Evaluation and Implementation of Public Health Registries

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Synopsis

A rapid proliferation of registries has occurred during the last 20 years. Given the long-term commitment of resources associated with registries and limited public health funding, proposals for new registries should be carefully considered before being funded. A registry is defined as a data base of identifiable persons containing a clearly defined set of health and demographic data collected for a specific public health purpose.

Criteria for evaluating whether a registry is needed, feasible, or the most effective and efficient means of collecting a specific set of health data are presented. They include an evaluation of the stated purpose; a review of the function, duration, and scope of the registry; consideration of existing alternative data sources; an assessment of the practical feasibility of the registry; the likelihood of sufficient start-up and long-term funding; and an evaluation of the cost effectiveness of the registry.

Creating a public health registry is a complex process. A range of technical and organizational skills is required for a registry to be successfully implemented. Eight requirements are identified as crucial for the successful development of a new registry. They include

- *an implementation plan,*
- *adequate documentation,*
- *quality control procedures,*
- *case definition and casefinding (ascertainment) procedures,*
- *determination of data elements,*
- *data collection and processing procedures,*
- *data access policy, and*
- *a framework for dissemination of registry data and findings.*

THE DEVELOPMENT of registries can be traced back at least as far as 1086 to the preparation of England's "Domesday Book" (*1*). Today the use of registries for public health monitoring is firmly established. However, as Weddell noted more than 15 years ago, the rapid proliferation of registries currently taking place calls for critical examination.

The concern over the increasing number of new registries prompted the Michigan Department of Public Health (MDPH) to conduct a review of the registries it maintained. Also, the concern prompted the department to commission the development of a set of criteria for determining if new registries should be created and standards for the development of new registries, once approved. The study, conducted between April and August 1989, consisted of a systematic review of the literature, a survey of all registries funded by the MDPH, and face-to-face interviews with seven directors of health registries, three researchers who use registry data, and five key public health officials. While the project focused on registries sponsored by the MDPH, the proliferation of registries is a nationwide phenomenon, and the findings are relevant for other State health departments.

There are presently 42 registries partially or fully funded by the MDPH. The chart presents the number of currently operating MDPH registries by the decade when they were established. The rapid increase of registries over the last two decades is

quite clear. The dramatic upswing since the early sixties can be traced to a number of public health trends. The coordinating role that the Centers for Disease Control have undertaken to ensure that uniform data sets are established for surveillance and research purposes has resulted in the creation of a number of registries. Registries also have been created in response to programmatic needs of the MDPH. Finally, there has been a rapid increase of health-related interest groups that often lobby for State funds to develop new registries devoted to a particular disease or health condition.

The creation of a new registry requires a substantial long-term commitment of resources, and the decision should not be made lightly. As a result of this study, the MDPH has developed a policy (currently in draft form) for the review of proposals to create new public health registries and a set of guidelines for those that are already funded. The policy calls for assembling a working group to review proposed registries and a user's group to facilitate communication and problem-solving among registry managers. It is hoped that these guidelines can be of use to others, both as a means for determining which registries should be implemented and as a framework for ensuring that those that are selected are successful.

Definition and Function of a Health Registry

A clear definition is central to the process of evaluating potential registries. We focused on developing an operational definition of a registry as one of the first steps in our review of Michigan public health registries. A literature search indicated that there is no universal agreement on what constitutes a registry. Bellows (*2*) defines a registry as

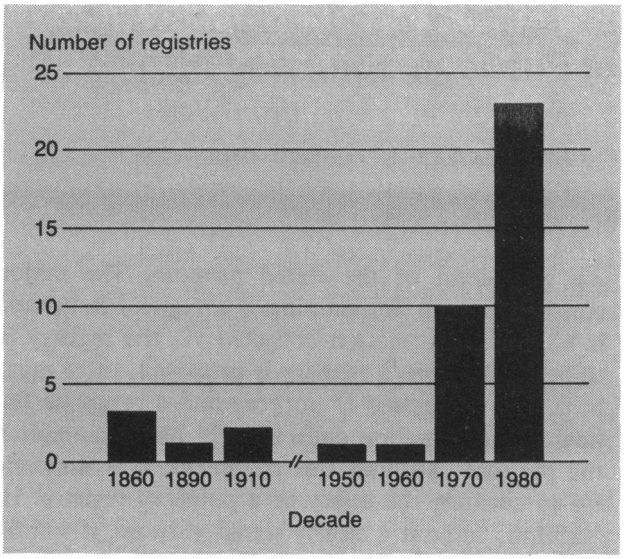
> . . . a system of recording, frequently used in the general field of public health, which serves as a device for the administration of programs concerned with the long-term care, follow-up or observation of individual cases.

Brooke (*3*) defines a registry as

> . . . a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose.

According to Thacker (*4*), registries are designed to collect information on a specific topic and are usually limited in scope. He makes a distinction between surveillance systems and registries, but feels that the data from registries may be useful in a surveillance system.

Number of registries funded by the Michigan Department of Public Health



The term "registry" is generally used to describe health-oriented data bases. The one factor that emerged in our interviews that distinguishes registries from other data bases is that the data collected are related to specific, identifiable persons. The following definition of a registry is quite broad, but for our purposes it was useful: A registry is a data base of identifiable persons containing a clearly defined set of health and demographic data collected for a specific public health purpose.

Evaluating Proposals for New Registries

We identified six critical issues that need to be addressed in determining if a registry is warranted. They include

1. an evaluation of the stated purpose;
2. a review of the function, duration, and scope of the registry;
3. consideration of existing alternative data sources;
4. an assessment of the practical feasibility of the registry;
5. the likelihood of sufficient start-up and long-term funding; and
6. an evaluation of the cost-effectiveness of the registry.

'To help ensure that duplication of effort across registries does not occur, State health departments should maintain accurate, up-to-date inventories of funded registries . . . .'

An evaluation of the stated purpose. The major consideration in determining if a registry is needed is how the information collected via the registry is to be used. When a registry is proposed, there must be a clear statement of purpose and a rationale for how the information collected will help accomplish the purpose. Without this statement, it is impossible to evaluate the utility of a potential registry. In addition, without a clearly stated purpose, it will be impossible to design the registry. Factors such as inclusion criteria, data elements, sampling requirements, quality control, and reporting standards depend on how registry data are to be used.

While no registry should be funded without a statement of purpose, the stated purpose itself should be evaluated. The evaluation of a proposal for a registry should focus on what health problem(s) the information can solve, or facilitate solving, and whether these problems should be pursued. The following questions are examples of issues that might be considered when evaluating the purpose of a proposed registry.

- What actions will be taken based upon the data collected by the registry?
- Is the registry likely to provide useful information or improved techniques for reducing morbidity and or mortality?
- How will the data be used to make policy and administrative decisions?
- How will the data facilitate the delivery of health services?
- What impact is the information provided by the registry likely to have on the health of the public?
- Can the data base provide a substantial contribution to health research?

Review of the function, duration, and scope. "The critical question is: can this be done in any other way? If the answer is yes, then it is probable that the register is a luxury" (*1*).

As Weddell implies, registries are a very expensive method of obtaining health information and when other methods are available, probably a luxury. In many situations, a focused research study can collect the necessary information at a much lower cost. There should be a justification of the need for a permanent health data system and the proposed scope of data collection in a proposal for a new registry.

When there is a specific goal to assess the efficacy of treatment or factors related to the incidence, prevalence, and etiology of disease, a research study may be more efficient than a registry-based surveillance system. A focused study can adequately identify and estimate the scope of health service requirements in a population more efficiently than a registry. In general, epidemiologic research is better suited for addressing specific questions or hypotheses (*5*). Registry-based surveillance is better suited for problem detection and identification as well as tracking important, new, rare, or rapidly developing health problems. Registries are also needed for monitoring the delivery of public health services and the documentation of events such as births, deaths, and marriages.

A registry should be created only when there is a need to collect information over a long term. When the data collection requirements of a project are temporary, they are more efficiently handled through a research study. Setting up the administrative structure of a formal registry is both inefficient and unnecessary if only short-term data are needed. In addition, once a registry is created with an administrative structure and staff, it may be difficult to terminate even though the registry has served its purpose.

While there are fixed costs associated with maintaining a data collection system, much of the cost is directly related to amount of data collected. Costs of data collection, editing, and processing can be reduced substantially by sampling; that is, collect information on only a fraction of the target population. In many instances, sampling can provide adequate information at a substantial savings for research, the identification of health service requirements, and the evaluation of health services delivery systems. However, although sampling may be adequate for some purposes, it is not appropriate in all situations. Sampling would be inappropriate, for example, for the maintenance of vital records, health service tracking, and maintenance of referral information.

A review of alternative data sources. Existing data sources should be reviewed carefully before implementing a new registry. Based on a survey within the MDPH, we identified 42 registries maintained

or funded by the MDPH. Other registries and sources of public health data are available in and out of the State government. Medicaid paid claims files and the social services client demographic files, for example, offer a rich source of health information. Other States are likely to have a similar breadth of data sources. A careful review of existing sources of information could save substantial wasted effort and resources in developing a registry to collect information that is already available.

To help ensure that duplication of effort across registries does not occur, State health departments should maintain accurate, up-to-date inventories of funded registries and the information they contain. It became clear from our survey of registries and discussions with registry managers that such an inventory was greatly needed. There are registries maintained by the MDPH that are mandated and can be easily identified from legislation. The MDPH also has a broad mandate to develop a comprehensive health information system for monitoring health in the State and providing health services. Under this mandate, registries are often developed by individual units within the MDPH. We found that in some cases these registries were known to only a few persons directly connected with the unit in which the registries were developed. An up-to-date inventory of MDPH-sponsored registries has been prepared based on the survey conducted in this study, and it will be maintained by MDPH.

Assessment of the practical feasibility of the registry. Registries should only be implemented if there is a reasonable expectation that they can achieve their goals. There are a number of situations when a registry may not be viable even though the data it is designed to collect are needed. A number of issues should be considered.

- Is it possible to identify the persons who are to be registered? Would case ascertainment be too costly or invasive? Are the number of persons meeting the inclusion criteria so small as to make locating the number needed to obtain useful information unlikely?
- Will it be possible to obtain an adequate level of compliance in reporting? Is the fear of a breach of confidentiality so great as to make reporting unreliable? Do the health professionals who are to provide data perceive the registry as necessary, and are they likely to be responsive? Would the effort required in reporting make compliance unlikely?
- Is timeliness an issue, and if so, is it reasonable to assume that data can be collected and processed speedily enough to be useful?
- Is case ascertainment and data collection likely to be so expensive as to make the registry impractical?
- Is it possible to obtain reliable and valid measures of the crucial variables?

Likelihood of sufficient start-up and long-term funding. The foremost problem in the establishment and maintenance of a registry is cost (*6*). A consistent complaint we encountered in our interviews with registry managers was the lack of funds and resources for fully utilizing registry data. Registry budgets were often exhausted by the data collection and processing tasks alone. This left few resources for quality control, data analysis, interpretation, and the reporting of important findings to appropriate medical and professional communities. In a number of cases, registry directors indicated that statisticians and data analysis personnel were available on a temporary basis, but different persons were assigned to provide support on different occasions. Under these circumstances, a great deal of time was spent familiarizing personnel with the registry data, making the temporary personnel far less useful. Resources such as epidemiologists and statisticians are not luxuries but necessities if the information that is collected is to be used effectively.

The development and operation of a registry also requires a long-term commitment. In many cases it can take years to realize the full benefits of a registry. For some registries, the fact that years of longitudinal data are needed to answer the questions that the registry is designed to address is the reason for their existence. For complex large scale registries, it can take years to develop the case ascertainment, reporting, data editing, and analysis structures to where they are fully operational, and meaningful data are available.

A good example is the Michigan Kidney Registry. The registry has been in operation for more than 20 years and by 1988 contained information on more than 14,000 persons with end stage renal disease—approximately 1,600 of these persons were renal transplant patients. It is only through data sources like the Michigan Kidney Registry that questions can be addressed such as the effectiveness of transplants if both recipient and donor are from the same race compared with different races.

It is a waste of resources to go through the developmental phase of a registry only to have it terminated because of lack of funding. To the

extent possible, funding should be ensured before the decision to implement a registry is made.

An evaluation of the cost-effectiveness of the registry. The potential benefits of a proposed registry should be evaluated in light of what the registry will cost to develop and maintain. There is a wide range of social needs and only limited funds available for addressing health problems. Public health officials have a responsibility to ensure that funds are used wisely.

Despite the difficulty of determining the value of a registry, this issue has to be addressed when determining if a registry should be funded. Listed subsequently are some factors that might be considered in determining the public health impact of the information a registry can provide (*7*).

- total number of cases, incidence, and prevalence;
- indices of severity, for example, the case fatality ratio;
- overall mortality rate;
- indices of lost productivity, for example, bed-disability days;
- index of premature mortality, for example, years of potential life lost;
- medical costs; and
- preventability and expected benefit of registry provided information in reducing morbidity and mortality.

Development of a Successful Registry

Creating a public health registry is a complex process. A range of technical and organizational skills are required for the process to result in an effective data system. We identified eight requirements that are critical to the successful development of a new registry.

1. an implementation plan,
2. adequate documentation,
3. quality control procedures,
4. case definition and casefinding (ascertainment) procedures,
5. determination of data elements,
6. data collection and processing procedures,
7. data access policy, and
8. a framework for dissemination of registry data and findings.

Implementation plan. There are many issues that should be carefully thought through and resolved prior to developing the registry. The implementation plan should address basic start-up issues including

- development of a timeline;
- discussion of the registry with the relevant medical community;
- identifying (or hiring) and training of registry personnel;
- estimating registry size (prevalence, incidence) and projecting what size the registry might be in the next 3 or 5 years;
- identifying sources of case ascertainment and data;
- developing and organizing casefinding;
- development of a data collection instrument, as well as data collection, editing, and entry procedures;
- obtaining hardware (if necessary);
- selection, development, and implementation of software and data processing procedures;
- planning how the data can be used by the health community in a timely way (for example detecting changes in disease trends, estimating morbidity related to a health event, assessment of treatment measures, improving clinical practice); and
- development of a quality control system.

There should be a pilot phase when procedures are carefully evaluated and refined. It is much more efficient to identify and resolve problems in this fashion than to invest a great deal of effort and resources developing software, equipment forms, and procedures that must be altered later. The pilot phase should include sufficient cases and be long enough to detect problems in all the phases of the registry.

Adequate registry documentation. Adequate documentation is essential for ensuring the quality and efficient operation of the registry. Documentation should generally include

- who will operate the registry (organizational chart including personnel, advisory board, consultants);
- a thorough description of the inclusion or exclusion criteria;
- definition of data sources, data collection, data editing, and data entry procedures; a schedule and timeline for these procedures;
- protocols for matching to other data sources;
- data processing procedures, and hardware and software manuals;
- analyses that will be routinely conducted;

- confidentiality guidelines; and
- access procedures.

In addition, a flow chart is helpful in visualizing data collection, processing, analysis, and reporting.

Quality control requirements. Quality control is a critical issue and needs to be considered in the context of how the registry will be used. In describing the quality of data in any registry, Goldberg (*6*) asserts there are at least two and in some cases three goals. They are completeness, validity, and for some registries, timeliness. Completeness is the proportion of cases in the target population that appear in the registry data base. If completeness is not guaranteed (and it rarely can be), it is important to identify factors that may be systematically related to the decision whether to include a case in the registry.

These factors can result in the calculation of misleading rates of disease. For example, if a registry is 60 percent complete and the data that are missing come from a random group of cases, the extent of disease will be underestimated, but the underestimation will be the same for all patient subgroups. However, if the missing cases are concentrated among persons with specific characteristics (for instance, the least severe cases), the error in the calculation of rates would be compounded. The extent of the disease will be underestimated as before, but in addition, the relative frequency of severe cases will be overestimated.

Validity is the percentage of cases in the registry with a given characteristic (for example sex, disease type) that "truly" have this attribute. In practice, it is the percentage of agreement between registry data and an independent source objectively measuring the same variable. Once again, the importance of differentiating between random errors and systematic errors must be stressed.

Quality control can be very expensive. The costs associated with quality control need to be recognized and built into the budget of any proposed registry. In general, the higher the level of completeness and accuracy and the more quickly the data need to be made available, the more costly the registry. These factors should be evaluated in relation to the way registry data are to be used. If a registry is to identify persons needing critical services, completeness is likely to be crucial. In registries used for infectious disease surveillance, timeliness may be extremely important. A registry focusing on research may be able to tolerate a higher level of missing data, and timeliness may not be as important. This is not to say quality control is not an issue, only that the degree and focus depend on how the registry data are primarily used.

Quality control is most effective when it is built into the registry's data system (*8*). Ideally, quality control should be implemented at every point in the registry, from identification of new cases to distribution of the final reports. While data collection and entry into the registry are generally the most likely sources of error, cases can be lost and data corrupted at any point in the system. General principles of quality control are

- Build quality into the system—do not add it later.
- Somebody must be responsible for quality control at each point in the system.
- There should be explicit standards and procedures for evaluating the system on a regular basis.
- A feedback loop should be incorporated into the system to inform data handlers of errors.

Case definition and casefinding (ascertainment). Unambiguous operational definitions of who should and should not be included in the registry are critical for success. They are an essential element of data quality.

Inclusion and exclusion criteria generally focus on two aspects of the person: his or her characteristics and location (*9*). Individual characteristics are factors such as presence of a particular set of conditions or disease. Examples include existence of a cancerous tumor, exposure to a potentially hazardous substance, or an event such as a birth. Location can mean where the persons live or work or the medical institution where they receive treatment.

Inclusion and exclusion criteria should be clear and unambiguous so that people involved in casefinding will make consistent decisions about inclusion across the range of potential cases that arise. An example might mean specifying test values or laboratory results as an inclusion criterion rather than a diagnosis. It is necessary to anticipate the possible anomalies that may occur in case ascertainment and how they should be handled. For example, when the geographic criterion is residence in a particular State, would part-time residents be included? This was an important issue in the development of a cancer registry in Michigan. Without clear specification on how to handle such cases, different people involved in casefinding are likely to make different decisions, particularly

when casefinding is not performed by registry staff, and communication among those persons responsible for reporting and registry staff is limited. Piloting casefinding procedures for a new registry is essential for adequately defining inclusion and exclusion criteria.

There are indicators that may signify that inclusion criteria are too complex or difficult to apply in real life settings.

- What is the reporting rate from physicians, laboratories, or hospital-clinics participating in the registry?
- Are reporting instruments filled out completely and accurately?
- Is reporting occurring regularly or sporadically?

Another critical requirement for a new registry is determining what method(s) will be used to locate persons who should be included in the registry (case ascertainment). Three basic issues must be addressed (*10*). The first is the choice of active versus passive case ascertainment or some combination of the two. The second is the identification of sources of ascertainment. A third is how case reporting will be enforced.

In active case ascertainment systems, registry staff locate persons who meet the inclusion criteria. Passive systems rely on physicians, hospital staff, or other health care workers to report cases to the registry staff. Active systems generally result in identifying a higher percentage of people meeting the inclusion criteria. They are also generally much more expensive (*10,11*).

The second issue concerns methods of identifying persons meeting the inclusion criteria. In most cases, there are a number of potential sources; but none of them will include all the appropriate people. Generally more complete identification of registrants is achieved through the use of multiple sources. However, multiple sources increase costs.

The third issue is that authority of the health department or other agency maintaining the registry to mandate case reporting. Three methods are used by the MDPH. The first is by request of the MDPH, the second is by specific legislative mandate, and the third is by administrative rules directed by a legislative mandate. When reporting is required by law, compliance is likely to be better. Administrative rules based on a general legislative mandate have a number of advantages. Like a specific legislative mandate, they provide the legal requirement to report and the potential penalties for failing to report. They also provide the MDPH with the flexibility to adjust the reporting requirements to the realities of the specific situation. The Registry for Alzheimer's and Other Dementing Diseases is an example of a specific mandate for reporting when a broader mandate, implemented through administrative rules, might have been more effective. The mandate requires reporting from individual physicians; the MDPH has found reporting from institutions to be more productive.

The degree of completeness in case identification has a direct impact on the precision and level of bias in registry data. It should be kept in mind that precision and bias in data are a matter of degree. No system is likely to result in 100 percent ascertainment. Increasing completeness through active case ascertainment and the use of multiple sources can dramatically increase costs. Vogt and coworkers (*11*) found that supplementing a passive system with active ascertainment for locating cases of hepatitis, measles, rubella, and salmonellosis resulted in a cost of $861 per additional case located with no improvement in timeliness. Holzman (*10*) found the average cost per live birth in adverse reproductive outcomes surveillance systems to range between $.56 and $12.

The choice of sources of ascertainment methods should be based on the goals and purpose of the proposed registry. There is no sense in implementing a very expensive active ascertainment system using a wide range of sources when adequate case identification can be achieved with a much less ambitious approach. Both the purpose of the registry and the difficulty of locating and obtaining information that it will contain should play a role in making this decision on methods. It may be worth trying different approaches during the pilot phase of implementing a registry, such as Vogt and his colleagues did, to determine the approach that is both effective and efficient. Reporting is generally best when case providers receive timely feedback from registry personnel concerning the information that they report. Too often this group is not included in the process of information dissemination.

Determination of Data Elements

"What data should be recorded? The golden rule here is to keep it as simple as possible" (*3*).

There are a number of reasons why Brooke's suggestion is relevant. Reducing the amount of data collected lowers costs, increases compliance, and reduces the time it takes to get data into the system. The temptation to collect data is hard to

resist, particularly as its storage and retrieval by use of computers in easier than ever before. The respondents in our sample cautioned that health officials contemplating new registries should carefully weigh the value of each data element to be included. Too often registries fail in their original purpose because information collection becomes too complex and unmanageable. Planning linkages with other registries and information systems during the developmental phases of the registry can eliminate redundant data elements from the system.

The key to keeping the amount of data collected to a minimum while retaining the usefulness of the registry is a clearly defined purpose. Although it is desirable to avoid collecting unnecessary data, it is also important to try to ensure that all the essential data elements are collected from the inception of the registry. Changing the data elements that are collected over time limits the usefulness of the registry. Changing data collection procedures, forms, and file structures to accommodate additional data elements greatly increases the likelihood of confusion and the introduction of errors into the data set.

Registries should include basic demographic information on each registrant. Adequately describing the persons in the registry increases the ability to generalize findings from registry data to other populations and facilitates matching and merging the data with data from other registries. In addition, collecting demographic information may lead to identifying characteristics related to morbidity and mortality observed in the registry data and may even help to identify causes of morbidity and mortality.

Definition of data elements. The definition of data elements is a critical part of developing a registry. Whenever possible, definitions of items should conform to those used by similar well-established registries. Not only will this avoid problems that others have already resolved in defining data elements, it facilitates data sharing and consistency (*8*). We found the lack of common identifiers to be a major issue in our review of registries. Common identifiers, for example race, county, and name, are often coded in nonstandardized formats making the merging of information from different registries difficult.

The Michigan Cancer Surveillance Program is a good example. This registry receives data from many sources, including cancer registries located in other States where Michigan residents have received treatment. A great deal of effort is required to reformat, recode, and merge these data into the registry.

'The dramatic increase in registries in the last decade raises the concern that limited funds available for providing public health services may be wasted implementing registries that are not needed, impossible to adequately develop, or so underfunded as to be ineffective.'

The development of a coding scheme for categorical variables is a major part of the data definition task. The definitions need to be designed so that every case unambiguously falls into one and only one category. While this may sound simple and straightforward, there are generally exceptions that need to be handled in some fashion. Piloting the data collection system is the best way to locate ambiguities that do not fit in the predefined categories.

Data collection and preparation. Data collection and preparation consume a major portion of the resources required to maintain a registry and is also a key area in the maintenance of data quality. At least two issues need to be addressed in the development of a new registry: (*a*) choice of data collection and entry methods, and (*b*) implementation of data verification and editing procedures.

Data collection is difficult to implement and often the major source of error. In many cases, data collection will require abstracting information from a health provider's records. This process is both time consuming and prone to errors. Written instructions for abstracting should be piloted and refined. A regular review and systematic reabstracting of a sample of cases should also be incorporated into quality control procedures.

Clear and unambiguous data collection forms are needed for obtaining information from health care providers. Their proper design will allow the data to be entered directly from the form, significantly reducing the cost of data entry. All collection forms and procedures should be piloted, carefully reviewed, and modified as needed in the developmental phases of the registry.

A data access policy. The ability to access information in an efficient, flexible, and timely fashion is a key element to the success of a public health regis-

try. Public health registries, however, often store highly personal and sensitive information. Registry administrators must safeguard the confidentiality of the information in the registry. Confidentiality is enforced by statute in legislatively mandated registries in Michigan. Beyond the ethical and legal implications of maintaining confidentiality, case ascertainment and data collection would be greatly compromised if the people supplying the information are not confident that it will be protected. Although reasonable access to registry data and maintaining the confidentiality are related issues, they are not necessarily in conflict. In most cases, it is possible to maintain the anonymity of the registrants as well as medical providers who contribute information while providing registry users with the information that they need.

Allowing access to registry data without breaching confidentiality requires thought and planning. Even after removing personal identifiers of registrants and institutional identifiers of providers, confidentiality can be breached. It may be possible to identify a registrant or institution from other information contained in a data set generated from a registry. Establishing a policy for data access is a crucial task in the development of a registry. When data are requested, registry administrators will have to respond. It is far superior to have a fair and effective policy for determining how to handle such requests rather than handling them on an ad hoc basis. If requests are ignored, side-tracked, or arbitrarily rejected, a lawsuit could ensue, and access to the data will be determined by the courts.

A framework for dissemination of registry data and findings. Closely related to the access policy is how registry findings will be disseminated. The survey of MDPH-sponsored registry administrators indicated a majority did not disseminate information beyond the administrative unit in which the information is maintained. Many registries had no mechanism or procedures for evaluating and responding to requests for data from outside researchers. The value of a registry is limited by the extent that the information collected is fully analyzed and then disseminated to relevant audiences. New registries should include a plan for the dissemination of information and a mechanism for responding to requests for data.

It is also necessary to define the routine data products and reports that will be needed to fulfill the goals of the registry. These definitions should be made before determining requirements of data processing and collection.

Conclusions

Registries are an integral part of the nation's public health system. Their importance for surveillance, research, health service delivery, and the documentation of events is firmly established. The dramatic increase in registries in the last decade raises the concern that limited funds available for providing public health services may be wasted implementing registries that are not needed, impossible to develop adequately, or so underfunded as to be ineffective. With limited funds available and pressing public health problems facing State health departments, it is imperative that the registries that are funded be as effective and efficient as possible in gathering the information they are designed to collect.

This paper delineates some of the issues that should be addressed before a new registry is funded and the major considerations that will need attention when creating registries. It is hoped that they will provide a framework for evaluating requests for new registries and guidelines for creating those that are funded.

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