

## Consultants' and patients' views about patient access to their general practice records

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### Summary

Semi-structured interviews were conducted with 24 hospital consultants and 47 general practice patients, asking for their opinions about a proposed policy of partial access to records in one general practice. Eleven consultants were opposed to the policy, 10 were in favour and three were classified as ambivalent. Arguments against access were couched largely in terms of consultants' own interests whereas arguments in favour of access were couched in terms of patients' interests. Although 81% of patients interviewed said that they should in principle be allowed to see their own records, only 51% wanted access to their own records. Fears expressed by consultants on patients' behalf are not necessarily well founded.

### Introduction

The Data Protection Act of 1984 gave individuals access to personal information about themselves held on computer. The question of whether or not this access would include medical data was debated at great length in the period leading up to the final implementation of the Act in November 1987. In 1983 an Inter Professional Working Group on Access to Personal Health Information, chaired by Sir Douglas Black, recommended in favour of partial access to medical records. The Department of Health and Social Security issued a consultation paper in 1985 which also recommended modified access. In 1986 it was decided to give access to computerized health records, subject to safeguards for those patients who might be harmed.

Since the implementation of the Data Protection Act, a Private Member's Bill giving patients the right to see medical reports about them prepared for employers or insurance companies, came into force as the Access to Medical Reports Act in January 1989<sup>1</sup>. A non-statutory code of practice giving patients access to manual records was issued for consultation by the Department of Health in May 1989, and this allowed health professionals to withhold information likely to cause serious risk of harm to the patient or which would identify another person. Mr Roger Freeman, the Parliamentary Under Secretary of State told the Commons that the code was a compromise between removing obstacles to patient access and legitimate medical concern about the implications for patient care. The *BMJ* stated that 'the new code is based on the presumption that patients are entitled to be adequately informed about their condition and treatment'<sup>2</sup>. However, in March 1990 the attempt to introduce a voluntary code was

abandoned, and Mr Freeman told the Commons that the government accepted the need for legislation. The Access to Health Records Bill has now been passed and comes into force on 1 November 1991. The Act will allow access to manually held health records unless this is likely to cause serious harm to the patient or if it would identify another person who had supplied information in confidence. The medical profession has been split on this issue: in 1986 general practitioners (as represented by the BMA General Medical Services Committee) decided to support patient access whereas hospital consultants (as represented by the Central Committee for Hospital Medical Services) called for the exemption of medical records from the provision of the Data Protection Act.

There are certain groups of patients who already have access to their medical records. Some general practitioners allow patients access to their GP records as a matter of course<sup>3,4</sup>. Pregnant women have been allowed to carry their own maternity records in some hospitals<sup>1,5</sup>.

The aim of this paper is to explore the views of both patients and hospital consultants towards patient access to general practice records.

### Method

Consultants listed as members of one hospital's Medical and Surgical Officers Committee were stratified into their 10 specialties. Those with purely academic appointments were excluded as were those based on sites other than the main site. A random one in three sample was then taken from each specialty. If a consultant in a particular specialty was unable to take part, one of the remaining consultants from that specialty not originally selected was picked at random. Out of 29 consultants chosen, it was possible to interview 24. The final sample consisted of two psychiatrists, one paediatrician, seven consultants in medicine, five surgeons, one dermatologist, three ophthalmologists, one ENT consultant, one genitourinary consultant, two gynaecologists and one consultant in oncology/radiotherapy. Three of these consultants refused to allow the interviewer to audiotape the interview and in one case the tape recorder failed to work. The analysis of consultants' data is therefore based on 20 audiotape recordings and four written synopses of interviews conducted in 1988.

Semi-structured interviews were held with these consultants, asking for their opinions about a proposed policy of partial access to records in one local general practice. The proposed policy allowed for the removal from the records of material thought to be potentially harmful by the general practitioner.

Consultants were asked to comment on the advantages and disadvantages from the patients' point of view and from their own point of view. They were asked if there were any particular kinds of patients who should or should not have access and whether there were any particular types of information that patients should or should not have access to.

All 24 consultants were classified according to whether or not they were in favour of the implementation of the proposed policy of patient access. Independent classifications were made by at least two members of the study team listening to each audio tape, and there were no disagreements. Consultants' views were not necessarily taken at face value. For example, four of them stated at the beginning of the interview that they had no objections to the proposed policy but in the course of the interview raised so many difficulties that it was clear that they did oppose the idea. These consultants were classified as being against the policy. There were no consultants who stated initially that they opposed the policy but who were subsequently classified as being in favour of it.

The patient sample was drawn from a group practice situated in the London Borough of Lambeth. Fifty patients were selected for interview from those attending the practice in the week beginning 13 June 1988. A random sample was taken which excluded temporary residents and those under the age of 16 years and which was stratified by the day of the week and by the patient's own (registered) doctor. Those patients who could not be contacted in time were replaced by other patients seeing the same doctor that week, with two exceptions. One patient who was also a doctor was excluded, leaving a final sample size of 47. Patients were interviewed at home. The interviews were semi-structured and patients were asked for their views on patient access to medical records and some questions about communication with their doctor. Data analysis is based on audiotapes of the interviews and on the interviewer's notes. Data from the records of the selected patients were coded onto an extraction sheet, including age, sex, date of registration with the practice and number of consultations in the past year. The general practitioners had drawn up a list of 14 diagnostic categories which they considered might distress a patient reading their records, and the presence of these sensitive data was also recorded on the extraction sheets. The interviewer was not aware which patients had sensitive information in their records.

## Results

Eleven consultants were opposed to the policy, 10 were in favour and three consultants were classified as ambivalent. Three of the consultants whose interviews were not taped were against the policy and one was classified as ambivalent. Of those in favour of access all except one supported some restrictions to access whereby the GP would be at liberty to remove material thought unsuitable for the patients' eyes. Only one consultant supported the idea of unrestricted access to records.

The arguments advanced against giving patients access to their notes fell into two main categories: those to do with patients' interests and those to do with consultants' own interests. In the first category it was argued that patients would be upset by what they read and numerous examples were given of the

ways in which this might happen. It was also argued by most of the consultants (not always as a justification for denying access) that patients would misinterpret what they read because they were unfamiliar with medical terminology. A few consultants made reference to the derogatory language in which other doctors sometimes referred to their patients, particularly (it was claimed) in the past. It was also argued that patients do not want to know the truth and that access should be withheld for this reason.

In the second category of arguments against access it was asserted that patient access would affect the content of letters written by consultants to GPs. Consultants said that they would have to omit some of what was currently included in their letters and some said that two sets of files would have to be kept. Some spoke of the need to convey information that is not hard and fast but to some degree speculative, and argued that patient access would make this more difficult. The fact that doctors like to maintain a private dialogue between themselves and that notes are only intended for doctors was also used as an argument against access. Some thought that it might spoil the relationship between GP and consultant. It was felt that previous letters written in confidence between doctors who had no idea that patients might be shown them should not be made available. Some consultants felt that they would lose control of the diagnostic process and that the management of illness would also be out of their hands. Others said that it would affect treatment. Many spoke of the need to give patients information at the correct time and felt that patient access would interfere with their control of the timing of information giving. The implications for workload were mentioned: that the vetting of records would be time consuming and administratively difficult for GPs and that consultants would have to remember which GPs gave access and which GPs did not. Some mentioned the possibility of litigation arising from patient access, and others foresaw patients using access as a means of canvassing opinions from several different doctors.

A few arguments were advanced which did not fit clearly into the categories of patients' interests or consultants' interests. The most common of these was the problem of third party information. It was also argued that access was unnecessary given a reasonable doctor-patient relationship and that it could damage this relationship. Some consultants said that patients who asked to see their notes were the ones who had problems anyway. Another argument claimed that to show patients their notes was an abdication of doctors' responsibility. Consultants both for and against the policy said that if the notes were being vetted first, then patients were not really being given access.

The arguments advanced in favour of giving patients access to their notes focused mainly on patients' interests. Some consultants argued that patients have the right to see their own records and that patients should have as much information as possible. It was argued that patients would understand their illness and treatment better and that access would help patients remember what had been done. Some said that access would help patients cope better and that those patients who worried would be reassured. It was felt that patients would be better prepared for the consultation and would be better able

to ask appropriate questions. Several consultants said that access would improve doctor-patient communication by creating a more open relationship and that patients would believe what the doctor had been telling them was the truth.

A second set of comments related to the practice of medicine and particularly the issue of letter-writing. Consultants in favour of access felt that it would improve the quality of letters and would bring about changes in practice which would benefit the patient, as doctors would have to be more careful in what they wrote. A third set of comments related to treatment. It was argued by some that adherence to treatment regimes would be improved and that access would particularly benefit those patients with chronic illness whose own participation was vital. Some argued that access would help to recruit the patients' own resources to the task of therapy.

Interviews were obtained with 47 patients between the ages of 16 and 80 years, 68% of whom were women. The great majority, 81%, of patients answered yes when asked 'do you think that, in principle, all patients should be allowed to see their own records?' (see Table 1). Only 4% said that patients should not be allowed access and the remaining 15% were unsure or did not know. While the principle of patient access to notes was largely supported, when it came to seeing their own records only a little over half (51%) answered yes when asked 'would you yourself like the opportunity to read your own records?' A substantial proportion (26%) gave qualified agreement, saying that they would only like access if it was actually being offered to them by their doctor. The main reasons that patients gave for wanting to see their own records were general curiosity and to check that the doctor had not made a mistake. The patients who were definite about seeing their own notes also said that it would improve their understanding and refresh their memories, that they had a right to see their own notes and that the notes concerned them as it was their health and their bodies. Several people said that if they did see their notes, they would want to discuss them with their doctor afterwards. Some said that they wanted to look at their notes in order to read about a specific incident in the past. When asked about the effects of reading their notes, over two-thirds of those interviewed said that it would not affect their relationship with their doctor nor the type of care received. As regards knowledge of their own

Table 1. The relationship between the view that in principle patients should have access to their records and their actual desire to do so

	Patients' desire to see own records				Total
	Yes	If offered	No	Don't know	
Patients should have access	23	11	3	1	38 (81%)
Patients should not have access	0	0	1	1	2 (4%)
Don't know	1	1	4	1	7 (15%)
Total	24 (51%)	12 (25%)	8 (17%)	3 (6%)	47

health, 45% said it would be improved as a result and 40% said it would make no difference. Asked about the effect on the quality of the records, 38% said it would have no effect and 21% said that doctors would have to be more careful. The reasons given by those patients who did not want to see their own records were that they trusted their doctor, they were not interested, that it would worry or frighten them, and that they would not understand what was written.

It was argued by some of the consultants that those patients who asked to see their records would be an atypical group. The data were examined to see if those patients who definitely wanted to see their own records differed from the remaining patients on a number of variables (Table 2). Patients who said that they definitely wanted to see their records were more likely to have educational qualifications, to have been registered with the practice for less than 5 years and to be owner occupiers. There was a suggestion that patients who were low consulters, who had sensitive items in their notes, and who were younger were more likely to want to see their notes, but these relationships were not statistically significant.

### Discussion

This paper has explored the attitudes of consultants at one hospital and patients registered with one nearby practice in order to see how these relate to each other. The results may not be generalizable to other hospitals or practices.

Table 2. Relationships between patients' desire to see their own records and other patient characteristics

Patients' desire to see own records	Educational qualifications*		Years registered with practice*				Sensitivity of notes		Number of consultations in previous years		Age		Total
	None	Some	1-4 years	5 years or more	Owner occupiers	Tenants	Not sensitive	Sensitive	<5	>5	<35	>35	
Yes	10 36%	14 74%	12 75%	12 39%	9 82%	15 42%	13 45%	11 61%	21 58%	3 27%	14 67%	10 38%	24
If offered, no and don't know n=100%	18 64%	5 26%	4 25%	19 61%	2 18%	21 58%	16 55%	7 39%	15 42%	8 73%	7 33%	16 62%	23
	28	19	16	31	11	36	29	18	36	11	21	26	47

\* $P < 0.02$

Arguments against access were couched largely in terms of consultants own interests whereas arguments in favour of access were couched in terms of patients' interests. Of the arguments against access that were to do with consultants' interests, several were acknowledged by those in favour of access. For instance it was acknowledged that patient access would alter the way in which letters were written, but those in favour argued that this was to the patients' benefit and therefore a potential advantage. The threat of litigation was seen as an argument against access by some, but others described ways in which litigation could be avoided. Thus not all of the arguments put forward against access were accepted as such by all consultants.

It is possible from the data reported in this paper to ascertain the extent to which arguments against access which cited the patients' interests were referred to by the patients. The two sets of reasons which were echoed most strongly were those to do with the trust between patient and doctor, and the fact that some patients felt that they would be frightened or worried by what they saw in the notes. Both of these were given as reasons why patients did not want to see their notes. Consultants opposed to access argued that access would upset patients whereas consultants in favour of access said that if patients did not want to know they would not ask to see their notes. From the patients' accounts it appeared that patients would exclude themselves if they felt anxious or worried, and therefore that the latter argument had some validity. Half of those not wanting to see their notes cited the fact that they trusted the doctor, which corroborates those consultants who claimed that access to notes was not necessary given a good doctor-patient relationship. The corollary of this argument is that people who want access to their notes do not have a good relationship with their doctor. But in fact those reporting fair or poor communication with their GP were no more likely to want to see their records than those reporting good communication.

Not surprisingly patients did not refer to the possibility of misinterpretation, although not understanding what was written was given as a reason for not wanting to see the records. Consultants opposed

to access claimed that patients do not want to know the truth and it may be that when patients say that they are not interested in seeing their notes, it is because they do not want to know. It was not possible to explore the claim that difficult patients would ask to see their notes, but those with sensitive records were not significantly more likely to want to have access.

There was also mutual corroboration between consultants' reasons in favour of access and patients' reasons for wanting to see their notes. These reasons included access as a way of improving patients' understanding of their condition and treatment, and as a way of finding out exactly what was wrong with them. Consultants and patients both said that patients had a right to see their records and that access was appropriate as it was patients' health and bodies which were being written about.

In summary the results of the study suggest that between half and three-quarters of patients would want to see their own notes, depending on how the offer was actually made. Arguments against access given by consultants opposed to the policy were not accepted as such by all the consultants interviewed. The patient data suggest that fears expressed on patients' behalf are not necessarily well founded.

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