Chapter 3

The Impact of Privacy Legislation on Patient Care:

A Canadian Perspective

Jeff Barnett
University of Victoria BC, Canada

ABSTRACT

This chapter looks at how privacy legislation in Canada may interfere with patient care and the use of electronic health records. A review of the literature shows that legislation across Canada is not uniform and varies to the degree in which it addresses issues of privacy and confidentiality. What is not clear is what impact legislation has on the movement towards electronic health records. A case study was undertaken to look at a specific project involving the design of an electronic health record as a means of sharing information between physicians and prostate cancer patients. Through interviews with those associated with the project, it was clear that legislation itself was not a barrier. The problem was that the legislation was open to interpretation. The author hopes that an understanding of the issues raised by this chapter will lead to further discussion and research on this topic.

INTRODUCTION

Patient privacy is a topic of great interest both in Canada and internationally. Many health conferences and academic journals often have several papers devoted to this topic. This issue has gained more attention in the last five years as there is a continuing trend in healthcare towards more electronic capture and sharing of information between providers and patients. It has been recognized that healthcare has typically been behind other industries like the airlines and banking when it comes to embracing its users in the sharing of electronic information. Patients and their healthcare providers have expressed an interest in sharing of information to facilitate optimal patient care. Unfortunately as more patient information is made available electronically there is an increased potential for loss of privacy and confidentiality.

In Canada most provinces have legislation to ensure that there are safeguards in place to protect confidentiality and security of sensitive personal

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data. However it may be that this legislation is too restrictive and interferes with patient care activities. Many initiatives such as those led by federal and provincial governments are looking at novel ways of providing access to and sharing of electronic patient information. Often these initiatives involve the use of the Internet or some form of information and communication technology (ICT). These initiatives may run into issues with current legislation to the extent that they never get off the ground or, at best, are significantly delayed in implementation. In general, the topics presented usually deal with how to be compliant with legislation or how to go about addressing issues related to privacy. Little has been discussed that addresses how legislation may have an impact on patient care. Indeed there is scarce information in the literature that looks at how the legislation in any particular jurisdiction may have an impact on novel approaches to the delivery of care.

The aim of this chapter is to look at a new and innovative project for the sharing of information for prostate cancer patients in the Canadian province of British Columbia (BC). A case study was undertaken in order to examine whether current legislation has had an impact on this project, known as the Provider Project.

BACKGROUND

The Provider Project

The British Columbia Cancer Agency (BCCA) provides cancer care programs for the people of BC, including prevention screening, early detection, diagnosis and treatment services, support programs, community programs, research and education. BCCA, along with seven other provincially mandated healthcare agencies is a member of the Provincial Health Services Authority (PHSA), which is responsible for governing, managing, and funding this group of healthcare agencies and services.

BCCA is committed to providing all patients with access to a full range of quality cancer services, regardless of where they live. To serve the people of BC, BCCA has a complete network of facilities, such as regional cancer centres, community cancer centres, research centres, and foundations. There are five regional cancer centres located in Victoria, Vancouver, Kelowna, Surrey and Abbotsford. Through these five cancer centres located around the province, various cancer care programs are provided to patients, including assessment and diagnosis, chemotherapy and radiation therapy, counselling services and follow-up care.

One of the many types of cancers treated at the BCCA is prostate cancer. Prostate cancer patients are often exposed to a variety of treatment options such as surgery, radiotherapy, hormonal therapy and, rarely, chemotherapy. Prostate cancer is often referred to as a chronic disease. This is because the tumour is slow growing and with currently available treatments, patients remain very active and alive for many years after diagnosis. Caring for these patients during treatment is complicated and often involves a multidisciplinary approach to care. The members of the care team are usually radiation oncologists (specialized physicians), radiation therapists, nurses, pharmacists, social workers and, most importantly, their primary care physician.

More recently with the increasing involvement of patients in shared decision making, patients have become very active members of their own care team. This is especially true for prostate cancer (PC) patients. Several studies have indicated that these patients are keenly interested in their care and often are very active in seeking out information. However with the complexity of their care, gaps in information between PC patients and their care team can exist. It has been demonstrated that a growing number of patients now refer to the Internet as a source of information in order to fill those gaps. However the web sites dealing with PC are often generalized and do not provide

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