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REGISTRY EVALUATION METHODS: A REVIEW AND CASE STUDY[1]

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The great proliferation of disease registers is a relatively recent phenomenon. During the 18th century and the first half of the 19th century there were few disease registers; the early leprosy registry in Norway (1) and several tuberculosis registries (2, 3) are notable. An increase in the number of disease registries began in the 1950's as a result of two interrelated factors: 1) the increasing concern with chronic disease, and 2) the failure of the traditional methods of infectious disease epidemiology to provide an adequate framework for the study of chronic disease. The increasingly widespread establishment and use of disease registries is most pronounced in the field of cancer epidemiology. For example, the third volume of *Cancer Incidence in Five Continents* (4) presents data drawn from 78 population-based cancer registries. Other conditions, such as blindness (5), mental illness (6), rheumatic fever (7), burns (8), heart disease (9), child abuse (10), and trauma (11), have all been subjected recently to the registry approach. The widespread availability of computer resources has contributed to this trend.

While registries provide an excellent mechanism for studying the distribution and pattern of disease, their usefulness is governed by the quality (as well as the quantity) of data they contain. To date, no systematic analysis of the methods which would be useful in evaluating the quality of registry data has been offered. This review has four objectives: 1) to describe disease registries in terms of definitions, types, uses and problems, 2) to outline a framework for the evaluation of registry data, 3) to critically review and classify studies which describe registry data systems or utilize registry data, and 4) to present a case study evaluating the quality of data in the Illinois Trauma Registry.

THE CONCEPT OF DISEASE REGISTRIES

Definitions

A number of definitions have been suggested for the word "registry." One dictionary (12) defines the verb "to register" as meaning: "to set down (facts, names, etc.) formally in writing; to enter or record in a precise manner." Bellows (13), in her classic paper on case registers, defines registries 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 longterm care, follow-up or observation of individual cases . . . (with their single distinguishing feature being) that changes in status of cases are recorded over a period of time." Brooke (14) in a recent monograph for the World Health Organization defines a register 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." The main difference between

Abbreviations: ESP, estimated survival probability; ITR, Illinois Trauma Registry.

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the latter two definitions is that Bellows emphasizes the use of registers for program administration and patient follow-up, while Brooke focuses on the uniformity and comprehensiveness of data collection.

Types

Several registry typologies have been proposed based on the uses to be made of the data. Weddell (15) classifies all registries (not just those for diseases) into seven types: registers used in preventive medicine, disease-specific registers, treatment registers, aftercare registers, at risk registers, registers for prospective studies, and specific information registers. Amsel (16) suggests that registries can be categorized as either clinical or research, the key distinction being that research registers anticipate no clinical intervention and therefore "case reporting then reflects the natural history of a condition." While both Weddell's and Amsel's classification systems are useful, they are limited because they fail to recognize that potential registry uses are related to the sources of registry data.

Pedersen (17), rather than approaching registry classification by use, attempted to classify registries by their sources of data. He proposed three types of registries (specifically for cancer): local hospital registries, central registries, and population-based registries. The characteristics of each of these types are as follows:

1) The *local hospital registry* serves just one hospital and is a file of all patients seen at that hospital with a particular disease. Its function is to ensure complete and accurate data on diagnosis and treatment and its primary use would be in preparing a detailed statistical profile for cases of a specific disease.

2) The *central registry* is analogous to the local hospital registry, but it includes a selected group of hospitals in a region. Its chief function is to supply data on diagnosis and treatment for the hospitals involved. The combining of several local hospital registries provides a sufficient number of cases for a more detailed breakdown of data into subgroups for analysis; central registries are particularly valuable for comparing end results among different therapeutic regimens.

3) The *population-based registry* represents an attempt to collect detailed information about all new cases of a disease in a population of known size and composition. Its essential feature is the effort to account for all diagnosed cases of a specific disease, whether in hospital or not, and its specific use is to determine the risk of disease in a population.

Uses

Registry data have been used for a wide variety of purposes. Brooke (14) has surveyed many of the registers currently functioning and has identified eight major purposes:

1) *Identification of individuals*—to provide the physician with access to a large number of individuals with a particular condition.

2) *Immediate protection of the individual*—to make readily available information on cases which can be vital in the event of an emergency.

3) *Surveillance*—to help ensure that medication is received and taken for conditions which require long-term treatment.

4) *Epidemiology*—to provide a basis for estimating incidence and prevalence rates for a defined population.

5) *Planning, operation and evaluation of service*—to make it possible to calculate estimates of need for services and to evaluate program efficiency and effectiveness.

6) *Evaluation of treatment*—to provide the basis for calculating the efficacy of various therapeutic techniques.

7) *Research*—to permit the natural history of a condition to be followed and to attempt to identify etiology.

8) *Education*—to assist in educating

physicians by sharpening their diagnostic skills in identifying cases.

Problems

While registries may serve a wide variety of uses, there are many problems associated with their establishment and maintenance. Foremost among these is the *expense of operating a registry*. As early as 1956, Haenszel and Hon (18) noted that the primary concern in establishing a central cancer registry should be cost: "Follow-up of surviving patients at annual intervals contributes to the total cost, but maintenance of central files for elimination of duplicates, follow-back for incomplete or missing data, resolution of contradictory information, revision of coded data to meet changing concepts, and tabulations for routine, periodic reports all entail sizable expenditures."

A second major problem is *organization and staffing*. For central registries, and even more so for population-based registries, major impediments include the difficulties encountered in developing cooperative agreements, defining goals and objectives, identifying staff and funding sources, and specifying the computer resources available. The staffing problem is especially important; most registries will, at the very least, require three types of personnel: research support staff, computer specialists, and data ascertainment staff. The research support staff are those individuals (biostatisticians, epidemiologists, clinicians, health planners) who determine the variables to be collected and the analyses which will be conducted. Computer specialists design the system for data entry, storage and retrieval; recurrent concerns for registry computer specialists are that the data bank be secure, that the computer system be flexible enough to handle a large quantity of follow-up information, and that the data can be interfaced with a statistical analysis system. Data ascertainment personnel are those who identify, code and enter cases. The need to adequately train and maintain this level of staff is basic for the smooth functioning of a registry.

The third problem with which all registries must deal is the *quality of registry data*. Several authors (19–22) have noted that insufficient attention has been given to the quality of the information which registries collect. The need for stringent methods to assure data quality has been underscored by Brooke (14): "Every year an enormous quantity of medical statistics is compiled and published, and very little is known about the quality of the data on which these statistics are based. However, since many theories and even expensive research projects are established on the basis of statistical findings, it is important that their quality should be as high as possible."

Evaluation of Registry Data

Two fundamental concerns should govern the evaluation of registry data: completeness and validity. The *completeness* of data is defined as the proportion of all cases in the target population which appear in the registry database. If a registry is population-based then all diagnosed cases of a disease for a defined population theoretically appear in it. For local and central registries, all cases of the disease seen at the reporting source should be included. If completeness is not guaranteed (and it rarely can be), it is necessary to identify those factors which are related to the selectivity of case inclusion. The result of systematic bias in case reporting is the calculation of misleading rates of disease. For example, if a registry is 60 per cent complete and the data which 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 data are concentrated on one case characteristic (for instance, the least severe cases), the error in the calculation of rates would be com-

pounded; the extent of the disease would be underestimated as before, but, in addition, the relative frequency of severe cases would be overestimated.

Validity is the second essential component in assessing the quality of registry data. In this context validity may be defined as the percentage of cases in the registry with a given characteristic (e.g., age, sex, disease type) which "truly" has this attribute. In practice, it is the percentage of agreement between registry data and an independent source objectively measuring the same variable. The need for registry data with a high degree of validity is obvious; case ascertainment may be nearly complete, but the registry may contain a high percentage of information which is incorrect. Once again, the importance of differentiating between random errors and systematic errors must be stressed.

The following is an attempt to classify registry data evaluation methods in terms of completeness and validity. This review is not exhaustive; our approach is selective, to present a representative sample for a wide variety of disease registries.

Completeness

The completeness of case ascertainment has been measured by four distinct methods:

Death certificate method. In this approach, completeness is defined as the proportion of registered cases which have not been first identified by death certificate. The rationale is that if cases are found by death certificate, they have eluded prior registration and represent incomplete reporting. This method is commonly applied to cancer registries (4, 23, 24) and recently has been used for a stroke (25) and a myocardial infarction (26) registry.

The death certificate method is relatively inexpensive because independent data collection for the specific purpose of registry evaluation is not necessary. However, the method is not sensitive in the instance of diseases which have low case fatality rates. Even for cancer, the method would fail to identify many cases in diagnostic categories which are not uniformly fatal.

Independent case ascertainment method. By comparing the number of cases found in the registry with that ascertained in an independent survey, a measure of completeness can be derived. Registries for cancer (27), myocardial infarction (26), blindness (5), and rheumatic fever (28) have been evaluated in this fashion. A variant of this technique is the intensive survey of a single hospital or small area, the development of completeness estimates for this sample, and then the extrapolation of the results to the total registry.

Independent case ascertainment is perhaps the most definitive method for determining registry completeness. The value of this method is greatly enhanced if an attempt is made to link cases identified in the survey with cases appearing in the registry; the subsequent examination of case selection bias is then easily accomplished. However, the expense of this approach often prevents its use for large registry systems. Even for small registries the intensity and care with which the survey is conducted will directly affect both the results and the costs.

Historic data method. In this method a comparison is made of an "expected" number of cases with that observed in the registry. The expected number is calculated by applying a known incidence or prevalence rate (derived from a demographically similar population) to the registry population. The difference between the expected and observed rates is a rough measure of registry completeness. This approach has been used by Saxén et al. (29) on a registry of congenital malformations and by Brennan and Knox (30) on a blindness registry.

The historic data method, while rapid and inexpensive, is a relatively crude technique for developing estimates of registry completeness. At a conceptual level, it is flawed because the expected rates (which form the basis for estimating completeness) are not independently derived from the study population. This method permits the possibility that a truly low incidence rate will be mistaken for a low degree of registry completeness. Also, this method does not permit examination of the possible biasing factors in case selection.

Simulation method. This approach does not measure completeness directly. Instead, it takes the registry database and simulates patterns of incomplete reporting to examine the possible effect upon a specific dependent variable. Schork et al. (31) have used this technique on a burn registry to examine the effects of 24 patterns of simulated underreporting on burn mortality.

The simulation method is a powerful tool for determining the impact of case selection bias on a particular dependent variable, such as mortality. It does not, however, give any indication of the actual completeness of reporting. Serious difficulties could be encountered in interpreting simulated reporting patterns unless the actual completeness of reporting to the registry is known.

Validity

Three basic methods have been utilized to assess the validity of registry data:

Diagnostic criteria method. This method determines the proportion of registry cases which meet stringent diagnostic criteria. Cancer registry evaluators typically judge the validity of data by the proportion of cases with histologic confirmation (4). An analogous measure for stroke is the proportion of cases confirmed by lumbar puncture, angiography, or brain pathology at autopsy (32). For myocardial infarction it would be the proportion with elevated enzyme levels or unequivocal serial electrocardiograph changes (33).

The diagnostic criteria method is subject to two main difficulties. First, the meaning of a test or measurement instrument used to ascertain diagnostic validity may be open to differing interpretation by medical specialists. For example, studies of cancer registry data have identified substantial interobserver and intraobserver variability among pathologists in classifying the histopathology of neoplasms (34, 35). Second, the diagnostic criteria method has a limited focus. Because the technique is solely designed to determine if a case is diagnosed correctly, it does not permit the assessment of the validity of other variables (e.g., sex, age, marital status). The principal advantage of this method is that independent data collection is not required; the type of diagnostic test used to confirm the final diagnosis is often routinely recorded during case ascertainment.

Reabstracted record method. In this approach, records appearing in the registry are reabstracted at the ascertainment source and then compared to the registry records. Because the reabstraction process is more thorough, the reabstracted record is assumed to be correct. The extent of agreement between the reabstracted records and the registry is the measure of validity. This method has been employed to evaluate several cancer registries (36, 37).

The reabstracted record method is an excellent means to appraise the validity of registry data. Because the same variables are contained in both the registry and the reabstracted record, detailed analysis of the validity of particular case characteristics can be conducted. The cost of identifying and reabstracting records is the primary limiting factor in using this method. Strict control needs to be placed on the process of reabstracting data, since the determination of registry validity is

wholly dependent upon the accuracy of the reabstracted data.

Internal consistency method. In this method, records are examined (usually by use of the computer) to check the registry database for legitimate codes (e.g., sex can only be male or female). Because of its simplicity this method has been used by cancer (38), psychiatric (39), burn (8), and trauma (40) registries.

The usefulness of the internal consistency method for assessing registry validity is limited. Only cases which are outside the boundaries of the prescribed logic are identified as invalid. For example, a specific case characteristic (such as sex) may be consistently coded wrong (e.g., all males are coded as females) and never be identified. While increasingly sophisticated algorithms are being developed to test internal consistency, this does not change the basic problem; illogical cases can be identified but incorrect logical cases cannot. The most attractive aspect of this method is its low cost. No independent data are collected and the checks for internal consistency are conducted by computer programs.

Evaluation of the Illinois Trauma Registry: A Case Study

Background and method

In 1971 the first statewide registry for traumatic injuries in the United States was initiated in Illinois. The Illinois Trauma Registry (ITR) was designed as the principal evaluative tool for the comprehensive set of medical programs known as the Illinois Trauma System (41). The ITR is a central registry that was designed to record all hospitalized patients with traumatic injuries treated at 50 hospitals designated as Trauma Centers in Illinois. The stated objectives included those related to the improvement of patient care, descriptive and analytic epidemiology, and program management and evaluation (40).

As part of a critical examination of the Illinois Trauma System, an evaluation of the utility of the ITR was conducted. Specifically, the evaluation focused on three characteristics which determine the "quality" of registry data: 1) the completeness of case reporting from hospital records to the register, 2) overreporting, i.e., fraudulent cases in the register not found in the hospital records, and 3) the validity of the items of information attributed to registry cases, as compared with the same data found in hospital records.

To accomplish these objectives two independent samples were selected for a one-year period: a Hospital Sample and a Registry Sample. (Because the overall objective of our research focused on "downstate" Illinois, 17 Trauma Centers in the Chicago metropolitan area were excluded from both these samples.) The Hospital Sample required a search of the diagnostic index at the Trauma Centers to compile a list of all patients with 20 selected trauma diagnoses ("tracers"), specified according to the *International Classification of Diseases* (42). A 10 per cent systematic random sample of these cases was then retrieved and transcribed onto a standard coding form. An attempt was then made to match those tracer cases found in the hospital records with those contained within the ITR. The Registry Sample was a 10 per cent systematic random sample of cases with tracer diagnoses in the ITR. Where possible, these cases were matched to the corresponding hospital records.

In the ITR evaluation, the completeness of case reporting was defined as the proportion of cases in the Hospital Sample which were also found in the ITR. Overreporting is the converse, and was defined as the proportion of cases recorded in the Registry Sample which were not found in hospital records. The validity of ITR data was determined by the concordance of specific variables in the matched cases—

those individuals whose records were found both in the ITR and in the hospital record rooms. Two sets of matched cases were available in this study—Hospital Sample cases which were located in the ITR, and the Registry Sample cases which were found in hospital records. Either would serve the purpose, and the latter set was utilized.

For the validity assessment the *predictive value* of positive and negative ITR data (the converse of measures of sensitivity and specificity) was calculated for each item recorded on the ITR record (43). The predictive value was used because the orientation of the overall study was to determine the utility of the ITR for epidemiologic research. The "predictive value of ITR positive data" was defined as the percentage of ITR records with a given attribute which had that attribute in the matched hospital records. The "predictive value of ITR negative data" was the percentage of ITR records without a given attribute which also lacked that attribute in the matched hospital records. For example, if the ITR classified 200 individuals as having a fractured clavicle and the hospital record identified 160 of these as having a fractured clavicle, the predictive value of ITR positive data would be 160/200 or 80 per cent. Conversely, if the ITR classified 500 individuals as not having a fractured clavicle and the hospital record identified 450 of these as not having a fractured clavicle, the predictive value of ITR negative data would be 450/500 or 90 per cent.

It should be noted that the completeness of case reporting can only be measured if a Hospital Sample is available for use, and that overreporting can be measured only if a Registry Sample is available. Matches based on either sample can be used for assessing the concordance of case characteristics.

Four groups of variables which may influence the completeness and validity of ITR data were examined:

1) demographic—age, sex, race, marital status;

2) accident—mechanism of injury, means of transportation, time and day of admission;

3) clinical—specific tracer diagnoses, severity of injury; and

4) outcome—mortality, length of hospital stay, admission to an intensive care unit, patient transfer from one hospital to another.

The analysis of ITR completeness and validity for each of the listed variables has been presented elsewhere (44, 45). For the purposes of this review, detailed results are presented for only one variable—injury severity.

Severity of injury: An illustrative example

Since severity of injury would be an important primary or adjustment characteristic in almost any epidemiologic use of the ITR, it was selected to illustrate our approach to registry evaluation. The estimated survival probability (ESP) index (46) was used as the method to establish retrospectively the severity of a traumatic injury. The ESP takes into account the nature of the injury and the effect of multiple injuries in assigning numerical severity scores; these scores reflect the probability of survival from combinations of traumatic injuries. Thus, the lower the ESP score the more severe the injury.

Table 1 shows that there was a monotonic decrease in the completeness of reporting to the ITR as severity of injury decreased, from 42.3 per cent for ESP values of 0.90 or less to 33.3 per cent for ESP of 1.00. This table also shows the validity of ITR records as measured by the predictive value of positive and negative results. The predictive values for positive results vary in a linear fashion with injury severity; the lowest predictive value is observed for cases with severe injuries and the highest predictive value for cases with minor injuries. Specifically, this

TABLE 1

Completeness and validity of the Illinois Trauma Registry (ITR) records for injury severity, July 1973–June 1974

Severity level	Completeness of reporting			Validity of reporting	
	No. of cases in the Hospital Sample*	No. of cases found in the ITR	% completeness	Predictive value of	
				Positive results	Negative results
ESP ≤0.90	52	22	42.3	60.9% (23)†	94.4% [161]‡
ESP 0.91–0.99	237	90	38.0	92.3% (104)	90.0% [80]
ESP = 1.00	147	49	33.3	94.7% (57)	97.6% [127]

* Twenty cases are excluded from the total Hospital Sample because they could not be identified by using the specified tracer diagnostic conditions, although they appeared in the ITR.

† Numbers in parentheses represent positive case classification according to the Registry Sample (i.e., cases having that estimated survival probability (ESP) level). The adjacent percentage is that of Registry Sample positive cases in agreement with the hospital medical record.

‡ Numbers in brackets represent negative case classification according to the Registry Sample (i.e., cases not having that ESP level). The adjacent percentage is that of Registry Sample negative cases in agreement with the hospital medical record.

means that of all cases in the Registry Sample which were classified as having ESP scores of 0.90 or less (N = 23), only 60.9 per cent were similarly classified by the matched hospital record; and of all cases in the Registry Sample with ESP scores of 1.00 (N = 57), 94.7 per cent were in agreement with the matched hospital record. The predictive values for ITR negative data do not vary directly with injury severity. The poorest concordance for negative results was for ESP scores of 0.91–0.99; the predictive value of the ITR for those cases classified as having other than ESP scores of 0.91–0.99 (N = 80) was 90.0 per cent. This would imply that 10.0 per cent of the ITR cases which were classified as not having intermediate severity do in fact possess intermediate severity, according to the information contained in the hospital records.

Table 2 was prepared to illustrate the misleading conclusions that would have resulted from the uncritical use of the ITR to estimate the proportion of patients hospitalized with tracer conditions who were treated at Trauma Centers, overall and by level of case severity. It is based on the Trauma Center case samples referred to above, plus a sample of tracer cases admitted to hospitals not designated as Trauma Centers (Non-System Hospitals) and not otherwise discussed in this review (47).

In table 2, column (a), the number of cases in the 10 per cent Registry Sample are listed by ESP severity level, and in column (e) the estimated number of cases treated at Non-System Hospitals are similarly displayed. If the ITR had been accepted without evaluation, the proportion of each severity level (and of all cases) treated in the Trauma System would have been as indicated in column (g).

We may accept the 10 per cent Hospital Sample as demonstrating the true ESP distribution and total number of cases treated in Trauma Centers, as shown in column (d), and the proportions as shown in column (f). A comparison of columns (f) and (g) shows that the ITR greatly underestimated the role of the Trauma System.

In this instance, attempts at partial adjustment of the ITR (i.e., the Registry Sample) fail to correct its deficiencies. Correction for ITR overreporting as made in column (b) results in little change in the estimated proportions (column (h)). Correcting for both overreporting and misclassification of ESP level results in

TABLE 2

Effect of incomplete and invalid registry data on calculations of the proportion of cases treated in the Illinois Trauma System, by level of severity, July 1973–June 1974

Severity level	Cases in Trauma Centers			
	No. of cases in Registry Sample	No. of cases in Registry Sample corrected for overreporting*	No. of cases from (b) corrected for misclassification†	No. of cases in Hospital Sample
	(a)	(b)	(c)	(d)
ESP ≤0.90	26	23	23	54
ESP 0.91–0.99	108	104	104	251
ESP = 1.00	59	57	57	151
Total	193	184	184	456

no changes in numbers (column (c)) or proportions (column (i)). Although misclassification did occur for individual cases (as demonstrated in the analysis of the predictive values of positive and negative ITR data), the net effect on the distribution of injury severity was negligible. This implies that systematic biasing did not occur and that the misclassification errors tended to cancel each other out in the overall distribution of injury severity. Since the principal error in the ITR was underreporting, only the Hospital Sample (column (d)) gives the true number and distribution of cases seen at Trauma Centers.

These results are instructive. If we had accepted *prima facie* that the ITR was correct, our conclusions would have been disastrously incorrect. Our experience with the ITR indicates that researchers using registry data should not rely solely on a single validity or completeness assessment, but must subject their data to a more thorough evaluation.

SUMMARY AND CONCLUSIONS

Registry data systems provide powerful tools for researchers in a variety of health related disciplines. In particular, extensive use of disease-specific registries is made by epidemiologists conducting studies of disease etiology. The use of registries for such investigations offers many advantages: a relatively large number of cases, uniform data collection, and the potential for longitudinal observation. However, for a register to be used as a valid tool in etiologic studies, it is essential that it contain data of high quality. As outlined in the review of registry evaluation methods in this paper, there are a wide variety of techniques whereby the completeness and validity of registry data may be assessed, each having advantages and disadvantages in its application. The internal consistency method for validity evaluation, for example, is inexpensive and rapid, but it is not definitive, whereas the reabstracted record method is definitive but is often prohibitively expensive. Nevertheless, since valid inferences can only be derived from studies based on valid and unbiased data, the difficulty and expense of registry evaluation must be accepted as a necessary cost of registry operation.

One peculiar aspect of registry evaluation is the lack of an interdisciplinary perspective. The problems of registry completeness and validity are ubiquitous and are not limited to specific diseases or conditions. The parochial development of disease-specific registries may actually hinder their successful operation. For example, many of the problems of the ITR might have been anticipated from previous experience with cancer and heart dis-

TABLE 2—*Continued*

Severity level	Cases in Non-System Hospitals	Estimated proportion of cases treated at Trauma Centers			
		From Hospital Sample	From Registry Sample		
			Uncorrected	Corrected for over-reporting	Corrected for over-reporting and misclassification
		10a ÷ (10d + e)	10a ÷ (10a + e)	10b ÷ (10b + e)	10c ÷ (10c + e)
	(e)	(f)	(g)	(h)	(i)
ESP ≤0.90	460	0.54	0.36	0.33	0.33
ESP 0.91–0.99	3091	0.45	0.26	0.25	0.25
ESP = 1.00	1940	0.44	0.23	0.23	0.23
Total	5465	0.46	0.26	0.25	0.25

* Correction for overreporting is accomplished by excluding nine cases not admitted to Trauma Centers, but which appeared in the Illinois Trauma Registry.

† Correction for misclassification is based on the estimated survival probability (ESP) distribution according to the hospital medical record.

ease registries. Communication among researchers developing or using registries deserves to be encouraged.

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