

Censoring of patient-held records by doctors

R.B. JONES, PhD

A.J. HEDLEY, FRCP

S.P. ALLISON, FRCP

R.B. TATTERSALL, FRCP

SUMMARY. *Computer-held information is increasingly shared between general practice and hospitals and with the provisions of the Data Protection Act now in operation, the practical issues of disclosure to patients need to be reviewed. Patients attending diabetic clinics at University Hospital, Nottingham, are routinely issued with a copy of their computer-held record but a previous study showed a high level of censoring by the hospital doctors. This paper reports a review of a sample of 251 censored records, containing 426 problems, whereby the doctors concerned provided reasons for the censoring and restored information they thought suitable. After the review, only 8% of censored problems, that is 1% of all problems, remained censored. An additional 2% of all problems were deleted from the patient's copy at the request of the patient. It is essential that systems which allow censoring of patient records have continuous built-in audit to monitor the reasons for censoring.*

Introduction

THE provisions of the Data Protection Act came into operation on 11 November 1987. On this date individuals gained the right to seek access to any computer-held personal data and be provided with a copy within 40 days. An order, under section 29(1) of the act, will probably allow information to be withheld if it could cause serious harm or distress to the patient. The details of such procedures will only become clear as we gain experience in interpretation of the Act, yet clinicians holding medical histories on computer urgently need to review the practical issues of how information should be disclosed and what information, if any, they would wish to withhold. The increasing use of computers in general practice makes this an issue to be considered by all general practitioners.

Sheldon¹ has reported a study in which 244 patients in a practice in north Oxfordshire were to be given a copy of their computer-held medical record. Ten problems, which included 'attempted suicide', 'abortion' and 'adopted child', were always censored (23 patients) and a further 11 patients (18% in total) had records censored. For a variety of reasons another 19 (8%) patients were not given their record.

Shared care schemes for the treatment of chronic conditions such as diabetes and hypertension are becoming increasingly common and often involve the issue of a record to patients and the sharing of records between hospital and general practice.²⁻⁴ Censored records which are issued by hospitals to patients put

the general practitioner in an awkward position if he or she does not know which problems have been withheld from the patient's record and the reasons for non-disclosure.

Diabetic clinics at University Hospital, Nottingham, are supported by a register and information system which allows a wide range of clinical information to be collected and presented in structured medical records.² Facsimiles of the hospital record are issued to general practitioners. Records were first issued to patients on an experimental basis in 1979⁵ and have been routinely issued to all patients since 1982. The system allows certain problems to be deleted from the patient's copy at the discretion of the clinic doctor or at the request of the patient. An earlier study showed that censoring of information was surprisingly high (13% of all problems) and included many organic medical conditions.⁶ There were no obvious reasons why problems had been deleted and yet nearly all the censored problems had been actively censored and not lost through failure to complete the record.⁶ We report here a review of a sample of the patients' records where problems had been censored by the doctors.

Method

At the time of the study 1002 patients out of 2346 attending the clinic (43%) had one or more problems censored from their copy of the medical record. The study sample comprised 251 consecutive patients who had censored records. The hospital doctors were asked to review each of the censored records, provide reasons for the censoring and, where they considered it suitable, restore the censored information to the patient's record.

Results

There were no differences between the sample and the whole group with censored records in age (20 year age bands), gender, treatment type (insulin; tablet; diet), duration of diabetes (10 year age bands) or periods over which the patient had held their own copy of the medical record (12 month intervals).

The 251 patients had a total of 426 problems censored from their records. After the review 295 of the censored problems (69%), involving 170 patients, were reinstated. The problems reinstated included virtually all the organic medical problems that had been censored and many social, psychological and family problems. Thirty one of the censored problems (7%) were deleted from the main record, including problems that were no longer active and not sufficiently important to be retained, incorrect problem descriptions, revised opinions by the doctor and irrelevant entries.

Only 34 problems (8%) remained censored on the records of 19 patients. These concerned comments about the personality of the patient, the patient's mental health or handicap, relatives' health or hereditary disease, criminal record, intelligence and educational attainment, compliance with therapy, marital problems, sexual performance or sexually transmitted diseases. Two patients still had the problem 'overweight' censored. A further 66 problems (15%) were problems known to the patients which did not appear on the patient's record at their own request. These problems included impotence, self-poisoning, mental health and marital problems and information on social status such as 'living alone'.

Discussion

In the original audit of patient-held records⁶ we found a high level of censoring by the doctors at the diabetic clinic and this

R.B. Jones, Lecturer in Medical Information Science, and A.J. Hedley, Professor of Public Health, Department of Community Medicine, University of Glasgow; S.P. Allison, Consultant Physician, and R.B. Tattersall, Consultant Physician, University Hospital, Nottingham.

© *Journal of the Royal College of General Practitioners*, 1988, 38, 117-118.

included many organic medical problems. As a result of the review reported here, the majority of these problems were either reinstated on the patient's record or deleted altogether. Only 8% of this sample of censored records remained censored by the doctors and, extrapolating from the original audit where 13% of all problems were found to be censored, we could conclude that only about 1% of all problems may need to be censored. A further 15% remained censored at the request of the patient, which is approximately 2% of all problems.

Virtually all the organic medical problems that had been censored were reinstated. The precise reasons for the initial censoring were difficult to identify in retrospect but two factors appear to be important. First, the original censoring often occurred when the patient was seen by a junior doctor who may not have had sufficient confidence to disclose several problems and include them on the patient's record. Secondly, we believe that the doctors seeing the patients were not able to make available the time necessary to discuss all of the problems and decided to postpone disclosure to a subsequent date. In either case, the doctors who saw the patients on subsequent visits were not prompted to review the problems or the reasons why they may have been censored. The choice of words used to record a problem is also important. For example, 'obesity' is seen as a derogatory term by both patients and doctors and its replacement by 'overweight' led to the reinstatement of almost all such entries on the patient's record.

This study illustrates two important points. First, when considered carefully, very little information on the computer-held record needs to be withheld from the patient, so that the subject access provisions of the Data Protection Act should be easily met. On the other hand, where records are shared between hospital, general practice and patient, a reason for censoring the patient's copy must also be stored. Such computer prompting and continuing audit improves the quality of data⁷ and may also be used to eliminate unnecessary censoring.

References

1. Sheldon MG. Giving patients a copy of their computer medical record. *J R Coll Gen Pract* 1982; **32**: 80-86.
2. Jones RB, Hedley AJ, Peacock I, *et al*. A computer-assisted register and information system for diabetics. *Methods Inf Med* 1983; **22**: 4-14.
3. Ezedum S, Kerr DNS. Collaborative care of hypertensives, using a shared record. *Br Med J* 1977; **2**: 1402-1403.
4. Hill RD. Community care services for diabetics in the Poole area. *Br Med J* 1976; **1**: 1137-1139.
5. Jones RB, Hedley AJ, Peacock I, *et al*. A patient-held record and new methods of long term care for patients with diabetes mellitus. In: JJ Velthoven (ed). *Eighth international congress on health records*. Pre-papers, volume 1, red book. The Hague, Netherlands: Congress Centre, 1980: 357-372.
6. Jones RB, Hedley AJ. Patient-held records: censoring of information by doctors. *J R Coll Physicians Lond* 1987; **21**: 35-38.
7. Jones RB, Hedley AJ. A computer in the diabetic clinic: completeness of data in a clinical information system for diabetes. *Practical Diabetes* 1986; **3**: 295-296.

Acknowledgement

We would like to thank Freda Giles and Lynn Ward for their invaluable work on the register and Drs Dornan, Scott, Kerr and Selby for their help with this project. R.B. Jones was supported by the Scottish Home and Health Department

Address for correspondence

Dr R.B. Jones, Department of Community Medicine, University of Glasgow, 2 Lilybank Gardens, Glasgow G12 8QQ.

Management Appreciation Programme

FOR

General Practitioners and Practice Managers

As part of a developing service on management, the Royal College of General Practitioners is pleased to offer a series of two-day MANAGEMENT APPRECIATION COURSES for general practitioners and their senior practice staff. These events will be held at 14/15 Princes Gate, where overnight accommodation is available if required.

The Course leader is Mrs June Huntington, Director of Educational Programmes at the Kings Fund College. The programme director is Mrs Sally Irvine, General Administrator of the Royal College of General Practitioners.

The Course aims are:

- To alert course members to changes in the nature of general practice as an organization and the corresponding need for more effective management.
- To clarify the management task and its relationship to better patient care.
- To explore in depth four specific areas of management in general practice — the management of self, others, the organization and change.
- To enhance the competence and confidence of course members in these aspects of practice management.

The cost of the course for members and their staff is £175 (inclusive of Friday's accommodation). For those not requiring overnight accommodation, the cost is £150. For non-members, the course fee is £200 inclusive of Friday's residential accommodation, and £175 exclusive. The fees include all meals, refreshments and extensive course notes. If further accommodation is required, an additional charge will be made.

These courses are zero-rated. Under paragraph 52.9 (b) of the Statement of Fees and Allowances practice staff attending the courses may be eligible for 70% reimbursement. Staff should confirm eligibility for reimbursement with their FPC.

The dates for forthcoming courses are as follows:

14–15 October 1988	course number MAK
25–26 November 1988	course number MAL

A follow-up RCGP/ICI Pharmaceuticals (UK) management consultancy advice service generously sponsored by ICI Pharmaceuticals (UK) for delegates on return to their practices will be available for a small additional fee.

Application forms and further details are available from: The Management Appreciation Programme, The Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU. Tel: 01-581 3232.