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Building capacity for risk factor surveillance in developed countries: the need for a vision-driven approach: lessons learned from the Canadian experience

Summary

This paper examines the question of capacity building for risk factor surveillance in developed countries, with reference to the Canadian experience. Special attention is accorded the issue of building capacity for utilization of surveillance information. The paper describes the development, evolution and current status of risk factor surveillance in Canada. It notes that there is evidence of ongoing improvement in surveillance capacities over the past 20 years, but that there remains considerable room for improvement – particularly in relation to building capacity for the utilization of surveillance information. A vision-driven approach to capacity building is recommended and described building upon concepts and principles followed by international organizations addressing analogous issues.

Keywords: **Surveillance – Risk factors – Capacity building – Utilization.**

There is no formal and coherent program of behavioural risk factor surveillance in Canada. However, a very considerable amount of research referable to risk factor surveillance has taken place in Canada over the past 20 years. It does not appear to have been guided by a coherent structure or plan. Nevertheless, this "patchwork quilt" of surveys has provided a remarkably comprehensive coverage of major risk factors and changes over time.

These risk factor surveys cover the gamut of issues: alcohol, tobacco, drug use, nutrition, exercise, safety, healthy weights, risk factors for HIV/AIDS, sun exposure and protective behaviours, driving after drinking, helmet and seatbelt use, sexual practices, violence, and socio-economic determinants of health. Frequently, they have been carried out as "single issue" surveys; at other times, multiple risk factors may be covered, for example in surveys addressing heart health, diabetes, healthy lifestyles, health promotion and /or as part of comprehensive national health surveys (ACPH 1999b). Risk factor surveys are being carried out not just at a national level, but frequently at a provincial and/or local level as well.

In many instances, these surveys have been repeated over time with sufficient comparability to allow ongoing monitoring of key variables influencing the health of Canadians (ACPH 1999a). In fact, some data bases, like tobacco go back as far as the 1970s (Pederson 1993). In other cases, surveys tend to be of the "one-of" variety providing no longitudinal information (Statistics Canada 1999).

One reason for this is that rightly or wrongly, risk factor surveillance in Canada unlike other countries (such as the United States, CDC) has never had a sustained institutional "home". At times, risk factor surveillance activity occurs within a "surveillance/science" portfolio. At other times, it takes place within a "programs" portfolio. At still other times, ongoing risk factor surveillance activities have been subsumed under mega-surveys carried out by Canada's national statistical agency, Statistics Canada (Statistics Canada 2002). Moreover, there has been a succession of "reorganizations" over the past years within Health Canada with various aspects of risk factor surveillance switching from one portfolio and institutional home to another.

Our experience suggests that a program based institutional home tends to promote relevance and utilization through its linkages to established program structures, networks, partners – but, possibly also promotes fragmentation and duplication of effort. By contrast, a surveillance based institutional home tends to promote more cost-efficient information collections, but may suffer from its more distant linkages to user communities.

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In sum, our experience suggests that there is no right or wrong institutional home for risk factor surveillance. This will depend upon the country, the circumstances, the policy environment, the resources available, and the objectives that are at stake.

Building capacity for behavioural risk factor surveillance in developed countries: 20 years of progress

There have been real and substantial improvements in risk factor surveillance capacity in Canada and many other developed countries over the past 20 years. But, there remains considerable latitude and need for further improvements.

Many aspects of risk factor surveillance have shown steady improvement over the past 20 years. It is difficult to document these changes with reference to the literature itself. So, much of the information provided in this section must be considered as anecdotal and experiential – as comparisons between current practice and those in place some 20–25 years ago when the author first became involved in risk factor surveillance. These observations, and brief notes on their experiential basis are summarized below.

- *Improving methods and techniques and enhancing the cost effectiveness of information collections, particularly related to the advent of CATI and other technologies*: When Canada's first Health Promotion Survey was carried out during the 1980s most surveillance data collections – even those using telephone interview formats – were slow, cumbersome and expensive processes, relying upon paper questionnaires, and laborious and time consuming data capture, coding, entry, cleaning and verification processes. This has changed and improved considerably in recent years.
- *Improving the measurements of key risk factors*: There have been ongoing improvements in the measurement of key risk factors based on advances in the literature, most notably, physical activity.
- *Documenting key aspects of the magnitude of the problem and changes over time*: During the 1980s many of the surveillance systems in developed countries were still in their initial stages. It takes a considerable period of time and a substantial investment to obtain sufficient longitudinal data to capitalize upon this important component of surveillance systems. When Canada's first Health Promotion Survey was carried out, there was very little longitudinal data to build upon – with the possible exception of the 1978/79 Canada Health Survey. Today there exists useful longitudinal data in Canada on most major risk factors.
- *Linking to other health data sets*: Increasingly, efforts are being made to link health surveillance information to health surveillance data sets – particularly, those related to health care, utilization and morbidity and mortality. While we still have a long way to go in that regard, this holds the potential to greatly enhance the utility of all of these collective surveillance efforts.
- *Advancing scientific knowledge and encouraging dialogue on technical issues*: Recent years have witnessed a considerable growth in national and international conferences and scientific publications, possibly evidencing a growth in the core size and capacities of the field as compared to 20 years ago.
- *Greater timeliness of information* and *increased efforts at broader dissemination:* When Canada's first Health Promotion Survey was produced in 1985, it took more than three years for the first major report to be produced. The budget for data collection was in excess of $ 1000000; the budget for dissemination was $0. This is no longer the case as, at least in Canada, surveillance workers strive for more timely information, and broader, more user friendly dissemination.

Building capacity for behavioural risk factor surveillance in developed countries: there remains considerable room for improvement

There are a number of areas where improvements have been difficult to document, and which at the extreme have been the focus of ongoing criticism of our current surveillance efforts.

These include the following:

- The people who are at greatest health risk are often the ones we are least likely to include in our surveys. Examples might include the homeless, geographically or socially isolated; institutionalized; extremely low literacy/language; certain subsets of infants, children and youth, and marginalized groups (e.g. aboriginal peoples).
- Preoccupation with a "Medical model". The Ottawa Charter notes that "health is more than the presence or absence of disease" – yet risk factor surveillance systems focus almost exclusively upon risk factors for disease. Similarly, there appears to be a disproportionate emphasis upon physical health as opposed to mental health, spiritual health and community health.
- Insufficient attention to the "Determinants of health" outlined in the Ottawa Charter as well as to the social and economic determinants of health as outlined in the Toronto charter (Raphael & Curry-Stevens 2003; Wilkerson & Marmot 2002). Together with this is an implicit bias

in risk factor surveillance systems toward admonishment as opposed to empowerment – i.e. the things people are trying to do to improve their health.

- Focus on an inappropriately narrow range of risk factors. Items frequently not included in such systems include, but are by no means restricted to: spousal, child or elder abuse; sun safety and protective behaviour; risk factors for HIV/AIDS; environmental risk factors; living and working conditions.
- Lack of reference to political, social, cultural and policy environments (e.g. non smoking by-laws) that influence behaviours.
- Widespread problems of underreporting and failure to triangulate and reconcile with other data-sets (e.g. cigarette, alcohol, food sales; seatbelt and impaired driving information from roadside surveys; police reports of illegal behaviours). The problem of under-reporting also may be influenced by changes over time in the social desirability of being labelled in certain ways (e.g. obese; smoker; heavy drinker; illegal drug user).
- Lack of useful information at a local level. Much of our capacity to promote health exists within local communities. Unfortunately, information from risk factor surveys is rarely available to empower community-based initiatives.
- Lack of systems to promote timely integration of surveillance information into environmental scanning and strategic planning; program and policy development; community action; social marketing; public information and awareness and creating demand and support for healthy public policies.

Each of the above "criticisms" reflects an opportunity for improvement and related capacity building. But, given the scope of areas for improvement, the question that arises is: "which of these areas should be the priority for capacity building?"

There is a need for resource trade-offs, as well as more directed resource allocations to increase their capacities in a systematic manner.

There is no single simple or correct answer to this question. There is a need for continued capacity building at all levels of the system. While there is no one single "idealized or optimal" model for risk factor surveillance, what is needed however, is a clear comprehensive plan for risk factor surveillance wherein the different needs sets and accompanying decisional choices and their consequences are clearly articulated and the trade-offs made explicit.

Challenges and barriers

In any attempt to enhance the quality and relevance of our surveillance systems, important challenges and barriers must be considered. Each of these, in turn relate to the question of building on existing capacity – with very limited resources.

1. How do we expand our capacity to enhance the quantity and quality of existing information collections? It is true that we have made important progress through continued incremental improvements to existing systems. But, there is little evidence that we have addressed the criticisms and issues noted earlier in a systematic manner. What would an ideal surveillance system look like? How do we enhance our capacity to get "there" from "here"?
2. How do we expand our capacity for integration of multiple data sets – our capacity to link our information to other information sources and data sets? It is extremely rare that findings from a single study or surveillance system are in themselves sufficient to have a major impact on policy and programs. While each new information collection reflects an important incremental improvement in our knowledge base, these findings are much more powerful and useful when combined with the larger body of evidence, from multiple sources that currently exists. How do we increase our capacity to enhance our information through triangulation with other sources of information?
3. How do we enhance our capacity to better understand the needs of diverse "user" communities – policy makers, environmental scanners, strategic planners, programs people, practitioners, voluntary health agencies/coalitions, health advocates, community activists the media and the general public? We have done a credible job of communicating with other scientists; but know far too little about the needs of other communities. There has been little effort thus far to identify key "market segments" or their needs. Who are the key users of surveillance information? What are their needs? What research questions should be addressed? How should information be made available and accessible to them? How should it be packaged, promoted and delivered?
4. How do we build capacity within diverse user communities? Very few members of user communities have the capacity to access and to utilize complex, large scale data sets. How do we increase their capacity to become users of this information?
5. How do we shift capacity from predominantly investigator-driven systems to more user-driven systems? Investigator-driven systems typically ask questions of interest to the investigator and deliver the information to other investigators through peer-reviewed journals.

User-driven systems ask questions of greatest importance to the community of prospective users, and deliver the information in a manner, a mechanism and a format which is appropriate to them.

6. How do we enhance our capacity to address the barriers to greater utilization of surveillance information? As noted above, there are great many limitations to greater utilization of information on the part of users. But, there also are barriers confronted by scientists as well. These relate to such issues as ethics, privacy and confidentiality, and perhaps most importantly, possible misuse (intentional or otherwise) or misinterpretation of the information. How do we build capacity to enhance utilization, while ensuring against the possibly deleterious consequences of inappropriate utilization? In addition, many surveillance scientists are employed within the governmental sector, wherein there may be constraints governing the nature and extent of their participation in public policy debates.
7. How do we enhance our capacity to maintain rigour, while enhancing relevance? Nothing is less relevant than a study without rigour. How do we enhance utilization, while maintaining rigour – especially among a diverse community of users with different skills, capacities and agendas?
8. How do we go about building a greater knowledge of the methods, techniques and limitations of "knowledge translation" – and building/ enhancing our relationships with other disciplines and specialities? Our knowledge of the methods, techniques and limitations to "knowledge translation" is still in its infancy. And while we have made progress, far too much of it seems to have been by "trial and error".
9. How do we adapt incentive and accountability structures? At present, the primary rewards structures for many surveillance scientists tend to evolve around publication in peer-reviewed journals. This creates an unfortunate disincentive to pursue other avenues of information translation and utilization. But this raises some important questions as well. Should we build the capacity (and increase the reward structures) for scientists to engage in knowledge translation and use by other communities? Should we enhance the capability of other communities, networks and partners to better utilize this information? Should we build capacity among knowledge brokers/translators to fulfill this role? How do we evaluate progress? Who should be accountable, and how, for ensuring that this happens?
10. How do we involve a broader group of professionals from other disciplines and specialties in order to enhance capacity for all? Many disciplines have much to offer in our attempts to build capacity – especially as it relates to knowledge translation and utilization. This includes professionals engaged in (health) communications, social marketing, information technologies, as well as those with expertise in the needs of different user groups, such as political scientists, journalism professors, community development specialists, and specialists working in non-traditional, but health-related fields such as employment, taxation, environment, justice, human rights, transportation, community development, social policy, and the private sector. In that regard, the private sector represents a huge, largely untapped resource through its linkages no only to occupational health, but also to policy issues (e.g. non smoking regulations) and to the specific health issues themselves (e.g. exercise/physical activity; healthy eating/obesity).

Toward a vision-driven approach to capacity building

To enable a rationalized and directed approach to capacity building, a clearly articulated vision of surveillance is imperative. This will ensure the allocation of resources to priority capacity areas as well as the development of rewards and incentives for innovative approaches to realizing this vision. It is important to stress that just as there is no one idealized model for risk factor surveillance, there also is no one perfect or optimal vision. The ideal vision is likely to vary as a function of existing resources and infrastructures; particularly in public health, health promotion and health research as well as the political and institutional arrangements that relate to the delivery of these important collective goods in different countries.

Nevertheless, the allocation of resources to capacity building for surveillance should proceed on the basis of a vision rooted in the answers to the following questions(Crossman et al. 2002; Yip 2001; Beamish & Woodcock 1999):

- What are the fundamental *goals* of surveillance; what are the *desired and valued outcomes* of surveillance? To be sure, the primary goal of surveillance relates to knowledge development. But, knowledge development for what and for whom? Is the purpose of knowledge development to contribute to:
- Increased knowledge within the scientific community?
  - Greater knowledge and skills of health professionals and/or those in other sectors?
  - Increased public information and awareness generally and/or for vulnerable populations specifically?
  - Healthy public policies?
  - Informed community action?
  - Improved policy, programs and priorities?
  - Enhanced evaluation and accountability?

Each of the above (and the list is by no means exhaustive) requires the development of a different set of capacities, and a different approach to knowledge translation.

- Who are the *primary* stakeholders? What *partnerships and alliances* should be developed to achieve these goals? As many years of community development research have demonstrated, key stakeholder groups need to be involved at the outset, and throughout the process, not only for their expertise, but also as a window/conduit to much larger user communities.
- Who are the desired *end users* of the information? What are their needs, their resources and their capacities? What mechanisms currently are being used to deliver health information to these end users in a manner and a format that is meaningful and useful to them (e.g. social marketing campaigns, community action programs, training systems for health professionals, etc.)? How do we establish partnerships with existing health communications, health education and training, health advocacy and health promotion initiatives to capitalize upon existing networks, infrastructure and systems?
- What *outputs* should be produced – for whom – by whom? How should they be developed, produced, and made available to these different stakeholder groups and partners? It is readily evident that different products are required for each of these groups, delivered in a manner that is appropriate to them.
- How should the products best be delivered to the relevant end user communities – directly, or through "empowerment of intermediaries"? If the products are to be delivered directly to end users, what capacities do we need to develop/or co-opt to ensure that we are delivering timely information in a manner that is useful and relevant to them? If the information is to be delivered via intermediaries, what capacities do we need to develop to ensure that this information is appropriate for them? What capacities do we need to develop among intermediaries to ensure that the information has its desired impact upon the ultimate target audience?
- How do we build knowledge, skills and capacities among prospective user populations to ensure that the information has its desired impact?
- How do we foster and encourage *innovation,* particularly as it relates to the information age, expertise in knowledge translation, the integration of other professionals and specialists and the experiences of years of increasingly progressive experience in health programming? How do we take better advantage of, and better enable the collective resources, partnerships, infrastructures, coalitions, and expertise that already exist?
- How, by whom and for what should the outcomes of surveillance activities be held *accountable*? As noted above, given the multiplicity of stakeholders/ market segments, delivery channels and factors affecting utilization, the best possible contribution of surveillance activities is to *contribute to* the valued goals described above. There are far too many extraneous factors at play within these diverse groups and complex issue areas to guarantee any specific outcome – no matter how effective the knowledge translation process.
- What is the plan for *sustainability* ? At the end of the day, capacity building requires resource allocations. Which is why, at the end of the day, sustainability and optimization are contingent upon making the best use of the resources available – in this case, not just the resources available to surveillance activities per se, but also the resources available within the broader community.

Where do we go from here?

The existence of a sophisticated and refined information collection infrastructure connotes a major strength and competitive advantage to the field. These strengths are further enhanced by concurrent trends associated with the maturation of the information age and toward evidence-based decision making for health at all levels of society.

The opportunities for development of a coherent vision of the potential that can be realized by building upon these strengths, overcoming apparent weaknesses, addressing challenges and barriers and capitalizing upon these opportunities should be a first order of business.

Primary among this is the need to involve a much broader range of networks , partnerships and disciplines in the endeavour. At one level, these are all potential "users" of surveillance information. At another, more important level, they are all key partners in our efforts to create a healthier society.

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