Monitoring Health Care Using National Administrative Data Collections

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Declaration

Except where otherwise acknowledged in the text, this thesis represents my own original work.

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Abstract

With the inevitable adoption of information technology into all areas of human pursuit, the potential benefits for health care should not be overlooked. In Australia, details of most health care encounters are currently recorded for administrative purposes. This results in an impressive electronic data-bank that could provide a national resource for health service evaluation.

Evaluation of health services has become increasingly important to provide indicators of the benefits, risks and cost-effectiveness of treatments. However, if administrative data are to be used for this purpose, several questions must first be addressed: Are the current data collections accessible? What outcome measures can be derived from these data? Can privacy issues be managed? Could the quality of the data be improved? Is the existing infrastructure adequate to supply data for evaluation purposes? Could the existing system provide a basis for the development of an integrated health information system?

The aims of the project were:

- To examine the potential for using administrative data to generate outcome measures and surveillance indicators.
- To investigate the logistics of gaining access to these data for the purpose of research. This to be achieved within the current ethical, political and financial framework.
- To compare the Australian health-service data system with the current international state-of-the-art.
- To develop suggestions for expansion of the present system as part of an integrated health record and information system. This system to manage patient records and provide data for quality management, treatment surveillance and cost-effectiveness evaluation as a routine activity.

The thesis is presented in two parts. In the first part, a historical cohort study is described that involved patients with implantable medical devices. The potential to evaluate outcomes was investigated using all national health-service information currently available in electronic form. Record linkage techniques were used to combine

and augment the existing data collections. Australia's national health databases are to varying degrees, amenable to such linkage and cover doctor visits, pharmaceuticals, hospital admissions and deaths. The study focused on medical devices as an illustrative case but the results are applicable to the routine assessment of all medical and surgical interventions.

For the Australian 'Medical Devices study', the records of 5,316 patients who had medical device implants in 1993-94 were selected from the archives of a major private health insurer. Five groups of medical implants were studied: heart valves, pacemakers, hips, vascular grafts and intra-optic lenses. Outcomes for these patients, including death, re-operation and health service utilisation, were compared and analysed.

A comparison study was performed using data from the Manitoba Health database in Winnipeg, Canada. Manitoba provides a very similar demographic group to that found in Australia and is an example of a prototype integrated-health-information system. One of the principal advantages for research is that *personally identified* data about medical and hospital services are collected for all patients. Selection bias is eliminated because individual consent is not required for this type of research and all selected patients could be included in the study.

The two studies revealed many barriers to the use of administrative data for health outcomes research. Service event data for the Australian cohort could be collected but only after long delays and hospital morbidity data were not available for the entire cohort. In contrast to the situation in Australia, the Manitoba data were both accessible and complete, but were lacking in detail in some areas.

Analysis of the collected data demonstrated that without the addition of clinical data only general indications of trends could be deduced. However, with minimal supplementary clinical data, it was possible to examine differences in performance between brands of medical devices thus indicating one of the uses for this type of data collection.

In the second part of the thesis, conclusions are presented about the potential uses and limitations of the existing system and its use as a basis for the development of a national

Integrated Health Record and Information System (IHRIS). The need for the establishment of a systemic quality management system for health care is discussed.

The study shows that linked administrative data can provide information about health outcomes which is not readily available from other sources. If expanded and integrated, the system that is currently used to collect and manage administrative data, could provide the basis for a national health information system. This system would provide many benefits for health care. Benefits would include the monitoring, surveillance and cost-effectiveness analysis of new and existing treatments involving medical devices, drugs and surgical procedures. An integrated health information system could thus provide for both clinical and administrative needs, while in addition providing data for research.

Unfortunately, in Australia, the use of administrative data for this purpose is not currently feasible. The principal barrier is the existence of a culture within the Australian health care system which is not supportive of research and is deficient in quality and safety measures.

Recent initiatives by both the Commonwealth and state governments have supported the introduction of measures to improve quality and safety in health care. It is argued here that an Integrated Health Record and Information System (IHRIS) would provide an essential component of any such scheme. The results of this study have important policy implications for health care management in both the administrative and clinical domains.

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The desire for safety stands against every great and noble enterprise
Cornelius Tactitus, AD 56-120

Anyone who has never made a mistake has never tried anything new. Albert Einstein.

Preface

This research project was conceived during my time working within the Commonwealth Department of Health in the area of medical device regulation. As medical advisor, I witnessed the limitations of pre-market evaluation of new products, the inadequate system of 'problem' reporting and the challenge of implementing safety alerts and product recalls for faulty devices. When problems with a heart-valve, pacemaker-lead or intra-uterine device were detected, it was often appropriate to advise patients of the need for investigation or removal of the implant. However, since no systematic record is kept about who had what implant, contacting patients and doctors was complicated. It became apparent that a better tracking system existed for motor vehicles than for life-saving medical devices.

An implant tracking system was envisaged; there are several possible approaches available.

- A purpose designed, centralised database maintained by either the public or private sector. Registration may be either obligatory or voluntary. The database may incorporate all devices or be confined to a certain type. (An example is the Norwegian Arthroplasty Register. Outside the medical device area, registries of infectious diseases are widely used.)
- Hospital based registries (ie at place of implantation). This approach has recently become a legislative requirement in the USA for selected implantable devices.
- 'Boutique' registries run by manufacturers. This can occur in an ad-hoc manner where patients return a warranty card as occurs for some cardiac pacemakers.
- The function may be combined with the collection of administrative data. This is the approach adopted for example in Sweden and Norway.

The Medical Devices study, which is the basis of this thesis, examines the last of these options. The original aims of the project were:

- To assess the feasibility and potential health and cost benefits of using routinely collected administrative data to monitor health outcomes of medical device implants.
- To develop a data collection and record linkage model for the routine determination of a range of intervention outcomes.

- To assess the cost benefit of the model.

In Australia, several health administrative data-sets are routinely collected. Almost all doctor visits, hospital admissions and deaths are systematically recorded across the country. The existing infrastructure could provide an appropriate means to collect the additional data needed for a medical implant register. It would probably be the most cost-effective option and would require minimum system changes. Importantly, when clinical detail is added to national administrative data-sets, a powerful resource is created that could be used for health outcomes evaluation. It is this possibility that will be examined in this thesis.

Introduction

To investigate the potential for using administrative data collections for health outcomes analysis I decided to conduct a study that would draw its information from all currently available electronic national data-sets. Health service data are collected by the Commonwealth government in the Medical Benefits, the Pharmaceutical Benefits, the Department of Veterans Affairs, the National Death Index and the National Hospital Morbidity collections. In order to provide the maximum information for analysis, these data sets would require linkage at the patient level. Detailed demographic data is collected by the Australian Bureau of Statistics (ABS). Unfortunately, all personal identifiers have been removed from the ABS collection and as a result these data were not able to be incorporated. To test the usefulness of this linked resource for health outcomes evaluation, it was necessary to select a medical intervention to examine. Implantable medical devices were chosen as a typical, well defined and widely used procedure.

In order to provide a comparison with a state-of-the-art, purpose designed health data system, it was decided to perform a parallel study in Manitoba, Canada. Manitoba Health collects service data specifically for the purpose of health care evaluation, in addition to the needs of administration. These data are available for approved research projects.

During the initial stages of the study, it became apparent that some modifications to the original aims would be required. The changes were necessary because of the limited availability of Australian data and the poor quality of data that was available. Taking this into account, I decided to conduct comparative analyses on three different 'levels' of data quality that were conceivable, if not actually available.

- The currently available Australian data
- The reasonably high quality data collected in Manitoba
- A 'simulated' data-set that might be available from an integrated health information system. This was achieved by using all Australian service data supplemented with detail from a private health insurer.

Because it involved using and evaluating almost all the relevant administration data sets, the implant study provided invaluable insight into the use of nationally collected administrative information. The thesis therefore, has two distinct parts. The first and main part, is concerned with the Medical Devices study. The second part builds from my experience in conducting these studies. It discusses the potential for expansion and integration of the existing administrative data system for the purpose of building an integrated health record and information system (IHRIS) which would be an essential component of a new health care structure based on a quality management philosophy.

In the first part, Chapter 1 describes the history and state-of-the-art of record linkage in Australia and overseas, the need for evaluation and surveillance of new medical interventions and the growing industry of health data collection. Chapter 2 presents an overview of the study methodology while Chapter 3 enlarges on the processes involved in selecting a study cohort. Chapters 4-6 describe the Medical Devices study, its implementation, results and analysis. Chapter 7 describes the Manitoba study and Chapter 8 compares the Manitoba and Australian data collections, pointing out their various advantages and limitations.

Chapter 9, which introduces the second part of the thesis, discusses in more detail the strengths and limitations of the use of administrative data for research and examines the trend towards the introduction of integrated data collections and quality management in health care. The potential for the existing administrative data system to provide a basis for an integrated health information system that caters for systemic quality management is discussed. In Chapter 10, recent initiatives supporting the introduction of a quality and safety system in Australian health care are reviewed. The importance of an IHRIS to support such a system is discussed.