

Confidentiality:

a core feature of general practice

In the medical press in July 2010, Professors Pattison and Marshall ask *Is Confidentiality a Con?*¹ and repeatedly state that confidentiality of medical information is now 'a delusion'. The text makes it clear that Professor Pattison is a Professor of Religion, Ethics and Practice and a member of the RCGP Ethics Committee, and that Martin Marshall is Chairman of the Ethics Committee of the RCGP. It includes a disclaimer 'that this article does not represent the views of the College or of the Ethics Committee but is intended to provoke discussion'. In view of the high importance of the subject, the danger of patients being misled, and the request for discussion, a response is needed.

THE LAW

This article makes no reference to the law, which provides the framework for medical practice in the UK and which is the starting point for discussion of confidentiality in the modern world. There are many legal aspects. The Data Protection Act² which covers England, Scotland, and Wales, requires all those handling personal information to do so 'fairly and lawfully'. All general practices need to register under this Act, as the data which practices handle fall within the definition of this Act. 'Lawfully' includes acting within the Common Law. It is necessary to distinguish corporate and professional confidentiality.

The common law duty of confidentiality³ applies in all parts of the UK. This provides protection for patients against disclosure of information given to their doctors and nurses. This position is important to all patients and all practising doctors. Patients have rights and while it is obviously for patients to decide how much to tell the doctor, anything that they do decide to say within a medical consultation to a doctor is confidential. The law both protects patients and empowers them. The authors imply that doctors can somehow decide what information to disclose. This is not so.

There are a very small number of

exceptions which arise from public interest for example: the statutory notification of a few diseases; the investigation of some serious crimes; and, if Section 251 has been recommended by the Ethics and Confidentiality Committee of the National Information Governance Board, a small number of nationally-approved research studies. All such exceptions put together are still very rare and affect only a tiny number of the over 250 million general practice consultations which take place each year.

Pattison and Marshall¹ write that the present system is 'leaky and incoherent' but offer no evidence of this as far as general practice in Britain is concerned. On the contrary, there is widespread trust in doctors who are the most trusted of all professions.⁴

Family doctors are expected to keep confidences and do so. Breaches of confidentiality by GPs and their teams are remarkably rare. Complaints to the NHS or the GMC, or legal action against doctors on the basis of an alleged breach of confidentiality are also extremely rare. GPs and their teams can take great pride that, despite the real and increasing complexities of modern medical practice to which Pattison and Marshall rightly refer, they are still upholding the law, medical ethics, and maintaining the trust of their patients.

The authors make much of the fact that other organisations such as credit agencies, Facebook, and also Tesco now hold much personal data about people. This is true, but is not the point. First, much permission to use financial information has been signed away in writing, for example on mortgage applications, more than people often remember. Facebook use is voluntary. However, the main point is that credit agencies, Facebook, and Tesco do not operate under the same common law duty as medical practice — nor do many of us want to be equated in that way.

The authors are right that in a tiny number of cases, special investigators have lied to

and tricked some health staff into letting them have confidential health information. This is not a common problem and such actions are always improper and usually illegal. They form no basis for developing national policy.

PRINCIPLES OF MEDICAL ETHICS

The first ethical principle is to respect the autonomy of the patient. This means informing the patient properly, respecting the patient, and obtaining consent if disclosure of information is contemplated. Every day GPs rightly require the written consent of the patient before completing insurance forms.

Other core principles of medical ethics include non-maleficence (see later) and justice which includes respecting rights, including the Right to Privacy.⁵ Obtaining consent is the usual method of doing this.

POLICY IN THE NHS

In addition to the law and ethical principles, policy in the NHS is important as most general practice takes place in the NHS. The Ministerial Guarantee issued by Government Ministers in the Department of Health and later renamed The NHS Care Record⁶ Guarantee is clear and states that in the NHS '... We have a duty to keep records about you confidential ...' and '... We will allow only those involved with your care to access your records unless you give your consent'.

PRACTICAL ISSUES

Practical issues are relevant. Asking sensitive questions is a great skill and an integral part of general practice. For example, asking depressed patients if they have ever considered killing themselves is an accepted component of good care but is hardly practical if the doctor is simultaneously telling the patient about the 'reality of non confidentiality'.

Sensitive questions and answers about sexual activity are also covered by other

COMMENTARY

Sir Denis is quite right in saying that confidentiality is the cornerstone of general practice. General practice is still a relationship-based profession and confidentiality allows patients to say things they would not, could not say anywhere else. The idea that these deep secrets may be available on Facebook would ruin the doctor–patient relationship instantly. He is also quite right in saying that ‘We will allow only those involved in your care to access your records unless you give your consent’. So what is the problem?

The problem is outlined by Professors Pattison and Marshall in their *RCGP News* article.¹ We GPs are sharing more and more patient data with more and more people. One of the great complaints about the NHS is the lack of communication between different carers, especially primary and secondary care. General practice is highly computerised, secondary care is catching up and we now have the technology to share as much data as we care to store electronically.

The problem is that we have decided that presumed consent is the same as consent and that you have to opt out of having your data shared rather than opt in. As a GP I regularly send a computer summary print out when sending patients into hospital; my electronic referrals automatically carry the patient summary with them; the Emergency Care Summary (Summary Care Record in England) is regularly shared with out-of-hours doctors and nurses as well as A&E staff and pharmacists and many more people are applying for access to that data. All this is done in the name of patient protection and better communication. It is possible to access 100 000s of patients’ lab and X-ray records from nearly every ward in my health board via a system called Sci Store. This data is less and less secure, the potential for a breach of confidentiality rising exponentially. The Professors would appear to have a point.

However Sir Denis may not have to worry too much. Even though we have the technology and we are not afraid to use it, the information which really matters, those deep secrets, those consultations which cannot be measured, but are the essence of our work, these consultations are rarely recorded. We use coded language or simply do not record them. We may record everything we need for the QOF, but the really important stuff is stored in our heads not on hard discs.

So although our profession is changing with the new technology and it will throw up a lot of new problems as well as solutions, it will rarely touch the most important part. There is no computer programme yet which can replace the human, humane relationship which powers our consultations. That relationship gives a depth of trust which allows our patients to let themselves be healed. That personal interaction is not programmable and will always be confidential between a patient and their doctor.

Chris Johnstone

REFERENCE

1. Pattison S, Marshall M. Is Confidentiality a Con? *RCGP News* 2010; July: 4. http://www.rcgp.org.uk/pdf/RCGP_News_July10.pdf (accessed 13 Sep 2010).

DOI: 10.3399/bjgp10X532486

laws, for example, the Venereal Disease Acts of 1917 and 1974 cover doctors in both general and hospital practice, and require confidentiality. Staff of NHS trusts, including staff of primary care trusts, are also covered by this law. The Human Fertilisation and Embryology Act 2008 also covers some identifiable information.

POTENTIALLY HARMFUL TO PATIENTS

One of the core ethical principles is non-maleficence, that is, not to do harm to patients. This doctor-centred article,¹ published in the medical press from two prestigious authors may mislead and worry patients, especially those who read it via one of the approximately 2000 patient groups now associated with British general practices.

Repeatedly stating that they consider

confidentiality of information in general practice is now a ‘delusion’, may worry the thousands of people who have already disclosed sensitive information to their personal doctors believing it to be in confidence. It may also act to deter other patients from speaking frankly to their doctors.

Patients often come to GPs in distress, and unburdening themselves can be, and often is, therapeutic. This response seeks to support such patients and to assure them that their legal, ethical, and ministerial safeguards remain in place.

WIDER ASPECTS OF CONFIDENTIALITY — HISTORY, INTERNATIONAL, AND COLLEAGUES

Pattison and Marshall write from a narrow viewpoint. They may find it helpful to reflect

on the history of medical confidentiality which goes back at least to Hippocrates. A principle which has survived 2000 years and been added to over time by legislation in numerous countries is not to be taken lightly.

Nor is this just a GP or a British issue. The Human Rights Act of 1998 brought into UK law the principles of the European Convention on Human Rights, some of which, such as the Right to Privacy (Article 8) are directly relevant. Confidentiality of medical information is accepted not just across Europe, but around the free world.

Thirdly, the legal and ethical principles on the confidentiality of medical information do not just apply to doctors. They cover nurses, dentists, and all health professionals too. A dentist has been struck off the Dental Register for a breach of confidential medical information.

HUMAN RELATIONSHIPS

Finally, confidentiality is a feature of important human relationships. We confide in family, friends, especially longstanding ones, and trusted professional advisers, especially doctors. The key is trust. Doctors trust patients to tell the truth and patients trust doctors to be competent, and, for example, to prescribe appropriately. Patients take tablets on trust.

Confidentiality is associated with trust in human relationships. In general practice, the development of trust by patients in their doctors has been shown to be associated with continuity of GP care in both the UK and the US.⁷

Pattison and Marshall conclude that 'widely sharing information may well not damage the patient-doctor relationship.

Indeed it should deepen and clarify it.' I believe the opposite.

If patients cannot trust their personal doctors to keep their confidences, they may not trust them at all.

Denis Pereira Gray

Competing interests

Sir Denis Pereira Gray is Vice Chairman of the Ethics and Confidentiality Committee of the National Information Governance Board and Patron of the National Association for Patient Participation.

REFERENCES

1. Pattison S, Marshall M. Is Confidentiality a Con? *RCGP News* 2010; **July**: 4. http://www.rcgp.org.uk/pdf/RCGP_News_July10.pdf (accessed 13 Sep 2010).
2. The National Archives. Legislation.gov.uk. Data Protection Act 1998.

<http://www.legislation.gov.uk/ukpga/1998/29/contents> (accessed 7 Sep 2010).

3. The National Archives, Department of Health. The Common Law Duty of confidentiality. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/browsable/DH_5803173 (accessed 14 Sep 2010).
4. IPSOS MORI. *Public trust in doctors is still high*. London, IPSOS MORI, 2006. <http://mori-eire.com/researchpublications/researcharchive/poll.aspx?oltemId=371> (accessed 7 Sep 2010).
5. Gillon R. Medical ethics: four principles plus attention to scope. *BMJ* 1994; **309**: 184–189.
6. National Information Governance Board for Health and Social Care (NIGB). *The NHS Care Record Guarantee: our guarantee for nhs care records in England*. <http://www.nigb.nhs.uk/guarantee/2009-nhs-crg.pdf> (accessed 7 Sep 2010).
7. Mainous AG III, Baker R Love M, *et al*. Continuity of care and trust in one's physician. Evidence from primary care in the United States and the United Kingdom. *Fam Med* 2001; **33**(1): 22–27.

DOI:10.3399/bjgp10X532477

COMMENTARY

There are two circumstances when I might want to share my medical information: to improve my own care or to improve everyone's care through better planned, efficient services.

England's roll out of the Summary Care Record managed to mix these two up with disastrous results: people think they have agreed to a small, unexceptional subset of their data being uploaded to the spine so that should they have a heart attack while on holiday everyone can see that they are diabetic or allergic to penicillin. But buried in the consent are words that allow any other information as agreed by the NHS alone to be uploaded.

The state pressed for this blank cheque because, to plan services, it needs to know my blood pressure, total cholesterol, and smoking status regardless of whether I actually have coronary heart disease. In short it needs accurate denominators as well as accurate numerators. 'Pseudo-anonymisation' is supposed to hide my personal identity in this process but is being increasingly questioned. As people come to understand that the NHS spine potentially knows about their divorce, alcohol status, stress incontinence, erectile dysfunction, or depression they will begin to object. As more and more opt out and refuse to share their data, denominator accuracy will degrade and its usefulness will decline.

Supposing we settled for just that first, sensible, limited subset of data — could we make that secure? For this we need to:

- Give up the dream that we can improve everyone's health by sharing everyone's data using pseudo-anonymisation.
- Agree a small set of data that will clearly improve everyone's individual care if shared between clinicians. And that does as little violence to the person as possible if it does happen to become more widely known.
- Tighten up the legal and technical regimes to make sure that this limited sharing is widely understood and cannot be lawfully or technically exceeded without significant pain.
- Allow people to easily opt out of even this limited sharing if they wish.
- Proceed on the basis that patients are the owners (although not the authors) of their own records and routinely make sure they can see and comment on what we write.

Confidentiality is both essential and defensible. So is sharing of limited, agreed subsets of key data. Legal and technical regimes are essential in balancing these conflicting goods. No matter that from time to time these regimes will be breached just as they always have been. When such breakdowns do occur then having our patients own their own records will form a final, 21st century bulwark around mutual trust because they will have taken as much responsibility for the record as us. And along the way patient ownership of the digital record is likely to lead to better, more useful records.

Paul Hodgkin

DOI: 10.3399/bjgp10X532495