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Information management and patients' rights

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ABSTRACT

General practitioners have a responsibility to provide good quality care for patients and to ensure that services provided within their medical centre, and referrals to and from other providers, are well co-ordinated.

Information technology is a valuable quality improvement tool for general practitioners. For example, computerised prescribing may reduce medication errors, and audit data may prompt changes in the way care is delivered and improve patient outcomes. Well-managed information flows are critical for continuity of care among different providers.

The increasing availability of health information, and improved 'health literacy' of the population, presents both challenges and opportunities. Several case studies from the Office of the Health and Disability Commissioner illustrate some of the benefits and pitfalls of information technology and information management for general practitioners and their patients.

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Key words

Patients' rights, information management, Code of Health and Disability Services Consumers' Rights

Introduction

The first successful telesurgery was carried out in September 2001 when a surgeon in New York performed a robot-assisted laparoscopic cholecystectomy on a patient in France.¹ Less sensational, but of far greater practical importance, are the changes happening all around the country as general practitioners adopt new technology and come to terms with what it means for them and their patients.

In New Zealand, both doctors and patients have been quick to embrace the use of health-related information

technology. In terms of medical information technology use, New Zealand is second only to Britain, and 56% of general practitioners have used the Internet for patient care.² Many general practitioners have electronic clinical records and prescribe, order and receive laboratory investigations electronically. We can expect that the use of information technology in medicine will continue to expand rapidly.

Properly managed, information technology can result in improved communication between health providers, more up-to-date doctors, bet-

ter informed patients, safer prescribing, and more efficient business practices. Poorly managed, the use of information technology in medicine may do more harm than good.

This article discusses doctors' responsibilities under the Code of Health and Disability Services Consumers' Rights in relation to information management. A series of case studies based on complaints investigated by the Health and Disability Commissioner illustrate some of the benefits and pitfalls of information technology in medicine.

Responsibilities under the Code

The Health and Disability Commissioner Act 1994 (NZ) (the Act) was passed in 1994 in the wake of the 1988 Report of the Cervical Cancer Inquiry.³ The Act is the primary vehicle for dealing with complaints about any health or disability service provider in New Zealand. The purpose of the Act is to promote and protect the rights of consumers of health and disability services and to facilitate the fair, simple, speedy, and efficient resolution of complaints.⁴

The Code of Health and Disability Services Consumers' Rights,⁵ in force from 1 July 1996, sets out 10 rights of consumers and corresponding duties of providers.

In relation to issues of information management, Rights 4 and 6 are of particular importance. Right 4(1) provides that patients have the right to have services provided with reasonable care and skill. Right 4(2) provides that patients have the right to services that comply with legal, professional, ethical, and other relevant standards. Under Right 4(5) patients have the right to co-operation among providers to ensure quality and continuity of services. Right 6 deals with information provision. Right 6 provides that every patient has the right to the information that a reasonable patient, in that patient's circumstances, would expect to receive.

A good information technology system can improve the quality of patient care and help to prevent breaches of the Code. For example, a computerised recall system may reduce the risk of patient test results 'falling through the cracks', as happened in the following case.

CASE STUDY: Results recall⁶

Mrs B saw her general practitioner, Dr Y, for antenatal care in the 14th week of pregnancy. Dr Y carried out an initial antenatal check and ordered routine antenatal bloods. Two days later, Dr Y received the results of the blood tests: Mrs B's syphilis serology was positive. As Mrs B had

no clinical signs of syphilis and there was nothing in her history to suggest increased risk, Dr Y assumed that it was a false positive result. He decided to discuss the result and arrange a repeat test at the next visit in six weeks' time. Unfortunately, Mrs B thought that all was well and did not return for a further check until she was 27 weeks pregnant. By that time, there had been no foetal movement for three days. An ultrasound revealed intrauterine death and a post-mortem showed evidence of chronic foetal infection. Dr Y was found in breach of Right 6(1)(f) for failing to provide

Mrs B with timely information about the abnormal test result. (In relation to normal test results, the Commissioner's general view is that a patient does not have to be contacted about every normal test result, as long as the doctor and patient have agreed that only abnormal results will be notified, and the patient knows how to confirm a normal result if desired.) Following the investigation, the provider informed the Commissioner that he had undertaken additional training in sexual health and had arranged a computerised recall system for follow-up of abnormal results.

However, an electronic system is only as good as the people using it. As the following case study illustrates, medical practices should give careful thought to who should be allowed to access files and authorise actions.

CASE STUDY: Filing failure⁷

Mrs A's husband told her that he had a fungal infection of his genitals, and advised her to get checked out. Mrs A saw her general practitioner, Dr X, who took vaginal swabs. Three days later the laboratory electronically forwarded the results of Mrs A's vaginal swabs to the medical centre. Dr X was not working the day the test results

were sent through, and it appears that an unknown staff member filed the result in Mrs A's clinical records, instead of leaving it in the computer in-box for Dr X's attention. Dr X only became aware of the result seven days after the swabs were taken, when Mrs A rang to say that she had developed a green vaginal discharge. Mrs A complained to the Commissioner about the delay in commencing treatment for gonorrhoea. Dr X was found to have breached Right 6(1)(f) of the Code (the right to be informed of test results) by failing to take reasonable steps to ensure that the test

results were promptly communicated to Mrs A. Following this incident, Dr X advised the Commissioner that the medical centre had upgraded its computer system so that no one other than the provider is able to file a patient's test results.

Reasonable actions in the circumstances

The rights in the Code are all subject to the qualification that a provider is not in breach of the Code if he or she has taken '*reasonable actions in the circumstances*' to give effect to the rights in the Code. The onus is on the provider to show that he or she took reasonable actions. Relevant circumstances include '*the consumer's clinical circumstances and the provider's resource constraints*'.⁸

CASE STUDY: Reasonable actions⁹

Mr C was a 29-year-old man with a history of rheumatic heart disease, and significant aortic valve disease. A cardiologist reviewed him in October 1997 and recommended annual follow-up. In December 1998 the patient presented to his general practitioner, Dr Z, with shortness of breath and a cough. Dr Z rang the hospital to find out why Mr C had not yet received an appointment for cardi-

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ology follow-up. The hospital clerical staff reassured Dr Z that the computer system showed 'appointment pending'. No appointment was ever sent and the patient died at home in February 1999. Post-mortem showed acute pulmonary oedema due to degeneration of the aortic valve replacement. A review of the hospital computer system showed that 'appointment pending' simply meant that follow-up was required, and an appointment time needed to be manually booked by clerical staff. The Commissioner found that Dr Z had taken reasonable actions in the circumstances to ensure that a cardiology appointment was forthcoming, and had not breached the Code.

Information as a quality improvement tool

The New Zealand Quality of Health Care Study reported an overall rate of 12.9% of adverse events associated with admissions to New Zealand public hospitals, roughly one-third of which were classified as highly preventable.¹⁰ Lessons can only be learned if information on such adverse events is collected, analysed, shared and acted on. Currently individual providers, District Health Boards, the Accident Compensation Corporation, the Ministry of Health, and the Health and Disability Commissioner all hold pieces of the quality puzzle. Improved information sharing, made easier by effective information management systems, will help to identify patterns of medical injury and contribute to quality improvement.

Properly analysed information can be a valuable tool for assessing the performance of providers and informing behavioural change. Research shows that publishing comparative data (without identifying individual doctors) improves organisational performance.¹¹ However, to date, Ministry of Health proposals to publish comparative public hospital morbidity and mortality data have been met with a cool response.

Information technology can also contribute to improved quality in many other ways. Web-based guidelines, such as those prepared by the Cochrane Centre,¹² offer up-to-the-minute, evidence-based information for use in clinical decision-making. Internet-based information is particularly useful in rapidly changing areas, such as travel medicine, where up-to-the minute knowledge is important.

Clinicians can join web-based forums where difficult management problems can be presented and advice sought from other forum members. For example, the ear, nose and throat forum at www.otohns.net is very popular amongst otolaryngologists.¹³ E-mail holds the promise of revolutionising general practitioners' ability to access specialist opinions. In theory (although rarely in practice) it is possible for a general practitioner to send a query to a subspecialist and receive a reply within a day.

There is good evidence that rules-based computerised prescribing can contribute to safety and patient care. A computerised system ensures that prescriptions are complete and legible, avoids transcription errors, provides relevant patient information, and alerts clinicians to potential errors.¹⁴ In the following case, a computerised prescribing system may have prevented a simple medication error and associated breach of the Code.

CASE STUDY: Allergy alert¹⁵

Mrs D, a breastfeeding mother, presented to Dr N, with a painful breast. Dr N diagnosed mastitis. Mrs D was wearing a penicillin allergy medic alert bracelet at the time, and advised the Commissioner that she told Dr N of her allergy (though Dr N disputed this). Dr N, who had not previously met Mrs D, acknowledged that he did not ask her whether she had any allergies before he prescribed her

Augmentin. Mrs D began the course of Augmentin as instructed and developed a headache, rash and severe vomiting, requiring medical treatment. She then rang the dispensing pharmacist, who confirmed that Augmentin should not be given to patients with a penicillin allergy. Dr N was found in breach of Right 4(2) of the Code for failing to check whether Mrs D had any medication allergies. Dr N responded that following this incident he had taken steps to ensure that all patient records include documentation of any medication allergies.

Internet medicine: better informed patients?

The availability of free medical information on the Internet has altered the power balance between patients and doctors forever. With the click of a mouse, patients can now access research findings that were previously confined to the quiet corridors of a medical library. Already more than half of all Internet users search the web for health information.¹⁶

On the positive side, health information on the Internet can contribute to well-informed patients who take greater responsibility for their own health. The Internet offers

an anonymous and non-threatening source of information, which can be particularly valuable for patients wanting to know more about sensitive subjects such as impotence, incontinence, or sexually transmitted infections. Consultations with web-based doctors, such as the New Zealand based Doctor Global, are increasing. Web-based support groups can offer invaluable support for patients with rare and/or chronic conditions (and the parents of such patients). Patients who have previously read up on their symptoms or illness on the net should be able to attend consultations with a good back-

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ground understanding, enabling more balanced and informed discussion. The Medical Council's website (www.mcnz.org.nz/registration) allows a patient with Internet access to quickly and easily check whether his or her doctor has vocational or general registration, and whether any conditions have been placed on the doctor's practice.

On the downside, there are serious problems with much of the health information available on the Internet, and many general practitioners have experienced a sinking feeling when they see a patient arriving at a consultation with a wad of paper downloaded from the Internet. In particular, there is too much hype, including anecdotal stories of miracle cures. The quality of information is variable, with many websites containing biased

or poor quality information that has not been scientifically evaluated. A recent review showed that many websites for mental health consumers are of particularly poor quality.¹⁷ Pharmaceutical companies are well aware of the power of the Internet as a medium for promoting their products, and the information on commercial websites should be interpreted with caution. Worst of all, much information on the Internet is simply wrong, and can lead patients to abandon life-

Few patients have been educated on how to critically assess the quality and relevance of health information

saving treatment or adopt risky alternative treatments. For example, the website www.virusmyth.net/aids denies that HIV is the cause of AIDS, and claims that most AIDS deaths are caused by poisonous medications such as AZT. Compounding these problems is the fact that few patients have been educated on how to critically assess the quality and relevance of health information.

The following case study is an example of the problems that can arise (for doctors and patients) when health information from the Internet is taken out of context.

CASE STUDY: Great expectations

F was born with congenital adrenal hyperplasia, a rare endocrine condition. His mother surfed health sites on the Internet and consulted with specialists in the United States, seeking a cure for her son's condition. Armed with mountains of information from the Internet, she approached her son's paediatrician, insisting that her son undergo inappropriate invasive investigations and be treated with medication that is not funded in New Zealand. When the paediatrician refused, the mother complained to the Health and Disability Commissioner. The matter was referred to an advocate in an attempt to assist

the mother and paediatrician to improve their communication, and address some of the mother's unrealistic expectations. The mother remains dissatisfied with the outcome and is seeking care from another paediatrician.

Patient responsibilities

While the Code does not explicitly set out patient responsibilities, rights and responsibilities are a two-way street, and patients as well as doctors have responsibilities in relation to the use of information technology. In particular, patients have the responsibility to act in good faith, treat their doctor with respect and consideration, share all relevant information, and comply with any agreed treatment plan.

Any person making a complaint about a doctor has a responsibility to be fair, truthful and accurate in making the complaint. Where a complaint is frivolous or vexatious or not made in good faith, the law allows the Commissioner to take no action on the complaint.

Conclusion

In summary, information technology offers both challenges and opportunities. As long as general practitioners and patients remain mindful of their rights and responsibilities, information technology can promote a more equal partnership between doctors and patients, and contribute to the quality of health care.

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