Discussion

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At the outset, let me indicate that both papers submitted for this session were outstanding and represent major contributions to the overview of record linkage concepts as applied to health care policy issues. I will begin by discussing the paper by Martha Fair and then turn to the paper by Harvey Schwartz.

An Overview of Record Linkage in Canada

(Martha Fair)

Martha Fair has provided an excellent survey of record linkage as applied to health care and public policy in Canada. She has done an extremely thorough job in defining record linkage and giving a succinct historical perspective on the work of our Canadian neighbors. She has provided a very accessible and nontechnical treatment of the probabilistic underpinnings of record linkage methodologies. A point that Fair makes is very important to underscore: the quality of record linkage is completely dependent on the quality of the files. This points to the importance of assuring the quality of data that are used in all of our efforts for quality improvement in health care, and that data quality is one of the most important aspects of this effort.

Fair has provided a useful set of criteria for assessing the value of personal identifying information in her paper, most of which appeals to common sense.

She has provided some major uses of record linkage, including:

- ☐ longitudinal studies of mortality;
- ☐ follow-ups of clinical trials;
- ☐ building, maintenance and use of disease registries;
- ☐ regional variations in incidence of disease; and
- ☐ comprehensive multi-file databases.

In concluding her paper, Martha Fair has provided some future directions in record linkage. These include:

- ☐ administrative data will be more broadly applied;
- ☐ disease registries will become greater users;
- ☐ quality control will become more critical to every effort in record linkage; and
- ☐ new technologies hold great promise for merging data from multiple sources.

The bottom line of all of the discussion in Martha Fair's paper is that record linkage is an ***important research tool.***

Building Data Research Resources from Existing Data Sets: A Model for Integrating Patient Data to Form a Core Data Set

(Harvey Schwartz, Selma Kunitz, and Renee Kozloff)

Harvey Schwartz and his colleagues have provided the reader with a broad ranging and extremely thorough treatment of a topic of critical importance in health care reform, namely, the automated patient record or computerized patient record. The authors suggest that to achieve the goal of having a Core Data Set built on a computerized patient record two activities should be undertaken. We must:

☐ synthesize current endeavors and

☐ develop a model for a prototype patient care record.

I couldn't agree more with these two activities and consider them to be at the very foundation of health care reform.

In the paper, the authors pose and address seven very important questions.

☐ What data are needed?

☐ What are the potential sources for these data?

☐ Are the currently collected data sufficient and accessible?

☐ How will data be linked to form an automated patient record?

☐ Where will the automated patient record reside?

☐ Who will own the automated patient record?

☐ How will misuse of automated patient records and a health data infrastructure be determined and controlled?

Each of these questions raises a very important issue for consideration in the course of developing an automated patient record. Clearly, deciding what data are required in advance of creating such a vehicle is critical. One also needs to assure that the data be of good quality. One needs to be certain that currently collected data will be enough for the future and will be accessible. There are issues of longitudinal analysis that need to be considered, as well, so that there are not numerous definitional changes made mid-stream. Data linkage to other sources from an automated patient record will necessitate that careful consideration be given to the idea of a unique patient identifier -- and a universal one, at that. Consideration must be given to where the automated patient record will reside. The electronic medium can reside in a number of places and this issue must be resolved. Ownership issues are rampant now in the area of data, and the issue of who is the actual owner of the data will need to be determined. Misuses and privacy issues will need careful attention as we move forward.

The authors conclude that the current paper patient record is inadequate. This is absolutely correct. Not only is the patient record inadequate from a comprehensiveness standpoint, but there are often issues of legibility, improper completion, and so on. They also conclude, however, that the computer-based patient record is not yet a reality, and, indeed, it is probably many years off into the future, but we must get started. They also observed that part of the lack of what I would say is measurable success of medical effectiveness in outcomes research may be due to the lack of clinical data and automated longitudinal patient records. I think this is absolutely correct and is an important point to underscore.

The authors list six entities/efforts in health information automation and suggest that they need to be coordinated and synthesized. Indeed, there are quite a few efforts ongoing in a number of arenas related to performance measurement in hospitals, managed care organizations, networks, doctors' offices, and so forth that need to be synthesized. I think that if the Agency for Health Care

Policy and Research and the authors are able to stimulate coordination of activity, the whole will be much greater than the sum of its constituent parts.

A comprehensive summary of the policy issues in endeavoring to automate health care data is provided. The reader will find it useful to understand the myriad of issues that surround the issues of automating the patient record.

A proposed model is advanced by the authors for building an automated patient record. It has the following four steps:

- ☐ identify core data set;
- ☐ identify existing data codes;
- ☐ elicit support; and
- ☐ utilized linkage mechanisms.

The authors also identify a number of policy issues that are important to consider:

- ☐ ***Legislation*** -- A number of legislative activities are taking place today in communities, and at the state, as well at the national, level. With the recent failure of compreshensive national health care reform, a number of legislative activities are now focusing on the sub-national level.

- ☐ ***Fair Information Practices*** -- Numerous issues surround what is fair in the provision of information, and legislation/legal activities also surround this issue.

- ☐ ***Informed Consent*** -- It is clear that before patients would allow information of a private and confidential nature to be automated, they need to be informed of the uses to which these data can and may be put.

- ☐ ***Unique Patient Identifier*** -- This is the absolute cornerstone of the proposal for an automated patient record. Unless there is a unique patient identifier that is universal and can be used to comprehensively link databases and individual measures for the patient, the future is dim, indeed.

- ☐ ***Data Linkages*** -- Much was said by Martha Fair with regard to data linkage; the importance of being able to link records for the same individual rests very strongly on the availability of a standardized identifier.

- ☐ ***Data Ownership*** -- Once again, the issues of who owns the data, and who has the proprietary rights to these data, need to be addressed. It has been said that information is power, and that is, indeed, true. Data and information can and will be used as a competitive advantage in today's health care market place.

- ☐ ***Oversight and Monitoring Body*** -- There needs to be a body not unlike the Joint Commission on Accreditation of Health Care Organizations (JCAHO) for hospitals, and the National Committee for Quality Assurance (NCQA) for managed care organizations, that has oversight responsibility and monitors the activities surrounding the automated patient record. Whether this should be a Federal government agency, a non-profit organization, or some other body is an important question.

- ☐ ***Education and Training*** -- It is extremely vital that we take into consideration the necessity of educating all levels of an organization with regard to the importance of these activities; we must include training of those who are going to be responsible for the collection of data, coding of diagnoses and procedures, as well as the maintenance of these very important data files.

A Few Personal Thoughts

Let me now add a few of my own thoughts with regard to the content of these two papers and the thinking that they stimulated.

First and foremost, **data quality** issues must be addressed. It is clear to me that, in the modern era of quality improvement through TQM/CQI, we must attend carefully to the issue of the quality of data that are being used for quality improvement. If the data are flawed or inaccurate, it may be harmful to make interventions and to devise quality improvement strategies based upon these incorrect data.

We must also find efficiencies in our data collection strategies, so that additional burden and cost is not heaped on the delivery system. With the advent of such measurement systems as HEDIS (Health Plan Employer Data and Information Set), from the National Committee for Quality Assurance, health plans have found it extremely difficult, time-consuming and expensive to do medical record review, which is required by some of the measures in HEDIS. We must devise clever, efficient, and cost effective strategies for capturing information in a timely and high quality fashion.

Standardization is critical. We must agree, as an industry, upon measure definitions, data collection methodologies, and standardized approaches throughout the collection, analysis and reporting phases of any quality improvement-based data collection effort.

Careful **coordination** of the various efforts underway is essential. It is clear that there are a number of emerging efforts to develop computerized patient records. There are several legislative activities underway, with a number of private, for-profit activities and related non-profit activities involved, so we must ensure that these are coordinated. Whether the Agency for Health Care Policy and Research is going to be the convener of these bodies remains to be seen, but the authors have made a valiant plea for coordination of the numerous activities underway.

It is clear to me that achieving consensus on the issues is going to be difficult, but vital to success. Leadership is essential, and it is imperative that leadership come forward in a concerted and long-term sense, in order to ensure development of standardized measures of performance for the health care delivery system. ■