

Patients' knowledge and expectations of confidentiality in primary health care: a quantitative study

THE BOLTON RESEARCH GROUP

SUMMARY

Patients and health professionals differ in their understanding of the meaning of confidentiality. We investigated this by sending a postal questionnaire to 1000 patients asking their opinions on who does and who should have access to their medical records. Analysis of 756 replies showed that patients have clear opinions as to who should have access to their records, with a substantial minority wishing to restrict it.

Keywords: confidentiality; patient attitudes; medical records.

Introduction

CONFIDENTIALITY is perceived to be at the heart of the consultation, since it is thought to allow the patient to be open and frank with the doctor.¹ The principle of confidentiality has been reaffirmed as fundamental by the World Medical Association's *Declaration of Geneva*² and the United Kingdom (UK) General Medical Council publication *Confidentiality*.³

However, it has become apparent that there may be a discrepancy between the patient's understanding of confidentiality and that of the doctor. Carmen and Britten⁴ indicated that there is still a divergence between patients and professionals: in their qualitative study, patients were generally not aware that practice staff had access to their records and some even had concerns about other doctors' access. Our study was designed to add a quantitative dimension to their findings, from another part of the UK, by determining the extent of patients' knowledge about access to patient records and one aspect of confidentiality, and to establish patients' preferences.

Method

The study was carried out in 1998 in Bolton, Greater Manchester, in six different group practices by 10 general practitioners (GPs). A questionnaire was developed to ascertain from patients which members of the primary health care team (PHCT) and clerical staff currently do, and which should be able to, read or discuss their medical records. A pilot study was undertaken involving 10 patients from each practice and no changes were made. Computer-generated random lists of 100 patients over the age of 16 years were produced for each participating GP. The questionnaire, an explanatory letter, and a stamped addressed

envelope were posted to each patient and non-responders were sent a reminder after four weeks. Each GP sent out 100 questionnaires (total 1000) and patients were free to add comments.

Results

Eight hundred and sixteen replies were received (82% response rate). Returns that omitted age or sex, or had uninterpretable responses, were excluded from analysis. Seven hundred and fifty-six valid returns were analysed. A clear demonstration of consensus was seen in answer to the questions covering whether the patient's usual doctor does, and should, read and discuss their records (Table 1).

Views about access by the other health professionals showed a lower level of acceptability. Most patients believe that only the doctors and the practice nurse currently have access to their records. However, almost 50% of patients believe that other health care professionals should have access to at least part of their records. Only 27% of women over 55 years of age indicated that midwives should have access to their medical records, in contrast to those under 55 years of age where 60% were happy for midwives to have access. Seventy-five per cent of men believed that the midwife does not, and should not, have access to their records: 'As a personal situation changes so would who I expect to have access to medical records' (Patient number 362).

There was a high level of consensus on the questions about office and reception staff. Five hundred and nineteen (68%) patients felt that they should have no access and a further 110 (14%) agreed to only partial access.

Discussion

Responders believe that few professionals have access to their records but indicated that other people should have access if required. Our results suggest that the responses reflect the views of patients in their current circumstances. Many patients commented that professionals involved in their treatment should have access to their records and assume that the GP will adopt a gate-keeping role for access by these other groups. 'One trusts one's own doctor to determine those who need to be briefed on part or all of the patient's records' (Patient number 348); and, 'Those using their particular skills should be allowed access to a patient's medical record but only at the discretion of the patient's doctor' (Patient number 351). Our results show that many patients would have significant reservations about sharing information at open PHCT meetings.

Most patients thought that reception and office staff do not, and should not, have access to medical records. These staff have the opportunity to read the medical records, though one patient commented: 'I doubt if they have time to.' Patients often make enquiries of the reception staff. We assume that on these occasions this gives consent for the receptionist to open the medical records rather than simply handle them blindly. Perhaps our questionnaire was understood to imply a freer access than this since only 20% of patients thought receptionists should read or discuss their notes.

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Table 1. Positive responses to the questionnaire.

PHCT member	Does have access		Should have access (all)		Should have access (part)	
	Yes	Percentage (95% CI)	Yes	Percentage (95% CI)	Yes	Percentage (95% CI)
The doctor you usually see	717	94.8 (93.2–96.4)	739	97.8 (96.8–98.8)	10	1.3 (0.5–2.1)
Other doctors in the practice	574	75.9 (72.9–78.9)	637	84.3 (81.7–86.9)	73	9.7 (7.6–11.8)
Practice nurse	326	43.1 (39.6–46.6)	256	33.9 (30.6–37.2)	299	39.6 (36.2–43.1)
District nurse	108	14.3 (11.8–16.8)	140	18.5 (15.8–21.2)	276	36.5 (33.1–39.9)
Health visitor	99	13.1 (10.7–15.5)	108	14.3 (11.8–16.8)	252	33.3 (30–36.6)
Midwife	102	13.5 (11.1–15.9)	111	14.7 (12.2–17.2)	168	22.2 (19.3–25.1)
Physiotherapist/occupational therapist	93	12.3 (10–14.6)	85	11.2 (9–13.4)	280	37 (33.6–40.4)
Mental health workers	95	12.6 (10.3–15)	133	17.6 (14.9–20.3)	228	30.2 (27–33.4)
Reception/office staff	113	14.9 (12.4–17.4)	40	5.3 (3.7–6.9)	110	14.6 (12.1–17.9)

Rigby *et al*⁵ suggested that centrally held records accessible to the extended PHCT are the way forward to provide well-integrated care but that this would only be permissible with 'the explicit consent of the patient'. Given the opinions expressed by patients about access to their records by members of the PHCT, the sharing of confidential information on NHSnet is likely to give them considerable cause for concern, a view already expressed by Keeley.⁶ It is uncertain that even the concept of 'Caldicott Guardians'⁷ would reassure patients and they may be less likely to confide in their doctors if confidentiality is no longer assured.

References

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