Record linkage: Data quality, tool development, and substantive research

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Abstract

Science is shaped by "entry points" which facilitate the study of important problems. Such entry points may be concepts or theories; they may be tools that permit asking new questions or approaching old questions much more efficiently. I believe two such entry points for the study of health and health care to be longitudinal administrative data and record linkage techniques. Research with such administrative data has been conceptualized as a triangle, with the base of the triangle being data acquisition, maintenance and enhancement. In the middle is tool development, tools to facilitate population-based, provider-based, spatial and temporal analyses. At the top of the triangle is substantive, multi-disciplinary research in health care and health.

Record linkage is an essential tool for dealing with both the base of the triangle – data and its quality – and the top of the triangle – substantive research. The role of record linkage in both these areas is discussed. Other tools (such as the Manitoba Centre for Health Policy's (MCHP) Concept Dictionary and hospital costing algorithms) valuable for the task of creating an information-rich environment will be described.

Almost twenty years ago, we recognized the need for a simple record linkage system to integrate well with existing operations. Such a system has been used to build the Manitoba research registry from periodic snapshots of the population registry used to administer the provincial health insurance system. The critical design feature of the research registry is its ability to provide key variables for the entire population at any time since 1970. Linkage can also be used for assessing database quality. By substituting for record reabstraction when both hospital and physician files are available, record linkage can cost-effectively highlight the quality of both variables and data sets.

Record linkage has actively been used to support new kinds of research. Several projects have used one or more types of administrative data to identify the study cohort; hospital discharge abstracts have been used to define surgical cohorts in several countries. Researchers have initiated several projects defining the cohort from clinical data and then tracking subsequent morbidity and mortality.

The information-rich environment in Manitoba has led to analyses linking epidemiology, health services research, and policy. For example, using Winnipeg hospital data from the last 11 years, Menec et al. (1999) discovered that overcrowding during the winter was most often due to increases in influenza associated illnesses (i.e., pneumonia, influenza, and other respiratory conditions). As a result both preventive measures (immunizations) and management initiatives (i.e., better planning of discretionary surgery) were adopted to avoid beds in hallways and overcrowded emergency rooms. Another MCHP report on the health of children highlighted a startling number of hospitalizations and deaths due to injury. Within weeks, Manitoba Health announced a new public initiative aimed at preventing childhood injuries in the home.

In the future, an information-rich environment should facilitate the study of genetic, family, and residential factors on health and health care. The developing field of social epidemiology will benefit from this environment. Longitudinal research using administrative data will become more and more important as databases continue to expand.

Introduction

Science is shaped by "entry points" which facilitate the study of important problems. Such entry points may be concepts or theories, or they may be tools that permit researchers to ask new questions or approach old questions more efficiently. I believe two such entry points for the study of health and health care to be longitudinal administrative data and record linkage techniques. These entry points have helped create "information-rich" environments in sites around the world, including several Canadian provinces, Western Australia, and Oxford. How can researchers work effectively in such environments?

Creating and managing an information-rich environment can be conceptualized as a triangle (Figure 1). At the base of the triangle are data acquisition, maintenance, and enhancement. The middle section represents the development of tools to facilitate population-based and provider-based analyses. Such tools will also help conduct analyses across space and time. At the top of the triangle is substantive research; work may be in specific fields such as epidemiology, clinical epidemiology, health services research, health economics, and health policy.

Data repository: confidentiality and access

Information-rich environments depend upon data repositories. In Manitoba, Canada, the Population Health Research Data

Repository is a comprehensive anonymous database developed to describe and explain patterns of health and health care. The Manitoba Centre for Health Policy (MCHP) developed this database from existing Manitoba Health data. Prior to data transfer, personal identifiers have been encrypted; names and addresses of patients and physicians have been deleted. The data include person-specific information derived from the population's contact with the health care system.

Physical access to this database is tightly controlled and monitored. Projects must pass screens and reviews by ethical and peer review boards, as well as by the Manitoba Health Information and Privacy Committee. Security procedures are periodically audited.

Administrative data

Figure 2 presents an ideal administrative database with a population-based research registry playing a central role. The data would be longitudinal and linked together as needed for each study. In Manitoba, our database is close to this ideal. The components of such a database are worth describing.

The research registry is critical for an information-rich environment, integrating information from various sources in a convenient format and providing certain variables for any date since 1970. Specifically, the Manitoba registry contains an encrypted number assigned to each resident, demographic characteristics, place of residence (a 6-digit postal code), and family composition. Population-based registries can provide information on all residents in an area, as well as their dates of arrival and departure (births, deaths, and moves). Each substantive file can be checked against the registry for accuracy of the identifiers and particular information (for example, date of in-hospital death)

The Manitoba databases can be appropriately aggregated at the level of the individual, the physician, the hospital, or the population. Examination of hospital and physician utilization by the entire Manitoba population over the 1970–2000 period is relatively easy. Nursing home and pharmaceutical data were incorporated more recently; home care files are currently being added.

Record linkage is an essential tool used to monitor data quality and organize such large files. The outer ring of studies in Figure 3 represents various research projects that involve special files – both clinical and survey data. Increasingly, data are collected with record linkage in mind.

Tool development

In addition to record linkage, researchers at MCHP rely upon two other tools for facilitating the research production process: the web-based Concept Dictionary and an algorithm for costing hospital stays. As the value of these tools is evidenced in the Centre's work, other researchers are adopting them. Our monthly "hit rate" on the Concept Dictionary continues to climb; in March 2002 it was over 29,000.

Record linkage

Record linkage brings together information from two independent source records believed to relate to the same individual or family and is critical for creating an information-rich environment.(Acheson, 1967; Newcombe, 1988) Almost 20 years ago, we recognized the need for a simple linkage system that would integrate well with existing operations in Manitoba. This system (built on a set of SAS macros) is used to help build the Manitoba research registry from periodic snapshots of the provincial health insurance registry.

Linkage is used for building databases and for assessing their quality. Vital Statistics files have been linked and incorporated in the registry.(Roos and Roos, 2001) Checks between the registry data and substantive files help maintain the registries for longitudinal studies. Data maintenance activities also include data quality checking, managing comprehensive multi-file databases, and linking records to allow follow-up. Linkage is often able to substitute for costly record abstraction when both hospital and physician files, with personal identifiers, are available. Linkage is also vital to the use of special files from external sources. Negotiated relationships with organizations providing other types of data (as seen in Figure 3) result in a plethora of files and coding schemes.

Concept dictionary

The Concept Dictionary was developed as a centralized knowledge repository. The Dictionary continues to evolve as MCHP's working knowledge expands and requires documentation. The philosophy underlying the Concept Dictionary is to make as much information publicly available as possible. The modular design has proven very efficient in relaying research information to students and analysts; concepts can be used as hyperlinks in other research aids (such as research protocols) and in teaching materials (both site-specific courses and the Epidemiology Supercourse). By standardizing various concepts, the Concept Dictionary enhances collaboration among researchers within a single research group (such as MCHP). Access to standard methods is also critical to research involving multiple centres that use similar or identical technology.(Kohler, 1994) With documentation provided on an external web site, documentation and dissemination overlap, keeping marginal costs low.

Within the Concept Dictionary, several types of information might be highlighted. Data on individual place of residence are typically available at the postal code or municipality level. This type of information can be organized in several ways. Canadian research centres typically provide a crosswalk between these residential codes and Statistics Canada census enumeration areas. This facilitates the generation of socioeconomic categories based on census data.

Similarly, format statements are used – building up from postal codes to define Regional Health Authorities (RHA's), districts within the RHA's, and hospital (or physician) service areas. This approach has been particularly helpful for studies of Regional Health Authorities in Manitoba.(Roberts et al., 2002; Black et al., 1999)

Although the concepts per se are important, additional structure helps organize approaches to large files. Recently, a protocol for conducting research with administrative data was added to Manitoba Centre's on-line knowledge repository. This protocol provides a methodological checklist or template that groups items into two broad categories. The Study Population category is more general in nature, outlining the criteria to be addressed in almost any study, regardless of data source or design. The Data Preparation section has two main components – data cleaning and record eligibility; basic characteristics and idiosyncrasies of administrative databases in Manitoba and elsewhere are addressed.(Bond and Roos, 2002) This type of protocol can be viewed as "intellectual middleware," highlighting the concepts critical for working with the files in Figure 2.

Considerable work has gone into developing indicators of key variables. These indicators – based on registry and administrative data – are expressed in modular form so they can be applied across a variety of projects. Both a verbal description of the concepts and, when appropriate, SAS programs containing the code to implement the concept are integral to the Dictionary. Finally, the Concept Dictionary is supplemented by a glossary that provides a shorter description of important terms. The Dictionary and glossary enhance the research production system in that previously developed concepts can be readily applied to new projects.

Costing for hospital stays

In the Canadian health care system, patients are not charged for hospital stays. With no charges, estimating costs associated with each hospital stay is a challenge.

After extensive work, Manitoba and Canada lookup tables (with an annual inflation adjustment) were developed to permit costing for each hospital stay. Hospital costs can then be produced for each individual for any time period.(Jacobs and Roos, 1999; Jacobs et al, 2000)

Several studies have used these tables. For example, ongoing research is examining the practicality of Medical Savings Accounts.(Forget et al., 2002) Physician bills and estimated hospital costs are being aggregated to produce a cost of care figure for each individual in the Manitoba population. The costs are very skewed, highlighting the difficulty with Medical Savings Accounts: few individuals are in the " moderate cost" category where they can readily save health care costs by cutting back on system use.

Approaches to data quality

Three approaches to achieving data quality are relevant for an information-rich environment. Record linkage typically connects two or more sources of information and compares their extent of agreement on key items. Primary data collection involves contacting individual respondents "in the field" to obtain the necessary information. Reabstraction studies typically go over hospital charts or physician records again to check on the initial coding.

A record linkage approach to data quality is diagrammed in Figure 4. The first step involves specifying individuals. When two files are supposed to contain the same individuals, the degree of overlap between both files provides a measure of data quality. When each individual has been specified, the degree of agreement between items on both records can be calculated. The process of linkage builds knowledge about the general quality of the information system and can often be readily done in conjunction with substantive research. If the same individuals are supposed to be on both files, are they? If not, why not? Such issues are important for registries (linking between registry and Vital Statistics) and for substantive files (linking between hospital and physician files). Comparing items is the second step. When individuals are specified as being on both files, the individual items (date of death, presence of a procedure or diagnosis) can be compared as to degree of agreement.

Quality of provincial registries

When registry and substantive files are linked, the overall match between these files provides an indicator of quality. Cross-sectional comparisons matching unique personal identifiers have reported high levels of agreement as to the number of 'individuals' on both files. For examples a series of British Columbia linkages between the provincial health registry and substantive files provided percent agreement between 96 and 99% (Chamberlayne et al., 1998).

Because of personal mobility, assessing the accuracy of these variables is likely to depend on primary data collection. One Canadian study using primary data collection found approximately 98% of Manitoba deaths and out-of-province moves (migration) to be recorded by one year after the event; (Roos and Nicol, 1999) this quality of follow-up extends back to the 1980s. A second study (Shannon et al, 1989) found very high correspondence between individual follow-up and linkage using a national resource – the Canadian Mortality Database. Accurate information on place of residence is important for small area comparisons and for work in social epidemiology. For example, the length of time an individual resides in a community (particularly a low income community) may be of causal importance for health status.(Lynch et al, 1997)

Comparing approaches to data quality

The reabstraction approach expends considerable resources trying to measure formal reliability, how reliably information (generally from hospital charts or physician records) moves into computerized form.(Potvin and Champagne 1986) In addition to assessing transcription errors, test results or chart entries may be scanned. Such measurement is likely to be expensive, varying with the amount of information needed, charges assessed by hospital record rooms, and so forth. Linkage-based comparisons rely on "end points," computerized files after the possibilities for error have been incorporated into the data. Comparisons made in linkage studies (factual reliability) incorporate possibilities for disagreement beyond those in reabstrac-

tion studies. Not only might transcription errors occur in the clerical processes producing both discharge abstracts and physician claims, but short-term change in patient condition and physician memory could affect the precise diagnoses coded. This logic suggests that reabstraction studies of data quality tend to generate equal or greater agreement than linkage-based studies. A comparison of approaches to data quality is diagrammed in Figure 5.

Quality of hospital and physician files

Four Saskatchewan studies combined the record linkage and reabstraction approaches, and found similar results vis-à-vis demographic and clinical information. The linkage-based studies occasionally produced less concordance (for example, with regard to the diagnoses accompanying hysterectomy).(Edouard and Rawson 1996; Rawson and Malcolm 1995a; Rawson and Malcolm 1995b; Rawson, Malcolm and D'Arcy 1997)

Measures of agreement for procedure and diagnosis are fairly similar between linkage and reabstraction studies. Nine hospital reabstraction projects and eight using physician claims (equally divided between linkage-based and reabstraction approaches)(Roos et al., 2002) showed parallel results between the two methods.

Academic projects

Central to many of the academic studies using the Manitoba data is cohort definition. Various projects have used one or more types of administrative data to define the cohort – in several countries, surgical cohorts have been defined using hospital discharge abstracts.(Donnelly et al., 2001; Birkmeyer et al., 1998; Tu, 1998) Cohort definition using diagnoses from administrative data is more difficult, but generally acceptable levels of reliability and validity have been achieved for asthma, diabetes, hypertension, acute myocardial infarction, and stroke.(Muhajarine et al., 1997; Robinson et al., 2000; Tu et al., 2001a; Tu et al., 2001b) Kozyrskyj et al.(2001) used physician and pharmaceutical files to examine childhood asthma over time. Hospital files were used to study acute myocardial infarction (hospital files) in a number of sites (Tu et al., 2002; Tu et al., 2001).

Record linkage also supports multi-method Manitoba research programs building on more detailed clinical data to study sleep disorders, inflammatory bowel disease, diabetes, various cancers, and alcoholism. The designs typically look backward and forward from an index event (e.g. treatment at a university-based Sleep Disorders Centre). Individuals in these cohorts have been linked to the research registry and then to substantive data (i.e. hospital, physician files). One program (investigating sleep disorders) has utilized a number of features of the database: longitudinal tracking of utilization and mortality, place of residence information to generate appropriate controls, cost data, and record linkage with both survey and clinical information.(Kryger et al., 2002;Smith et al., 2002)

Selected policy studies

Hospital overcrowding

The information-rich environment in Manitoba has led to analyses linking epidemiology, health services research, and policy. Over the 1988–1998 period Winnipeg's acute care hospitals showed a short-term (one to three weeks) increase in hospital admissions of about 10% over the average winter use, regardless of bed supply.(Menec et al., 1999) Using hospital data from the last 11 years, Menec et al. tracked the number of patients in hospital or admitted to hospital each day to establish the normal range of fluctuations in inpatient census, and to identify periods when beds aren't available and backups occur. These high-pressure periods happened almost annually; they occurred in the winters of 1988, 1989 and 1991 when there were about 700 more beds in the system. The same level of pressure was seen in the winters that followed, regardless of the number of beds in the hospital system.

Influenza and pneumonia were the most common diagnoses responsible for this increase. Both preventive measures (immunizations) and management initiatives (better planning of discretionary surgery) were adopted to avoid beds in hallways and overcrowded emergency rooms. Such measures were very helpful in Western Canada in the winter of 1999/2000, while Ontario hospitals neglecting such efforts suffered a number of adverse effects.(Gorey, 2000; Roos and Roos, 2001)

Physician resources

This report, a collaboration between MCHP and a provincially-appointed Physician Resource Committee challenged the popular belief of an increasing shortage of physicians in Manitoba. While access does not seem to be a problem, the distribution of physicians is uneven across regions and specially constructed physician service areas. Winnipeg and Brandon have more physicians per person than any other area; a potential surplus of generalist physicians in these urban centres was reported. To help improve physician supply in rural and northern areas, the Manitoba government offered incentives to attract more physicians to these areas.(Roos et al., 1999)

Child health

Brownell et al's (2001) work on the health of children in Manitoba noted a startling number of hospitalizations and deaths due to injury. Analysis of the relationship between income and income-related factors (i.e., education and employment levels) and the health status of children highlighted several findings. Compared with low-income areas, high-income areas tended to have:

- a lower percent of its children born underweight
- a lower percent of its children die before they are one year old, and
- a lower percent of its children killed by injuries or hospitaized for injuries.

Within weeks of the report's release, Manitoba Health announced a new public initiative aimed at preventing childhood injuries in the home.

The future

In the future, clinical epidemiology and health policy studies will continue to benefit from the longitudinal administrative data; such data are particularly important since changes are often occurring simultaneously. Assessing the consequences of specific changes in service delivery implemented at the provincial, regional, institutional or community level imposes significant challenges. The design issues are analogous to those that have plagued community intervention trials.(Koepsell et al, 1992; Koepsell et al., 1995; Fortmann et al., 1995) Change will be best understood by comparing (over an appropriately long period of observation) variations in service use and health outcomes among areas (regions, provinces, or states) that have been experiencing markedly different patterns of health reform. Changes in specific aspects of health care delivery can be observed across different contexts, while long periods of follow-up can assess discontinuities in outcomes associated with these changes.

Some important types of data have been neglected in the research literature; an information-rich environment should facilitate their use. For example, studies of family influences on health and health care utilization over a considerable period of time are possible given the available capabilities of the registry and linkage systems:

- Information from mothers, fathers, and siblings can be correlated over time, across socioeconomic groups, and through changes in place of residence.
- The influence of conditions such as mental illness on family stability and health can be traced over a significant fraction of the life course.
- Combining genetic, family, and place of residence data may allow examination of the influence of these factors on health and health care.
- The new field of social epidemiology has been concerned with neighborhood, as well as individual, characteristics.(Berkman and Kawachi, 2000) One study has shown that, with variables such as income recorded at both levels, risk estimates derived from ecologic income measures were not attenuated relative to estimates from household income. Such results support the use of ecologic-level measures of income in studies not able to access individual-level income measures.(Mustard et al., 1997) On the other hand, multilevel modeling has examined the extent to which neighborhood income might influence health status, taking into account the effect of individual characteristics. In Canada, community-level income inequality appears to have had little effect on premature mortality beyond that predicted by individual income.(Ross et al., 2000; Ross et al., 2002)
- Canadian provincial governments have not defined criteria for investing in the development of information on health and health care. Filling in "missing pieces" (i.e. data collection which has been poorly designed or implemented) should be a very high priority. Information-rich environments create settings for research that is reproducible, cost-effective, and cumulative. Integrated systems that cover an entire province have been shown to assist population health monitoring, support policy analyses of critical issues, improve management of the overall system, enhance quality of care, and reduce costs by increasing efficiency.(Brownell et al., 2001) As techniques change and problems emerge, the ability to shift into new areas should be enhanced. Building on an in-depth knowledge of file content and having a research production system is important for long-term productivity. Lessons can be learned from studies building on extensive knowledge of certain laboratory animals (e.g., Drosophila) where innovative work has continued over almost a century.(Kohler, 1994; Weiner, 1999) Information-rich environments seem destined to become more and more important in the future.

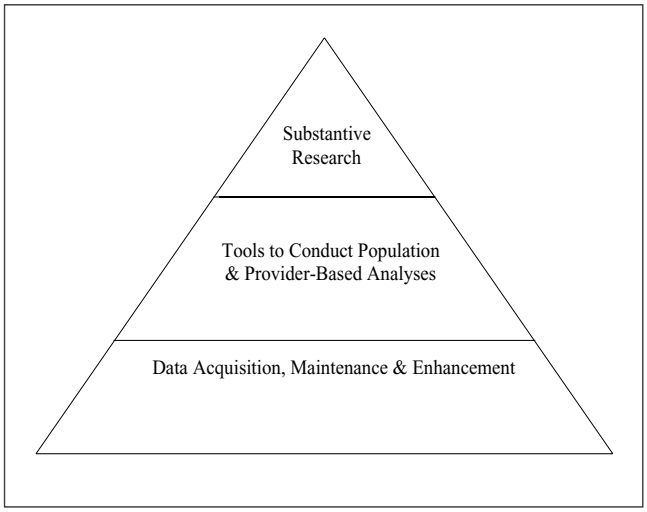

Figure 1 Creating & Managing an Information-Rich Environment

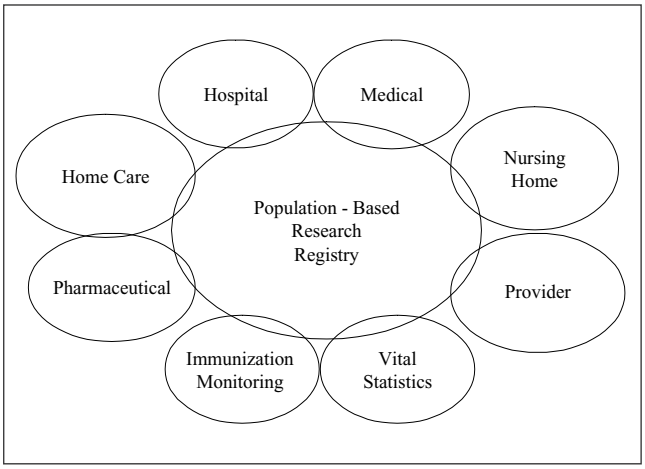

Figure 2 An Ideal Administrative Database

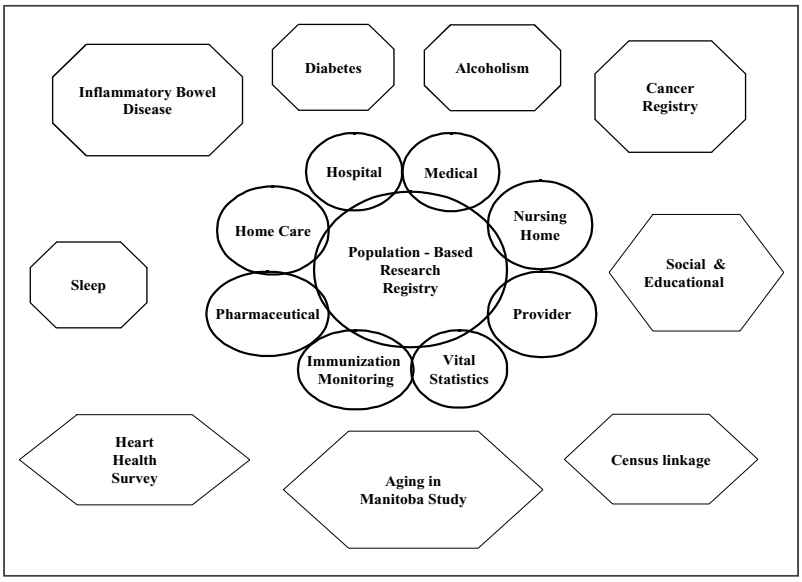

Figure 3. An Information-Rich Environment

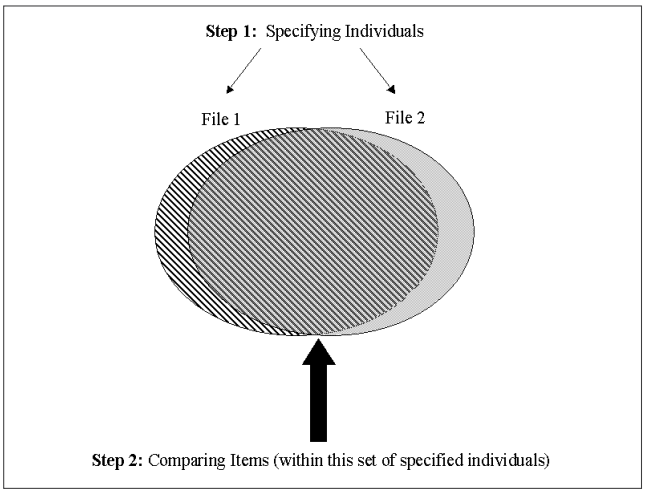

Figure 4. Record Linkage for Data Quality

Note: Files 1 and 2 represent registries and/or substantive files

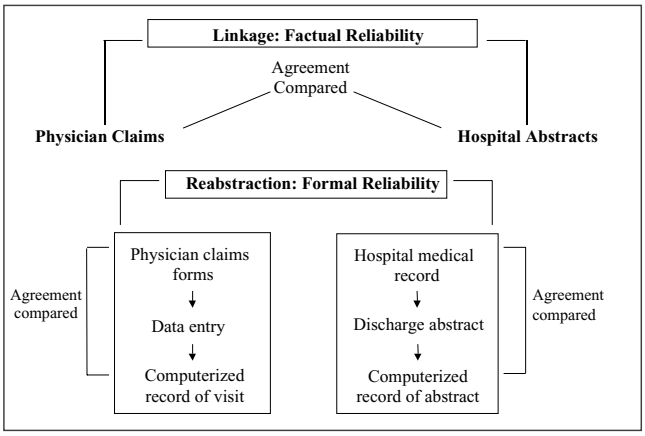

Figure 5. Comparing Approaches to Data Quality

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