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FROM HEALTH STATISTICS TO HEALTH INFORMATION SYSTEMS: A NEW PATH FOR THE 21ST CENTURY

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Charlyn Black MD, ScD

Noralou Roos PhD

Leslie Roos PhD

Manitoba Centre for Health Policy and Evaluation

Department of Community Health Sciences

Faculty of Medicine

University of Manitoba

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"The road to health passes through information"

World Health Organization

Introduction

This paper was commissioned by the U.S. National Committee on Vital and Health Statistics to provide input to an initiative to develop a 21st century vision for health statistics. It recognizes that many countries are making significant investments to enhance their health statistics capabilities. As outlined in an accompanying paper by Zelmer, Virani and Alvarez (1999), these activities include renewing traditional data collections and extending their content and coverage, increasing the flexibility and integration of data, enhancing approaches to protecting privacy and confidentiality of data, and improving the utility and accessibility of data.

We argue that a bold new vision is required to seize the opportunities of the 21st century and provide direction to these efforts. While enormous progress has been made in health statistics systems during the 20th century, our current approaches fall short of providing a framework for moving into the future. Several major forces are moving us in a new direction: increased computerization, automation and computing power, improved ability to measure health, an increased appetite for evidence, a focus on accountability and outcomes, and an evolving conceptual understanding of health and the factors that contribute to health.

The paper first provides perspective on some of the forces that provide impetus for a new vision and from this, identifies several characteristics that are critical to incorporate into future efforts. It then provides an update on experience gained in Manitoba, Canada with development of a prototype health information system. Finally it concludes by considering opportunities for the future.

Background

As the 20th century draws to a close, a number of critical developments and perspectives are challenging us to rethink our approach to health statistics. Together, these factors support a more targeted and cohesive approach – one that focuses on health and the factors that influence health.

Evidence and the outcomes movement

In the 1970s and 80s, research focusing on the health care system revealed a surprising degree of variation in the way health care services were delivered to populations. For a relatively small number of services, rates of intervention were quite similar across population groups. However, for the vast majority of services, profound variability in intervention rates was the norm. These patterns of variability in service delivery were found at many different levels, both across and within countries; and they were remarkably stable over time. Surprisingly, the variation often was most striking within – rather than across – countries and states (or provinces).

These *small area variations* raised profound challenges for the health care system. Subsequent research revealed that the variations were not clearly related to differences in population groups' underlying need for health care. Instead, they seemed more likely to be driven by differences in providers' practice style. Most importantly, they raised the troubling question "Which rate is right?" – to which there was no simple answer. It became clear that there was very little evidence indicating that a higher level of intervention was more (or less) appropriate than a lower level of intervention. A quest to develop better evidence began, fueled by a new understanding of the importance of studying the impacts of health care in terms of the health outcomes it produced.

In the 1990s the U.S. embarked on an explicit program of research that was designed to produce knowledge and evidence about the impact of the health care system (Roper WL et al. 1988, U.S. Department of Health and Human Services 1990a, U.S. Department of Health and Human Services 1990b). Since then, the U.S. health agenda has been strongly influenced by the outcomes research agenda. This massive effort has provided perspective on the relative risks and benefits of medical care and it has led to a focus on clinical data sets and the development of detailed instruments for disease-based (as distinguished from health-based) research. Much has been learned, and much more remains to be learned about the impact of specific medical interventions on the patients to whom they are applied.

The population health agenda

Meanwhile in Canada, a different conceptual and policy framework – one that encourages a focus on understanding factors that contribute to the health of populations – was gaining prominence in policy discourse. The framework underlying this perspective is most clearly articulated in an article by Evans and Stoddart (1990). They suggest that while tremendous value is ascribed to *health*, modern societies devote a very large proportion of their economic resources to the production and distribution of *health care*, reflecting a widespread belief that health care is central to the health of both individuals and populations. Instead, they argue that the model of the relationship between disease and health care that underpins our investments is too simplistic. They have developed a more complex model that incorporates many other factors known to influence health. Moreover, they argue that further investments in health care may not be the best way to improve the health of populations: "A society that spends so much on health care that it cannot or will not spend adequately on other health-enhancing activities may actually be reducing the health of its population." In other words, expansion of the health care system uses up resources that would otherwise be available to address other factors that influence health.

This framework has underpinned the recent report of the National Forum on Health, a panel of experts convened by and reporting to the Prime Minister. The population health framework, as it is known, reorients us to consider health and the improvement of health (rather than a focus on disease) as fundamental goals of the health system. It builds on an earlier Canadian framework (Canada 1974) to encourage consideration of a broad range of factors that influence health, recognizing that both medical care and other determinants of health play important roles. It therefore supports a more explicit understanding of the contribution of medical care to the improvement of health. However, whereas the outcomes movement focuses on patients who receive specific interventions for identified diseases from the health care system, the population health framework encourages conceptualization of populations defined by characteristics *other* than by their interaction with the medical care system. More importantly, within the context of health reform, it challenges managers to understand how the health care system, as currently structured, is responding to the goal of improving health, and how proposed changes may support or detract from that goal.

The notable absence of such an agenda to date in the U.S. is exemplified by John Eisenberg's (1997) statement shortly after being appointed Administrator of the U.S. Agency for Health Care and Policy Research (Association for Health Services Research 1997):

> AHCPR is the nation's lead Agency in ensuring that there is a scholarly and scientific foundation for a rapidly changing health care system. … Our shared goal is to enhance the way health care services are organized, financed and provided. We want to improve the care patients receive… One of the most critical needs is to ensure that we continue to build capacity for health services research.

Nowhere was there a reference to the health of patients, although no doubt it is assumed that in improving the care patients receive, health would be one of the measuring sticks. More critically, nowhere is there a reference to the health of the population or to understanding the potential contribution that health care does or does not make in determining the health of populations.

The population health agenda has provided a number of important perspectives that have tremendous implications for the development of information systems. Most importantly, it has stressed the importance of health and underlined how little we really know about health and about what produces health. Second, it has provided conceptual models that challenge some of our central beliefs about what factors do contribute to health. This model suggests that factors outside of the health care system may be as important – or even more important – than the health care system itself in producing health. Third, it has challenged us to think more broadly and yet more critically about the contribution of medical care to producing health in populations – beyond the perspective of the outcomes movement, which has focused more specifically on patients rather than populations.

Expanding data and analytic capabilities

A third major factor that provides important opportunities for rethinking our approach to health statistics in the coming century relates to the remarkable improvements in our ability to routinely collect, store and analyze data. We now have the potential to collect data about the environment in which people live and work, their social and economic status, educational experiences, states of health, contacts with the health care system, their involvement with various government

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programs and their health outcomes – all important aspects of understanding what contributes to health.

Whereas previously, we had to rely on primary data collection activities that focused on answering specific questions with small samples on a one-time basis, we can now ponder the possibility of designing systems that will collect a rich set of data elements routinely. Whereas previously, it was useful to think of developing statistics to address specific health issues (e.g. communicable disease control and surveillance, perinatal morbidity, hospital utilization), it is now possible to consider a set of data systems that provide a person-oriented, cradle-to-grave set of data records that provide the basic infrastructure to develop statistics and information to serve any number of purposes. Whereas previously, compilation of statistics was laborious and resulted in outdated information, increased analytic power now provides us with opportunities to produce analyses that can be conducted in real time and are tailored to meet users' specific requirements.

In fact, given the opportunities, the real challenge before us is to think broadly and boldly enough.

Our experience with an early prototype: The POPULIS system

The Manitoba Centre for Health Policy and Evaluation (MCHPE) is a university-based research group that was created in 1991 to undertake health services research and policy analysis. The mission of MCHPE is to provide accurate and timely information to managers, decision-makers and providers, in order to support them in offering health care services that are effective and efficient in maintaining the health of Manitobans. In conducting its analyses, MCHPE draws on a unique data base that has been created from administrative data used to run the provincial health insurance system and which is now housed in a research data repository at the University of Manitoba. According to the contract with the Government of Manitoba, the Centre undertakes a defined number of projects related to relevant policy issues on an annual basis. One of the most important undertakings has been the development of a population-based information system, a system known as POPULIS. This system embodies a number of features that provide critical lessons for development of health information systems of the future.

The population-based information system

POPULIS is a system of data, an approach to analysis, a set of concepts and indicators, and a way of organizing these elements to produce information. It permits us to study, for a given population, the factors that influence health, the state of health, and the availability and utilization of health and other services. It uses a population-based approach to analysis, whereby characteristics of defined groups of people are examined and compared. This concept is intuitive for studying health and social characteristics of populations, but is less so in the analysis of health services. Using this approach, all services, regardless of where they take place, are attributed back to the individual and the individual's region of residence. Population-based analysis therefore provides perspective on how services *are used by population groups*, which is fundamentally different from understanding how services are delivered by providers. In so doing, it facilitates planning and evaluation from the viewpoint of the health needs of the population.

Information can be configured for many different population groups. For most of our applications these groups are defined by geographic boundaries (and we have several different versions of these). However, we can also define populations by disease states, by social and economic circumstances, and by other characteristics. Another advantage of population-based analysis is that it makes it relatively easy to adjust for differences in the age and sex structure that may contribute to observed differences between populations. After adjustment, one can expect similar use and health status across different regions. This makes it easy to compare indicators across population groups and across time.

The other important feature of POPULIS is that it enables the user to simultaneously relate characteristics that affect a population's *need* for health care to that population's *use* of health care, to that area's *supply* of health care resources, and finally, to the *health status* of a population. The importance of this feature is that it permits the structuring of more complex and different questions (and answers) (Roos 1995). It allows us to ask, for instance: Does health status vary across regions? By how much? What factors are associated with poor health? Are high risk populations poorly served by the health care system or do they have poor health status despite being well served? What are we spending on acute hospital care per capita? How much does it vary across our health regions? Is reducing investment in acute care compatible with good health? Where might cuts be made without jeopardising at-risk populations? In short, we can focus on understanding the linkage between use of health care resources and population health, instead of merely understanding how providers deliver care.

The foundation: A strong underlying data system

A recent initiative to make data available to Canadian researchers has stressed the central importance of data (Watkins 1995). The rationale for this project provides perspective on the importance of constructing strong data systems to facilitate observational research:

> Data are unlike other tools of the research endeavour. They provide the raw material from which information can be created… Unlike printed tables which, like a postcard, provide a larger view of a larger phenomenon, data can act as a camera, allowing the researcher to manipulate the foreground and more fully investigate the object under study.

The data system underlying the POPULIS system provides the critical foundation for its capabilities (Figure 1). The system relies on the unique Manitoba health research database, which comprises information produced in the administration of the provincial health insurance system. At the hub of this data system is a population-based research registry. This research registry, derived from a real-time provincial administrative system that provides insured benefits to provincial residents, contains a unique but non-identifying research number that is assigned to each provincial resident, together with information about demographic characteristics, residence and family composition. Other files within the data system use the same non-identifying research number to track use of services, making it possible to compile comprehensive histories for individuals over time.

Administrative databases provide an information-rich environment for researchers; a system such as POPULIS fundamentally depends on the availability of such data. For billing and administrative purposes, every contact that the population has had with hospitals, nursing homes, and physicians over a 25 year period has been documented and is incorporated into the research database, even though for some services, there are multiple payors. Recently, data on immunizations, pharmaceutical use, use of home care and other community-based services have been added to the data holdings. Vital Statistics data, documenting date and cause of death, as well as public-use census information have also been integrated into the database, making it possible to provide more comprehensive information – beyond the health care system – about the population of individuals.

Population-based research registries, combined with administrative data files containing unique non-identifying research numbers to indicate the service recipient, provide the ability to generate meaningful information on each individual's life course, and multiply the types of studies that can

be performed. Indicators focusing on quality of care (readmissions or emergency room visits within 30 days of discharge from hospital) or indicators identifying disease cohorts (individuals with diabetes or hypertension whose outcomes can then be monitored across different delivery systems) are all enhanced if a population registry and cross-file linkages are possible.

The research database builds on currently available data, but can accommodate other data, such as surveys, clinical data sets, public health data sets, disease registries and other data. Indeed, we have learned that when designing population-based health surveys, the possibilities of linking data and conducting validity studies using administrative data should be foreseen and incorporated into the study design (Muhajarine et al. 1996). Our data holdings include an important population-based study of the elderly (Havens 1996), as well as provincial samples of recent national surveys. Currently, plans are being made to expand our data holdings to include provincial social services and educational data.

In the interests of protecting privacy, no identifying information is ever introduced into the research database. In addition, each of the individual data sets exists within the system in an unlinked format. Often, important data analyses can be conducted without the need for linkage. In fact, because of the focus on populations identified at the geographic level, most of the analyses undertaken for POPULIS projects require no linkage at the individual level. Linkages between the research registry and other data sets are undertaken only on a project-specific basis – once approvals from ethical review and data access review committees have been received. During the review process for each project, consideration is given to the importance of the research question and the offsetting potential risk of identification of individuals or violation of confidentiality. Strict protocols have been developed to reduce such risks during the research process and security monitoring processes are in place and are continually being upgraded. We have recently received funding, in a national competition, to further upgrade our facilities to develop a state of the art data research laboratory.

An approach to analysis: Our conceptual model

Adoption of a conceptual model has been central to the progressive development of our POPULIS system. It has influenced many aspects: the data elements and files we have worked to add to our research database, the concepts and indicators we have developed, our approach to analysis, and the research questions we have pursued. Such a conceptual model has been critical in helping us move

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our research database from one that is easily focussed on health care, in the direction of a resource that can begin to answer important questions about what produces health.

This model (Figure 2) represents a modification of that proposed by Evans and Stoddart (1990). It recognises a range of background factors that influence health status and well being, including socio-economic factors that characterise the economic, social, and physical environments in which individuals live and work, as well as demographic and genetic factors. Health states are influenced by these background factors, but are mediated by an individual's response to socio-economic and biologic circumstances. Health status reflects the absence or presence of disease and functional impairments. While it strongly influences a person's need for health care interventions, the interplay between health status and health perception (which is shaped in part by other factors such as practice patterns) influences an individual's sense of well being and resultant demand for health care services. Need and demand influence use of specific health care services, but utilization is also affected by supply and practice patterns factors operating within the health care system. Use of health care services, mediated by individual responses, may affect the health status of individuals later at Time 2. Health states, as identified at Time 2, are influenced by socio-economic factors, initial health status, and utilization of health care services at an earlier time (Time 1). The model provides a framework for considering the relative contribution of each of these factors to health status and population health. Conversely, the model suggests that health status ultimately feeds back to influence the socio-economic environment in which individuals operate and further influence utilization of health care.

This model recognizes that biological factors (including, but not limited to, genetic predispositions to developing specific diseases), physical environmental factors (such as housing and pollution), social context (such as income inequality) and individual socioeconomic characteristics (poverty, lack of education, unemployment) have a strong negative impact on the health of a population. While we anticipate eventually incorporating several key environmental indicators into the information system, we have initially focused on the socioeconomic determinants of health and their relationship to utilization, supply and health status indicators – and we have actively tried to increase our data and analytic capabilities in this area..

Development of key concepts and indicators
Another important principle in developing POPULIS has been to use a consistent approach to operationalize key concepts and indicators – in other words, to develop a consistent and coherent set

of statistics to underpin the system. Our approach builds on what is currently available – data created routinely as part of administering and paying for services delivered – and turns it into information about key concepts such as need, health status, use and supply (Figure 3).

The initial approach to development of the information system involved several key steps. First, we created meaningful geographic areas and for each area, obtained denominator data – by age and sex. Second, we developed indicators of socio-economic risk (note that these are available only at the aggregate level) for these same areas. Thirdly, we developed indicators of health status, and finally, we developed indicators of utilization of services. Population-based rates were used to develop all of these indicators. Where possible, they were age- and sex-standardized to permit comparisons across populations. A comparative population-based approach has driven the development of indicators (Figure 4).

In developing indicators of these key concepts, several additional key concepts were developed. For example, to develop indicators of utilization of services for relevant data sets, standard approaches to measuring the number of users of services were developed to describe access; and different approaches were used to measure the intensity of service use, such as frequency, volume and cost of services. Data on the usual supply parameters of health planning (hospital beds, nursing home beds and physicians) were also developed, but our system has given equal or more emphasis to measures such as access, focusing on the proportion of individuals resident in a given area who use a service, regardless of where the service is obtained

Indicators or statistics have been developed because of their potential value for health care system management. The hospital indicators distinguish between medical, surgical, pediatric, psychiatric and obstetrical admissions. Also, use that takes place within the region of residence can be compared with that occurring out-of-region. The physician supply indicators distinguish between physicians available to area residents because they live in the area, and the physicians effectively available to area residents because patients travel (as physicians sometimes do) (Roos et al.1999).

This information system also permits summing usage across sectors, using a dollar figure where possible and, in the case of nursing home and hospital use, summing total days of chronic institutional care. Finally, regional profiles showing how each region's health, socioeconomic risk and health care use characteristics differ from the provincial norm can be readily created.

Translating data into information

Developing these capabilities has been useful for descriptive analyses, for more applied analyses that target the big questions in health and health care, as well as to facilitate more targeted policy-relevant and evaluative research.

Our first steps in developing our health information system focused on conducting population-based analyses in key areas that we felt were critical to underpin such a system. These included focused and comprehensive analyses in key areas where we had data capabilities or needed to develop them – for instance, developing capabilities to measure health status of the provincial and sub-provincial populations. Similar population-based analyses were conducted with key data sets – our hospital discharge data sets, our nursing home and physician claims files. This involved considerable work to develop and validate measures, understand whether they are all telling us the "same story" and understand which indicators inspire confidence. To consolidate this working knowledge, we have developed the concept dictionary, which focuses on providing a working historical documentation of key developments in a web-based format (Roos et al. 1999).

Our next major steps involved using these data and information tools to develop a general understanding about some of the big issues in health and health care. This permitted us to understand some key issues that in turn helped us focus our research agenda. As a consequence, we have developed this system to help the public understand that more health care is not necessarily better, and to help planners identify the levers for pursuing a policy agenda based on health, not health care. The system is organized around issues relevant for policymakers. For example, questions concerning intensity of use can easily be answered: How much do residents of regions vary in their use of high-tech teaching hospitals versus their use of small rural hospitals for acute care? What is the relative use across regions of resource-intensive procedures (eg. hysterectomy) versus less intensive procedures (such as hysteroscopy)? We can also compare usage patterns across regions in which residents have similar levels of good health, allowing policymakers to approach the question of "which rate is right?" in terms of "what is the least-costly rate associated with good health?" Costs incurred by a region's residents will be affected by how often residents access care (for example, how often they are admitted to hospital or contact a physician), the average cost of the service incurred (whether the physician was a specialist or whether the hospital day was spent in a teaching hospital or a small rural institution) and the number of services provided per user. Furthermore, POPULIS facilitates an assessment of how each of these factors interact in determining cost per resident.

The real power of the data and information infrastructure becomes apparent in applying it to more focused policy questions. This became possible once we had developed the basic data and information tools and developed an understanding of some of the big picture issues from an empirical perspective. Now, we are able to identify emerging policy issues and think creatively about applied research that could provide perspective on the issue – and because of the critical and lasting investments in developing data infrastructure, developing and documenting indicators and approaches – we can now move relatively quickly to provide analyses that provide perspective on emerging issues. For instance, having developed key measures of health status and utilization, it was possible to study changes in health status over time. We have been able to detect improvements in the health status of some regions and groups, while at the same time detecting significant declines in health status of other groups. In fact our work has shown that gradients in health status have increased over time (Mustard et al. 1999), despite the relatively higher use of health care by the less healthy groups in the intervening years.

We have also been able to study how well the system adapted to bed closures, in which 25 percent of available hospital beds were closed over a three-year period. Our analyses showed that, in spite of predictions of chaos, the system was able to handle almost the same number of cases, due largely to decrease in length of stay and a shift to outpatient surgery. There was no indication that quality of care, as measured by readmission rates, was affected or that the overall health of the population declined. Moreover, the groups whose health needs were greatest maintained their relatively greater access to hospitals, in comparison to groups whose health need was lower (Brownell et al. 1998). This set of analyses was so critical to policymakers that we were asked to provide two updates to our initial report to determine if the initial findings were sustained.

A more recent project has been able to show how winter pressures in emergency departments – an issue that has received considerable media attention – are related to a relatively small number of influenza admissions that occur for a fairly circumscribed period on an annual basis. This study has suggested that adding permanent system capacity – the obvious solution according to many commentators – is not the answer. The answer lies in finding new strategies for dealing with a fairly predictable annual requirement for more medical admissions (Menec et al. 1999). A followup to this study focuses on conducting a more broadly-based analysis of influenza across the system, in cluding preventive strategies (i.e. patterns and extent of influenza immunization),

surveillance (i.e. influenza monitoring), physician and emergency services utilization, hospital and nursing home patterns and deaths. This project will provide information to support greater system integration in dealing with the population-based effects of influenza.

A prototype for the future

The health information system we have developed in Manitoba, Canada has enabled us to use data to develop a cohesive set of health statistics that can be used to study health, as well as the impact of factors that influence the health of populations. While we are still developing the system, it is fair to say that we have managed to take a data system that is largely based on interactions with the health care system and develop its capabilities to produce information about health. While its capabilities as a population health information system are still being developed, it provides some important perspectives for future data and information system development on a grander scale.

What aspects are critical for future development of health statistics?

Based on the challenges forcing us to rethink our approach to health statistics, and our experience with a population-based health information system, several factors emerge as critical to consider in designing systems of the future. Some of these important features are outlined below:

A focus on health

The World Health Organization's emphasis on health, with its theme "Health for all", together with the population health agenda have clearly provided a context in which improving health must be acknowledged as the central goal of health systems. In developing capabilities for the 21st century, therefore, the key word is health. A system of statistics that will *focus* our attention on health, allow us to make comparisons of health status across individuals, groups and populations, as well as make it possible to understand how health status changes over time, is needed. Moreover, health statistics must position the improvement of health as the central goal of the health care system and build capabilities to bring critical analysis to understanding how the set of activities in which society invests can be configured so as to maximize health impacts.

Not statistics, but an information system

The term "health statistics" has come to refer to the set of data and aggregate indices that have relevance to health. These statistics often arise from very different perspectives and aim to meet very different needs. In the U.S. for instance, they include: statistics on births and deaths from the National Center for Health Statistics (NCHS) and the National Vital Statistics System (NVSS); statistics developed as part of the surveillance systems being developed for the Healthy People 2000 and 2010 initiatives by NCHS; figures released by NCHS to report on patterns of care (e.g. ambulatory day surgery); manpower data from HRSA; disease surveillance systems from CDC; HCFA reports on the Medicare program; population surveys sponsored by the NIH; and many others.

The population health framework provides a compelling impetus for us to think in a more integrative fashion about health statistics. It provides a "big picture" perspective in which all of the existing "stovepipes" of activity can be located. Moreover, it provides a framework that suggests a need for a more inter-related approach to health statistics, one where all of the activities can be related to the important goal of producing health. Instead of using the all-encompassing term "health statistics", it is perhaps useful to consider three explicit areas of activity: 1) producing data – the raw material that provides the basis of statistics and information systems; 2) producing statistics – the indices and measures that are developed to measure specific concepts; and 3) producing information – the compilation, comparison, and triangulation of statistics in order to provide perspective on issues of critical interest. While all of these levels of activity are important, it is this final set of activities – and the development of a health information system that we should be striving for in the future.

Population-based

Given the expanding capabilities of computer systems, it is becoming increasingly possible to collect rich and detailed data on the entire population. This, in turn, makes it possible to relate the health characteristics of populations to other factors that influence health – socioeconomic status, health care use, quality of health care and supply of health resources. Even small amounts of data on every individual (with appropriate protection of privacy and confidentiality) make it possible to explore and understand the dynamics and distribution of health in a population in a very dynamic manner. In addition, population-based data provide a type of statistical framework against which more detailed, but less comprehensive data collections (e.g. surveys) can be positioned.

Focus on the determinants of health

Clearly, given the population health framework, a useful health information system must be able to focus attention on understanding the factors that contribute to health. Specifically, it must be able to provide information about medical care, and the extent to which investments in medical care contribute to improving health. In addition, a health information system must also provide perspective about factors that influence health but are outside the realm of medical care – for example, the impact of social and living conditions on health. Moreover, information systems must provide capability to track and understand the impact of the large societal investments that are made in domains outside the traditional medical care sector (such as public health, education, support to families with dependent children, food supplementation and other programs). Finally, this type of approach requires that we identify and routinely report indicators that can serve as key markers of success or failure of our efforts to influence health.

Mapping links across areas: Determinants of health, investments in improving health and health status

A critical aspect of information systems is the ability to build in capabilities to make links across key areas, to examine various types and levels of investment in medical care for different populations. For instance, it must be possible to examine patterns of medical care for populations with the same and with different levels of health status to examine whether they make sense, given our assumptions. It must also be possible to study investments in other areas (as mentioned above) for these same populations. What is critical is the ability to reconfigure information to highlight the distribution of health in relation to the distribution of resources directed toward maintaining or improving health. Only this way can a health information system provide critical perspective on the likely effectiveness of societal investments.

A critical emphasis on protecting privacy and confidentiality

A centrally important issue for the development of health information systems is the development of standards to protect privacy and confidentiality of health records. The experience in Manitoba suggests that it is possible to develop systems capable of answering important questions that serve the public interest, while at the same time, preserving confidentiality. Without attention to this issue, ability to develop new knowledge from the study of observational data will likely be sharply curtailed by rising privacy concerns.

Summary

The National Committee on Vital and Health Statistics faces an enormous set of challenges in envisioning a system of health statistics for the 21st century. Accompanying these challenges is an equally enormous set of opportunities to drastically revamp health statistics: to truly develop a focus on health of the population and to develop an integrative framework that can provide critical intelligence on how to improve health in the next century. Experience with development of a population health information system from Manitoba, Canada provides some critical lessons for such an undertaking and hints at some of the enhanced capabilities that may be possible in the future.

While the example described here may appear to be an impossible model for the United States, given the pluralistic nature of the system, it is important to take note of areas where progress in pursuing related agendas has been made. The United States has been a leader in the development of population-based data sets., most of which fall into three categories: public health surveillance systems (e.g. vital statistics, reportable diseases), surveys with ongoing support from federal or state levels (e.g. ???), or state mandated administrative data systems (e.g. hospital discharge data sets. Many states have developed useful data collections that have been used in various ways. For instance, ?Maryland (talk to Mary Stuart), Massachusetts (describe MassCHIP), New Hampshire, Vermont etc (describe Dartmouth….), ?California, ???others??. The Dartmouth practice atlas has been produced on a national scale. These individual approaches suggest that it is possible to build more integrated data and information systems in the U.S. The Manitoba model provides a vision for an expanded and more cohesive model – one that can provide critical perspective on what makes people healthy.

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