

Personal Child Health Records

Ten years ago a model personal child health record (PCHR) was launched. The ethos behind parents holding their child's records was that it would encourage partnership between health professionals and parents, improve communication between health professionals leading to enhanced continuity of care and increase parents' understanding of their child's health and development. About 90% of mothers now hold their child's health record.

In conducting this review of the PCHR and determining the way forward, several sources of information have been used. These include published and unpublished literature, the findings from a survey of trusts and Health Authorities on the use and policies of the record, discussions which took place at a national conference held in 1999 and the discussions of the PCHR subgroup of HFAC4. Of the 166 Trusts surveyed, 98 have responded to date.

Key issues identified

In spite of the intent to empower parents, there is a lack of consensus as to whom the record belongs. In the survey, 38 trusts reported that the record belonged to the Trust, 35 to the parent alone, 12 to the parent and another, 5 to the Secretary of State alone, and one jointly to the Secretary of State and Trust. Only 2 specifically reported that the record belonged to the child. Since the launch of the model record, there has been a proliferation in different formats with many areas designing their own. This has limited the usefulness of the record in a number of ways, making it difficult for parents who move from area to area and for health professionals to find their way around it. Although they have basic similarities, it can be difficult to know where to find a particular piece of information

Policies also differ with the record distributed at different ages. The majority (58) are currently given to parents by the health visitor at the first visit, although the majority (66) would prefer them to be distributed either antenatally or in the first 48 hours after birth by either midwife or health visitor. Policies with respect to information provided on confidentiality and transfer of information vary with just over a half of the responding trusts (47) providing information about these issues in the PCHR.

The use made of the PCHR as a source of information for transfer to data systems was explored with the majority collecting information regarding programmed child health contacts (93). Fewer trusts reported using the PCHR as a source of information regarding immunisation (33) and breastfeeding (50).

Variation also exists in the coding systems used to record details of routine child health contacts. 'SPOTRN-(satisfactory, problem, observation, treatment, referral, not examined) is the most widely used (75 areas). However, 16 other recording systems were described from 21 areas. This limits the ability to utilize these data on a national basis.

Although many records contain health promotion material, there is a lack of evidence to show that it is of value or that parents read it.

Other issues identified

Although the record is intended primarily for parents its appearance is not always user-friendly. Even some health professionals find it difficult to complete. There is evidence that the use of the record by some professional groups, in particular GPs and hospital based doctors, is suboptimal. This is in part due reluctance to duplicate information recorded in GP notes. To ensure continuity there should be a follow on from the national maternity record (NMR), with a page provided with details of the birth and immediate post partum period. Development of the post partum component of the NMR is currently in progress.

Recommendations

The design needs to be updated-this is a task that should be undertaken by experts in design.

Content should be reduced to the bare minimum to ensure that it is a *record*.

The core pages should be standardised in line with the recommendations of HFAC4, the National Screening Committee (NSC) and informed by the minimum core data set recommended by the Child Health Information Consortium (CHIC).

Pages of the record should be in the same order, well indexed and numbered.

Detailed health promotion material should not be included, but rather signposted eg the Health Promotion England Birth to Five Book. Health promotion pages that are distributed should be given at the appropriate age, rather than included in the book as standard.

Local information can and should be included but should not interfere with the order of the pages.

The record should be given to parents antenatally with an explanation or as soon as possible neonatally with an explanation by the health visitor at the first visit

Proposed contents

Index

Biographical details, NHS number

Information re screening, consent to transfer of data, confidentiality,

Summary of birth, receipt of vitamin K, hepatitis B vaccination, newborn examination, neonatal hearing screening

Feeding, collected at standard ages eg 4/8/12/16 weeks using a standardized question

Immunisations given by whom, date, site of injection, batch number, information about adverse reactions

Developmental reviews - standardised coding for results

Feedback of outcome of referrals

Growth charts

Issues to be clarified

Little information is available on what parents want from the PCHR. Further work is required on development of a record for school age children. The issues of consent to transfer of information to data systems and on ownership require further thought.

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