

FOREWORD

I approached my task of writing the *Foreword* to this book with considerable trepidation. I was concerned that the author had made the wrong selection – I have a fleeting appreciation of the complex issues covered in *Protecting Personal Health Information in Ireland: Law & Practice*, but no practical expertise with which to explore the vast canvas that Peter Lennon has so painstakingly created with erudition, skill and a customary attention to detail and scholarship.

However, having read the book, I can now discern a certain method in what might appear at first glance to be misguided judgment. I suspect he wanted to force his book upon a novice, such as me – after all, the health service, his ultimate readership, is staffed by such when it comes to issues of information technology law. Moreover, he may have known, or at least suspected (after working closely with me for some years on ways of forwarding electronic information between a teaching hospital and primary care), that whereas my enthusiasm for developing innovative ways of harnessing computer technology to halt the epidemic of cardiovascular disease was without question, there was a need for some education in a broader sense, if for no other reason than to temper enthusiasm with the restraint that is now inevitably and increasingly being imposed on all healthcare personnel by government in the interest of the individual in society.

If one seeks a point of commencement in *Protecting Personal Health Information in Ireland*, it has to be an appreciation of the right of the individual in society to that most precious ideal – the right to personal privacy and the right to be, within certain constraints, master of how that privilege is used and protected from abuse. All that follows, be it confidentiality, consent (implied, explicit but always informed and voluntary), security, use of databases, transfer of information, the definition and obligations of a data processor or data controller, anonymisation and pseudo-anonymisation, the intricacies of

establishing an unique identifier, data protection, data retention, freedom of information, or the need for data protection law and data commissioners to enforce those laws, all stem from the individual's right to privacy.

If we move from the starting point of privacy, we suddenly find ourselves having to grapple with the protection of privacy in a healthcare system in the throes of momentous change. Much of this change has little to do with information and communication technology, but an example illustrates the power of government to influence radically how we practice medicine. The closure of hospital beds in the 1980s was an act of political expediency that spawned today's crisis in the Accident & Emergency departments across the country. The way in which doctors practiced medicine had to adapt accordingly; if beds were not available, patients had to be discharged prematurely or inappropriately to make way for others with more acute problems. In the same way, but hopefully with more discussion and consideration, in protecting the right of the individual to privacy, government will influence traditional practice by forcing us to abandon, or at least adapt rather drastically, the traditional method of recording our consultations with patients. In passing, it is not untimely to admit that the old system was far from ideal – records scattered on shelves and floor (or in the boot of the consultant's car), illegible entries by numerous personnel, frequent failure to locate records, duplication of investigations because of inability to retrieve the original results, and inability to co-ordinate care, introduce safety alerts or perform even the most rudimentary audit of practice. This chaotic state of affairs has to end and while, on the one hand, we must be willing to embrace change, we must also be ever-cautious of the consequences of change. For example, who would think that the traditional method of taking a family history from a patient potentially could be compromised by the right to consent of a living family member about whom we are going to record (with the potential to disclose) sensitive personal details?

The significant use of the Internet by business and individuals in Ireland is consistent with the Government's public commitment to developing the Information Society by delivering public services over the Internet – what is known as eGovernment, of which eHealth is an integral part. But, and this is a big but, has the Government invested in

information technology in the healthcare system as have, for example, banks and businesses? The answer has to be a resounding “No!”. The budget for information technology for the current year for the Irish healthcare system is small by international comparison, especially with the UK. A recent major study on eHealth found that Ireland currently spends less on information and communication technology in healthcare than other comparable countries and than other economic sectors within the country, and recommended a significant increase in Government spending. If Ireland hopes to compete in the field of bioinformatics and, more importantly, if government is intent on transforming our health service radically, the newly-established Health Service Executive will have to persuade the Department of Finance to make a major investment in eHealth.

So who will be the beneficiaries of *Protecting Personal Health Information in Ireland: Law & Practice* or, put another way, who will read it and why? The answer is dependent quite simply on where you stand in the healthcare system. With the possible exception of our legislators, it is not a book that will be read from cover to cover, but a diverse corpus of personnel will find invaluable information within it for their individual needs. Administrators, be they officers in the Health Service Executive or the Department of Health & Children, must have the book within easy reach to ensure that they and their employees are acting within the law. The same consideration applies to the chief executives of all hospitals and many of their administrative personnel; to general practitioners, who constitute the core of the Irish health system – some 1,600 individual centres that effectively are independent private sector business entities, and who can be both data processors and controllers, have many obligations relating to consent, processing, and, importantly, security, that call for a knowledge of the subject as it pertains to them; to consultants, whose responsibilities may differ (as indeed is also the case in general practice) as between private and public patients, must be familiar with the data protection laws, disregard for which can be a criminal offence; to doctors, nurses and scientists involved in medical research; to members of ethics committees and statutory bodies, such as the Health Research Board, Science Foundation Ireland, the Irish Medicines Board and others; to sponsors and promoters of medical research, be they universities, bodies such as the Irish Heart Foundation or the Dublin Molecular

Medicine Centre, or indeed the pharmaceutical industry, who must be conversant with the pitfalls of misusing data in research; and one could go on. I suspect also that this book, which presents so much comparative national information demonstrating different approaches to privacy protection, will attract a substantial international readership.

I have said that this is a complex book dealing with a fundamental issue – personal privacy – from which arise a myriad of related topics, some of which have been resolved but many of which are under ongoing debate. Many of the problems within this discipline of health data management (it probably does now justify such categorisation) have been dealt with by the legislators in Ireland and the European Union. Many others, such as the need to obtain consent for recording the history of a living family member, are presently being studied. We can anticipate, therefore, that the rules governing the practice of medicine will change. We should be grateful to Peter Lennon for providing us with awareness as to where we are today – hopefully, he will continue to chart our passage into the future.

As a practicing doctor with a particular interest in research, I carry away two important messages that will guide my practice in both these areas in the future. First, regardless of what information I seek to hold electronically in my day-to-day practice, or propose to enter onto a database for future research, I will err on the side of caution by obtaining consent – explicit, where possible – from my patients. This may not be as difficult as might appear at first glance, if we adapt computer technology to assist us and remember that our patients are generally more than willing to comply with such requests, given that it will ultimately improve their management and treatment. Second, if I am in doubt, I will approach the Data Protection Commissioner for advice, simply because one of the recurring themes in *Protecting Personal Health Information in Ireland* has been the desire of successive Commissioners in this country, and also of those in other countries, to make the provision of healthcare more efficient and to facilitate and encourage research and audit so as to enhance scientific endeavour. This was expressed aptly by one Irish Commissioner, who urged that the data protection law should not be seen as:

"... an obstacle to progress, even if its prescriptions sometimes seem irksome to those enthused by what information technology can do. On the contrary, it exists to ensure that this technology is used properly and to create the climate of public confidence in which application of the technology can flourish."

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PROTECTING PERSONAL
HEALTH INFORMATION
IN IRELAND
LAW & PRACTICE

PETER LENNON

Dear Gin
Many thanks for all
your help.
Best Wishes
Peter Lennon



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