness of sample
- Adequate response rate
- Data availability, usefulness, and access
- Data use at the program level, with accuracy and satisfaction at the different levels
- Cost effectiveness
- Comparability to NPHS and other surveys
- Potential for use as a model for all of Canada

During the course of the pilot project Statistics Canada received additional funding to expand the NPHS with a cross-sectional survey every two years. This additional survey, entitled the Canadian Community Health Survey (CCHS), will have an adequate sample size to provide regional level data. A critical goal of the evaluation of the RRFSS pilot project is to identify its contribution to surveillance beyond the CCHS.

Evaluation Method

Appendix B contains the evaluation framework for the RRFSS. Three questionnaires were used to collect data from the partners on each of the two surveillance methodologies - the RFSS and the NPHS-Ontario Supplement.

1. Survey Unit Questionnaire - The Institute for Social Research reported on the survey methodology
2. Partner Questionnaire - All the partners reported on the planning, collection, analysis, and use or potential use of data; and
3. Partner Content Questionnaire - Partners who developed the questionnaire content reported on the process.

The RRFSS Working Group assisted in the development of the evaluation framework and the questionnaires. All partners met in early December 1999 to discuss the positive and negative aspects of the project, and the means for carrying it out on a broader scale. Their recommendations about the feasibility and potential usefulness of the RRFSS surveillance method are included in the discussion section of this report.

This report was based on interviews of individuals. Opinions expressed by these individuals does not necessarily represent the view of the organizations.

Description of the RRFSS Project

Project Initiation - January-March 1999

The Director of Surveillance at Cancer Care Ontario was interested in improving the availability of data on risk factors. In the fall of 1998, he attended a conference in which the American Behavior Risk Factor Surveillance System (BRFSS) was discussed as an efficient and effective way to collect state based nationally comparable data on risk factors. Discussion among Cancer Care Ontario (CCO) and with the Ontario Public Health Branch (PHB) and the Laboratory Centre for Disease Control, Health Canada (LCDC) revealed a strong mutual interest in providing funding for a pilot project.

The interest in the study came form several directions. First, the BRFFS model was successful in the states. Second, many health units were already conducting surveys of varying quality and with different variables precluding comparability among regions. Third, there was no on-going source of timely data on either program processes or outcomes that could be used to monitor progress for Ontario's public health mandatory programs. Fourth, provincial and national organizations did not have access to timely data on risk factors for program planning and evaluation. Fifth, the technology existed to improve health information availability. This was the way of the future and the public health community needed to take advantage of it.

The concept of a Rapid Risk Factor Surveillance System (RRFSS) was then discussed at the Ontario Prevention Cancer Network. The Durham Regional Health Department (DRHD) expressed strong interest in operating as the site for the pilot project. With its strong epidemiology unit, DRHD would be in an ideal position to support the pilot project. In addition, the management group had identified the need for specific data that would support planning and evaluation of the mandatory public health programs. This would be useful in the development of the content of the questionnaire.

The Rapid Risk Factor Surveillance System project was managed by a Working Group consisting of members from all the partners. Cancer Care Ontario (CCO)and the Durham Regional Health Department (DRHD) had the most consistent representation throughout the course of the project. The LCDC representatives changed but all were committed to the project. As a result of the consistency in CCO and DRHD representation, these two organizations became the most involved in the pilot's implementation.

CCO, LCDC and PHB each provided $15,000 toward the total cost of the project ($40,000 for the data collection and $5,000 for the evaluation and report). This was determined in advance and did influence the extent of the project With funding came specific short timelines, creating an additional time pressure for the Working Group.

The Working Group considered two options for data collection - a local survey unit or Statistics Canada. While Statistics Canada would likely have been able to achieve a higher response rate,

it would not have been able to meet the short time frame for planning. As well, the cost per completed interview would also have been higher. In early February 1999, the Institute for Social Research at York University was asked to participate as the data collection agency for two reasons. First, it had extensive experience in conducting high quality risk factor surveys; and second, it could meet the timelines. The fact that that the survey unit was based in a university that had demonstrated interest in innovative activities toward improving population health information was an added bonus.

In March, 1999, a formal memorandum was signed by the four partners - Cancer Care Ontario, Ontario Public Health Branch, Durham Health Department, and the Laboratory Centre for Disease Control, Health Canada. The agreement outlined each partner's responsibilities. The Durham Health Department managed the funds for the project.

The Working Group split into two sub-groups - one to develop the questionnaire content and one to co-ordinate the implementation of the process. The Content Group worked quickly to develop and test the questionnaire. Unfortunately, the implementation group did not get a strong start. This was due, in part to a change in representation by some of the partners, which caused a loss in continuity. As a result, decisions about the project fell to those who were active in the Content Group from the Durham Health Department and Cancer Care Ontario. While this kept the project moving ahead, it meant less involvement by other partners. Documentation of the process also suffered, because minutes of meetings where key decisions were made were not recorded.

Lessons Learned

1. Organizations can work together effectively to develop a risk factor survey including the pooling of resources. Face-to-face meetings at the beginning assisted the group in making decisions quickly and sorting out options effectively.
2. Continuity in the representation from the partners is essential to ensure active involvement by all involved in the project.
3. Resources are needed for administrative support for the process, including documentation of decisions made.
4. The planning group benefited from strong epidemiologic expertise from the partners.
5. The early involvement of the survey unit in the design of the survey and the questionnaire contributed to the development of a high quality product in a short time period.

Questionnaire Development - February - May 1999

Representatives from CCO and the DRHD worked with the Institute for Social Research to identify the content of the questionnaire. The other partners were to provide input by reviewing the draft questionnaire.

This process was heavily influenced by the need to develop the questionnaire quickly to meet the project timelines. The following criteria were used to decide which topics were to be included:

- Risk factor for an important health issue, particularly cancer.

- An issue targeted for action by partner
- Need for baseline data that was not otherwise available
- Suitability to an adult telephone interview

Existing questions from the BRFSS, the NPHS and the Institute for Social Research Unit were used as the basis for the questionnaire. Some questions were modified to meet partner needs, and other questions were added based on the needs of the DRHD and CCO.

The selection of questions was an iterative process. The Content Group developed a preliminary set of questions. The DRHD program managers then reviewed them to ensure their relevance. The Institute for Social Research also reviewed the proposed questions. Through an intensive session with the Content Group, the set of questions was reduced to the number that could be completed in a twenty-minute interview. The group faced the challenge of choosing between questions that had been previously used but not worded in the way that they would have preferred, and new questions that were not comparable to other surveys and had not yet been validated. The small number of people (3) and the collegial attitude made the question selection process feasible within the timeframe.

The questionnaire was piloted in late April and early May, and data collection started on June 1st and continued until the end of October. The Content Group revised the questionnaire after the first cycle to create a better flow of questions.

The pilot was designed so that the questionnaire could be changed quickly in response to the changing needs of the partners. A proposed draft set of questions would be considered for inclusion if:

1. It represented a high priority area for one or more of the partner agencies - the more agencies in favour, the greater the weight. "Partner agencies" are the four that originally collaborated to get the survey going (Ontario MOH, DRHD, CCO, and Health Canada);
2. None of the partner agencies had strong objections to its inclusion;
3. Enough data could be collected in only one or two data collection cycles (i.e. months). This was not a necessary condition, but it would increase the weight in its favour;
4. There were no other sources of adequate/timely data on the topic;
5. Data could be reasonably obtained by telephone interviews;
6. The topic area fit with other questions/topic areas already in the RRFSS;
7. It was assessing something that could be expected to change over time;
8. It addressed an emergent need (e.g., a TB outbreak).

The following process was set up to decide which questions would be included.

1. The proposer would justify the inclusion of the question set in terms of all items except 2. in writing.
2. The content area group would identify the implications of its inclusion on the length of

the survey and possible question sets that could be excluded from some of the survey cycles. (This was done to some extent as they went along).

3. The entire group would review the proposed draft questions set, the proffered justification, the implications in terms of the existing survey, and possible trade-offs in terms of exclusion and make a decision.
4. If accepted for inclusion, the content group would fashion the draft question set was into a format compatible with the rest of the survey instrument.

Four changes were made to the questionnaire during the course of the survey. All changes were included in the next data collection period. In one instance the questions arrived two days before the start of the next monthly cycle. In all but one instance the new questions were approved by both Cancer Care Ontario and the Durham Health Department. Initially, the other partners were consulted. As time progressed, however, decisions were made by the two more active participants in the project (CCO and DRHD).

Lessons learned

1. More than one organization can collaborate in developing a risk factor questionnaire that can meet both their individual and collective needs.
2. The questionnaire can be effectively developed by a small working group.
3. In order to ensure that the collected data collected is relevant, a strong link between the data users and the questionnaire developers is essential. An existing set of indicators from the DRHD assisted in identifying the data that should be collected.
4. An ongoing review process must be in place to assess the method and questionnaire content. The review should be based on feedback from the interviewers and the responses of the interviewees.
5. On-going research is needed to assess the validity and reliability of questions.
6. All questions need to be critically assessed before they are used in a survey. Popularity of use does not justify a question's continued inclusion if the quality of data that it produces is questionable.
7. A formal mechanism to document the process, the source of questions, how well they work, etc., would facilitate the management of the questionnaire development and revision.
8. The telephone survey method has limitations. It limits the type of data than can be collected. Time constraints (maximum of approximately twenty minutes) restrict the number of questions. It also limits the population group that can be reached (e.g. adults, able to speak language used in survey).

Survey Implementation

The Institute for Social Research (York University) conducted the telephone interviews using a CATI system with pure random digit dialling. Within each household, adult members were selected for the interview at random. A minimum of 12 calls was made to each household before

the household was discarded from the sample. Calls were made on weekdays during the morning, afternoon and evening and in the afternoon and evening on the weekends. A supervisor verified ten percent of the calls. A 1-888 number was available for respondent verification.

Interviewer training took about three hours. Interviewers experienced only minor difficulties with question clarity. Respondents' difficulty in answering applied to only a few questions.

Interviews were done on a monthly basis during the five month pilot period to obtain 1,051 completed questionnaires. The response rate per month ranged from 67% to 70% with an overall response rate of 69%. Almost one-half of the respondents (47%) were reached within one to three calls. 87% were reached with ten calls or less.

Most respondents completed the questionnaire in 10 to 25 minutes.

Lessons Learned

1. Working with an experienced external survey unit freed the project team from the details of managing the survey. They were able to focus on the need for additional questions, and the analysis and use of the data.
2. Ongoing review of the questions is necessary to identify and resolve problem areas early in the process.
3. Persistent attempts at recruiting household can ensure a reasonable response rate.
4. A risk factor survey can be developed that has enough flexibility to add new questions on a monthly basis.

Use of the data

In the initial plan, the data was to be posted on a secure Internet site on a monthly basis to ensure ease of access for the partners. This changed during the survey: the data was emailed to the Durham Health Department and Cancer Care Ontario instead. Each organization then analyzed the data for its own needs using SPSS or SAS. The results were then discussed with the relevant program managers.

Use of the RRFSS at Durham Regional Health Department (DRHD)

The Durham Regional Health Department (DRHD) is currently in the process of analyzing the data from the survey. Some examples of its use are:

Smoking - The survey provided immediate results on smoking prevalence. This immediacy allows the tracking of the effect of such changes as tobacco prices or legislation. This is a great improvement over waiting a few years for another provincial survey. Data from questions on attitudes toward smoking in restaurants were useful to the program planning by-laws. According to the RRFSS, women were less tolerant than men of smoking in restaurants.

Smoke-free homes - At the start of the project, DRHD had no information on the

prevalence of smoke-free homes in Durham, yet each fall since 1997 it had devoted considerable resources to its "Open the Door to a Smoke-free Home" campaign. The NPHS-OHS question differed from RRSFF's. It asked, "Does anyone in this household smoke regularly inside the house?" (35% said "Yes"). The RRFSS, on the other hand, allowed DRHD to tailor the question to its own needs. The question consisted of three parts:

> "Do you or anyone else living in your household currently smoke cigarettes, cigars, cigarillos inside your home?" (25% yes)
>
> If yes, "Are there rules, understandings or agreements about smoking inside your home for people who live there?"
>
> If yes, "Is smoking not allowed in your home?" (2% not allowed at all inside)

Sun safety - This program was in the planning stages during 1999. In 2000, it will target day nurseries, golf courses and travel agents. DRHD wanted baseline data for program planning. When the RRFSS becomes fully operational, surveillance of behaviours, knowledge and attitudes would be useful for monitoring the effectiveness of DRHD's interventions. Questions on sun safety will be included in the second phase (provincial estimate survey) of CCHS (Sept. 2001).

Flu and Pneumonia vaccinations - The DRHD had no information on annual vaccination rates, leaving program staff feeling that they were "shooting in the dark". Monthly data from the RRFSS would help to monitor the success (or lack thereof) of the strategies over the winter months. Questions on flu and pneumonia vaccinations are part of an optional module in the first phase of CCHS.

Food access and sufficiency - DRHD hired consultants to investigate food access problems among low income families in Durham Region and recommend possible solutions. DRHD decided not to spend resources on prevalence estimates when this could be addressed through the RRFSS. DRHD conducted a more qualitative focus on barriers and solutions to food access problems. Although the numbers are very small, there were a few respondents in higher income categories who stated that they could not afford to eat healthy meals. The NPHS-OHS had also asked some food security questions and some will be included in the CCHS, but a full set of questions on food access can only be included at a later date. In the future, the DRHD will need to monitor whether the interventions initiated as a result of the needs assessment have had any effect.

Physical activity (Awareness and use of trails (walking, hiking and biking) in the region) - The trails map was distributed in early September. The awareness of local trails appeared to increase in September and again in October, but the difference was not statistically significant.

Rabies immunization - Before it could introduce and enforce new vaccination requirements, DRHD needed to know the probable number of unvaccinated cats and dogs. During the course of the pilot, additional questions were added to the RRFSS to obtain this information.

Evaluation of the Pilot

The detailed responses to the evaluation questionnaires from each partner are included in Appendix C. The following chart summarizes the success of the project in meeting its objectives.

Criteria for Success	Summary of Results
Rapid, timely, useful at the local level	All partners agreed that the receipt of the data was very rapid and timely, arriving less than two weeks after data collection was completed. Both Durham Regional Health Department (DRHD) and Cancer Care Ontario (CCO) found the data useful for planning programs and evaluating the impact of strategies.
Flexible, adaptable and allow for different options	The questionnaire was tailored to the needs of DRHD and CCO within the limitations imposed by time. Additional questions were able to be added based on local needs during the course of the pilot. The DRHD, CCO and the Institute for Social Research (ISR) were satisfied with the process.
Meet time frames	In spite of a slight delay in the start of data collection, all time frames were otherwise adhered to. The Survey Unit completed its assigned tasks promptly and effectively.
Representative sample	The language distribution of the RRFSS respondents was very similar to that of the 1996 census (93% English, 6% French and 1% other for the RRFSS, and 95% English, 4% French and 1% other for the census). The age and education distribution was similar to other surveys but the income levels were higher with the RRFSS than the census and the Ontario Health Survey (supplement to the NPHS). See Figures 1 - 4 in Appendix D.
Adequate response rate	69% of eligible households completed the questionnaire.
Data availability, usefulness, and access	Partners received the data within two weeks of completion of the interviews. Those who accessed it found it very easy to use with an SPSS or SAS program. The production of a batch file would have facilitated broader access to the data by program managers.

Criteria for Success	Summary of Results
Data use at the program level, with accuracy and satisfaction at the different levels	DRHD found the data very useful. It provided baseline data for such measures as use of fitness facilities and trails in Durham Region. Data was used to monitor progress toward goals and support policy development in such issues as workplace smoking. The sample size created some limitations. It limited some comparisons between municipalities and age groups. For example, since not all areas have road watch programs, awareness by municipality could not be compared. Information for planning for a target population would need larger sample sizes. CCO also found that usefulness of the data was limited by the inclusion of only one region. Nonetheless, data on breast cancer and PAP screening provided some interesting insights.
Cost effectiveness	The survey cost $40,000 for preparation of the survey tool, data collection and preparation of a data file for analysis. ($40/completed questionnaire). This amount does not include the time contributed by the partner organizations in the development and modification of the questionnaire (about 100 hours DRHD and 140 hours CCO) nor the work with DRHD staff to use the data.
Comparability to NPHS and other surveys	The one variable that could be compared between the RRFSS and the Ontario Health Survey was prevalence of smoking. Prevalence was very similar for the two studies. Men / Women RRFSS daily smoker 24.6% 20.9% OHS (aged 20+) 96/97 26.8% 21.2%
Potential for use as a model for all of Canada	According to all participants, the partnership worked effectively. The content of the questionnaire met their needs, and the data was readily available for individually-tailored use. A comparison of the partners' experience with this local/provincial model (RRFSS) and a centralized model (NPHS) found that the RRFSS was superior in terms of • Flexibility • Ability to meet local needs (i.e. having some say in the content) • Timeliness • Accessibility to data The centralized model requires less investment, however.

Discussion

Rapid Risk Factor Surveillance System

This pilot project demonstrated that it is possible to develop and implement a Rapid Risk Factor Surveillance System (RRFSS) using a Computer Assisted Telephone Interview (CATI) system that provides useful, timely data to a regional public health unit. The use of an external experienced contractor who was committed to working in a collaborative fashion with the planners was an essential factor in its success. Monthly surveys allowed partners to make changes to the questionnaire in response to their programs' needs. They also permitted immediate tracking of changes in knowledge in the population.

A representative number of participating regions could provide the provincial perspective that is needed by Cancer Care Ontario (CCO) and the provincial government for planning and evaluating prevention and health promotion initiatives. Each step of the process taught many lessons that could facilitate the development of an effective RRFSS in other health regions.

Co-ordinating Committee

A Co-ordinating Committee could oversee the development and implementation of the RRFSS across the province. It would require representatives from the partner organizations who could commit to regular attendance for at least one year to ensure continuity. As the system expands, participation on the Co-ordinating Committee could be rotated among health units.

The duties of the Co-ordinating Committee would include obtaining funding, developing partnerships, and monitoring the overall implementation and expansion of the system. It would require the support of a secretariat with a co-ordinator and administrative assistance.

Questionnaire

The questionnaire developed for the pilot is a good starting point, but more work is needed to improve the existing questions and develop new ones. A Working Group reporting to the Co-ordinating Committee could develop a question bank using existing questions where possible. Assessing the reliability and validity of the questions will present an ongoing challenge.

The questionnaire would require four components to ensure both flexibility and comparability across the regions

- ***Core questions*** that need continuous monthly data collection. The need for comparable data among the provincial partners would heavily influence the group of questions selected. Data may be required from all or a reasonable sample of regions in order to form a provincial picture;
- ***Rotating core questions*** that do not need constant monitoring but are needed on a biennial or other basis;

- ***Regional health unit questions*** developed and used by each region; and
- ***Trial questions*** for testing new questions prior to their regular inclusion in the survey.

Based on the experience of the pilot, it is essential that the implementation of the questionnaire be monitored to identify and solve difficulties related to clarity and/or comprehension by the respondents.

This data collection method does not yield all types of data that program planners and evaluators find useful. The questions must be easy to understand over the phone and the respondent must have the answer readily available. For example, nutrition questions that ask for food recall are difficult with this methodology.

Data Collection

The health unit found definite advantages in conducting the telephone survey on a monthly basis. Questions could be added and changes tracked immediately. Seasonal changes in behaviours, such as physical activity, can also be tracked with monthly data collection. Monthly data collection can also be used for an annual roll up to increase the sample size to assess changes over time..

The monthly sample size for the pilot was 200/month or 1,000 for the five month pilot period. This sample size presented some limitations for the health unit in analyzing specific geographical parts of the regions or population sub-groups. The availability of resources will influence the sample size selected by each health unit.

Contracting out the data collection to an experienced unit was very effective. The chosen contractor must have the ability to conduct the monthly surveys, make changes to the questionnaire quickly, and prepare a computer file for analysis shortly after the completion of the data collection . Depending on the number and location of participating health units, one or more contractors could be used. One contractor could develop the CATI (Computer Assisted Telephone Interview programming) and then share it with the others to reduce costs.

Data Analysis and Reports

The contractors doing the data collection should prepare a data file that can be used with any of the commonly used data analysis programs. Each partner will require the capacity to do the analyses of the data for its own purposes. Based on the experience in the pilot, timely data summaries would be facilitated by an automated analysis. In addition, a central data analysis capability, perhaps in the Public Health Branch, would not only facilitate comparisons across regions and but track trends in the province as a whole as well.

If the full benefit of the system is to be realized, dissemination of the information in the RRFSS is critical. A variety of mechanisms could be used, including paper reports, Internet access to data tables, and data files on CD.

Funding

The continuation and expansion of the RRFSS depends heavily on the availability of ongoing funding. Funding will need to support:

- Administration - a secretariat to support the Co-ordinating Committee and the Working Groups;
- Data collection - The estimated cost of the on-going survey is approximately $30 per completed questionnaire. A sample size of 1000 per health unit/year would require $30,000/health unit region annually;
- Questionnaire development - could consist of in-kind contributions by the partners, but the work should be housed in one place;
- Data analysis - provided by each partner for its own needs; in addition, one partner will need to provide both the overall analyses and the analyses of the different regions for comparison purposes.

The pilot found that joint funding was an effective approach to funding a project from which many organizations benefited. Possible partners include participating health units, the Public Health branch, Health Canada, and non-government health organizations such as CCO. Other partners such as the regional Health Information Partnerships (HIP's) and the Public Health Research, Education and Development Partnerships (PHRED's) could provide methodological and analytic assistance. The Public Health Branch Indicator Working Group could provide assistance with the type of data that is needed.

Expansion process

A logical place to begin the expansion of the RRSFF is to add a few (three to five) other health units that have a capacity to participate similar to the Durham Regional Health Unit (epidemiological expertise and senior management support). Ideally, these health units would form a representative group so that a provincial picture could be obtained. Other health units could be added gradually as the system becomes more stable and funding becomes available.

Future of the RRFSS

The RRFSS Pilot Project was conceived and developed at a time when there was a lack of recent data available for program planning and evaluation at either the provincial or regional level in Ontario. By the end of the pilot project, Statistics Canada had received additional funding to conduct an ongoing community survey (CCHS) every two years that would have sufficient sample size to provide regional level data. In the intervening years, a provincial survey would be conducted. The future of the RRFSS must be considered in light of these changes.

The RRFSS could complement the CCHS. It offers the regions and province more autonomy, timeliness, and flexibility than the CCHS, which is controlled federally by Statistics Canada, but requires additional resources. The CCHS could be used for surveillance of health issues that only need monitoring every two years and the RRFSS used for those requiring more frequent assessment and those not included on the CCHS.

Conclusion

The Rapid Risk factor Surveillance System (RRFSS) pilot was very successful. It provided timely, useful data to the Durham Regional Health Department. The partnership worked effectively in developing the methodology and the questionnaire content. The Institute for Social Research provided excellent expertise in completing the survey on time with a good response rate.

The RRSFF model has great potential as a risk factor surveillance system at the regional level. The next step is to determine whether it can be expanded effectively in other health unit regions to develop a broader base for an Ontario provincial risk factor surveillance system. To be most useful at the national level, all the provinces would need to participate in the RRFSS. Ongoing funding is the most significant challenge facing the continued use of the RRFSS in Durham and its expansion to other regions.

The future of the RRFSS project needs to be considered in light of the new Canadian Community Health Survey (CCHS) implemented by Statistics Canada. It could provide a complementary role by collecting data on variables that are not included in the CCHS or that need to be collected more frequently than every two years.

Recommendations

The Project Working Group identified the following recommendations for the future of the project.

1. Continue the project to explore its usefulness over time and its application to a broader group of health units.
    a. Continue project with Durham Regional Health Department to assess its value over time.
    b. Explore partnerships with other health units - one in the west, one in the east, one in central Ontario, and one in a culturally diverse region.
    c. Continue the Working Committee with a core group of dedicated people from the partners who will commit to regular attendance at the meetings to co-ordinate the project.
    d. Identify stable core funding for a two- to five-year period, including secretariat support for project management. (LCDC has offered to provide the secretariat function)
    e. Prepare a survey method protocol for other regions based on the results of the pilot. This should include the development of the questionnaire, process for modifications, telephone interviews, analysis and reports.
    f. Secure the services of a contractor experienced in CATI method who can provide the flexibility and meet the timelines that the survey requires.
2. Organize a workshop in conjunction with a public health meeting to disseminate the pilot findings and explore interest by other health units, organizations, and provinces. Bring individuals who are involved in the United States' Behavioural Risk Factor Surveillance System in to the meeting.

Appendix A

Description of the Behavioural Risk Factor Surveillance System

CDC
Atlanta, Georgia, USA

BEHAVIOURAL RISK FACTOR SURVEILLANCE SYSTEM

The American Behavioural Risk Factor Surveillance System (BRFSS) is a population-based ongoing surveillance system for risk factors associated with chronic diseases. It was founded in 1984[3]. The definition of a risk factor is any activity in which a person engages either occasionally or frequently that increases his or her risk for illness, injury or death.

The BRFSS was designed to complement but not duplicate national surveys of risk factors. Its purpose is to provide good quality data to policy makers at the state level to assist in the planning and evaluation of health promotion and risk reduction programs. A recent survey of the states found they used the data for:

- Development of policies and regulations
- Program planning and delivery
- Education and training
- Development of public recommendations, using the media to communicate health messages

The BRFSS is state-based and, in general, is funded jointly (50/50) by the Centers for Disease Control and Prevention (CDC) and the states. Some states have put additional resources into the system to expand the sample size across the state as a whole or to over-sample some particular areas.

Data is collected via a telephone survey using CATI (computer assisted telephone interviewing) technology. CDC provides the CATI programming for the CDC supported modules. The survey takes place during a two week period every month. In some states the state itself conducts the survey while in others it is contracted out to private companies. Both methods have their advantages and disadvantages. Response rates in the states vary from 50% to 75%.

The questionnaire has three parts:

1. The core component consisting of the fixed, rotating and emerging core.
   - The fixed core is a standard set of questions asked by all states.
   - The rotating core is comprised of two distinct sets of questions, each asked in alternating years by all states.
   - The emerging core is a set of up to five questions that are added to the core for one year and then reassessed to determine their potential value in future surveys.
2. Optional CDC modules.

---

[3] CDC. A Brief History of the Behavioural Risk Factor Surveillance System, July 1996, CDC. Atlanta, Georgia, USA.

CDC. The Behavioural Risk Factor Surveillance system: survey Design, execution and Use. July 1996, CDC, Atlanta, Georgia, USA.

- The optional CDC modules are sets of questions on specific topics supported by CDC that states can decide to use.
- CDC supports the analysis of the two components and makes the final decision about the content. States have input into the questionnaire at the annual conference. These two components are not changed during the year.

3. State-added questions.
   - State-added questions are developed by each state on their own and added to their questionnaire. They can be added at any time of the year or for specific time periods. The analysis of these questions is not supported by CDC.

Each state collects data on a minimum of 1,200 residents per year (100 per month). Some states have added additional resources and the sample includes about 4,000 people. The sampling method varies from state to state. Some use simple random sampling, others use the Waksberg method and others use truncated list-assisted designs.[4] The main advantage of the last two methods is that the final sample of numbers has a higher probability of being residential rather than business numbers. This reduces the cost of doing the survey but makes the analysis more complicated by requiring a weighting procedure.

The data is edited at the state level and then forwarded to CDC for analysis. CDC produces a statistical report that is sent to all state co-ordinators within four to six months of the end of the year. CDC can respond to some special requests for data but has limited resources to do so. A small group of researchers conduct research projects on the data. Many of the states do their own data analyses.

The end-users view the BRFSS viewed as a valuable resource. Current challenges facing the BRFSS are:

- The need for secure, sustained funding.
- Concern about response rates given the increase in telemarketing and viewer display telephones.
- Determination of the best sampling method that will keep costs down but still produce a representative sample.
- The need for local level data.
- Continuous pressure to add new questions that extends the length and cost of the questionnaire.

---

[4] CDC. A Brief History of the Behavioural Risk Factor Surveillance System, July 1996, CDC. Atlanta, Georgia, USA.

CDC. The Behavioural Risk Factor Surveillance system: survey Design, execution and Use. July 1996, CDC, Atlanta, Georgia, USA.

Appendix B

Evaluation Framework

Table 1 - Evaluation Framework

Criteria	Evaluation Questions	Expectations of the Project	Type of Tool	Who could Provide the Data? (Source)	Who Can Get the Data? (Collector)
	Content				
Simplicity Acceptability	1. How was the content of the questionnaire determined?	• Process to decide content included an assessment of needs of all partners • Content was based on important health issues • Partners were satisfied with process given the need for expediency in terms of time	Interview	Content Group	Paula Stewart
	Data Collection				
Simplicity	2. What data collection method was used?	• Pure random digit dialing • Systematic selection among household members • CATI method • Minimum 14 calls, at least five made during weekday evening hours and at least five made during the week-end • At least three call attempts or one contact with the most first refusals obtained in the first two weeks of data collection for the month (?) • Supervisor verification of 10% of all interviewer calling • A 1-999 number for respondent verification	Interview and review of survey records	Institute for Social Research - David Northrup	Paula Stewart
Timeliness	3. When was data collected?	• Data collected on a monthly basis (number of questionnaires per month)	Interview and review of survey records	Institute for Social Research - David Northrup	Paula Stewart
Representa-tiveness	4. What is the response rate?	• At least 70% response rate overall (of all calls, and of eligible households) • Minimum 60% response rate in each month • All questions have at least an 85% response rate.	Interview and review of survey records	Institute for Social Research - David Northrup	Paula Stewart
Simplicity	5. How many calls does it take to reach respondents? (distribution of calls)	• Mean of < 5 • Less than 10% more than 10 calls	Interview and review of survey records	Institute for Social Research - David Northrup	Paula Stewart

Criteria	Evaluation Questions	Expectations of the Project	Type of Tool	Who could Provide the Data? (Source)	Who Can Get the Data? (Collector)
Acceptability	6. How long does it take to complete questionnaire?	• mean of ≤ 20 minutes • 90% less than 20 minutes	Interview and review of survey records	Institute for Social Research - David Northrup	Paula Stewart
Simplicity	7. Was it easy to train the interviewers? 8. How satisfied were interviewers with the questionnaire?	• Training needs were similar to other same length surveys • 90% of interviewers found the survey easy to administer	Questionnaire	Institute for Social Research - David Northrup	Paula Stewart
Flexibility	9. Can the survey be adaptable to changing needs?	• Question changes were agreed to by the end of the third week of the preceding month and implemented for next month • Content group discussed and agreed to changes • Partners were satisfied with process to change questionnaire	Interview and review of survey records	Institute for Social Research - David Northrup Content Group Partners	Paula Stewart
	Quality of the Data				
Representa-tiveness	10. Does the survey yield quality data? (this can only be answered indirectly)	• Proportion of population with a risk factor is similar to proportion in Durham from NPHS survey	Survey data reports and NPHS report	Mary Anne Petrusiak	Paula Stewart
	Data Reports				
Acceptability	11. How was data reported to partners, and how did partners use this within their organization?	• SPSS data file • Data reports created by partners	Questionnaire to partners	Partners	Paula Stewart
Timeliness	12. What is the time interval from data collection to data report?	• SPSS data file available two weeks after the end of the month	Questionnaire to partners	Partners	Paula Stewart

Criteria	Evaluation Questions	Expectations of the Project	Type of Tool	Who could Provide the Data? (Source)	Who Can Get the Data? (Collector)
Acceptability	13. Is the data report easy to understand and data provided in the format required by the partners?	• Partners are satisfied with SPSS file format. • SPSS file format is easy to use and is useful to create the specific reports needed by the partners	Questionnaire to partners	Partners	Paula Stewart
Flexibility	14. Can the data be analysed as required by the partners?	• SPSS file format is easy to use and is useful to create the specific reports needed by the partners	Questionnaire to partners	Partners	Paula Stewart
	Costs				
Acceptability	15. What was the time involved in developing the questionnaire?	• Hours per member of the Content Group	Questionnaire	Content Group	Paula Stewart
Acceptability	16. What are costs of collecting the data ?	• Actual cost (expected less than $40,000 for 1,000 completed questionnaires ($40/questionnaire)	Interview and review of survey records	David Northrup	Paula Stewart
	Outcome - Usefulness				
Representa-tiveness	17. Does the survey identify change in indicators of population health? Or show a differences by population characteristics?	• At least one indicator changes over the duration of the project. • Variation sin indicator by geography or personal characteristics	Data reports	Phillipa Holowaty	Paula Stewart
Representa-tiveness	18. Is the survey population representative of the population?	• Survey population has similar characteristics (age, sex, education) to general population (from census)	Data reports	Epidemiology unit of health unit	Paula Stewart
Acceptability	19. Did the survey data influence health unit programs?	• At least four programs accessed data reports • At least four programs used data to develop or assess impact of a program (describe how it was used).	Questionnaire	Phillipa Holowaty	Paula Stewart

Criteria	Evaluation Questions	Expectations of the Project	Type of Tool	Who could Provide the Data? (Source)	Who Can Get the Data? (Collector)
Acceptability	20. Do you think this method is useful for your organization, and how would it need to be carried out to yield useful data?	• Comments indicate it would be useful under certain circumstances • Method is more useful than other existing surveillance methodologies (repeated one-time surveys, national survey)	Questionnaire	Partners	Paula Stewart
Acceptability	21. If similar data existed at the provincial/national level how would it be used? What are the implications of this type of data not being available? What are the unique contributions of this type of data?	• Comments on usefulness	Questionnaire to partners	Partners	Paula Stewart
	General				
Acceptability	22. Did the partnership work effectively?	• Product met each partner's needs • Partners felt they were respected by others • Joint decisions were made about content of questionnaire, sample, timing, data report that were satisfactory to partners	Questionnaire to partners	Partners	Paula Stewart
Acceptability	23. Is the survey method acceptable to stakeholders?	• Health Unit, Ministry of Health, CCO, Health Canada, Canadian Coalition on Cancer Surveillance rate it as very good or excellent • Comments on what worked well and what could be improved	Questionnaire to partners	Partners	Paula Stewart

Appendix C

Responses to Questionnaires by Partners

Partner Questionnaire - Summary of Responses

Content

1. Were your organization's needs considered in the development of the questionnaire?

Partner	Monthly	Biennial/National
LCDC	Yes	No - Contents determined by an advisory committee.
Durham Regional Health Department	Yes	No
Cancer Care Ontario	Yes	No - Not in any direct, formal way; I'm not sure, why not. Perhaps CCO was not considered to be a large enough stakeholder , or perhaps it was not seen as having a national mandate, or a broad enough mandate.
Public Health Branch	yes	

2. How satisfied were you with the process used to identify the content of the questionnaire?

	Monthly	Biennial/National
LCDC	Very satisfied - As a partner we have been participating actively.	Somewhat satisfied - There are consultation sessions organized by Statistics Canada.
Durham Regional Health Department	Very satisfied - Fully consulted on content of relevant sections. Allowed to ask a few key questions, but understood that in-depth analysis of any sections was not possible. Dental division was not satisfied with this survey because it was unable to meet their needs.	Somewhat dissatisfied - Not involved in the process at all. It is impractical to have too many players involved.
Cancer Care Ontario	Very satisfied - The purpose of the pilot study was mainly to assess the feasibility, cost and utility of the RRFSS, not to reach complete agreement on the ideal content. I was happy that we started with the current USA BRFSS questionnaire. This strategy allowed us to fast track the development, and to permit some comparability with BRFSS results in the USA (e.g. compliance, incomplete answers, etc). Even so, the pilot demonstrated that questions could be added and removed, using an *a priori* set of guidelines to identify useful questions to add. But it still involves value judgements about the relative worth of the questions to all of the partners. Even within the same organization, judgements differ, largely because many programs do not have explicit objectives. Eventually, the success of this approach will require co-ordination to see that a pool of validated questions can be readily accessible, and so that areas for validation research can be defined and encouraged.	Somewhat dissatisfied - The process to identify the content in the first place was largely unknown. Presumably, it is documented in the rather detailed User's Manual, but this was produced "after the fact".
Public Health Branch	Very satisfied	

3. How satisfied were you with the process used to change the content of the questionnaire?

	Monthly	Biennial/National
LCDC	Very satisfied - The system is flexible.	Very dissatisfied - There is no way for external input for changing the content.
Durham Regional Health Department	Very satisfied - Able to make last minute changes to answer developing issues. Could not make major changes, but understood reason for this.	Somewhat dissatisfied - Not involved.
Cancer Care Ontario	Very satisfied - If I had any complaint, it was that the pilot didn't last long enough to test a few areas of special interest to me, such as the public's perception of the causes of cancer, self-reported family history, intentions and recent changes, etc. Certainly, some of these issues would not have to be addressed through continuous data collection. Indeed, a mini- cancer control supplement could be run every 2-3 years to see if self-reported beliefs, behaviours, etc., have changed.	Somewhat dissatisfied - Again, the process is unknown. Incidentally, this is also the case for the new enhanced NPHS.
Public Health Branch	Very satisfied	

Data Access

4. How was data provided to your organization?

	Monthly	Biennial/National
LCDC	Other - I have not seen any data.	Other - An internal database called DAIS
Durham Regional Health Department	Computer data file	Computer data file
Cancer Care Ontario	Computer data file	Computer data file, report.
Public Health Branch	Did not receive data - individual initially involved in the project moved before data became available	

5. How satisfied were you with this method of receiving the data?

	Monthly	Biennial/National
LCDC	Not applicable - Have not seen data.	Somewhat satisfied.
Durham Regional Health Department	Very satisfied - SPSS file was labelled and ready for analysis. Epidemiologist was able to analyze data on receipt of it.	Very satisfied
Cancer Care Ontario	Very satisfied - This ensured that work files and standard tabulations could be created quickly and distributed to others.	Somewhat dissatisfied - Timeliness, accessibility and cost are major impediments to use. The data file was only available to us for free through the Data Liberation Initiative at the U of T Library. Otherwise, we would have to pay thousands of dollars for it. And the fact that the data are only accessible a minimum of 2-3 years after the survey is conducted means that it is likely not timely enough for program planning and evaluation, particularly at the local level. This is probably less of an issue for epidemiological research.

6. How long did it take from the time of the data collection to receiving the report or data?

Tables, Report or Data Printout

	Monthly	**Biennial/National**
LCDC	Not applicable	Not applicable
Durham Regional Health Department	Less than a month	12 to 24 months
Cancer Care Ontario	Less than a month	> 24 months.

Data File

	Monthly	**Biennial/National**
LCDC	Not applicable	6 to 11 months.
Durham Regional Health Department	Less than a month	?? 12 to 24 months
Cancer Care Ontario	Less than a month	> 24 months

7. How satisfied were you with this time interval?

	Monthly	Biennial/National
LCDC	Not applicable	Somewhat satisfied - We perform our own analysis and generate reports.
Durham Regional Health Department	Very satisfied - Unbelievable turn-around time, particularly for receiving the data - less than one week after end of data collection. Data was very relevant and timely	Very dissatisfied - We received the 1996/97 NPHS in January 1999, and the 1996/97 OHS (a subset of the NPHS) in March 1999.
Cancer Care Ontario	Very satisfied - Ideal! It demonstrates that clean, labelled data can be produced very rapidly.	Somewhat dissatisfied - OK for epidemiologic research applications, but much too slow for program planning and evaluation. A turn-around time of 3 months would be much better – then, administrators could see within a few months whether a significant change in some facet of health determinants or outcomes.

8. What was the frequency of the data collection?

	Monthly	Biennial/National
LCDC	Monthly	Biennially
Durham Regional Health Department	Monthly	?? One time only
Cancer Care Ontario	Monthly	Biennially

Data Use

9. How was the data distributed within your organization?

	Monthly	Biennial/National
LCDC	We're not at this stage yet.	Report.
Durham Regional Health Department	Tables and report	Tables and report
Cancer Care Ontario	Data files, data printout sheets, and tables.	SPSS program, report.

10. How was the data used within your organization (or would be used, if a representative sample was available)?

	Monthly	Biennial/National
LCDC	Potentially the data will be very useful for surveillance and prevention and control.	For surveillance, for example, prevalence and trends of asthma. For prevention and control, for example, targeting strategies to high risk groups.
Durham Regional Health Department	Used for providing baseline data, for example, use of fitness facilities, trails in Durham Region. Data for monitoring progress toward goals. Data to support policy development, for example, workplace smoking. Information for planning for target population would need larger sample sizes. Comparisons between municipalities and age groups were very limited. We run road watch programs in some areas only and wanted to compare awareness by municipality.	Program planning and evaluation, health status reports, answer enquiries from general public and other organizations.
Cancer Care Ontario	I concentrated on screening utilization. It was interesting	The respondent-specific file was loaded on our network

	to note that about 80% of women 50-74 yrs of age and living in Durham have had at least one screening mammogram. Of women in their 40s, about 50% have ever had a screening mammogram. This is a relatively high level of utilization. Because data were only collected for 5 months, it was not possible to do a time series analysis to test for a trend or identify significant change points in this screening behaviour. The high proportion of hysterectomies in the population of older women was quite startling. About 40% of women 60+ yrs. Have had a hysterectomy. Adjusting the estimates of Pap smear compliance for hysterectomies raised appreciably the estimates of compliance (85 to 95% for ever/never; 72 to 81% for Pap within 3 yrs). For CRC screening, which is only now emerging as an organized program proposal for CCO, it is interesting to note that about 20% of adults 50-74 yrs report ever having had this screening. And finally, for PSA, 48% of men 50-74 yrs report having had at least one PSA test. This confirms the large background level of PSA testing in the general population.	server and accessible to analysts in our Division. Strictly speaking, only those with a proper U of T affiliation (faculty, students) can have access to it. From this raw data file, other working files are prepared, and frequency tabulations and cross-tabulations are run and shared among the staff. This information is useful for interpreting geographic differences in cancer risk, and temporal changes, too. Thus, it is incorporated in many of our information products, incl. Monographs and fact sheets.

Overall Assessment

11. Overall, how satisfied are you with this method of conducting surveillance on health problems? (For provincial and national organizations, assume that a representative sample across the province or country has been included in the survey.)

	Monthly	Biennial/National
LCDC	Very satisfied - Collecting data on risk factors is very useful for predicting health outcomes and evaluating the success of prevention and control strategies.	Very dissatisfied - NPHS is a longitudinal survey, so with time the estimates are not representative of the population. Also, it does not allow for time series analysis.
Durham Regional Health Department	Very satisfied - This method provided very timely data that we had no other way of obtaining. It took the place of multiple smaller questionnaires run by different programs. The external survey house provided help to produce questions and meant that we did not have to run the survey ourselves - time effort and lack of expertise would have been problematic. Partnership meant that others helped in designing questions and shared costs. The initial set-up was time consuming and the questionnaire was not validated.	Somewhat satisfied - There is extensive information in the NPHS/OHS, but it would be more helpful if the data were available more frequently at the local level (we had 1990 and now 1996/97 data) and more rapidly (almost 2 years before we could to data analysis). For such a large survey, a telephone survey was the most practical. Response rate was very high. Non-response was generally very low.
Cancer Care Ontario	Very satisfied - Much more timely, very accessible, with the necessary flexibility to permit adding time-limited issues to the questionnaire.	Somewhat dissatisfied - While these expensive national surveys are clearly necessary, they are not sufficient. They do not exhibit the granularity and flexibility that many agencies need to make optimal use of them for planning and evaluation purposes. This includes many of CCOs less-than-province-wide partners, including CCO-Regional Councils, Regional Cancer Centres, Public Health Units, etc.
Public Health Branch	Very satisfied - it could provide tailored data to health units to help them assess program process & outcomes	

12. What could be done to improve the usefulness of this methodology in conducting surveillance on health problems?

	Monthly	Biennial/National
LCDC	Linking risk factor data to health outcome data and to intervention/program data. Expanding the data collection to a national level.	Cross-section surveys. Continuous data collection.
Durham Regional Health Department	The basic questionnaire should have a core that used by many regions for comparability. Validation of the questionnaire is needed. Some local flexibility to change a few questions during the course of the questionnaire was very helpful. Syntax files for analyzing the content can speed up dissemination to users once the data is received.	Not sure.
Cancer Care Ontario	The Durham Pilot should run for at least 3 years to properly explore time series analysis. More sites should be started up in Canada, partic. in Ontario, perhaps with a coordinating center to help with Q dev't, interpretation, etc. CCO would need this system to be running in a number of sentinel counties/regions for it to be useful enough. Need wider dissemination of results. Perhaps if stakeholders continue to contribute financially, this will facilitate their buy-in and use.	Recognize the importance of designing and conducting these in tandem with rapid, cheaper surveillance systems, such that what can be done adequately at a cheaper unit cost is actively encouraged, and the more expensive periodic national surveys are used for validation, more extensive data collection (e.g. physical measures, biologic indicators, banked serum), and legitimate research (longitudinal studies, record linkage studies). Additionally, extensive supplements could be designed and administered less frequently, e.g. Tobacco Control or Cancer Control Supplement every 3-5 years.

13. What are the unique contributions of this type of data collection for surveillance?

	Monthly	Biennial/National
LCDC	Provide data on risk factors. Flexible - we can add questions. We have ownership of the data. Timeliness - we have data in a short time.	It is the only large-scale national survey available on population health.
Durham Regional Health Department	Timeliness, flexibility and local input.	Often our only source of information.
Cancer Care Ontario	Timeliness of reporting, effective partnership of local, provincial and federal health authorities. __Once running, could permit time series analysis, to identify temporal trends, sudden changes, more precise modelling of relationship between neighbourhood factors (at PC level) and outcomes, more precise descriptive information at the smaller geographic level, more local empowerment.	National and international standardization; calibration of cheaper measures e.g. self-reported tobacco consumption; self-reported height and weight; linkage to national data files; analytic research.
Public Health Branch	Questionnaire can be tailored to local health unit needs. Timeliness of data. Can get information on program processes as well as outcomes. Comparable data from health unit comparisons. Improved quality of data using a well developed questionnaire databank. Potential cost savings for health units presently doing their own surveys if they don't have to take the time to develop the questionnaire.	

14. What implications would there be for your organization if this type of data were not available?

	Monthly	Biennial/National
LCDC	We could not enhance our current surveillance actives.	Rather serious, since a lot of our surveillance activities are based on NPHS estimates at this time. A few years down the road, data from NPHS will not be a useful because it will not be representative of Canada due to its cohort longitudinal nature.
Durham Regional Health Department	We would have had to do several smaller surveys ourselves to answer key questions for program planning and evaluation.	We would not be able to assess many of our objectives, risk factors, health status. A lot of our health information would be limited to mortality and hospitalization.
Cancer Care Ontario	Design and deployment of independent data collection system- which would be more costly, more time consuming to undertake, but probably more customized. Uncertainty re periodicity of such a system. Without this, would just rely on the slow national surveys, and make the best use we can with this historical information.	No national benchmark; haphazard approach to collection and use of health survey data

15. How satisfied were you with the way the partnership worked?

	Monthly	Biennial/National
LCDC	Very satisfied - It will be better and more efficient if the partnership can be expanded.	Somewhat dissatisfied - No efficient mechanism for comments, inputs and feedback.
Durham Regional Health Department	Somewhat satisfied - The partnership worked well, particularly between the CCO and DRHD whose mandates did not change during the pilot study. Health Canada and the Ministry of Health had changes in personnel and/or mandates that made their roles less transparent.	Somewhat dissatisfied - We do not have a partnership as such - we are just users of the data.
Cancer Care Ontario	Very satisfied - I think CCO played a major role in the design and conduct of this Pilot Study. More stability in terms of the participants from the Federal and Provincial governments would have been more desirable.	Very dissatisfied - We're not partners at all in what is clearly a national venture, tightly controlled by Statistics Canada.
Public Health Branch	Very satisfied. This was a great group to work with. This was an excellent model of collaboration. It was very good to work with the federal government.	

Appendix D - Comparison of Data from RRFSS and other Data Sources

Figure 1 Comparison of population distributions of age group from RRFSS, census and Ontario Health Survey, Durham Region, 1996-99.

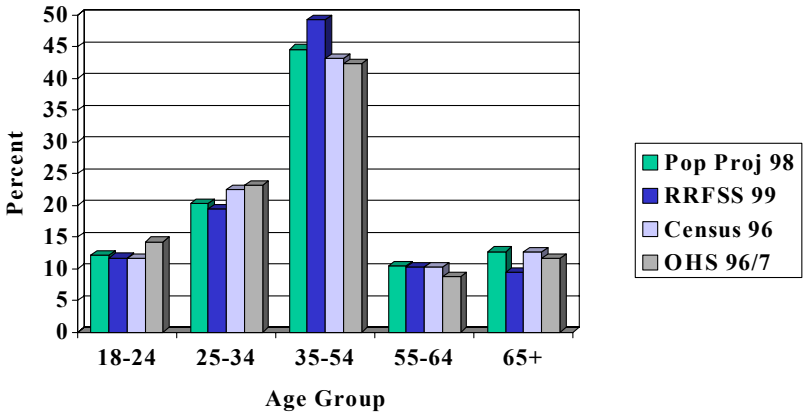

Figure 2 Comparison of population distribution of gender for RRFSS, census and Ontario Health Survey, Durham Region, 1996-99.

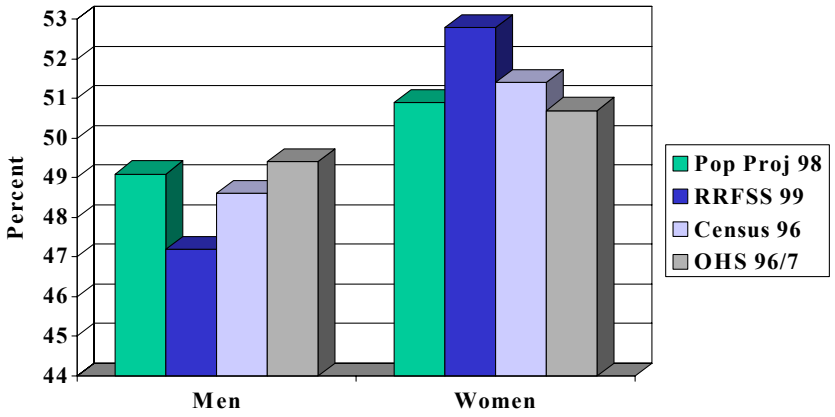

Figure 3 Comparison of percentage distribution of household income from RRFSS, census and Ontario Health Survey, Durham Region, 1996-99.

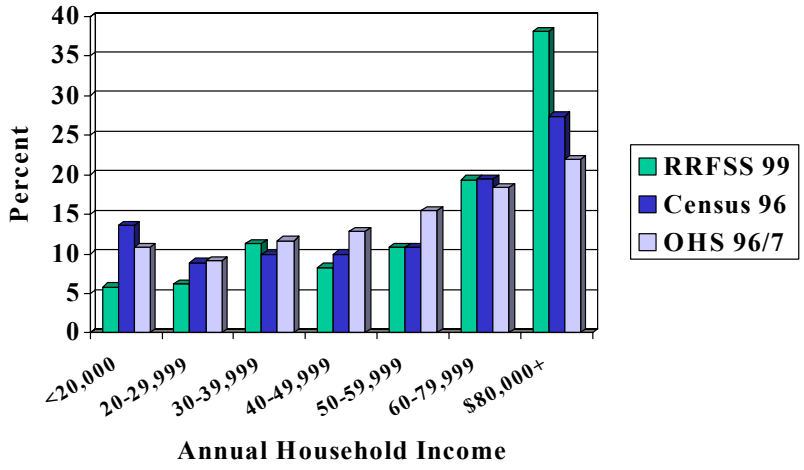

Figure 4 Comparison of percentage distribution of education (age 20+) from RRFSS and Ontario Health Survey, Durham Region, 1996-99.