Personal health records: an evaluation

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SUMMARY A cohort of mothers whose babies were born over one calendar month were followed up eight to 11 months after being given a personal health record for their newborn babies. Eight per cent of mothers lost the records and three more said they had not been given a record while in hospital; a total of 10% of mothers had either lost or misplaced the record. There were no particular demographic characteristics which identified the mothers who were more likely to lose the record. Most parents liked personal health records and used them frequently, as did the community health staff. Most private doctors, however, did not find them useful. Before wider distribution of such records is contemplated health workers should be adequately prepared, especially doctors in the private sector.

The concept of patients having more control over the decisions that affect their health is becoming more popular. One step along the path of sharing information is the use of a personal health record (PHR) that contains information about a person's contacts with health workers concerning major health problems and treatment. Such records are already in use in South Australia where since 1981 they have been given to the mothers of all newborn children (CO Auricht, personal communication). They are also used in New Zealand, France, and in some African countries.¹ The records may be used by patients or their parents to review written information to consolidate the advice given at a consultation. They also provide a record, kept by the patient, which can then be used when patients change address and which identifies their general practitioners. The records may also contain relevant information about health education.^{2,3}

There are few reports about the reactions of patients to PHR or whether they keep and use the records. To establish if such records would be useful to patients and professionals in New South Wales we evaluated the effect of introducing records for all newborn children at Camden Hospital in south western Sydney. This hospital was chosen because it had a maternity unit which served a population that was largely urban but had some semirural communities; in this sense it differed from the remainder of Sydney which is totally urban.

This study is similar to one carried out in South Australia in 1976, but we sought additional demographic details of the parents who did not retain the record for their child to see if there was a particular

group who would be less likely to use or keep the record.⁴ Because it was felt that the record would be most useful for the mobile members of the population we also recorded demographic details of those who had left the address given at the initial interview. The reaction of health workers in the hospital catchment area was also sought.

For the purposes of this article we have described the Australian health system as being made up of broadly defined public and private sectors. The former is based in government funded institutions (public hospitals and community health centres). The private sector comprises self employed general practitioners, specialists, and a growing number of private hospitals.

The existing record system in the public sector is the traditional one of professional notes being made by nurses and doctors with the actual record kept in offices or a central records department. In the community health system records on young children (aged less than 5 years) would normally be stored until the child had been at school for one year and then destroyed. The record system used by the private sector varies from doctor to doctor.

Subjects and methods

A PHR was developed based on the one already in use in South Australia. It was divided into patient and professional sections, and designed particularly for children aged 0 to 5 years. It included information about health education—immunisation; milestones of normal child development—vision and hearing questionnaires for parents; accident preven-

tion advice, and information about normal growth including percentile charts. Pages for professional use included personal information (name, address, telephone number); birth data; growth graphs (length and height, weight, and head circumference); immunisation record; school health screening record; local doctors' and clinic nurses' names, addresses, and telephone numbers; progress notes for everyday problems, and a health problem summary sheet for important illnesses and allergies. Various colours were used to distinguish the sections. The pages, A5 in size, were bound in a folding plastic wallet.

A PHR was given at the time of discharge from the maternity unit (usually five days after delivery) to all mothers of babies born after 1 February 1985 at Camden Hospital. A cohort of mothers whose babies were born in one calendar month (June 1985) were interviewed and demographic details noted. These included age, education, marital status, number of children other than the index case, ethnic group, occupation of major breadwinner in the family, and combined family income. Certain babies were excluded from the study (stillbirths, babies who died in the neonatal period, babies who were to be adopted, babies who were transferred for intensive care, and babies of mothers who refused to accept the PHR). There were 180 births during the month of the study. Of these, one child was transferred to a referral hospital for intensive care; there were three stillbirths and one baby was adopted. Four mothers did not receive the PHR, all having been discharged within 48 hours of delivery. Four mothers refused to take the record home with them. Of the four, two mothers stated they would not use the PHR and two gave no reason for their decision. This left a sample population of 167.

Eight to 11 months after the child was born an attempt was made to interview all 167 mothers at their homes. At that stage they were contacted by a second research assistant who was unknown to them. The mothers were asked if they had been given a PHR, when they were meant to use the record, whether they had read various parts of the booklet, and whether they were satisfied with the time when they received the PHR. We gauged how useful they found the PHR by asking three questions: what were the advantages and disadvantages in the record; what changes they would like to see if any; and if they would like a similar record for any of their other children.

We then posted a questionnaire to all health workers in the private and public sectors in the three local government areas served by Camden Hospital.

All the health workers had been contacted by mail during the six weeks before the introduction of the

record. At that stage they were supplied with a copy of the record as well as two posters advertising and promoting its use, and an explanatory letter. The second questionnaire was sent to 151 health workers including 123 doctors, 21 generalist community nurses, six clinic nurses, and one medical officer in child health who was included in the community health team. The second mailing was done 15 months after the introduction of the record. In the questionnaire they were asked, in three slightly different ways, if they were aware that the PHR was to be introduced. Firstly, they were asked if they had seen a PHR; secondly, if they had received a copy of the PHR plus the advertising posters through the mail; and thirdly, if they were aware that the record was going to be introduced locally. They were also asked to indicate how many patients or clients had brought the PHR with them at various contacts and whether they (the health workers) had read any of the information. Their opinion about how helpful it was, what advantages and disadvantages it had, and what changes they would suggest was also requested. They were also asked to identify the professional group to which they belonged.

During the trial community health workers were asked to keep dual records—that is, to complete the usual entry in their own professional records plus the appropriate part or parts of the PHR. No directions were given to doctors in the private sector except that they were encouraged to complete the PHR.

Results

SURVEY OF THE PARENTS

Twenty mothers had left the address which was given at the time of the original interview. Of the 147 mothers who were able to be contacted, 12 mothers could not produce the record when they were seen, and three said that they had not received a record at the hospital, making a total of 10% of all the mothers contacted. There were no significant differences in maternal age, maternal education, marital status, number of children, ethnic group, occupational prestige, or combined family income between the mothers who still had the PHR and those who had lost or misplaced it.

When the progress notes and the number of contacts with health workers were studied, four of the 135 records had no entries. Seventy five per cent, however, had nine or more entries with separate dates.

Ninety one per cent of the records had progress notes made by the local clinic nurse but only 18.5% of the records had notes made by a doctor. Twenty eight per cent of parents had written in the progress

Table Reactions of professionals to PHR

	PHR helpful	PHR not helpful
General practitioners	16	6
Specialists	8	4
Community nurses	26	1
Child health medical officers	1	0

notes themselves. Eighty seven per cent of parents said that they would like records for any future children and 37% of parents said that they would like records for siblings of the index child. Ten per cent of parents said they would not like similar records for other children.

Ninety two per cent of the mothers said they liked the wallet. A similar percentage of parents indicated that the index child had received the required number of immunisations. When this was cross tabulated with the actual record that had been made of immunisation it was found that an accurate record had been kept in 75% of cases. Ninety per cent of mothers said they were satisfied with the time that they were given the wallet (just after the birth of the child). Interestingly, over 80% of the mothers were prepared to pay for the wallet, and 52% said that they would pay between A\$1.00 to A\$3.00 for it.

Those who had moved away from their original addresses tended to be younger mothers (mean age 23.3) than those who were still at the address given at the time of first interview (mean age 27.0). This was significant ($p < 0.01$). Those who left were also less likely to be married or in a stable relationship ($p < 0.05$).

SURVEY OF THE PROFESSIONALS

Ninety (60%) of the questionnaires were returned. Eight doctors and one community nurse had left the addresses they had previously given. The 54 doctors comprised 36 general practitioners and 18 specialists. Thirty one general practitioners and 12 specialists (80% of the doctors) said they had seen the PHR and all of the community health staff said that they had done so. The same 31 general practitioners but only seven specialists (70% of the doctors), had made at least one entry in the PHR. All but one of the community nurses had recorded comments, but the one dissenter had only just started work in the area. Thus a total of 80% of the surveyed local health staff had completed at least one entry in a PHR.

In response to how helpful they found the PHR, 24 (44%) doctors—16 general practitioners and eight specialists—found it moderately or very helpful. The eight specialists comprised three obstetri-

cians, three paediatricians, one surgeon and one other. Ten (19%) doctors (six general practitioners and four specialists) found it no help at all. The specialists (three dermatologists and one psychiatrist) admitted to seeing no children professionally. Ninety three per cent of the community health staff found it moderately or very helpful. The reasons for the PHR not being helpful were sought but only five doctors responded; all five said that they felt that it was too time consuming.

Discussion

This survey resulted in three major findings. Firstly, most parents liked the idea of the PHR for their children. Ninety per cent had retained the PHR and 136 of 140 records had entries made in the progress notes, 75% of which had nine or more entries. In addition, 87% of those studied would use similar records for future children. Thus parents are likely to keep a PHR and use it frequently. In this respect our findings are similar to those of the South Australian study in which 88% of the mothers still had the record in their possession one year after it was introduced. The second major finding was that no particular socioeconomic group was more likely than any other to lose a PHR. It is impossible in the context of the study to know whether a PHR was retained or what use was made of it by the 20 mothers who had left their original addresses.

The other major finding was that professional acceptance contrasted sharply between the public and private sectors. In the former (community nurses and one medical officer) 93% found the record useful. Only 44% of the private sector, however, found the record to be helpful. This compared with 58% of the 40 doctors who took part in the South Australian trial. While this needed to be taken in the context of those who tended to see children more frequently (for example, paediatricians and general practitioners) and who therefore tended to accept the PHR more readily than those whose paediatric workload was less, it highlighted a major obstruction to the success of such a programme. We postulate that the apparent reluctance of the private sector doctors to fill out a PHR is because they fail to see any benefit for themselves or their patients.

We feel that the PHR encourages parents to be key members of the 'team' offering primary health care to children. Their actions in dealing with most childhood illnesses are to be encouraged and facilitated with accurate, easily understood health education advice such as that available in a PHR.⁵

Though it was not possible to examine the impact of such material during this study, the PHR included

'professional' sheets which would effectively replace other documents in present use in the community health system, for instance the infants' health records, the immunisation records and the school health screening cards. We feel that the drawing together of such information would enhance the passing on of a child's health information and help to solve the storage problems which plague most medical records departments.

Our conclusion was that the record was well accepted by patients. It was used well by the public sector health workers but not by private sector doctors. We recommend that before wider distribution of a PHR takes place the various medical colleges and organisations should be consulted and their support sought. The campaign should be preceded by general advertising in the community but the results of both our study and that in South Australia indicate that with little preparation there is still likely to be wide acceptance of such a policy; most of the preparatory efforts must therefore be directed at the private health sector.

Finally, though the record that we used was not quite the same as that presently in use throughout South Australia, it would make good sense to have as universal a record as possible throughout Australia. Though trials up to now have been aimed at

children, the major thrust of such an idea is for patients to use the PHR throughout their lives. This is already occurring in some general practices and is outlined in a positive report by Gawthorn, who described a PHR used especially in the elderly patients.²

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