

A call for the regulation of prescription data mining

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The data necessary to generate individual physician-prescribing profiles are compiled using information from retail pharmacies and are sold to the pharmaceutical industry. Many physicians and pharmacists are not aware of physician-linked prescription data mining and their informed consent is not sought. The intent of this article is to foster debate about prescription data mining practices in Canada, especially with regard to the statement of principles concerning the sale and use of data on individual physicians' prescribing¹ drawn up by the Canadian Medical Association (CMA).

Prescription data mining in Canada

The major player in the provision of physician-linked prescription data to the pharmaceutical industry is IMS Canada, a division of IMS Health, a multinational corporation. We have conducted extensive telephone and personal interviews with IMS representatives. We have also examined IMS Web sites (www.imshealth.com and www.imshealthcanada.com) and reviewed hundreds of pages of literature that IMS has supplied. IMS Canada collects prescription data from over 4000 Canadian retail pharmacy outlets through agreements with the head offices of chains of pharmacies and with suppliers of software designed for use in pharmacies who, in turn, have agreements with the pharmacists who have installed their software programs. The prescription information that IMS compiles includes the drug manufacturer, medication strength, the form of the medication, new versus refill prescription, prescription size, transaction location, authorized repeats, a physician-identifying number and the third-party payer, if available. IMS Canada reported that identifiable patient data are not collected as part of this detailed prescription information, which is sold to major pharmaceutical companies that use this information to develop and evaluate marketing strategies.

IMS Canada's analyses of physician prescribing are aggregated into groups of 10 or more physicians; however, individual physicians are identified within these groups. IMS Canada provided us with an example of a physician prescribing report. In this report, physicians were identified by a physician-specific identifier number (FINDr.) and divided into groups of 12 based on their prescribing for a particular drug class. The physician-specific identifier number allows the identification of each of the prescribers in the report and their level of prescribing. FINDr. is the IMS physician database that contains the names of all

Canadian physicians and their addresses, including mail, office, clinic and hospital, and identifies physicians by principal specialty, special interest, age, sex, language and telephone number. This list is sold to pharmaceutical companies and can be linked to an individual physician's prescribing information, enabling the generation of personal prescribing profiles.

IMS gathers physician-linked data across Canada with the exception of British Columbia. The BC Ministry of Health took the position that permitting the pharmaceutical industry to target physicians with customized sales strategies was not in the public interest and was a breach of physician confidentiality.² The bylaws of the College of Pharmacists of British Columbia were amended to prohibit the sale of prescription data linked to physicians.³ The BC government currently collects physician-linked data through a province-wide on-line pharmacy system called PharmaNet. Further information may be obtained about PharmaNet from the the BC government Web page (www.hlth.gov.bc.ca/pharme/net.html).

Following the introduction of the Act Respecting the Protection of Personal Information in the Private Sector in Quebec, IMS Canada established an advisory board in 1997 for its operations in Quebec. The board oversees the third-party use of IMS Canada's databases, deliberates on ethical questions and reviews complaints in Quebec. IMS Canada has also taken steps to make its activities more visible in the province: in 1999, a pamphlet was sent to all Quebec physicians and pharmacists informing them that IMS Canada collects physician-linked data and sells it to pharmaceutical companies.⁴ The mailing emphasized that aggregation protected individual physicians' "confidentiality."

The current practices of IMS Canada with respect to the collecting and selling of physicians' prescribing information will require modification to comply with the Personal Information Protection and Electronic Documents Act (federal Bill C-6) that was enacted on Apr. 13, 2000. This act will apply broadly in 3 years and outlines principles for the collection and sale of personal information in the course of commercial activity, which includes informed consent and individual access to the personal information collected.

CMA policies regarding prescription data mining

When it came to light in 1996 that IMS Canada was compiling and selling physician-linked data to pharmaceu-

tical companies, many physicians objected to the practice.⁵ The Ontario Medical Association complained to the Ontario College of Pharmacists (OCP), recommending full disclosure and the seeking of physicians' consent.⁵ In response to the controversy, IMS Canada sent a letter to Ontario physicians to give its side of the story and to report that, according to the OCP, IMS was not contravening "any obligations of confidentiality."⁶ IMS justified its practices then, as it presently does, by the data contributions it makes to researchers and policy-makers and the "benefits" to physicians of having "pharmaceutical companies better understand your practice so they can provide you with information that is more pertinent to your practice needs."⁶

The President of the CMA also objected to IMS' practices.⁵ The CMA published 5 principles regarding the collection and sale of physicians' prescribing data in 1997.¹ The present data mining practices of IMS Canada are at variance with all 5 principles.

Principle 1. Data on individual physicians' prescribing must be compiled, sold or otherwise used in a manner that does not compromise the privacy of patients or physicians; anonymity and confidentiality must be maintained.¹

Physician-linked data are compiled and sold by IMS and, as demonstrated earlier, aggregation does not prevent individual physician profiling.

Principle 2. Except as authorized by law, physicians must be informed of, and their prior consent obtained for, the compilation of prescribing data that identify them and the sale or other use of such data. The consent obtained must be informed, positive, documented and time-limited. For greater certainty, the right of physicians to consent also includes the right to restrict or to refuse to allow the compilation, sale or other use of identifying information about them.¹

The logistics of gaining such consent are not complicated; however, IMS Canada has deemed that it will presume consent has been granted unless a physician informs it otherwise.

Principle 3. The primary purpose of compiling data on individual physicians' prescribing and developing profiles must be to provide individual physicians with an educational tool to enhance their prescribing practices and the quality of care provided to patients.¹

The primary purpose for which IMS Canada compiles physician-linked data is to sell it and related analyses to pharmaceutical clients. Although physicians can contact IMS Canada to receive reports of their prescribing, this is not routinely communicated to physicians.

Principle 4. Having compiled and analysed the data on individual prescribers, the compiler must make this information directly available, free of charge, to each individual physician concerned, along with appropriate data for comparison purposes. This information is an educational tool that physicians are encouraged to take advantage of to enhance the care they deliver.¹

Once again, the problem is a lack of physician awareness; IMS Canada has not informed physicians of its data mining activities on a continuing and ongoing basis.

Principle 5. Physicians must be provided with the names of any organizations that have been sold, or otherwise given access to, data about them.¹

This information is not routinely provided to physicians even though IMS indicated in 1996 that it would be. "We also propose that, as one of the conditions of use, the names of pharmaceutical companies in possession of the data be disclosed to physicians."⁶

Contributions to research made by IMS

Prescription data are of considerable value to decision-makers, policy analysts and researchers, and such data are hard to come by. The data that IMS compiles have great potential value. A search of MEDLINE and HEALTHSTAR from 1996 to May 15, 2000, yielded 31 papers to which various divisions of IMS had contributed data. IMS Canada supplied us with a list of 125 other projects to which they supplied data in Canada from 1996 to Mar. 28, 2000. Thus, while not voluminous, the data collected by IMS are used by researchers.

Recommendations

In an attempt to balance the right of physicians to be made aware of and consent to their prescribing information being mined against the intrinsic value of this data to policy-makers, researchers and practitioners, we offer the following recommendations. At the very least, prescription data mining companies should be compelled to make their business activities better known to physicians in order that the opt-out aspect of presumed consent could be exercised and prescribing feedback sought, if desired, by physicians. Annual mailings to all physicians to establish consent and to offer feedback would be a good start. The establishment of independent provincial boards to oversee prescription data mining should be standard across Canada. Royalties paid for mining this valuable data originating from publicly funded health care should support these boards with additional funds directed toward research to support optimal drug prescribing. We contend that enforceable regulations are needed and that health care professionals should be the overseers of prescription data mining. The CMA should ensure prescription data mining of Canadian physicians' prescribing information is conducted in accordance with the 1997 CMA guidelines.

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