

**Exploration
of Attitudes Towards
Family Health Plans**
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Introduction

The White Paper *Towards a Healthier Scotland* identified child health as a priority and asked health boards and NHS trusts to 'put children at the heart of their work to improve health and tackle health inequalities'. More recently, *Our National Health: a Plan for Action, a Plan for Change* made children's health a new clinical priority for the NHS in Scotland.

In order to achieve this a range of general strategies has been developed, including changes to the ways in which nursing and family support services are delivered. *Nursing For Health* (2001: 43-5) recommended the introduction and implementation of Family Health Plans throughout Scotland, as part of a more 'family-centred' public health role for health visitors. Following this, the Health Education Board for Scotland (HEBS) was asked to lead on the recommendation for family health plans 'developed on the basis of need, agreed with and held by the family, setting out a clear set of goals and actions to achieve them'. This research was commissioned as part of the work of the advisory group set up to address this task.

Background

Family Health Plans have evolved from the parent-held child health records introduced in some parts of the UK in 1991. The PHCHR, or Red Book, as it is more colloquially known in Scotland, is widely viewed as a successful innovation. The majority of studies on the topic suggest that parents generally welcome the opportunity to be responsible for their child's health notes, especially those with limited access to health information (e.g. semi-literate or travelling families), and those with children with special needs or disabilities. However, low 'compliance rates' for use in areas of poverty and deprivation, or among parents with more than one child are common.

By common agreement health visitors are conscientious keepers of the Red Book record and have genuinely begun to use it to develop a more open and collaborative relationship with parents. GPs, on the other hand, are reluctant users of the document, finding it an additional burden to the systems of record keeping that they already operate. Moreover, many express discomfort at the different sorts of relationship implied in the open and negotiated form of record keeping encouraged in the Red Book.

How does the Family Health Plan concept change what is already in existence? Very simply a Family Health Plan (FHP) can be defined, as a core instrument for enabling a family to think (in partnership with the health visitor) much more critically and actively about their health, social and communal needs. Whereas the Red Book is both a record and an assessment tool (and incidentally a source of health information), the FHP is intended as a needs assessment tool and a format for goal setting and monitoring in relation to the health, not just of a single child but also of all the family caring for the child.

What is clear is that the FHP is expected to embody a distinct philosophy about participation and empowerment. Thus it should be designed to be used in a collaborative fashion, whereby parents and health visitors work in tandem with each other forming a 'partnership' approach to the family's health.

No fully piloted and evaluated schemes for FHPs are in existence in the UK. A number of projects in Scotland are trialling documents called family health plans, but none of these products fulfil all of the requirements of being a parent-held document used for planning/needs assessment and taking into account the needs of the whole family. Work being developed and piloted in England as part of the Health Action Zone scheme probably comes closest to the template described in policy documents and is described and examined in the full report.

Research aims and methods

The aims of the research, as specified in the initial brief were:

- to explore the views of parents and health professionals about the currently held PCHR and its future development
- to review the literature regarding the barriers to, benefits of and development of family health plans from the perspective of health professionals and parents and to review the currently approved methods of recording such information
- with reference to the literature, to investigate the current practice of how personal child health records/plans are held and used by nursing and other key professionals in each health board area.

A mix of methods was adopted in order to address the questions posed:

- A review of the published literature at national and international level
- A collection of the range of plans in use and the methods of record keeping in all 15 Scottish health board areas, and also in health demonstration projects in Scotland and in England
- An interview study with a sample of key professional/practitioner personnel from the 15 Scottish health board areas. Twenty-eight individual interviews with child health commissioners, community-nursing managers, directors of nursing, community paediatricians were undertaken and 14 group discussions with a sample of practitioners (health visitors, public health practitioners, school nurses, community paediatric health nurses, A&E nurses and GPs)
- Interview study with a sample of parents. A mix of group (6) and individual (20) interviews with parents was undertaken in three areas selected on the basis of their different use of parent held child health records. Within these three areas the sample was selected to take account of structural factors such as rurality, ethnicity, socio-economic status and disability. It also included different forms of family organisation and family circumstances, taking into account class, ethnicity, age of child, presence of children with acute or chronic illness and presence of children with disability.

Findings

The current context

Of the 15 health board areas of Scotland:

- All kept health visitor records
- All except one (Angus district of Tayside) used a parent-held child health record
- Several health boards have undertaken significant reviews of their Red Book material (notably Fife and Argyll and Clyde) and have produced recommendations for revised instruments
- In other areas attention has been paid to particular issues (e.g. specialised Traveller record developed by Dumfries and Galloway; work done in Ayrshire and Arran on child protection issues)
- Fewer than half have a form of family health record in operation or under development. These are usually simply records of the family's health status; they are not plans. In most cases they consist of a single page record of who is in the family and a brief health assessment for all. The record is held in the health visitor case notes (i.e. not by the patient/parent) and shared with the family
- Both Ayrshire and Arran and Dumfries and Galloway are in the process of developing plans from these records. Argyll and Clyde has perhaps got the furthest forward in developing a simple family health plan which is currently being piloted Board-wide.

Almost all of the parents interviewed had experience of some form of parent-held child health record. The majority had received the most widely used PHCHR, often referred to as the 'Red Book'. Some parents had also received other forms of PHCHR when living in other countries and were able to draw comparison between these and the 'Red Book'. None had experience of being asked to take part in a family health planning exercise.

Starting from current practice-the Red Book

In just over a decade of use the parent-held child health record - commonly referred to as the Red Book - has established itself as a useful adjunct to the professional record, and has helped shift the health visiting profession to a modern understanding of the need to develop collaborative dialogues over health with their clients.

Many health boards have themselves begun to review the form of the Red Book. The utility of the Book as a health information source (only ever an incidental function) is limited. Similarly it is recognised that the need to use limited resources well may mean the targeting of some groups in a more intensive way and a shift from the traditional activities of monitoring and recording all children at regular intervals.

These reviews and the evidence from both the literature and the empirical data collected here suggest that – on the whole – parents like holding their child's health record, but that their confidence in its importance and utility is undermined by the partial nature of the information collated. The Red Book has remained very much a health visitor tool and is generally disregarded by GPs, school nurses and by medical and nursing staff in hospital settings.

Parents of children with specific conditions become particularly exasperated by the failure of the document to do anything other than record the barest details of their child's health progress, when health is so high on their agenda of concern. A more complete record would also be of benefit to parents from ethnic communities who experience language difficulties in their contacts with health service personnel.

Most areas are aiming to standardise the PCHR in terms of its core content in line with the guidance published in Hall 4. However, there are local variations in layout, local contact information and so on. Within the research undertaken for this study the calls for greater standardisation of format were almost unanimous.

There is, of course, a conundrum in advocating a standardised format but also wanting to retain the flexibility to serve the needs of different groups within the community, such as those with a child with a specific medical condition. This could be overcome as is suggested in the Hall 4 recommendations by having a core document, which has the possibility of additions or extensions.

At present few health authorities north of the Border incorporate any document, which emphasises review and forward planning around health issues. Where documents have been developed as family records, they are usually intended simply to outline or record family circumstances.

Family health plans

The idea behind the introduction of family health plans is clearly to gain an extra tool which health visitors can use to help them function in the new roles outlined for them. None of the pilot Scottish documents currently in use fulfil all of the requirements for such a document expressed in policy templates.

Because the family health plan concept embodies many of the quite radical shifts in role that health visitors are being encouraged to make, both parents and professionals alike interviewed for this study often found it difficult to conceptualise how such a document might work. Fears that it would be both intrusive and time-consuming were rife, but that view relates very much to the fact that health visitors currently fulfil a health surveillance and support role for all families. The recommendations of Hall 4 and other policy documents, that health visitors move toward a more targeted approach to vulnerable families rather changes the complexion of such arguments.

Many of the parents interviewed in this study who were already targeted and singled out as vulnerable and in need of support and surveillance (e.g. those attending Family Centres) already live with services which operate towards them in an intensive and fairly intrusive way. The sorts of review and planning documents that they are already required to participate in regarding their own and their children's behaviour, for instance, indicate that they would be familiar with the approach of the family health plan, though others might not be.

Other parents who had faced taxing circumstances in relation to the poor health or disability of a particular child were usually only too ready for some form of tool. They felt that this would enable them to review the child's health in a more holistic way, and to explore the impact of that on the family as a whole.

Related to the above, evidence from the English study seems to indicate that – as with many other opportunities for health education – timing is everything. The imposition of the need to 'do' the FHP at a specified and similar point in every child's life seems to yield the promise of poor results if it is seen as irrelevant or unnecessary. Conversely, a system where the health visitor has the discretion to choose the moment when the parent/family needs the opportunity to review and to explore what support is available may aid in the presentation of the FHP as a tool which supports rather than acts as a further form of surveillance.

Many of the concerns about the FHP relate to the way in which it might be held, the negotiation of ownership and the potential for breaches of confidentiality. The need to develop a life course approach to health and to avoid the disjunctions in service provision between, for example, the health visitor service and the school nurse service are a potent argument for a record that passes with the child longitudinally as well as laterally. However, it is foolish to imagine that the Red Book/FHP documents must fulfil all these functions. The development of electronic record keeping within the NHS advances apace. The professional record of health events and treatments will be held separately from the parent record and will be available through the life course. It might be desirable for the parent-held record to have a longer life than presently, but there is no necessity for it to do so.

Some of these concerns arise because of an assumption by interviewees that the document would be held in a place or in such a way that they would have to make it available for others to inspect. This would indeed be the case if the Red Book and the FHP were merged into one document and if attempts were to continue to make the Red Book a multi-professional record of child health. Such problems are easily overcome where the FHP document, as in the Sheffield case, remains an entirely separate document.

Regarding the ownership of the FHP, if the document is to be patient-held, it is difficult to conceive of a position other than that the document becomes the property of the principal caregiver of the child concerned. Giving any other individual or agency the right to inspect the plan would jeopardise from the start the chance of an honest account and review of circumstances. A health visitor wishing to keep a record of the plan could summarise and retain information on an existing record, or the form could be designed in such a way that a carbon tear-off slip of summary actions and plans could be taken away for future use by the health visitor.

Another agenda that sits around the use of the FHP is the concept of life course health. Should the FHP become part of the child's record that passes from health visitor to school nurse and so onwards? This is certainly

something to consider in respect of a revised Red Book, but it is doubtful if this would work in relation to the FHP. Since the document is an account of the collaborative conversation between caregiver and health visitor, and relates to family issues as a whole, it is hard to argue for it to become the property of the child him/herself.

The potential of the FHP to function as a community needs assessment tool was roundly welcomed by service managers in this study, but it is probably true to say that neither parents nor health visitors themselves have much vision at this stage of how that might work out in practice. The notion that it might allow health visitors or their representatives to take part in (or even lead) multi-agency initiatives set up to address particular local problems was felt to be rather alarming by many of those on the ground. Clearly, a great deal more training and support will be needed as health visitors try to move towards the complete fulfilment of a public health role.

The Sheffield initiative, where family health plans have been piloted on a slightly broader scale, seems to suggest that health visitors can derive a great deal from sharing and pooling information deriving from the use of FHPs, but this does carry implications for the management of the service.

Similarly, the development of the family health plan is symbolic of the shift away from a light touch surveillance of all children's health towards something that is much more focused and deep on the vulnerable families and children within an area. These sorts of planning exercises, however, are likely to throw up the need for team resources that the health visitor can call on, including family support workers with few health skills, but with the ability to support families in other, practical ways. *Starting Well* offers good exemplars of how this is being taken forward in one demonstration area.

Training implications

Training in the use of the planning tool will need to be incorporated into both initial training and into continuing professional development for those already qualified. The skills for developing and managing a targeted caseload and working within a broad skill-mixed team will become more important. The use of the family health plans re-emphasises the need to develop the skills and experience which will help the health visitor to judge when the time is right to introduce the FHP and which will help extend the facility with which the health visitor develops collaborative working with the client using the document. The FHP will be started where there is a need identified by the health visitor, but there is no guidance about when it will close or be suspended as family circumstances change or the outcomes are achieved, and there are thus training implications regarding the withdrawal of support. Similarly training can help the health visitor to develop the capacity to use the FHP at a community level to assess need and then to take the assessments into multi-agency fora in the hope that change can be effected.

Senior staff may also need to be offered training in supporting staff in their new roles and changing patterns of work.

There may be a case for other professional groups also to be offered information and training about the change in health visitor roles.

Themes for discussion

Parent held child health record (Red Book)

Although the PCHR (Red book) was not the main focus of the research, in discussing current practice a number of findings related to the PCHR become relevant if we assume that the Red book is continued as a document for assessment and recording of pre-school children's health. These are raised here as questions for discussion.

- Is a further national review of Red Book use necessary, in order to provide a uniform core document for Scotland, incorporating the 'best practice' from developments around the country?
- How can we take into account the needs of particular groups like those from travelling communities or from different ethnic groups when redesigning the parent-held record?
- How can a re-designed parent-held record take account of the needs of parents of children with disabilities or with chronic medical conditions who often experience the strongest need to have a unitary record of problems, treatments, immunisations and so on?
- Should the Red Book remain as a document to be issued to all parents shortly after birth, even if the health visiting service moves away over time from a universal surveillance role?
- How can other professional groups, which come into contact with the child in the health domain, be encouraged to use the Red Book and not see it as a document whose ownership lies exclusively with the Health Visitor service?

Family Health Plans

Assuming that Family Health Plans are set up as brief and simple documents to be used in the health visitor's work with families.

- Should FHPs always be parent-held?
- Should they become the property of the principal carer of the child in question?
- Should the FHP document be devised to allow the health visitor to leave the main document with the client but to have a detachable summary, which can be taken away for record keeping purposes?
- Can the use of the FHP as a management tool to measure effectiveness against targets or as a means of community needs assessment sit comfortably with the most basic reason for their use?

- Should health visitors be given the discretion to use their professional judgement as to the best time to introduce the FHP into the relationship between health visitor and client?
- What forms of training will best underpin the general shift in health visiting roles in both primary training and in continuing professional development?
- How should the task of using FHPs, as a form of community needs assessment be developed?
- How should awareness raising of the new health visitor public health role be undertaken amongst other professional groups?
- In what ways can managers of health visitors best develop and support the new public health role demanded of the service?

1. Introduction and background

1.1 Children at the heart of health improvement

There is increasing emphasis on improving the health of children, especially children under the age of five, and their families. The White Paper *Towards a Healthier Scotland* identified child health as a priority and asked health boards and NHS trusts to 'put children at the heart of their work to improve health and tackle health inequalities'. More recently, *Our National Health: a Plan for Action, a Plan for Change* made children's health a new clinical priority for the NHS in Scotland. Childhood is thus clearly seen as a pivotal stage in the life course and as a point where policy changes have the potential to influence future health careers (Mielck *et al*, 2001) and reduce inequalities.

In order to achieve this overarching aim of child health improvement a range of general strategies has been developed. These include changes to the ways in which nursing and family support services are delivered, as evidenced in documents like the recent *A Scottish Framework for Nursing in Schools* (Scottish Executive, 2003) and *Nursing for Health – a Review of the Contribution of Nurses, Midwives and Health Visitors to Improving the Public's Health* (Scottish Executive, 2001). These documents encourage forms of partnership working between professionals and parents that will 'empower' parents to take greater responsibility for monitoring their own child's health and development. The importance of partnership working has also been well-rehearsed in academic, policy and planning literatures and has been identified as having a key role in underpinning changes in the organisation and delivery of services (*Towards a Healthier Scotland*).

Family Health Plans - the subject of this study - may offer a means of achieving this goal. Recent Scottish Executive documents such as *Nursing For Health* (2001: 43-5) have recommended the introduction and implementation of Family Health Plans throughout Scotland, as a way of addressing, tackling and reducing the number of families suffering from poor health. Similarly, south of the border, the 1999 Government White Paper, *Saving Lives: Our Healthier Nation* advised that health visitors develop a more 'family-centred' public health role. More specifically, the aforementioned report recommended that health visitors should increasingly employ plans agreed in partnership with families, in order to address effectively the latter's health and parenting needs (Department of Health, 1999: 133).

For this reason a steering group was set up by the then Health Education Board for Scotland to consider the issue.

1.2 The focus and remit of the steering group

Following the publication of *Nursing for Health* HEBS was asked to lead on the recommendation for family health plans 'developed on the basis of need, agreed with and held by the family, setting out a clear set of goals and actions to achieve them'. In consultation with SEHD they therefore agreed to set up a small initial working group to outline the issues and make proposals with the intention of recruiting a formal stakeholder group to oversee the developments.

Initial discussions within this group raised both potential benefits and significant barriers. In relation to current practice the group agreed that current records and plans were strongly professionally led, and that services were not joined up, with a lack of continuity being apparent even within the health service. There was no national overview of practice. Family health plans offered the potential to create a different relationship with parents so that the latter knew what to expect from services, knew who to contact, would perceive that services were more joined up, would feel more in control both of information about their own child and of encounters with health professionals.

The barriers to such an innovation were also evident at an early stage. Much multi-professional work would be needed, for instance, to develop and introduce a document that would be used across services, and to develop the document in a form that was accessible for all groups if it was to be parent-held. Issues of confidentiality would need careful consideration, as would the issues around child protection.

A mailed invitation was subsequently sent in October 2001 to various interested parties to explore a wider set of views on the potential benefits of family health plans, and the barriers that were seen to development. Respondents were keen to acknowledge the potential benefits of more unified systems, particularly for vulnerable groups, but envisaged a range of problems. These comments helped to make it clear that further research was needed into the views of both parents and practitioners working in the field.

In the spring of 2002 the Rowan Group from the University of Aberdeen was commissioned by HEBS (following the usual tendering process) to undertake a piece of empirical work which would gather views more widely in the field, taking into account parental perceptions as well as those of professionals working with young children and families. The steering group continued to meet at regular intervals, receiving reports on the progress of the research, as well as hearing from invited speakers about contemporaneous developments regarding electronic record-keeping, for instance. A list of members of the steering group, as well as those who were invited to speak to it is given as appendix A.

1.3 Research aims

Reflecting this general background outlined above, the aims of the research, as specified in the initial brief were:

- To review the literature regarding the barriers to, benefits of and development of family health plans from the perspective of health professionals and parents and to review the currently approved methods of recording such information
- With reference to the literature, to investigate the current practice of how personal child health records/plans are held and used by nursing and other key professionals in each health board area. This included reference to potentially adapted family health plans that are in local use

- To explore the views of parents about the currently held PCHR and its future development
- To explore the views of health professionals about the currently held PCHR and its future development.

1.4 Research methods

A mix of methods was adopted in order to address the questions posed:

- A review of the published literature at national and international level. This included a review of literature pertaining to existing parent held child health records, an exploration of questions arising in relation to the concept of Family Health Plans and of the different forms that these have taken in practice. Literature on parental perceptions of family health plans was also investigated. The broader literature on parent/professional participation and partnership was also consulted to form a backdrop to the specific material collected on this topic
- The collection of the range of plans in use and the methods of record keeping in all 15 Scottish health board areas, and also in health demonstration projects in Scotland and in England
- An interview study with a sample of key professional/practitioner personnel from the 15 Scottish health board areas
- An interview study with a sample of parents.

1.4.1 Sampling for professional/practitioner study

It was important that evidence was gathered that reflected the perceptions and perspectives of both decision-makers and practitioners in order to take account of the range of views and experiences, the implementation in practice and local interpretations of how plans should be used.

To this end, a sample of policy makers from each health board area was interviewed using a short structured telephone interview format. A total of 30 individual interviews were planned and 28 executed. The sample included child health commissioners, community-nursing managers, and directors of nursing, community paediatricians.

A sample of practitioners, (health visitors, public health practitioners, school nurses, community paediatric health nurses, A&E nurses and GPs), were also interviewed in group settings face to face. Fourteen group discussions using a semi-structured format were carried out, with a spread across five health board areas.

1.4.2 Sampling for parent study

Previous experience by the researchers had enabled the development of working relationships with a wide range of community-based agencies and parent groups across Scotland. This provided a useful starting point for the

recruitment of a purposive sample that reflected the range of parental experience and background sought in the brief.

A mix of group (6) and individual (20) interviews with parents was undertaken. The interviews took place predominantly in three areas selected on the basis of their different use of parent held child health records, namely the Angus district of Tayside where no PHCHR is in use, Grampian, which represents the average form of use of existing parent held records, and in Fife, where considerable development work has been done with the PHCHR, bringing it much closer to the form described in FHP documentation. Within these three areas the sample was selected to take account of structural factors such as rurality, ethnicity, socio-economic status and disability. It also included different forms of family organisation and family circumstances, taking into account such differences as class, ethnicity, and age of child, presence of children with acute or chronic illness and presence of children with disability. Other contacts were also made in relation to specific issues, e.g. West Lothian/Dumfries and Galloway in relation to travelling families, and Glasgow in relation to parents currently seeking political asylum. The Scottish Executive Health Demonstration project *Starting Well* was also approached. Health staff involved in the project gave freely of their time in relation to the practitioner interview study, but felt that the parents in the study were already at risk of being over-evaluated and advised against including them in the parent sample for this study.

Details of the sampling are given as Appendix B and further information on the formats for the interviews is given in Appendix C.

1.5 Format of this report

The focus for this study is the development of the Family Health Plan. Before we embark on development activity around the Plan, however, it is necessary to explore in what ways health visitors and other health service staff are already working with families. We need to know in what ways current systems of working and recording interactions with families succeed, as well as in what ways they may be deficient. We need to know what elements of current practice can be retained and built on.

Very simply, the proposals recommend the introduction of a planning document in addition to the simple forms of recording of child health currently used by health visitors. The current Red Book or PHCHR is a tool for recording and assessing, but also informing, since the majority contain various levels of health information and advice on issues related to child health. The recommendations do not specify whether the Family Health Plan should be separate or whether FHP and Red Book should be merged into a single entity.

This possible introduction of a new form, however, is also symbolic of a whole new way of working which is intended to be parent-led rather than professionally-led, which is supposed to be more targeted at vulnerable families than the existing universal surveillance and support system, and

which is supposed to lead to more seamless health and support services for those needy families.

It is evident that the existing forms of recording health used with young children, such as the parent-held Child Health Record (PHCHR), structure existing professional contacts between health visitors and parents and between health visitors, parents and other health and social support professionals. The way in which current systems of recording work, and the way in which issues like confidentiality, professional-parent relationships and so on are negotiated is clearly of relevance to the way in which any new mode of working can be established. It is fanciful to imagine that the introduction of a new system can simply wipe out what has gone before. It must build on and develop existing ways of working and extant relationships. For this reason the sections of the report which follow review evidence (both from published research literature and from new work carried out in the field) relating both to existing systems of parent held records and the environment in which they operate as well as to prototypical family health plans.

Chapter 2 focuses on existing parent-held records and the lessons learned from the literature about the use of these in practice by parents, health visitors, GPs and others. Chapter 3 looks at the templates set in policy documents for the development of family health plans, and then reviews how far these policy objectives and guidelines are being met in existing pilot forms of FHP in use in Scotland and elsewhere. In chapter 4 the empirical evidence gathered a part of this project from parents, health visitors and other health professionals is explored thematically. Finally, chapter 5 draws this evidence together into a discussion and concludes with some recommendations for taking forward the programme of work for the development of a Family Health plan in Scotland.

2 Parent-held records: lessons from past and current use

2.1 Introduction

One of the principal intentions behind the Family Health Plan is that it should be held by the family, and should become part of the process of ensuring a greater degree of openness with families whilst still ensuring that important issues are confronted and addressed (Nursing for Health: 44). The development of client held records is not a new concept. Family Health Plans have largely developed and evolved from antecedent parent-held child health records and other similar documents. Early trials go back at least two decades (Volkmer *et al* 1993; Miller 1990; MacFarlane 1992), and the parent held Personal Child Health record was introduced in some parts of the UK in 1991, coinciding with the enforcement of the Children Act 1989. They were widely viewed as a successful innovation, and were, as Hall (1996) reports, in use by more than 75% of districts in England by 1994. In this chapter the use of parent held child health records (hereafter PHCHR) as they are currently operated, in the UK and abroad is examined. What lessons can be learnt from their use?

There are many different versions of the PHCHR or 'red book' currently operating within Britain. The standard PHCHR is a relatively simple health record, which documents the operations and immunisations a child has undergone. Other PHCHR, however, are more sophisticated in structure and content, containing loose leaf, health promotion information and planning schedules.

In the UK at present, a health visitor gives the current PHCHR to parents at the ten-day post-natal check. The health visitor then uses the PHCHR on subsequent visits to record child developmental progress and surveillance checks. The record is also supposedly asked for at every visit to the school doctor and when 'looked after' children attend medical examinations.

2.2 Parental attitudes towards PHCHR

Many studies have attempted to analyse and document professional and parental attitudes towards parent-held records. Not surprisingly, due to social, geographical, cultural and methodological differences, these studies have uncovered mixed and at times apparently contradictory findings. On the whole, however, the majority appear to suggest that parents generally welcome the opportunity to hold, have access to, and be responsible for, their child's health data and notes.

Cormack *et al's* (1998: 375) quantitative study in Cambridge, for example, found that parents welcomed and valued the introduction of parent-held child health records, finding them useful for both recording information on their children and seeking information about illnesses and infant related issues and problems. Indeed, 96% of the parents surveyed felt the PHCHR was a useful and advantageous tool (*ibid*: 378). Moreover, Davies' (1999a) research showed that parents of all social classes and ethnic origins not only felt positive about using a PHCHR, but actually enjoyed the experience of holding their child's health notes and having increased access to information about their child's health care. Likewise, in her study of a health clinic in London, Charles (1994: 271) found that an overwhelming 98% of parents interviewed 'liked' and 'treasured' the record. Similar findings to the above are echoed and reinforced in separate research conducted by Campbell and Halleran (1993), Hooker and Williams (1996), Jeffs *et al.* (1994), O'Flaherty *et al.* (1987), Pearson (1985), Pearson and Waterson (1992), Saffin (1986), Saffin and MacFarlane (1991) and Volkmer *et al* (1993).

One has to point out, however, that this apparently overwhelming endorsement may say as much about the research methods as about the true feelings of the respondents. Many such studies were carried out at the site of health service delivery (e.g. in a clinic area), were questionnaire-based, and often administered by the health professional concerned. The lack of anonymity, the desire not to offend, the unequal power relationships involved, may all cause us to be therefore somewhat wary of the apparently overwhelming vote of confidence given by parents to such schemes. On the other hand these apparently contradictory results may simply illustrate the familiar dissonance between the theory and the reality of the lived experience, where the importance of any such document in the lives of the people

concerned is actually very small. The recent results from a pilot project looking at the development of child-held personal health profiles, (Morton and Hill, 2002), illustrates this perfectly. Despite the 'health fax' being regarded as an overwhelmingly 'good idea' by pupils, teachers and parents alike initially (and even in retrospect), a follow up study a year after their distribution found that the majority were lost, unused, or not used in the way intended.

However, these caveats aside, it would appear that the general theory and philosophy underpinning these schemes (i.e. to promote trusting partnerships and to empower parents to take greater responsibility and play a more active role in their child's healthcare) appears to be valued and appreciated by a significant number of parents.

Many reasons have been given in the literature for positive parental attitudes towards PHCHRs. For example, they are seen to save both the patient and doctor time by eliminating repeated history giving and by providing ready access to important facts. They allow patients the opportunity to keep all their health documents (for example, immunisation cards and repeat prescriptions) in one place (Jeffs and Harris, 1993: 1425). Most of all, it is claimed that they help improve communication between parents and professionals, thus allowing the former to be more autonomous and empowered in the medical encounter (Campbell and Halleran, 1993: 401; Davies, 1999a: 243; Jeffs and Harris, 1993: 1424; Jeffs *et al.*, 1994: 248)

More empowered parents it is argued, will remember important things such as advice given, appointments and so forth, because the information is agreed in partnership and then subsequently written down (Charles, 1994: 272; Saffin and MacFarlane, 1991: 251). Parents are enabled to monitor closely and in more detail, their child's developmental progress (Campbell and Halleran, 1993: 403; Jeffs *et al.*, 1994: 248; Saffin and MacFarlane, 1991: 250), and this helps increase and develop parental knowledge, confidence and parenting skills (Charles, 1994: 270-1).

In particular, the parent-held records are thought to provide a useful resource for parents with limited access to health information e.g. semi-literate or travelling families (see O'Flaherty *et al.*, 1987; Campbell and Halleran, 1993; Charles, 1994), for families who seek a more portable record to ensure continuity of care e.g. itinerant or nomadic families (see Miller, 1990; McMaster *et al.*, 1996) and for children with special needs or disabilities (see Moore, 2001).

The sections of the PHCHR in Cormack *et al.*'s (1998) Cambridge study which parents considered most useful were: immunisation, health promotion, help and advice, weight records, professionals' records, and developmental milestones. Likewise, Volkmer *et al.*'s (1993: 150) and Jeffs *et al.*'s (1994: 251) research in South Australia discovered that parents valued, and found most useful, the parts of the record on immunization, growth charts, progress notes and health checks. Similarly, parents in Davies' (1999a: 247) Pembrokeshire study found the health information/promotion material contained within the

record useful, so too the facility for parents to record their own observations about the child's overall health and development.

However, not all of the parental attitude studies toward the PHCHR uncovered completely positive findings. Work by Talbot (<http://www.healthpro.org.uk/publications/35.html>), for example, highlights the complex text contained within many of the PHCHR booklets. Some of the criticisms relate to practical aspects of the PHCHR's presentation and layout. Parents in Campbell and Halleran's (1993: 401) study, for example, complained that there was a lack of space in the PHCHR to record thorough and exhaustive findings. Likewise, parents in Miller's (1990: 1046) research would have preferred a smaller record than the A4 size Castlemead version that was issued. Moreover, numerous parents in Volkmer *et al*'s (1993: 151) study complained that health professionals had not explained the purpose and function of the PHCHR booklet particularly well. Parents also felt that the book could have been better organized and laid out. As Volkmer *et al* (ibid: 152) state: "the most common request was for the different sections of the PHR to be made more readily identifiable by using section 'markers'. Other requests were for resuscitation procedures to be included and provision for dental records".

On a less pragmatic level, Davies' (1999a: 246) research found that only 50% of parents interviewed felt the PHCHR actually enhanced their overall involvement in their child's healthcare. Further, a research site analysis conducted by Davies revealed that while fifty per cent of parents at site A took the PHCHR with them to the GP, a mere thirty-one per cent of parents at site B brought the record to their local surgery (ibid: 246). Moreover, of those parents who did utilise the record in the GP encounter, less than a quarter felt that the PHCHR aided the consultation process. Indeed, over half the parents believed the PHCHR did *not* benefit them when communicating with the doctor. Regrettably, Davies' study does not ascertain the reasons for such poor parent compliance statistics. It could be that parents did not value the booklet, hence failed to take it with them (Campbell and Halleran, 1993: 401); or simply that they forgot it (ibid: 401). Alternatively, perhaps it has something to do with how medical professionals view and respond to the PHCHR. Hence it is to an examination of professional attitude towards the PHCHR that this review now turns.

2.3 Health visitors' use of PHCHRs

Studies examining health visitors' perceptions on PHCHR are generally very positive, with the majority finding that practitioners value and encourage the introduction of parent-held family health records into the public health sphere (MacFarlane and Saffin, 1990; Jackson, 1991; Charles, 1994: 272; Davies, 1999a: 248). As Davies (1999b: 382) states: "[health visitors] who have used the PHCHR felt it promoted a more honest exchange of views, which helped to develop a trusting and mutually respectful relationship with parents as well as increasing parents' knowledge of their child's health and development".

Indeed, many health visitors see PHCHRs, (i.e. the use of a *single* parent-held record), as a way of addressing a number of child protection loopholes in

the present public health sphere, of implementing the current government rhetoric on partnership working and creating egalitarian relationships built on trust and honesty, and of renewing an outdated, cumbersome and repetitive record duplication system (Charles, 1994: 271; Davies, 1999a: 242; 1999b: 384&6). Furthermore, because the single record would result in less paperwork and copious note taking, the health visitors in Davies' (ibid: 386) study believed that more time could be devoted to patient care and health information.

As for using PHCHRs effectively, efficiently and on a frequent basis, Cormack *et al's* (1998) research, for example, found that over 90% of health visitors surveyed and wrote in the PHCHR regularly and competently. These figures are backed up by earlier research conducted by MacFarlane and Saffin (1990), and recent research administered by Emond *et al* (1995: 323) and Davies (1999a: 246). A review undertaken by Argyll and Clyde Health Board in 2000, however, found only 41% of health visitors agreeing that they recorded each client contact, with reasons given for non-completion ranging from forgotten books to the fact that some contacts were made over the 'phone or in the street, or were so fleeting and trivial that they were not worth recording in the document when space was so limited anyway.

One issue which bedevils the use of the PHCHR, however, is that of whether health visitors should retain a parallel (and unseen) health record on each child, to guard against accidental or deliberate loss of the record, especially in cases where there may be child protection issues. Because some families require more help and support from health visitors, Charles (1996) has suggested the use of a 'health visiting index card' to complement parent-held records. This 'index card' would serve not as a parallel, confidential family surveillance record, but rather as a record to remind the health visitor of the particular family's situation (i.e. previous goals set, immunisations taken etc.), profile community needs, identify health visitor training needs and measure the health visitor's and family's performance over time. It is, however, also designed to cater for children whose poor health or social circumstances may require additional and more detailed documentation e.g. those suffering from serious illness, disability or those who are in need of protection and regular supervision (ibid: 101). In order to maintain the 'partnership' approach to health visiting and childcare, this supplementary documentation is to be agreed in collaboration with parents, with the latter able to access and view the index card at any time.

Since the implementation of the PHCHR, several Health Care Trusts across the south of England have since discovered the need to maintain parallel records in the best interests of children (Knowles *et al*, 1999: 253). As a consequence, the Joint Professional Record (JPR) has been created. The JPR is a single, clinic-held parallel record designed for multidisciplinary use. Despite the fact that this record apparently goes against and conflicts with the PHCHR's open, honest 'partnership' approach to childcare, Knowles *et al* found that the JPR proved a 'useful adjunct' to clinical supervision in the arena of child protection and was: "appropriately used for children in need of protection and those with 'special needs'" (ibid: 253).

According to Knowles *et al.* (ibid: 261), the JPR is not only a successful innovation, but is also a safe and accepted form of multi-agency documentation. Indeed, partnerships and alliances have been formed between various practitioners working across the public health sphere. Moreover, in order to maintain partnerships with parents (a crucial component of the PHCHR) and to conform to the DOH's (1990) 'Access to Health Records Act', health professionals must – before the document is established – notify and explain to parents the purpose of JPR; seek their approval and permission; and remind them that they can view the record at any time (ibid: 262-3).

The implicit acknowledgement in the above that not all parents will view health visiting and the PHCHR with unalloyed joy, despite the rhetoric on empowerment and sharing brings us up against the hard fact that health visitors using such instruments will often be called upon to make some very hard choices in the field. A further key finding arising from Whitney's study was the need for health visitors to receive not only short-term training, but also long-term focused support, supervision and information from management and steering groups across the health board (ibid: 139&40). Health visitors, they found, wanted to meet on a regular basis with their peers and public health management, in order to discuss pertinent issues and novel developments as part of an overall 'team'. As Emms and Phillips (ibid: 140) write: "[Overall,] it is important that a range of support measures are available to meet the differing needs of individual health visitors".

2.4 General Practitioners' attitudes to PHCHRs

Whilst the *majority* of evidence shows that parents (and health visitors) continue to update PHCHRs and reliably present them at primary health care visits, doctors, in contrast, appear more 'reluctant users' of PHCHRs (O'Flaherty *et al.*, 1987: 1152&4; Emond *et al.*, 1995: 323). Robertson's (2002) report of a small study in Fife reviewing the use of the Red Book found that over a quarter of GPs responding would rather not have to write in the Red Book at all. Cormack *et al.* (1998: 378), for example, found in their study that only 30% of GPs recorded information within the document on a regular basis. Moreover, almost half of the parents interviewed claimed that the family doctor *never* used the PHCHR. As they state: "even when reminded, doctors still only wrote in the PHCHR on a minority of occasions" (ibid: 378; see also Campbell and Halleran, 1993: 404-5). Similarly, Charles (1994: 271) discovered that only 60% of GPs with experience of using a PHCHR 'liked' and 'valued' it. Furthermore, international research conducted by O'Flaherty *et al.* (1987: 1153) found that of the 167 PHCHRs distributed, only a mere eighteen per cent contained notes made by a doctor. In order to remedy this situation, Cormack *et al.* (1998: 375) suggest that, "an enhanced explanation about the value of the PHCHR at the time of giving it out, with particular emphasis on parental recording of events, illness and outpatient visits, may increase its value to professionals, particularly doctors, and empower parents to ask doctors to record in it". They also believe that if the PHCHR is to be a productive development then, "the general level of awareness of its value needs to be raised with doctors" (ibid: 379).

Negative comments from the GPs in Charles' (1994: 271) study, for example, tended to refer to the parent-held record as being too bulky and time consuming, generating additional clerical paperwork. GPs in Campbell and Halleran's (1993: 401) research had difficulty finding the correct page, felt there was insufficient space to record detailed findings and they complained about the extra time it took to record data in the PHCHR. Moreover, Charles also found that GPs were particularly perturbed about recording 'sensitive information' in the PHCHR (i.e. concerns regarding non-accidental injury) and with concomitant issues of confidentiality (ibid: 271; see also Campbell and Halleran, 1993: 401). Similarly, many GPs in Davies' (1999b: 384) study were opposed to parents having access to their notes, "believing it would change the way GPs expressed themselves in the notes".

Furthermore, MacFarlane and Saffin (1990: 108) discovered that the GPs in their research felt that parents may become 'unnecessarily' worried about some of the information recorded in the booklet or interpret the information wrongly. In addition, Davies (1999a: 243; 1999b: 386) points out that many GPs in her study were concerned that parents (particularly single parents), especially those with poor educational qualifications or from the lower social classes, would lose or abuse the record. According to Davies (ibid: 243), however, this prejudicial fear was unfounded as loss rates in her study were extremely low amongst the lower social classes and generally involved mitigating circumstances, such as fire and theft as opposed to carelessness, deliberate misplacement or neglect. These findings are reinforced by previous research conducted by Lakhani *et al.* (1984), Saffin (1986), O'Flaherty *et al.* (1987), Miller (1990), Campbell and Halleran (1993) and Dearlove and Illingworth (1999). Indeed as Davies (ibid: 248) puts it, "the use of the record was not affected by social class factors, which debunks some of the prevalent myths and misconceptions that abound. The record is accessible and appropriate for all parents regardless of social class, ethnicity and culture". Emond *et al.*'s (1995) research, however, found that parents from deprived backgrounds either forgot their books more often than those from affluent areas, or were less assertive in persuading health professionals to write in the records.

Current GP training pays attention to the need to take into account lay perspectives and to engage patients in as active a way as possible, but the professional relationship of the GP to the patient is still very different from that of the nurse or health visitor. However previously, a reason given why many GPs were so disinclined to engage and participate in the maintenance of PHCHR's, was that many were unwilling to relinquish their traditional role, status and position of power in the medical encounter (Davies, 1999b: 382&6).

2.5 Summary

Past and current use of the existing parent held record can give significant clues as to the ways in which the Family Health Plan concept might be developed and its use supported. From the evidence reviewed in this chapter it is clear that parents are generally keen in principle to hold their child's health record. In addition to general evidence that it increases their involvement in

and responsibility for their child's health, the document acts as an important record and also a source of health advice and information. Various adjustments to the design and presentation of the record are suggested from different studies, but a more important message from the research reviewed is that the system is undermined not by any feature of the Red Book itself, but by aspects of the context in which it is introduced and used. Thus poor explanation at the start regarding the purpose and use of the PHCHR and subsequent lack of consistency in the way the document is used by different professionals involved with the child's health undermine its claim to be a complete record and result in parents themselves apparently ceasing to see it as important to present it on each occasion or to write in it and update it.

Health visitors too are seen to be comfortable with the PHCHR. It fits the style of working that they have developed with their client group. They are relatively confident about discussing issues with parents and agreeing a record of the encounter, which will appear in the PHCHR. The difficulties of working with 'at-risk' children and families and the need for a professional record to be kept in parallel to the PHCHR have generally been tackled and dealt with by the Health Visitor service. Whilst the keeping of such a parallel record would seem to undermine in principle the notion of the parent's responsibility for the child health record, it is hard to deny the necessity for such arrangements. The solution reached through the use of the JPR seems eminently sensible and preserves the major principle that parent should be cognisant of comments recorded about them and their children.

The utility of the Red Book is clearly undermined however, by its strong identification with the Health Visitor Service that makes other health service or family support professionals reluctant to use it. This review highlighted GPs as reluctant users of the system. For them the red Book duplicates or adds to their existing commitment to keep a record of the patient encounter. Moreover the very different relationship described between the patient or parent and the professional, clearly impedes the recording and assessment of the child's health (or family circumstances which affect health). GPs do not work from the same set of assumptions about the function of records and sharing/allowing access to them.

What lessons then can be learnt from these findings that can be carried forward into the ensuing discussion on Family Health Plans? First, it must be noted that the existing parent-held record is just that – a record and an assessment, as well as a source of information. It is **not** a planning document. That aside, it must be seen as a very important first step in the establishment of a more consensual form of medical record-making between health professional and patient/parent.

The close identification of the Red Book with the Health Visitor service is both its strength and its weakness. It is a strength because, despite the variety of different formats throughout the country, the PHCHR would seem to be utilised within a fairly consensual professional understanding of appropriate forms of interaction between health visitor and client. It is a weakness in as much as other professionals involved with child health identify the document

as the exclusive property of the service, and thus do not collaborate in keeping it as a complete record, which, of itself, would do most to convince parents to use it consistently.

3. Family Health Plans

3.1 What is a Family Health Plan?

Recent Scottish Executive documents such as *Nursing For Health* (2001: 43-5) have increasingly recommended the introduction and implementation of Family Health Plans throughout Scottish society, as a way of addressing, tackling and reducing the number of families suffering from poor health. Similarly, south of the border, the 1999 Government White Paper, *Saving Lives: Our Healthier Nation* advised that health visitors develop a more 'family-centred' public health role. More specifically, the aforementioned report recommended that health visitors should increasingly employ plans agreed in partnership with families, in order to address effectively the latter's health and parenting needs (Department of Health, 1999: 133).

Very simply, a Family Health Plan (FHP) can be defined as a core instrument for enabling a family to think much more critically and actively about their health, social and communal needs. Indeed a recent Department of Health (DOH) FHP Reference Group (2000) defined the FHP as:

A tool that enables a family to identify their own health and parenting needs and plan, in partnership with the health visitor, how these needs can be met most effectively at a public health and an individual level (cited in Garside, 2001: 22).

Emphasis is often placed on these plans as being a vehicle for health promotion, for empowerment of patients and for facilitating joint working between professionals. However as yet, the evidence for the effectiveness of these schemes is mixed (O'Flaherty 1987; Jeffs *et al* 1994; Safin and MacFarlane; Campbell and Halleran 1993). Policy rhetoric implies that such plans may be of particular benefit to families defined as excluded, such as families with disabled children (Moore 2001), traveller families, families from ethnic minority groups and highly mobile families (McMaster *et al* 2000). However, some commentators have argued the converse, namely that the record will be less useful for lower socio-economic groups and those with chaotic lifestyles (Edmond 1995).

Health authorities have responded to these ideas at different rates and in different ways, so there is a proliferation of different forms of record keeping throughout the UK. Within Scotland some health authorities have already reviewed their parent held records of child health and have begun to press ahead with reforms that bring them close to FHPs; in others there are no signs of activity in this vein.

It seems likely, given these variations in the form and development of such schemes that a big element of their success or failure will relate to how such plans are viewed by different partners in the process, yet relatively little intensive illuminative qualitative data has been published on this aspect.

According to the Department of Health's *Health Visitor Practice Development Resource Pack (HVPDRP)* (2001: 21), a typical FHP should identify:

- The family's needs as they (i.e. the family) perceive them
- How the family wishes to address these needs
- A health action plan for the family, including support to be provided by the health visitor and others e.g. schools, social work departments, the police, housing departments, community development workers, local government etc
- What has been achieved.

As well as being a practical tool, providing a sound structure for family-based work, information from the booklets can also contribute to profiling and needs assessment, so that health visiting resources may be targeted and adapted to reach those in most need (Garside, 2001: 6). Indeed, as Garside (2001b: 1) points out, "information about family health will complement community health needs assessment, contributing to a more comprehensive picture of overall, local need."

At the present time, there is no single, universally agreed template as to what a FHP should look like. Rather, there are a number of formulations, models and designs circulating in the public health literature, which document and detail the central characteristics of a FHP. A vision of what it is, or what it could be, for example, is contained within the Scottish Executive's (2001) report *Nursing for Health*, The Department of Health's (2001) *HVPDRP*, Garside's (2001) *Family Health Plans: Working in Partnership to Improve Health* and Hall's (2002) *Health for All Children (4th edition)*. According to the Department of Health's *HVPDRP* (2001: 21-3), for example, a FHP should generally be comprised of the following key components:

- It should contain and utilise an open-ended question format, so that parents are encouraged to actively participate in the health visitor consultation and to fully develop and expand upon their responses
- It should be presented, wherever possible, in easy to follow language, headings, diagrams and illustrations, so as to give the FHP a 'user friendly' and 'straightforward' feel
- It should provide robust health advice, information and promotion material, and a wealth of useful contact numbers, postal addresses and Internet web sites etc
- It should ensure its users complete confidentiality, and strictly observe and adhere to the current Data Protection Act .

More specifically, however, according to the *HVPDRP* (2001: 22) and to contributing parents, a standard FHP should include within its design and conformation, sections, information, contact numbers and references on the following topics:

Section 1

- **Family health**
- Work and employment/unemployment
- Relationships (partner, children, others)
- Stress levels/relaxation techniques

- Diet/smoking/alcohol
- Illness
- Money
- Contraception and menopause
- Disability
- Depression/anxiety/insomnia etc.
- Caring for others
- Domestic violence/abuse

Section 2

- **Community issues**
- Housing
- Public transport/traffic
- Parks and play areas
- Noise/pollution/environment
- Crime/vandalism/alcohol abuse/drugs
- Racism
- Neighbours
- Childcare/school resources
- Isolation/loneliness
- Leisure facilities
- Community clubs and centres

Section 3

- **Bringing up children**
- Bullying
- Sleeping
- Behaviour
- Feeling alone
- Children's fears and anxieties
- Child growth, intelligence and development
- Parenthood
- Feeding
- Play/shared activities
- Safety
- Preparation for school
- Your own childhood experience
- What to do when your child is unwell

Some individuals interpret the FHP as a comprehensive health record, which would imply the incorporation of the existing Red Book detail on immunisations, weight gain etc. More commonly others (e.g. Garside, 2001) view it as a planning document only, an effective vehicle for mapping out the family's health needs and requirements. Thus whilst we cannot go as far as saying that the FHP is 'all things to all men', there appear to be four possible roles for a potential FHP: as an **assessment tool**, as a **plan** for action, as a **record** of events and actions, and as a **source of general health information**. Should it attempt to perform all four functions, or should it be used simply as a planning tool alongside a revised Red book system, which accomplishes most of the other functions?

What is clear however is that the FHP is expected to embody a distinct philosophy about participation and empowerment. Thus it should be designed to be used in an interactive and collaborative fashion, whereby parents and health visitors work in tandem with each other forming a 'partnership' approach to the family's health (*HVPDRP*, 2001: 7). In this regard, it is a stage on from the customary PHCHR, as the health visitor will no longer take such an authoritative, directive and leading role in mapping the family's health. In theory, then, it encourages and demands the use and incorporation of lay knowledge, experience and expertise, allowing for greater parental input, participation and responsibility than in previous PHCHRs. Indeed, according to Garside (2001: 15) a FHP, "enables the family to identify their own health status rather than be led by the health visitor's agenda". The philosophy inherent in the use of the FHP is that parents will become increasingly empowered and autonomous through closer contact, communication and links with their general practitioner (GP) and health visitor. The FHP, therefore, is designed to encourage greater 'openness' and 'trust' between the professional and the parent, so that a 'respectful relationship' can be built and maintained (*ibid*: 35). A concomitant of this is that 'secret'; confidential or parallel records will become a thing of the past (*Nursing For Health*, 2001: 44).

The FHP is not envisaged as coming in one standardised format. Rather, it is designed to be flexible, personalised and tailored to meet the specific needs and requirements of different and diverse families (*HVPDRP*, 2001: 7). This lack of a distinguishable structure, however, has led to the FHP's confusing and, at times, contradictory appearance and referencing in the public health literature.

Most importantly, in contrast to the standard PHCHR, the FHP will no longer focus on the health of a single child (*HVPDRP*, 2001: 14). Rather, it is to take account of a child's wider/extended family e.g. brothers and sisters, parents, grandparents etc, and look at how the aforementioned actors' health, lifestyles, social situation and life circumstances impinge upon the health and well being of the child, and the cohesion of the overall community (*Nursing for Health*, 2001: 30&45). Hence, the FHP will enable the health visitor to examine the child's health in the context of the broader family. It will also be a document which takes a far more holistic view of child health than previous child health records, thus allowing parents the opportunity to raise concerns about the wider social issues which may be having an adverse affect on the family's health e.g. crime, housing, unemployment, public transport, school resources, local pollution etc. (*HVPDRP*, 2001: 14&33). In other words, although health will be the central concern of the FHP and health visitor, broader issues will also be raised and considered in the parent/health visitor interaction, recorded in the FHP and dealt with by the health visitor. Thus the FHP is going to be a document that includes (and indeed attempts to address, deal with and tackle) community and social issues, as well as confronting the family's specific bio-medical health needs.

As a consequence of the above developments, the role of the health visitor will shortly diversify from that of a public health practitioner, to that of a multi-

disciplinary, social-community liaison officer (*Nursing for Health*, 2001: 23-5). Somewhat inevitably, the health visitor will have to take on many new roles and responsibilities; with a significant rise in workload and day-to-day obligations, not to mention increased individual, family and community pressures (Garside, 2001: 30). Moreover, the increased emphasis on 'partnership working' will also require that health visitors develop and expand upon their inter-personal communicational skills, and receive further training for dealing increasingly with patient, as opposed to practitioner-led, consultations (Garside, 2001: 6).¹

A further difference between the FHP and the basic PHCHR is that the former is not so much a record of previous illnesses or immunisations that have occurred through the child's life, but more a health promotion and planning document. Indeed, the FHP is specifically designed to deliver pertinent health information, so as to educate, empower and assist parents in the rearing and raising of healthy children (*Nursing for Health*, 2001: 44). The central idea or rationale behind the FHP, therefore, is that parents can increasingly take greater responsibility for the health of the family, primarily via the health information and knowledge provided by the FHP, but also through health visitor consultations. The FHP, it is suggested, provides not only a number of health promotion leaflets, advice, instruction and contact numbers, but also acts as a user-friendly, 'family health bible' for continuous and life long consultation. In short, the FHP is an advanced health schedule/diary, which enables parents to follow and pursue previously agreed strategies, goals and 'courses of action', in order to improve and maintain their family's overall health (ibid: 29&44).

An additional variation between FHPs and customary PHCHRs, is that the former is conceptualised as a 'lifetime document' to be maintained over and throughout the life course (*Nursing for Health*, 2001: 38).² Standard PHCHRs, in contrast, typically cease once a child reaches the age of five. Schools have traditionally transferred information from the 0-5 PHCHRs, creating, maintaining and holding a school child health record. Hence in previous years, parents have not held a record documenting their child's health after the age of five; this, as previously mentioned, has normally been kept and stored on file within the child's school. Nor have they possessed a parent-held family plan for maintaining, understanding and improving the family's overall health. This will all change with the introduction of FHPs, however, as the family will be the sole owner and keeper of the document (ibid: 44). Although the health visitor will generally stop his/her association with a family once a child reaches the age of five (a role to be taken on by teachers and school nurses), the idea is that the FHP will continue not only as a document for recording, gathering

¹ According to Garside (2001: 13), the skills that health visitors need to develop are those of: "communication, reflection and self-awareness, to be non-judgemental and to have an understanding of the issues of power and control". In addition, Garside (2001: 10) recommends that health visitors have leadership training, and are taught disciplines such as management, epidemiology and community development.

² This development is heavily influenced by current government rhetoric, which advocates a 'life course approach to health' (*Nursing for Health*, 2001: 12).

and storing important health data, but will also act as an informative reference point and a health planning/scheduling manual.

3.2 Summary and evaluation of the current pilot projects in operation

We turn now to look at a number of FHP projects within Britain at various stages of development. It is not possible to estimate exactly how many health boards in Britain (or even in Scotland) are developing family health plans. Problems in making such an estimate reside in the fact that many Boards are acting under their own initiative and aim to produce materials for practice; few or which are written up for publication or properly evaluated. Secondly, many of these informal initiatives, when finally tracked down, turn out to be single record sheets, are not patient-held, and so on. Few meet all the criteria previously outlined.

Within Scotland the '*Starting Well*' health demonstration project, and the WHO's rural *Scottish Family Health Nurse Project* are briefly discussed. Both interventions, however, are still underway and therefore incompletely evaluated. Argyll and Clydes' *Family Health Assessment Tool* is also examined. Again this is only just launched, with no opportunity yet for evaluation. One of the best-evaluated pilots has taken place in England (i.e. Sheffield Health Action Zone's (HAZ) '*Health and Your Family*' project) and this is examined in some depth.

In Scotland, the largest FHP project currently in operation is Glasgow's '*Starting Well Health Demonstration Project*' (SWHDP). As a core aim of the Scottish Executive's social justice agenda, the three-year, three million pound scheme is attempting to 'lead the way' in public health visiting by achieving sustained improvement in child and family health, and by acting as a fundamental teaching resource for the rest of Scotland (Starting Well Health Demonstration Project: proposal summary, 2000: 12). Led by the Glasgow Healthy City Partnership, *Starting Well* is endeavouring to demonstrate that child health can be improved and ameliorated through a range of services which support families, and provide them with access to enhanced community-based resources (ibid: 4). The *Starting Well* initiative is, in the period leading up to birth and throughout the first 5 years of childhood, also attempting to develop and deliver the best service in both health promotion and child protection.

In order to achieve these goals and to tackle general health inequalities between rich and poor, families from some of Glasgow's most deprived areas are getting extra support and their own personalised *Starting Well* Family Health Plan. The project has also recruited additional health visitors, as well as employing a number of lay health support workers from neighbouring local communities. Together, the two teams are focussing on: intensive home-based health visiting; providing parents with advice, support and education on parenting skills and health-related behaviours; creating extra provision and a strengthened network of community-based support services for parents and their children. Goals and targets for improving family health are mutually agreed among health visitors, lay health support workers and individual families, and are set in, and articulated through, a tailor-made Family Health

Plan. The central aims of the SWHDP FHP as set out in the 2001/02 Annual Report are:

- To provide a range of opportunities for the promotion of young children's health
- To reduce the adverse consequences of risk factors on children's health and well being
- To provide a comprehensive case record of family intervention
- To provide a detailed record of family assessment and goals and, additionally, an extensive record of family involvement with statutory, voluntary and community-based organisations
- To improve parents' self esteem, mental health, confidence, sense of empowerment and sense of achievement in their parenting role
- To enhance parents' knowledge and understanding of key issues of parenting and child development
- To increase parents' skills in dealing with the fundamental issues of child rearing
- To increase the support available for parents in addressing adverse life circumstances, such as low income and poor skills base
- To increase the ability of parents to access local services and agencies that can help them address the diverse needs associated with disadvantaged communities.

(SWHDP: *Annual Report 2000/01*, 2002: 1, 6&10)

The *Starting Well* plan is complex in structure. The questions asked in the document are closed rather than open-ended, and it uses terminology that would not be understood by the layperson. Its general layout and design indicates that this is a document in which the health professional will lead the discussion and enter the data. For example, much of the document utilises computerised codes, which the average family could not decipher. Families who are semi-literate or from non-standard cultural and ethnic backgrounds, would struggle to read or interpret this FHP document without professional help.

One of the principal functions of this FHP is to provide the intervention team with the sorts of data that help them to evaluate progress against goals (since this is a demonstration project). For this reason, the *Starting Well* FHP is more of a tool used to collect information on families and to monitor and record their progress (i.e. to examine whether families are achieving the goals that they have been set), than an empowering, parent-held health promotion document. Evidence of this assertion can be found in the *SW Annual Report 2000/01* that states:

“The Family Health Plan offers the opportunity to examine a range of demographic and practice-based variables, including:

- Detailed information on each family
- Content of visits
- Uptake of services and goal achievement” (2002: 17).

The *Starting Well* Health Demonstration Project FHP, therefore, is a more professionally led and created document. It encourages some goal setting and planning, but the document is not patient-held and contains no health promotion advice, contact numbers or references etc.

A further Scottish scheme currently being piloted in the Highlands, Western Isles and Orkney is the World Health Organisation's (WHO) *Family Health Nurse Project* (FHNP) (commenced February 2001). 'Family Health Nursing' is a concept developed by the WHO Europe and represents a new model for community nursing practice. Very simply, the FHN role combines caring for those who are ill, with a concomitant assessment of the whole family's health. Moreover, FHN is meant to perform public health activities using a 'life course' (Whyte, 1997) perspective.

Funded by the Scottish Executive, and currently under evaluation by Dr Bernice West of the Robert Gordon University, the two-year project broadly aims to test the Family Health Nurse (FHN) model as a means of delivering community nursing services in remote and rural areas of Scotland and to draw out implications from the study's findings for the future provision of education for FHNs and for the possible extension of service provision to other areas of Scotland, including urban areas. Not surprisingly the project has also developed a family health profile and plan of its own. This document, like that developed in *Starting Well*, is not apparently intended as a patient-held record. Its format and language are professional. Though some parts of the charts (the genogram, which outlines the family structure, and the ecomap, a tool which provides a visual representation of the contact family members have with those outside the immediate family) could clearly only be drawn with the close collaboration of the patient or family member, they both represent practitioner-led exercises. A checklist of family issues is incorporated with four sub domains: environmental and community, psychosocial, physiological and health behaviour/lifestyle. Whilst these in themselves carry neutral labels, by the time they are transferred to the pages of the family health plan itself; they have become identified as 'problem/issue number'. The FHP developed here would appear to take each problem singly, logging it according to type and then producing a set of agreed actions which both the nurse and the family member are required to sign, though it is unclear whether the signing happens at the point of agreeing the action or at the optimistically entitled 'completion date'.

A third scheme examined briefly here emanates from a review undertaken by Argyll and Clyde Health Board in 2000 of their health visitor documentation. At the time the personal child health record was in use in the area, as was a rudimentary 'family health assessment form' and a health visiting index card. The family health assessment form was only used for all clients by less than a third of health visitors. Only 8% of those surveyed felt that the tool was either essential or very useful; 42% felt that it was not at all useful. Some health visitors felt that the tool gave a clear holistic approach to care and was a much needed piece of work. Others felt it was particularly useful for vulnerable families. However, too much jargon and a long-winded form were criticised. The form was also seen as time-consuming to complete, and also

as too cross-sectional and not good at capturing the circumstances of family life which changed over time. Some health visitors disliked the intrusive nature of the document and felt that clients were threatened by being asked to sign a 'contract'.

Following this review a revised family health assessment tool was designed and piloted by practitioners and has just recently been launched Board-wide. It consists of a single sheet of A4 printed on both sides. On the first side a simple 5x4 table encourage the identification of factors affecting health, supports, identified needs and plan and health promotion for each of five different zones of the patient's life. The back of the sheet simply leaves space for an evaluation and summary and for a listing of priorities agreed with the family. Both client and health visitor sign the form.

The guidelines for use with the form identify the plan as using a theoretical model based on June Clark's model which is in turn based on Newman's systems model, crucial characteristics of which are:

- It incorporates the health visitor's crucial focus on primary, secondary and tertiary prevention
- It identifies the physical, emotional, environmental and lifestyle factors which may affect the family
- It recognises the support available
- It identifies unmet need
- Planned actions can be recorded in partnership with the family
- Change can be effected, including any health education or health promotion/improvement activities needed to achieve this.

The new document certainly answers the earlier calls of the critics for a simple document with less intimidating jargon, and it also appears more user-friendly in allowing the client to identify supports as well as problems. The document is intended, however, for completion within the first four months of contact, according to the guidance notes, and it is hard to see how the document can be adapted to take into account changing circumstances without going through the process again.

For all three of the above Scottish initiatives piloting is still underway. Proper evaluation of the planning documents - taking into account both professional and parent perspectives - will no doubt be part of the evaluation of all these schemes. Data from these evaluations will be vital in making recommendations about appropriate ways forward for the development of Family Health Plans in Scotland. In the interim, one of the few FHP schemes to be piloted and fully evaluated is discussed below.

In line with the recommendations proposed in *Saving Lives: Our Healthier Nation* (DOH, 1999), Sheffield Health Action Zone commissioned a pilot FHP under the guidance and leadership of Sheffield health visitor, Mary Garside (2001). Influenced by and drawing on an earlier prototype scheme piloted in Rotherham, the Sheffield project involved parents and health visitors in the joint creation and development of 'Health and Your Family' – a FHP booklet

that was piloted in a deprived, multi-cultural area of Sheffield (Garside, 2001: 34). Key personnel in statutory and voluntary organisations, locally and nationally, were consulted, and a steering group of community members and local workers was initiated to advise, instruct and support the development of the FHP. Parents' views on how family health needs can be better identified and how parents can be more empowered to ameliorate and enhance their family's health, were sought through four focus groups (ibid: 5). Three subsequent workshops – made up of parents from the focus groups and health visitors working in the locality – explored the issues of partnership working, the role of the health visitor and putting Family Health Plans into practice. The information gleaned from these workshops, and from a DOH Working Group on the development of FHPs, was then used to inform and progress the design and content of a local FHP tool. The booklet, 'Health and Your Family' was created and subsequently piloted by health visitors and families in the targeted area. Relatively simple in both design and content, the booklet nevertheless encompasses all aspects of health and parenting, offering families the chance to raise and discuss issues relevant to them (ibid: 6).

The document 'Health and Your Family' offers a holistic view of health, acknowledging the social, emotional, physical and environmental determinants, as well as considering the specific parenting needs of those bringing up children (Garside, 2001: 25). It also enables health visitors to target their services more competently and effectively, and to gather family health information so as to contribute to community needs assessment (ibid: 6). The structure of 'Health and Your Family' is user-friendly in that it employs an open-ended question format. This is done so as to provoke discussion, but also to encourage parents to expand on and indeed develop responses.

Overall, the study found three main advantages with the FHP:

- women particularly welcomed the FHP as it enabled them to discuss and focus on their *own*, as well as their family's, health
- the FHP helped stimulate and develop discussion around health issues that would not otherwise have been raised. In other words, difficult health issues were 'normalised' through their inclusion in the FHP
- health visitors felt they were able to explain their role to families more effectively with the FHP (Garside, 2001: 6&30-1).

Despite these positive attributes, however, the Sheffield HAZ FHP is simply a planning tool, not a recording or assessment document, or one containing information and advice. As such, it would need to be used in a complementary way alongside a more traditional parent-held record. It leaves, for example, no room for parents to record any serious illnesses or immunisations that the family have had. Moreover, it contains no health promotion information, advice, references or contact numbers. The booklet is also insufficient for a family being monitored regularly by the health visitor (i.e. every two to three weeks). In addition, lack of time and some unspecified 'local conditions' meant that the pilot was limited to a particularly small white sample. This meant that the project's overall effectiveness could not be

generalised to the population or adequately assessed, and its relevance to all families, particularly to black and ethnic minority groups, was left undiscovered (ibid: 35). Indeed, regrettably, the FHP was *not* piloted amongst any black or ethnic minority families (ibid: 6&28). Nonetheless, the project not only identified new areas requiring further research, but also put forward a number of recommendations for health visitors, FHP designs and for future FHP studies. The most important of these were:

- Health visitors should receive more rigorous training in 'partnership working' and self-reflection. They should also develop and refine both their public health approaches to family health and their inter-personal communication skills
- A comprehensive section with useful telephone numbers and contact addresses of local facilities is required in any forthcoming FHP
- Further pilot studies need to be undertaken concentrating on localities with black and ethnic minority families
- Greater consultation and collaboration with other agencies on the management of identified community health issues is required
- More research is required to explore how data from FHPs such as 'Health and Your Family' can be collated for community and individual profiling
- The design and content of future FHPs must take into account the recommendations of the DOH Reference Group, and the findings of the Sheffield project and other similar schemes
- A national network set up for FHP support, advice, networking and evaluation must be implemented.

A subsequent project has begun to implement the Sheffield FHP within the four English DOH 'whole system change' demonstration sites established as part of the DOH Health Visitor and School Nurse Development Programme. A report issued in October 2002 reports on the first phase of this implementation in two sites. Results continue to be encouraging with both families and health visitors broadly in favour of the innovation. It seems clear that no definitive verdict on the utility of FHPs, however, will emerge whilst the public health role of health visitors and school nurses is still developing. Garside concludes that the use of the planning tool does require new skills and new types of judgement by the professional, and does require the public to develop a reciprocal understanding of these new professional roles before they are likely to want to explore family health issues in depth. She also is clear that health visitors will need to be unburdened from routine work in order to explore new ways of working, and that this will have to be supported by managers, Primary Care Trusts and other agencies.

Garside is also explicit that not all families will need or want to use a family health plan, and that the timing of their introduction to families will vary quite significantly, depending on family circumstances. Collecting data through the use of the tool, especially on community or environmental issues, can seem pointless to some practitioners in the field unless all health visitors in an area are using FHPs and sharing information to some degree, so that it opens up the possibility of taking issues forward in multi-agency forums.

3.3 Summary

In this chapter we have reviewed the templates given for the design of family health plans in a variety of policy documents in England and Scotland, and looked at how they differ from existing parent-held records. It is clear that family health plans are seen as a tool for changing the relationship between health visitors and their client group, aiming to empower the parent and make her/him take greater responsibility for assessing and planning the health of children. The style of the document is designed to encourage the parent to take a holistic view of health which takes into account the situation and dynamics of the whole family, not just the individual child, and which also takes account of community and environmental issues. If the parent's understanding is to change, so too must the health visitor's. Their professional role becomes one of facilitator, supporter and advocate as much as assessor and record keeper. The developing public health role of the health visitor is emphasised through the use of the FHP as a needs assessment tool in communities. The templates would also seem to suggest that the FHP should be client-held and that the discussion should be led by the client wherever possible, rather than professionally led. Although there has been discussion in the literature of whether the FHP should become an all-purpose document replacing the Red Book, most discussion is focused around the notion of the FHP as a complementary tool, with health records continuing to be held in the current way.

The second part of this chapter looked then at existing attempts to implement the FHP notion. The caveats that must be evident when reviewing these are that, firstly, many are still at the piloting or developmental stage and - as yet - insufficiently evaluated, and, secondly, that several have been developed within settings where they operate almost as a research tool rather than a practice document (e.g. designed primarily to demonstrate the effectiveness of an intervention). They are therefore not client-held or even client led in some cases, though they are clearly documents designed to assess and plan changes and actions for the future of the child or family member. The closest to the template is probably that developed in practice within Argyll and Clyde Health Board. This revised FHP format is currently being trialled within the Board area. Slightly further along in terms of trialling and review is the Family Health Plan developed in the Sheffield Health Action Zone and now being rolled out in five 'whole system change' demonstration sites throughout England. Parental and practitioner views are constantly being gathered as this trial progresses, producing data on the types of support needed to implement the FHP as well as on the format of the document itself. Significantly, however, even this tranche of trials will not satisfactorily assess the use of the document with non-English speakers.

4. Findings

This chapter presents the findings from both the study of parent views and the study undertaken of people working within the health services in various roles. In the first part we look at how both groups – professionals and parents – used and regarded the current parent-held child health record (PHCHR). Clearly this gives us clues about how any new or additional form of documentation will be viewed. In the ensuing sections we look at how the interviewees regarded the introduction of a Family Health Plan. For both sets of interviewees this was inevitably something of an academic exercise, discussing a document the format and implementation of which can - as yet - only be guessed at. All quotes used in this chapter are anonymised. Full details of the sample for the interview study of both parents and practitioners are given in Appendix B.

4.1 The context

For many of those interviewed at both policy-maker and practitioner level, Family Health Plans are part of a possible future, a new facet of practice embodied in much of the new documentation and rhetoric, but of which they have no direct experience. Health professionals have therefore inevitably used their experiences with the current PHCHR to form their attitudes towards Family Health Plans. In the 15 health board areas of Scotland, all kept health visitor records and all except one (Angus district of Tayside) used a parent-held child health record. As noted in the previous sections a number of health boards have undertaken significant reviews of their Red Book material (notably Fife and Argyll and Clyde) and have produced recommendations for revised instruments which take account of practitioner and sometimes parent views of how the scheme has been operating over the last few years. In other areas attention has been paid to particular issues raised in relation to the recording aspects of the parent-held record (e.g. the specialised Traveller record developed by Dumfries and Galloway, and the work done in Ayrshire and Arran on child protection issues).

A relatively small number (less than half) have a form of family health record in operation or under development (see Appendix D for summary). These are usually simply records of the family's health status; they are not plans. In most cases they consist of a single page record of who is in the family and a brief health assessment for all. The record is held in the health visitor case notes (i.e. not by the patient/parent) and shared with the family. Both Ayrshire and Arran and Dumfries and Galloway are in the process of developing plans from these records. Argyll and Clyde has perhaps got the furthest forward in developing a simple family health plan which is currently being piloted Board-wide.

There is thus no standard method of record keeping on child and family health across Scotland. Although in theory all the various health professionals involved in child and family health should be working towards the same aim, they work in very different ways. Exchange of information is done in a very haphazard way. Although almost all of the 15 health boards use the PHCHR there are various versions of the document, and its actual use varies, with

some health visitors writing in it at each contact, whilst others document weights and immunisations only. Each of the health service interviewees in this study expressed the need for future forms of recording to be standardised across Scotland to aid use by practitioners when families move into a new area and to ensure that information is easily transferable. Most health visitors were supportive of the notion that a family health plan could and even should grow out of a revision of the existing PHCHR. It is worth noting here that health visitors did feel that they should be involved in developing a FHP format.

Almost all of the parents interviewed had experience of some form of parent-held child health record. The majority had received the most widely used PHCHR, often referred to as the 'Red Book'. Some parents had also received other forms of PHCHR when living in other countries and were able to draw comparison between these and the 'Red Book'. None had experience of being asked to take part in a family health planning exercise.

4.2 Current use of the parent held record

In this section we look at the views of parents and professionals on how the current parent-held record works for them. Did both parties like the idea of parents holding child health records? Did it improve partnership working and empower parents? Did the fact of the record being held by the parent lead to a more seamless service for the child and parent? Are there groups for whom the parent-held record is particularly advantageous or disadvantageous?

4.2.1 Do parent held records promote partnership?

The PHCHR was felt by some to encourage a partnership approach between parent and professional and was regarded as having the potential to develop more open dialogue with parents – at least in comparison to a system where notes were held entirely by the health visitor, for example. Professionals wanted parents to take more responsibility for the health and well being of their child and the PHCHR is seen as one method of promoting this.

It gives them control of what is happening. It's their child. It puts emphasis on them being responsible for their children. They are holding all the information. I try to emphasise that to the family - that they are the holders of the information. It creates that environment of sharing of information with families and about families being in charge, planning together.

Practitioner interview 18 - Lead Nurse

Others were less convinced that this was the case, and felt that families did not feel enough 'ownership' of the document.

I didn't feel it was highly regarded by families, I felt as if, yes it was there and held by them, but it was really for the health visitor when she came.

Practitioner interview 6 - Nurse Development Officer

It certainly records what are the particular issues; it looks at how families can record things that are ongoing with the child in terms of immunisation. People can add on in the wee wallet part at the back... can add on particular things. But I think the main thing around it is, it doesn't really assess the need. It is more an outline of good care and ... I really don't think it is conducive to a partnership approach with the family.

Practitioner interview 6 - Nurse Development Officer

The novelty of the Red Book appealed to most parents of a first child, and some expressed the sense of the care of the child's health being a joint enterprise:

I think both, both, because if you, eh, if you just depend on the HV to do all the stuff, but, but, hey, this is, this is my child, this is my family, so we should do this as well, that is why this is quite good, why the design is quite good, some of the information, we fill it in, some of the information the HV fill it in. But, yes, a lot of family, they leave it to the HV to do it, but I mean, in the book you can feed back how much you care for the child.

Parent 2 – rural - Chinese

4.2.2 A document used across sectors?

Interviewees, both professionals and parents, felt that the system only works really well if all health professionals are contributing to it. From parents' accounts it was clear that PHCHR were predominantly seen as a tool used by and with health visitors. When parents made contact with other health professionals it was much less likely that the PHCHR would be completed. In relation to the use of hospital services, many parents would either forget to take the PHCHR, or take it but not be asked for it, and they would not then see it as a priority to put it forward for completion.

P15: You've got the book and you give it to get it signed and say what they've done and they say that it doesn't matter... well what's the point of giving it if it doesn't matter...

Int: So it's something you would take along to the hospital?

P15: Aye, that goes everywhere

Int: Right, right,

P15: It goes in the bag if they go to their Granny's so just in case there is an accident, if they go to hospital, make sure it's there.

P15: But it doesn't get written in, I mean my son went to hospital last year and nothing got written in it

Parent 15 - Urban - White British

Equally in relation to contact with GPs, although parents often took the PHCHR with them to consultations it was rare that it would be completed.

Most parents were aware that the GP had another computer-based record to complete in relation to the consultation, which generally took priority.

Int: So, you would use the book with the Health Visitor, would you use the book with any other health professionals, like the GP or anyone else?

P2 The doctor, because my boy has a skin problem, and I talk to the doctor, and I bring along my book as well, because my Health Visitor, she obviously saw that, and she advise me to see doctor.

Int: And is the doctor quite happy to fill in the book?

P2 (seems surprised at this question) They didn't fill in the book

Int: They didn't fill in the book

P2 No, they just read it, and they fill in the information in my boy's file, in the computer. I mean they have a file, the GP, so they just put the information in the file.

Parent 2 - rural - Chinese

P7 Like I always take the red book with me, but they dinnae always write in it.

Int: So do you feel you can ask them to write in it?

P7 Well if you asked them they would probably say no, because they are writing down their own and they have got somebody else sitting waiting for their consultation you know.

Int: It just feels like it would be an extra burden?

P7 Aye. You don't want that because you appreciate they are giving you the time and space to speak to them about what is wrong.

Parent 7 – urban – white British

Parents were often surprised that other professional groups dealing with children over issues relating to their well being also tend to see the PHCHR as part of the health visitor's territory, and not for them to read or write in.

P8 We wrote in it and the health visitor wrote in it...

Int: What about other people like social workers - anything like that?

P8: No, nae social workers, they don't get to write in that.

Int: Right.

P8: They have nothing to do with that. It's the health visitor, doctor, midwife, hospital; it is to do with that, nae the social worker. Social workers are more interested in our care and the child's care.

Parent 8 - urban - white British

Lack of use of the PHCHR by health professionals other than health visitors was attributed by those working in the health service to lack of time, lack of awareness of the PHCHR scheme on the part of other health professionals and lack of assertiveness on behalf of the parent in asking for the record to be

completed. This has implications for the development of FHPs, if they are intended to be a multidisciplinary tool.

I think it's lack of awareness and also time, because appointments for GPs and for hospitals are very fixed for time. They're very focussed in their role that they are there to diagnose. They don't work the same way as us. To expect them to sit down and write that down... I think they would see it as time consuming. I'm sure they don't really know much about it either. They use their computer a lot now and have very brief notes already in the medical notes. You also have to write it in language for patients and in writing that they can read.

Practitioner interview 23 - Health Visitor

The focus group with family centre staff also demonstrated that they had no knowledge of the PHCHR. This is of particular significance as they work solely with vulnerable families whom it is hoped the introduction of the family health plan might particularly benefit. This demonstrates a lack of communication between health and social work, which is of consequence for joint working to improve the health status of vulnerable children.

Whose responsibility should it be to ensure that the PHCHR or any future record is kept in a more complete way? There are obvious difficulties if the onus is on the parent to present the record to a health professional and ask for it to be completed, so that it is at least a more complete record. The imbalance of power between doctor and patient, and the very different ways of working and relating to patients that GPs and hospital consultants were seen as having (compared to health visitors) make it unlikely that patients will feel sufficiently empowered to be the ones to make the system work.

I think parents need to be a bit more pro-active, and, you know I always said to people, Look, just open it up at the diary page, and say, "Could you fill that in?" But they are also in this kind of culture where they think the doctors know best and that I can't question and I'd better not just ask 'cos that would be cheeky.

Practitioner interview 10 - Public Health Nurse

4.2.3 Use of PHCHR with disadvantaged groups

The PHCHR was seen by health service interviewees to be less effective with excluded groups, e.g. chaotic and or vulnerable families, those with literacy problems and those whose first language is not English. The health professionals interviewed felt that those families who would benefit most from the PHCHR are usually the least likely to use it.

Parents interviewed in this study who were living in chaotic circumstances certainly tended to see less worth in the PHCHR and had not used the record to any great extent, and felt no sense of ownership:

I have never written anything in it. It is not for me to write in, I don't think. Just give it to the people who know what they are doing.

Parent 8 - urban - white British

Others had used the record initially, but later lost or misplaced the record. For some, it was seen as a means of professionals fulfilling their own agendas.

A confounding factor with some very vulnerable groups is that of literacy. Low levels of literacy made it difficult to record information or to use any form of written plan. It was felt that difficulties encountered by health professionals in knowing how to deal with literacy issues and people with low levels of literacy avoiding putting themselves into situations where they may have to read or write were likely to contribute to this.

I was lucky, I am the type, I have been educated, I have been to school, you know. Travelling people won't keep up with things because they can't read or write, and you go into a doctor's surgery and the first thing you are handed is a form and a pen, you know and for an adult to turn round and say, 'I can't fill that in....'.

Parent 19 - Gypsy traveller - white British

For some groups, for example, gypsy travellers, it was also felt that parents were unlikely to refer to written information, and thus felt that health information would be more effectively communicated through trusted individuals from within the community. In the gypsy traveller community, there was a feeling that men in particular would be unlikely to go to the doctor. This clearly would have implications in relation to the extent to which family members beyond the children's main carer would be likely to engage with Family Health Plans.

Men don't go to the doctors for nothing. I mean my husband ... it has been ten year since he has been to a doctor. He is generally healthy like, but, travelling people... Women will go, especially for urine infections and things like that you know, and mm, for the kids' health, coughs or lumps or anything. There are still a lot of women hold back on themselves, I mean, me personally, I go for my smears and things, but apart from that...

Parent 19 - Gypsy Traveller - white British

For gypsy travellers, a history of poor understanding by health professionals of their way of life and consequent need to have flexible access to health services in different areas appears to have compounded their reluctance to engage. Parents from the gypsy traveller community were shown a copy of a health record and plan developed in Dumfries and Galloway especially for travellers. They viewed this very positively and commented that it could aid communication between parents and health professionals.

If they had had these years ago and travelling people had used them I think a lot of doctors might no' have refused to see them.

Because if travelling people go to the doctor's surgery and they don't have any notes on them ...You would maybe get the odd one who would think, oh, no, or it would be mislaid or something, but you would get the most of them, it is something that should have been out a long time ago, you know.

Parent 19 - Gypsy traveller - white British

Equally, for parents from ethnic minorities who could not read or speak English, the written health advice and information contained in the Red Book was of little use. Interestingly, however, in contrast with those from British born families with disadvantage, those from ethnic minorities tended to see the written record as being advantageous, giving them something concrete to take away from a face-to-face encounter with Health Visitor or nurse, and which they could subsequently share or get translated, thus alleviating the problems of comprehension they had in entirely verbal encounters.

They will have difficulty in understanding it, but usually I am sure that they can find a person who can read it and tell them what is going on and and this is basic, as average, people will do it like that, if I don't understand the language I will bring along the book to the person who can speak bi-lingual and tell them what is going on, and then they will bring along with them to the doctor.

Parent 2 – rural -Chinese

Similarly, the very fact that it is written in English allowed parents to present it to, for example, their GP and know that it contained a full history of their child's condition and problem when they themselves were unable to give a complete or coherent verbal account at the appointment. Then, they could return to a friend or family member to have any further notes translated. Although far from being as satisfactory as the availability of an interpreter, it was seen at least to ease communication pressures in consultations with GPs.

Yeah, well, the Health Visitor may fill it in when the Health Visitor want to find out something from them, but that is it. And they will maybe understand the chart, but that is it. Because they can bring this book to friends, like me, or other friends who can speak English, we can talk about, oh, this is the information about this and that, and explain to them. But, of course we will not explain all the details, so, the book is a record for them, they keep the information so that they know what is going on with the child. Sometimes, they bring along to doctor because they can't talk to doctor, and the book is the information to pass to the doctor and say, look, this is my child's condition, that is why I have come to ask for help.

Parent 2 - rural - Chinese

4.2.4 Use of the PHCHR with a healthy child

The extent to which parents used the PHCHR varied. Most parents tended to use it more for their first child in his/her first year. Parents across all social classes tended to use the book in the initial weeks after the birth of their child whilst there was regular contact with their health visitor. Continued use then varied, with many parents seeing the recording of information on their child's development as increasingly irrelevant. Further, with subsequent children, it was felt by many parents that other priorities often took precedence. Hence, finding time to keep a record of events was more difficult.

I mean with G, I started off recording when she rolled over and when she did all her first things. Whereas with E, I don't think E has any of her progress written in it... there is an awful lot in that book which is not [relevant], and it is also mixed through with the sort of information about how to wean them, and it is not a very easy book to actually write things in and to record. You know you would have to sit down with it every week, or you end up falling behind with it.

Parent 1 - rural - white British

Parents were divided about the document's use as a source of general health education or health promotion information. Most had referred to it at some time or other, but many middle class parents with access to books and now the Internet found the general information within it simplistic and even out of date at times, e.g. in relation to immunisation, advice about infant care and so on. Similarly, how much of this information is used by parents often depends on the priority it is given by the health visitor. If the health visitor is using the PHCHR as intended, and writing in it at each contact and placing a positive emphasis on the record, then parents are more likely to make use of the record and the health advice given in it.

The health visitors interviewed also felt concern that some of the information currently included might now be out of date. They wanted the PHCHR to be updated in terms of layout, with less jargon and medical terminology, a better index and more use of graphics. Particular reference was made by many, about the fact that parents did not easily understand the centile charts, used for height and weight recording.

I think if there is to be any difference made to either knowledge or behaviour then health promotion material has to be worked into a relevant plan with the family. The professional seeing the parent has to discuss pertinent aspects of health promotion to that time and use written material to back it up.

Practitioner interview 5 - Nurse Consultant in Public Health

4.2.5 Use of the PHCHR for whole family issues

Many parents felt that they had not received the support they would have wanted from health professionals in relation to their own needs and the needs of their child. The PHCHR is a record of the child's health, not of the parent's problems or capacity for coping with issues arising from any

problems with the child's health and well-being. It thus has a tendency to individualise problems rather than looking at them in a holistic or ecological way.

P8 It was just the way it all happened, it just done my head in. They didn't try to help me as a person; they were just mainly interested in the baby. Everybody thinks 'Baby, baby'. I could actually physically harm this baby and none of them are interested in that side of things.

Int: So it tended to be you that filled it in rather than the GP?

P8: I went to the hospital with her, at first it was every two weeks and then it was once a month so they have written a lot in it.

Parent 8 - urban - white British

4.2.6 Use of the PHCHR when things go wrong

In general there was a feeling amongst parents that the recording of information and subsequent support from health visitors was fine when their children had progressed in line with normal developmental goals. As soon as their child had not however, they felt that support fell away.

An area of much contention was the inclusion of weight and height charts in the PHCHR. When children were developing in line with the averages stated, parents felt that they liked to be able to map their child's growth and development, seeing it as a positive indicator of the development of a healthy child. For parents whose children had dropped below the average however, the record often became a source of great concern and worry. Clearly at times the use of these norms is justified, and is useful to highlight problems and enable action to be taken. Many parents however consequently saw it as a rather poor indicator of their child's otherwise satisfactory development.

..... I was breastfeeding him. Because he wasn't on the chart where he should have been on the chart I was getting worried. I thought "Oh my God he's not getting enough" and I even said to them that I was thinking about stopping breastfeeding but it was my husband that said "No carry on doing it. You know he's fine, you know he's happy, you know he's healthy". So I stopped going after that They [health visitors] were saying to me "Oh it's OK, it's just a guide" but in the same way they were still making me feel it was my fault you know.

Parent 5 - Urban - white British

4.2.7 Use of the PHCHR for special medical needs

It was felt by many parents who had children with special health needs that the current PHCHR allows for a record to be kept in relation to children's normal development, but allows little space for the recording of information when significant problems arise.

Mm, I don't think there is enough space to write about specific problems in it. It is all; it is more about their development, rather than if they have got specific health problems. There is a little bit about it, but I don't think either of them, I used it a bit more with Grace, but I don't think... I mean the HV used to write things in when she came to see us, but it was always just, feeding well, you know advised on weaning, or whatever, but not a lot would be written in.

Parent 1 – rural – white British

In circumstances where children did go on to develop special health needs, the brevity and incompleteness of the Red Book as a record created problems, and parents sought their own solutions. For instance, a number of parents had taken measures to record information themselves (not using the PHCHR) in relation to their children to ensure they had a full account of what was happening in relation to their child's condition and care.

I mean I have started writing in my diary now when she has an infection, because you know that at some stage you are going to have to say, well, on 16th May she had a urine infection, or whatever. Mmm, and you know like the, you kind of sometimes do want to get all their records together, because the doctors in (name of place), the GPs have some records of infections, and the hospital have other records of infections.

Parent 1 - rural - white British

And do you know what I do now with K? I have got a plastic folder because of all the problems, because of having to go through it all, because you are getting drained. Did I remember to say this; did I remember to say that? And it is a lot on your plate, so what I do now is I have got this plastic folder and anything to do with K, right in that folder and I carry that folder about with me. I am actually thinking about writing down, from the beginning the pregnancy, because everybody is asking the same questions everywhere, it's a waste of time, a waster of their time because it has already been through for somebody else, and from that person to that person and then they are not getting true story of what is happening and you are thinking...

Parent 7.1 - urban - white British

Parents, irrespective of social class, engaged in these techniques in a bid to articulate their concerns. For some, generally middle class parents, it was a means to engage with professionals, in a way that was socially desirable and would demonstrate their competence as parents. For others, it was as a result of feeling that they were not being believed and that reports of, for example, their child's poor behaviour, were being viewed as symptomatic of their own poor parenting.

4.3 Thinking about the Family Health Plan

In this section we look ahead to what parents and practitioners thought about the idea of introducing a family health plan. Some practitioners in the health visiting field, already had a vision of what this might be like. However, few people in other sectors of the health services or care professions had thought about it in advance, and, of course, it came as a complete novelty to all the parents that were interviewed. Where possible, examples of family health plan materials from elsewhere were used as stimulus materials in interviews and focus groups. The comments that are presented here, then, do not concentrate on detail or design. Rather they address those fundamental issues that might change with the introduction of a document which is intended to act as a plan (rather than just be a record or an assessment), which is intended to be holistic in addressing a whole range of familial and environmental influences on a child's health, and which is intended to be empowering and to encourage parent participation in taking responsibility for a child's health.

4.3.1 Encouraging partnership

All practitioners in principle viewed the idea of FHPs positively. They were seen as a tool to facilitate involvement of the family in health care decisions, to encourage partnership working between parent and professional and to allow for the wider determinants of health to be looked at. Furthermore health visitors saw that use of the FHP would enable further clarification of the role of the health visitor by highlighting that their function is to provide support for the whole family and not just for the mother and baby.

Because you're working with the family, you're collaborating with them and there's joint discussion on what's to be put in, I think that's quite an asset because it could enable further discussion about several issues. If you're actually writing things down in front of them and with them then they are going to take part and probably take more of an interest. I think it is very much a tool for an expression of their views and their needs.

Practitioner interview 22 - Health Visitor

The health visitors interviewed do feel that they are already working in partnership with parents but in an informal way. So during a contact they will ask general questions about family members other than the child. Much of this information will not be documented but is retained by the health visitor for future use if required. The community paediatric nurses interviewed supported this view, in that they feel they already involve the family in decision-making. They are less enthusiastic, however, about the possibility of a FHP making any difference to the way their service is delivered to the family.

OK, it all sounds good in theory but in reality I'm not sure that it would be much different from the approach we have now. We involve parents as much as we can in decision-making because we need them on board to carry the majority of the care. We really just advise

and support. So I'm unsure how a family health plan would change that for us.

Practitioner focus group interview 9 - Community paediatric nurse

A variety of health professionals in the interviews were concerned, however, that assumptions are being made that parents wish for more involvement of professionals in their family life. The proposed approach of the FHP was criticised in that it involves identifying needs or problems within the family and setting goals to meet the needs or solve the problems. This could be interpreted as a negative way of working by focussing on problems and how professionals can help to improve the situation for the family. FHPs were therefore potentially creating a situation of disempowerment for the family, which is the exact opposite of the intention behind their introduction.

I think it all sounds very intrusive. I'm just of the opinion that we should be getting away from getting information about everybody and what their problems are. I don't see parents as finding it helpful for us to be going in and pointing out all their faults and then writing a plan to try and change it. Are we not setting up people to fail?

Practitioner interview 3 - Health Visitor

I think it's a huge intrusion of privacy and insulting actually. If they have issues about the care that is being provided or there are genuine concerns ...But to come in and tell me how to run my life, or to promote me thinking about how my life should be run so my family is healthier is, I think, not on.

Practitioner focus group interview 8 - Outpatient nurses

A number of practitioners, therefore, voiced concerns about the intrusive nature of Family Health Plans and the assumption that people would require and want professional support and intervention in the lives of their families.

We have noted already that, for some parents with strong and supportive family networks, and a high level of resource in terms of their own education and health literacy, it is clear that they are often in a position to solve problems independently. They do not need intrusion and help, and were frankly amazed that it should be suggested that they might need the level of involvement by health visitors suggested in relation to the Family Health Plan:

I would imagine the scope, from my experience, the scope of the health visitor is for the children and it is something specific to the children whereas you are sort of implying from this that this is, as in myself, and my husband, not coping with some of these issues. I would, in my experience, put them under the doctor's heading. So I suppose if what you are trying to say is that the health visitor is going to take on some of these roles, then I would think that people would

have to be made aware of it. These are quite specialised issues to go and speak to a health visitor about.

Parent 9 – rural – white British

Furthermore, when they have been forced to become “home-grown” experts over an issue of child or personal health that matters to them, they at times feel that health professionals know less than they do.

On the other hand, amongst those parents in the sample who one might class as vulnerable, e.g. those parents already receiving help and support through Family Centres, there was a great familiarity with high levels of surveillance and supervision, and the types of planning document suggested in the FHP template were not unfamiliar to them, as many were already engaged in planning exercises and target setting with Family Centre workers over their own or their children’s behaviour, and therefore familiar with the notion of agreed goals and client-held ‘contracts’. That is not to say, however, that they felt such instruments were the best type of support for them in the predicaments they encountered. The Family Centre mothers were adamant that the best type of support came either from other mothers in similar positions, or from support workers who could do practical things with them or for them, not just give advice.

They honestly think it is you that is the problem, have I brought them up wrong, am I not strict enough, am I not doing this, am I not doing that . Ken, what I mean all this help and support and I know there is these groups that you can go to, ADHD and everything like that but sometimes you can’t go because you dinnae want to.

(ALL TALKING AT ONCE)

INT: So do professionals, I mean health professionals provide that kind of support?

They can’t they haven’t got enough time. Common experience as well isn’t it? And it’s like well I did this and this worked and I did this and this and it worked.

That’s it, a lot of time you feel like health visitors haven’t got bairns either so they cannae really relate to what you are saying. We can say, ‘ Oh I ken that happened to me,’ not get it out a textbook...

INT: So thinking back now, you know with hindsight, what do you think might have been helpful through that period? Well, probably just somebody to practically do something to help me, you know, but then there was maybe practical truth in what they were saying but what would have been really helpful for me was if I could have had somebody who could have come round and said ‘Right, starting from tonight, get yourself a good night’s sleep. Do this,’ you know, ‘bla, bla, bla’.

Parent focus group 8 – Family Centre

4.3.2 Family surveillance and child protection issues

Despite this talk of ownership, interviewees in the health services, almost without exception, felt that if the FHP were to be held by the family then practitioners would want and need some kind of parallel document for themselves. Practitioners displayed concern over child protection issues in particular. Although it is recognised that health visitors should not be documenting issues without first discussing them with the client, there are a number of grey areas where it would be inappropriate to document issues in a parent-held plan, for example in cases of suspected child abuse or domestic violence when it might put family members at risk (or indeed the health visitor) or might compromise the health visitor's ability to gain access to the house.

This highlights the balance the health visitor has to reach in her/his role as a support to the family while at the same time being alert to any areas of concern related to the care of the child. Reaching a balance between surveillance and support is not a new problem, and the FHP should encourage more open dialogue between the parent and the professional. It would then be up to the professional's own judgement and in negotiation with the family as to what issues would be documented.

For things like child protection and 'cause for concern' families you need your own records to make links between events and to write reports. As a reference for your own work, who you spoke to, when, what is to be done about a certain situation. Of course you discuss these issues with the family anyway but you need to have your own notes on it. It's impossible to remember every thing.

Practitioner interview 2 - Health Visitor

For health visitors the issues about negotiating record entries over difficult issues is not necessarily new, but it was interesting that the GPs interviewed were more chary of working with records that patients had open and easy access to.

I think it comes down to whether you accept that professionals just aren't good at sharing information with their patients and feel vulnerable about doing it or you confront it and try and make people do it. I'm sure it is a good thing to be done but the reality of the culture at the moment is that it's got a long way to go before people will honestly write and let other people read what they actually think and what they actually do.

Practitioner focus group interview 3 - General practitioner

Clearly if the FHP is to be a multi professional document then there needs to be a shift in current thinking from medical and nursing staff. While both groups are able to point out the complexities of issues concerning working with families such as confidentiality and child protection, they have very different attitudes towards the sharing of information. Nurses are more open and positive about the need for this to occur if people are to take on more responsibility for their health. Medical staff admit that the sharing of information is beneficial but are less willing to move this into practice.

The extract below shows that, for some professionals in the health field, open and honest dialogue with parents is not a concept that they feel entirely comfortable with. There are then implications for whether a FHP would be treated any differently from the current PHCHR by health professionals other than health visitors.

I suppose the honest truth is that sometimes the things that you want to talk to the health visitor about are not things that you want to write for the parents to read about... if there are concerns about neglect or parenting skills. You don't really want to write that in the book for them to take away. ... it's a whole new set of skills that we probably aren't very comfortable with. That would be an issue for training or awareness raising I think - for GPs anyway.

Practitioner focus group interview 3 - General practitioner

If health service personnel are aware that records shared with patients represent perhaps just one (negotiated) version of the actuality of the situation, parents were equally aware that such accounts had to be managed and monitored.

Parents were very aware that the role of health visitors went well beyond support, and included a strong measure of surveillance. A number of parents felt that there were issues about which they wouldn't speak to their health visitor. One of the main reasons for this was a feeling that they were being 'checked up' on, and that to express anxiety or to discuss certain issues might reflect negatively on them or be blown out of proportion.

I just always found with the Health Visitor .. they do kind of like turn it, so that it's your fault in a roundabout way you know what I mean so.I would find that there might be the slightest little thing that I was concerned about and I'd mention it to her and she'd go in great detail about fifteen minutes and in the end it was like a big issue with me when it was just a small thing

Parent 5 - urban - white British

For parents whose children were on the child protection register, there was a high level of awareness of the level of surveillance placed on them and their families. Most parents had a sense as to why this was necessary and many of those interviewed were making positive moves to ensure the future safety and well being of their children. For parents under surveillance there were usually key people who they were able to identify who had provided support, but there was always a fear that becoming over-confiding would lead to children being 'taken away'.

Well, my health visitor comes out to visit me and she'll look at R and she will check him over and quite often she has to check him for bruises because he is on the child protection register in case I physically neglect him, which I never have. The slightest bruise I get accused .. like he bangs his head off the floor when he throws a tantrum and I get accused of it.

Parent 8 - urban - white British

I was 17 when I had my first child, and then I had one straight after .. so I was judged for being a young mum and having two children, .. so, the health visitor that we had judged us instead of getting to know us first. Mm, it was just her attitude towards us, the way that she spoke as if we didn't know anything. Me and my partner were young, so we were learning ourselves, but she wasn't giving us the benefit of the doubt to learn ourselves. She would just come in and criticise what we had did, and just said, well, you have done it wrong, you should do it this way.

Parent 10 - urban - white British

I did in the past talk to my health visitor, you know, about my partner and how we weren't getting on and like domestic violence and that. We weren't getting on basically, but they can only guide you, you know, but I think that they can know too much of your business as well. It is what to tell them, you know. You have got to be careful. There is a fine line about what you can tell them. I don't think what you say to someone is confidential. I think they possibly pass it on to someone else, you know, and you might be judged upon that or, you know, like I don't know, it might go against you, or they might judge you on it or... I don't know.

Parent 12 - urban - white British

There is clearly a problem buried within the ambiguity of the health visitor role that will not go away, but which may in fact deepen with the introduction of the Family Health Plan. Health visitors want to provide support and explore difficulties that parents may be experiencing, but their primary responsibility is to the child and his/her welfare, and parents can sometimes find their confidences or openness used against them. If other groups are going to contribute to and read the FHP, some merging of understanding and cultures around negotiated records is needed. Health professionals must also be aware that parents too will manage interactions to produce the account they desire. The final result will be very much a 'construction', rather than a transparently real account of the child's family health situation. Some may feel this does not matter a lot if a parallel (and largely unseen) professional record is kept alongside the FHP, but others interviewed could foresee problems if the two accounts differed drastically in terms of their judgements about a child's welfare.

4.3.3 Concerns about confidentiality

Parent-held records looked after in the home regarding the child's health already, of course, pose some problems in relation to confidentiality, but this is clearly exacerbated if the Red Book is to be supplemented by a family health plan containing assessments of the health of a variety of family members.

Many practitioners were worried about the confidentiality issues involved in a detailed and intimate record of family life and health problems being left in the

family home, with potential for it being lost and read by others, or of it creating disagreement and tension within families. Understandings about patient confidentiality are so entrenched in respect of avoiding leakage of health information between one patient and another (even within the same family), that the notion of a shared document is quite alien to many working in the health services.

Yeah, I know of parents who haven't disclosed a child's diagnosis to other members of the family. So I would have concerns about what was written in the record and who had access to it.

Practitioner focus group interview n – community paediatric nurse

I mean we're talking about vulnerable families here. These are the ones who won't be able to keep a hold of the record. It can get lost and then other people could be looking at it.

Practitioner focus group interview – community paediatric nurse

There are issues here related to who has access to the record and what is actually documented in it. The simplistic response is that as it is the family's record they would negotiate with the health professional as to what is documented in it. Also it would be up to the family to ensure its safekeeping and who could and couldn't look at it. This however is based on the assumption that ownership of the plan would rest with the family.

Some mothers who were working currently use the Red Book as a mode of communication with childminders and to ensure that there was a record of their child's health needs, if a problem were to occur when they were not with their child.

..... I used to have it inside her bag for the childminder so that if something happens to (name of child) there is a record of it, and you know it would all be there with the child.

Parent 4 - urban - white British

Equally, parents pointed out that when their children were living away from home, perhaps at their grandparents, having a health record with them was useful, particularly in emergency situations. Such free availability of the document would be jeopardised if it were to contain the family health plan containing details of all family members.

The health visitors from the *Starting Well* Project who currently work with a FHP which is not parent-held, were unanimously against a record being held by the family, mainly for reasons of confidentiality. They felt that the reality, therefore, was that a FHP could never be a complete assessment of the family's health circumstances.

If that was the only record you would think twice about what you were documenting. There might be things too that they don't want written

in a record that other people have access to. You have to think what it's purpose would be. Would it get lost? For older children there are things which they don't need to see, and issues that are confidential to them which they don't want the parents to know about. Potentially there is so much information that might then not be in it, so it wouldn't be a complete record anyway.

Practitioner focus group interview 12 – Starting Well health visitors

The issue surrounding confidentiality and the older child was brought up by all professionals. This was seen as potentially problematic, both from the point of view of children finding out about incidents concerning their parents when they were very young (e.g. post natal depression), but also from the point of view of the older child, concerning situations about which they would not necessarily wish their parents to know (e.g. asking for contraceptive advice).

What were parents' views on this issue? Sharing information within the family was not deemed problematic where there was family cohesion and issues were unproblematic. Where issues became sensitive however this was more problematic.

Int: So, take the example we were talking about earlier. Say your partner had mental health problems, and you were concerned, you have maybe spoken to your HV, but not to you partner, how might you feel about that being documented?

P1: Well, it would depend, if he would have access to the information as well. If it is seen as a family health plan and therefore we all have access to it, I probably wouldn't be all that happy at that being written down, but if it's just me, and the kids, then I would be happy enough with that, but if he is going to have access to see it, then I wouldn't be that happy about it.

Int: And taking that it is a FHP and potentially different people would have access to the information, how would you feel about that?

P1: I probably wouldn't feel that happy about that, because there are some things that you might discuss verbally with someone but you wouldn't want written down, but something like that, if you are concerned enough about it that it might influence your kids, then you may be wouldn't. But I think I would be worried, if potentially he could see it. You would probably worry about that, wouldn't you?

Parent 1 - rural - white British

In addition, some parents, particularly those in rural areas, expressed very real concern about the confidentiality of the health visitor encounter with regard to the leakage of information given in confidence being shared with others in the community, often inadvertently.

I personally wouldn't like a Health Visitor knowing too much about me. Anything that you say to a GP is very confidential, but my own experience with Health Visitors is that they will say things, you know, little things like who they have been to visit or who they are seeing next, mm, you know they will say things. So, you know that would be one concern, the confidentiality of Health Visitors. You know the example which is, I mean now she is retired, but my Health Visitor said, 'Oh, I saw your neighbour last week.' And I immediately thought if you have seen my neighbour then she must be pregnant, but I mean I knew that it must be her booking in, but she didn't actually tell me for another month or something. So, things like that, you think if they can say just an 'off the cuff' comment.

Parent 1 - rural - white British

I wasn't probably quite so concerned about it when I was in the city to be honest because it is so big, you don't feel quite so aware of it, but like I would certainly think twice what I would go to the doctor about here or the health visitor in particular because it is a small community. So regardless of what people say, you do hear stuff gets chit/chatted around ...

Parent 9 – rural- white British

Parents who were involved in child protection procedures believed there was a possibility of inappropriate information exchange.

It is hard to go through something like that, but if they are willing to keep it confidential, it is not too bad. But then you cannae ayeways say, you ken, they maybe go home to their wife and say, oh, you should have seen this poor lassie, she has got two kids and she was sexually abused, blah, blah, blah, and her kids are on the panel, you cannae blame her kids for being on the panel, look at her background, you ken, she must find it hard, because I would hate for somebody to be going home and saying something like that.

Parent 10 - urban - white British

Opportunities for such accidental lapses in confidentiality were felt likely to become more common if health visitors moved on to using a Family Health Plan format, especially where many of the issues touched on might genuinely be community level concerns.

4.3.4 Attitudes to information sharing

The confidentiality debate extends beyond the simple two-way relationship between patient (or parent) and practitioner, and starts to include issues about the suitability of other health or care workers having access to a record or plan about health. School nurses, paediatric nurses and family centre staff all pointed out the benefits of having a multi agency document but were sceptical as to whether in reality that would work. It was felt that both medical staff and social workers would not commit to using the plan as intended.

I'd be worried too just about confidentiality and who really needs to know all the information that's in that record. What about other professionals coming in the house and looking in it? It does just sound very intrusive.

Practitioner focus group interview 5 – community paediatric nurse

In the outpatient setting I just don't see the use or relevance of this plan. And therefore if it's of no use to what you're doing for that child at that time we shouldn't be looking at it in my opinion. It's to do with confidentiality. You know with any documents we shouldn't be looking at them unless we need to.

Practitioner focus group interview 8 - nurse

Parents conversely, often felt irritated that there was so little information-sharing between different layers of the medical services, since the upshot of so little information-sharing was that they had to tell and retell their story again and again, and they often found that the child's medical history existed in fragments all over the place, when what they desperately wanted was for someone to take a holistic look at the child's problems.

And like when I go to the hospital the GP hasnae sent information to [consultant] and when I go to the GP, the GP disnae kin what has been happening at the hospital and things like that. The health visitor is like, 'Oh and when were you back at the hospital and how is she getting on?' She doesn't have a clue what has been happening either.

Parent 7 – urban – white British

There was an expectation by almost all parents that there would be a parallel health record relating to their child held by health professionals. Most parents saw this as normal and did not on the whole expect access to it as long as their child had few health problems. If their child had had a lot of contact with health professionals parents then felt it was more important that they had access to this information or that they were at least aware of what was being written. The professional records however would often take priority leaving the PHCHR as an incomplete record.

In relation to sharing information between professionals, parents who had a number of professionals involved in the care of their child generally found themselves to be the conduit of information.

I mean I tend to feel that I have got all this information like in my head and unless I tell them all individually.... whenever I see anyone I have got to sit down and say, you know, exactly what has been wrong with her, when she has had infections, what they are doing with her. Even when I go to the hospital, when I see the consultant, you have to re-tell them when she has had things, whereas you

would expect that there would be some sort of information flowing about.

Parent 1 - rural - white British

Most parents felt that it was appropriate to share information within certain parameters.

They always let us know beforehand, ' we will pass this information on to... or we will contact the Health Visitor or we will let the doctor know what is going on...' you know, if you mention something to them. They will tell us, you know

Parent 3.1 - urban - Pakistani

4.3.5. Implications of current changes in nursing roles

The policy documents outlining the ideas around family health plans as well as the publication of Hall 4, the *Scottish Framework for Nursing in Schools* and *Nursing For Health* clearly imply major changes for the role of health visitors and others involved in nursing roles around child health. We look at several aspects of this: first, the shift to a public health role and what this implies; second, the change in workload and the possible need to become a targeted rather than a universal service; thirdly, the implications of this shift in emphasis and its implications for support, management and the introduction of a new skill mix in nursing; fourthly, the potential for integration with the school nursing service. Those working in the health services (particularly health visitors and nurses themselves of course) had strong views on these topics. Parents had little idea of the shifting tide in the professional world of nursing, but, however, still provide useful commentary on the way these changes look from the user perspective.

The move towards focussing on the public health agenda was accepted and endorsed by most of the health service workers interviewed:

I would see the sense of it because we view the whole family with reference to the child. I mean we're already aware of what some of the issues are. To me it makes sense that we actually become involved with the family as a whole. Hopefully we would pick up issues and guide the family to accessing other agencies. It would raise the profile of what's available in the community for the family.

Practitioner focus group interview 10 – Health Visitors

Some view this as returning to the way they worked in the past, prior to being attached to GP fund holders. Others see it as a natural progression from the way they are working now. The development of a standardised FHP was seen as a positive step, allowing health visitors to commit in a more formal way to working alongside families and addressing the health needs of the community.

Family health plans would enhance what we are looking to do through health visiting from the traditional health visiting role, moving to a public health nursing role with targets and target populations, target families if it comes to that. We need to move ourselves from being the universal screening service into a service where we are identifying need and addressing services. But I think there are workload implications, I think health visiting workload is going to change quite rightly and what I would see is them spending more time with fewer people than they are doing, than they have been doing.

Practitioner interview 13 - Director of Nursing Services

It is clear, however, that many parents do not yet view health visitors in this role. Most parents interviewed saw the health visitor's current role being limited to issues relating to children when they are pre-school and to some extent in relation to their own health to ensure that they were 'coping' as a parent.

No the health visitor is purely for children really.

Parent 6 – suburban - Nigerian

Few, if any, parents interviewed saw the health visitor as having any input in relation to, for example, their partner's or other family members' health. The exception to this would be if there were obvious impacts on their children's well being caused by the actions or behaviour of another family member. It is clear therefore that there will have to be a gradual culture change in the way services are provided for and viewed by the public.

Although parents were able to identify issues relating to many of the headings in the sample Family Health Plan, they often felt that these were outside the remit of their health visitor, as currently perceived.

To be honest with reference to the headings that you have got here, no. I didn't go and speak to the health visitor about my work or my relationship and I certainly wouldn't go and speak to them about smoking, contraception, no, housing, no. You see to me a health visitor wouldn't, in my understanding, in my experience of a health visitor, they would just look at you blank to be honest about 'I have a smoking problem, what do I do?'. They would probably tell you to go and see the doctor. From my experience, the scope of the health visitor is for the children and it is something specific to the children whereas you are sort of implying from this that this is, as in myself, and my husband, not coping with some of these issues. I would, in my experience, put them under the doctor's heading. So I suppose if what you are trying to say is that the health visitor is going to take on some of these roles, then I would think that people would have to be made aware of it. These are quite specialised issues to go and speak to a health visitor about.

Parent 9 - rural - white British

One aspect of working on a more needs-led basis, rather than providing blanket surveillance for everyone, is the issue of prioritising workload. Some of the health visitors interviewed stated that while they could see the benefits of a FHP they thought that in reality it would be difficult to put into practice without some method of targeting. This then brings in the issue of the potentially stigmatising effect of having a FHP and raises questions as to how a decision would be made as to who required a plan and who didn't.

The health visitors from the *Starting Well* project recognise that using a FHP changes their whole pattern of work which is now in response to the family's needs rather than in response to the standard set of child health surveillance checks. They felt strongly that the only way they can be effectively responsive to the needs of families in their area is to have significantly reduced caseloads and minimal clinic commitments.

I think it needs to be targeted. I mean when I was a generic health visitor that's what I was doing anyway. You have to prioritise your work and of course some families just don't require that level of input. Logistically I just don't see how it could work if you offered it to everybody. There aren't enough health visitors just now so if there were smaller caseloads there would be an even bigger problem.

Practitioner focus group interview 12 – Health Visitors

The profile of health visitors has thus undergone a huge turnaround in the past 10 years. Some interviewees remembered that in the late 80s and early 90s their very existence was being questioned. At this time health visitors clung on to their grade and resisted attempts to 'water down' their service with lower graded nurses assisting them. However recent documents from the government have thrust health visitors into the forefront of the public health domain and it is being recognised that this increased profile brings with it a greater workload.

As a consequence of the changed role and increased workload, many health visitors now realise the importance of skill mix in their team if they are to continue to provide a service to meet the growing needs of the community. Thus more and more health visiting teams now have a nursery nurse and administrative assistance to assist them in their increasing workload. Some areas have staff nurses who undertake routine home visits and screenings. If FHPs are introduced then interviewees envisaged that skill mix would increasingly become a feature of health visiting. While this is accepted, the general feeling of resistance towards it persists. This is related to the qualifications and pay of those undertaking traditional health visitor tasks. It may be that some health visitors are continuing to guard what they see as their traditional role. However if that continues, it is difficult to see how they will make the cultural shift towards their interventions being family orientated or needs led, as opposed to professional-led.

What did parents tell us about their needs? Interviewee's responses were varied, but highlighted the need for a skill mix in the team, so that health visitors could provide not just clinical assessment and advice, but also practical advice and support, emotional support, and help in accessing services.

When, you know, A wasn't sleeping and I was getting really depressed because I wasn't sleeping and I was exhausted, the health visitor said 'persevere', you know 'and it will come right' and I said 'Well, I have done it with E, I know what it is like and how to solve it and he is not falling into that bracket'. Then she said 'Well, why don't you go and see the doctor'. So I went to see the doctor and the doctor said 'Well, we won't prescribe you or the baby for anything because it is not a medical condition'. At which point you feel like saying 'Well, I will go and hang myself outside in the corridor'...Just somebody to practically do something to help me, you know. What would have been really helpful for me was if I could have had somebody who could have come round and said 'Right, starting from tonight, get yourself a good night's sleep, do this,' you know, 'bla, bla, bla'.

Parent 9 - rural - white British

For many parents it was support in, for example finding employment and securing childcare that they urgently needed. Interestingly the new skill mix brought in as part of the *Starting Well* project uses home support workers in back up roles to health visitors to give just this sort of practical hands-on support to the most needy parents.

For parents across social classes, emotional support was also highlighted as crucial. This ranged from support in relation to changing relationships with partners to support in crisis situations where parents felt that their own mental health was severely compromised and where they had considered or attempted to self-harm. The importance of having a person to talk to and who listened was highlighted by a number of parents. For some this was due to experiencing extreme isolation with little family support.

Just when my ex-partner split up from me she [health visitor] knew that I was going through a tough time, and she understood how I was feeling, yes, she was very understanding but obviously coping with three children after a separation is hard and it is nice to have someone, professional help to say 'things will be alright and you will get over this', and she did see me over the worse and I can't believe the change in me.

Parent 12 - urban - white British

For others, however, it was because of experiencing a very new situation, when for example, they had previously been working in a professional capacity in full time employment. For some parents, it was social workers who had provided them with support in times of crisis, highlighting the importance of a multidisciplinary approach.

For some parents the health visitor played an important role in enabling them to mobilise support from within their family.

I actually went to the health visitor when I fell pregnant with K. I was too scared to tell my mum and dad because it was by the same person who I had my first by, and I was too scared and I phoned up, and she [health visitor] come out to my house and spoke to us and said that the best thing to do is tell your mum and dad.

Parent 20 -urban - white British

For parents living in poverty, support for childcare was highlighted as vital. Parents who were the sole carers for their children and not in employment found themselves in a vicious cycle where there was little reprieve from their circumstances. When childcare was provided at, for example, family centres, finding transport to access this was difficult for some parents.

Although at one level parents thus had difficulty shedding the old image of the health visitor and her role, it is clear that there is a very real need for a more organic form of support that encompasses practical help, emotional support, information about access to services and so on, in addition to the traditional health visitor staples of measurement, recording, surveillance. The wide variety of needs expressed make it likely that health visitors will need to call on and work in teams with considerable skill mix.

Another feature of the Family Health Plans is that it is intended that they can be kept throughout childhood and onwards. In theory those interviewed for this part of the study viewed such a development as being beneficial to aid professional communication throughout the time of working with the family. Current thinking at policy level in terms of developing a more public health focus for community nurses, with a blurring of the role of school nurse and health visitor would support this change. Certainly at present there is no standardised method of passing information on from the health visitor to the school nurse when a child enters primary 1. It is very much dependant on the relationship between the two practitioners, and school nurses highlighted this as an area that needed to be improved upon.

It was also generally accepted that for the vulnerable families, it would be particularly useful to have one document, as there is often a breakdown in communication when the child transfers from the community child health service to the school health service. A number of the nurse managers and public health practitioners interviewed were of the opinion that, for this category of children, input should continue from whoever is best placed to deliver it. It is envisaged, then, that with some families further discussion would need to take place as to who should provide that professional support. Health visitors readily admit that it is not best practice for them to disengage (when the child goes to school) when working with those families who have required an extensive amount of support and with whom they have built up a trusting relationship. However they feel that their workload does not permit them to continue to provide a service, post 5 years of age. They are

supportive of the idea of the FHP continuing to be used when the child reaches school but - in contrast to their managers - they see the school nurses as being more involved with the families and taking on home visits to provide further support.

In addition to these concerns amongst health visitors about changing roles and increased workloads the research also highlighted alarm amongst school nurses. New developments seem likely to raise their profile, but they are being asked to take on more and more work with no extra hours and no increase in earnings. With the public health agenda, school nurses are being asked to change the focus of their work from providing a service based on screening to that based on need.

I think at the moment we're finding it's almost becoming too much. We've fought for years to get recognition for our role. *Nursing for Health* has certainly been the catalyst for recognition of our role almost to the point of where we've been invited to participate in so many different things that we are struggling to get anything done at all that would be our ordinary role.

Practitioner focus group interview 7 – School Nurses

The Scottish Executive has attempted to bring school nurses more in line with health visitors by funding a number of school nurses to undertake the Public Health Nurse training. These nurses then return to practice as grade G and become team leaders for the other school nurses in their area. The new guidance on the development of the school nurse role will clearly have a major impact on the extent to which their work can overlap with that of health visitors in relation to the use of family health plans.

4.3.6. *Assessing community needs*

Without exception, all those health service personnel interviewed, when asked about the changing role of health visitors, did not mention the potential for health visitors to become more involved in community planning with the introduction of the FHP or indeed as part of the move towards being more involved in public health issues. When prompted, some did see this as a potential area for change. However the health visitors did not regard it as part of their remit to play a lead role in multi agency planning for the community. Lack of time was given as the reason for this. Others had been involved in multi disciplinary meetings in the past, but felt that little was gained from the experience, as different representatives attended each meeting and there was 'a lot of talk but not much coming from it'.

And again attending things like that just takes us away from our other work. I think it's good to collate information from various sources in the community, but that can really be done by someone in a clerical role. Maybe someone in management can then take it forward to planning and strategy meeting and leave us to get on with the grass roots work. I just don't see us as having the spare time to contribute to these types of things when there's so much other work to be done.

It's such a huge job really to be doing a needs assessment of the community or a profile. We can't do everything.

Practitioner focus group interview 10 – health visitors

Interviewees also expressed concern that the invitation in the FHP to consider issues at community level that need addressing may raise expectations of what services can be offered to people to meet their needs. This could be problematic if the services do not exist to meet these needs. The health visitor needs to be clear about what services exist and therefore be wary of promising support, which might not be available.

It is interesting to note that those in a managerial position viewed the raising of expectations in a positive light. They saw the FHP as having the potential to uncover previously undisclosed needs. This information could then be used to plan services to meet these needs. This was a point also made in interviews with those involved in the *Starting Well* demonstration project:

Within *Starting Well* we probably are identifying some needs that perhaps haven't been identified in previous ways of working. I think that's maybe a good thing because if there are needs out there that currently aren't being met and there aren't services to meet them we need to be flagging that up. Saying, well here's a gap here and what are we doing about it. So I suppose although it might feel a little bit threatening in that ...well I really don't want to bring that up because I know there's nothing out there to support it... at least you could be putting a case to the powers-that-be to look at it. Really to me that's part of the job of a health visitor. So it may well raise expectations but I think that's a good thing.

Practitioner interview 20 - HV Co-ordinator

Two health visitors also pointed out that the FHP could raise awareness of services that are already in place. Again this was seen as a positive aspect of the FHP as it allowed the practitioner to have a structured approach to assessing the health needs of the family.

One of the intentions behind the Family Health Plan is that health visitors should start to focus on the community as the unit of intervention as much as on the individual. Thus embryonic FHPs ask questions about the way in which community issues impact on health. Most parents in this sample could identify with issues relating to their community that had an impact on their health. Few, however, thought that it would fall within the remit of health professionals to deal with these issues. They clearly saw health professionals as people to refer to when in 'ill' health or for advice in relation to children's development and upbringing.

..... Well stuff like the crime and drugs and stuff like that, I suppose you would phone directly to the police and stuff wouldn't you?

Parent 3.1 - urban - Pakistani

Many parents felt that the Family Health Plan would be useful in identifying issues, which were part of the 'bigger health picture' in terms of their family and community. Most, however, found it difficult to see what effective action could be taken by health visitors to address community problems.

Potentially information gathered through using Family Health Plans might be used in aggregate to influence the development of services. Although few parents referred to the acceptability of this or not, some did comment and felt that it would not be a problem as long as personal details were not used.

I don't think there is any problem if you don't mention the name and details you know what I mean. As a family, if we have problem like that, we just share the information, you know what I mean, like when I talked to you before, we share information between my friends, but I never tell you who is the friend that I know, and who they are and what is the name, so it should be no harm. If you don't pass on the information how can they improve the services?

Parent 2 - rural - Chinese

4.3.7 Training requirements

Professional interviewees had mixed views on their training requirements if they were asked to work with a Family Health Plan system. The general feeling was that many health visitors already have the skills to implement a FHP and indeed are already working with families on a needs-led basis, albeit in an informal way. Suggested areas for training focused on the documentation and how to complete it, rather than on making changes in the actual way in working. However, those with experience of some form of FHP (i.e. the *Starting Well* Project) do recognise that there are more complex training needs.

The training needs to centre around this change in focus of the role...the change in the way you work with families. It's not really so much just about how you fill in the documentation as what does this mean for the way we work with families and what does it mean for families if they're going to start to lead the interventions. And okay we might feel that we do that just now (and some health visitors do), but is this plan going to make a difference? In areas where they did that kind of training and consultation with health visitors, the PHCHR is used much better.

Practitioner interview 5 - nurse consultant in public health

Some interviewees felt that training could look at developing negotiating skills and how health visitors could work to change the focus of a contact from them assessing health needs to empowering the family to do so themselves.

There needs to be a cultural change in the way of thinking maybe for all health professionals and a whole support system in place to provide the back up to the document which really isn't the most

important part of the package. It's just a means to changing the approach.

Practitioner focus group interview 3 – general practitioner

There were calls also for clear guidelines as to what should be included in the plan, a need for further discussion with regard to the family holding the plan and how that will work on issues such as child protection and confidentiality.

In addition to initial training, many interviewees at both practitioner and manager levels identified the need for high quality ongoing clinical supervision. Each health board in Scotland claims to offer clinical supervision for their employees but few operate an actual service. Those areas that do claim the uptake are poor. However those health visitors involved in the *Starting Well* project remarked on the importance of receiving clinical supervision when working so intensively with families.

Some intensive training is clearly also needed if health visitor work is to be targeted at more vulnerable groups, including those, for instance in ethnic minority groups or travellers. We pick up these points in the next chapter where we summarise these results and explore what they may mean in terms of recommendations.

5. Discussion

5.1 Introduction

The commissioning of this piece of work is part of the need to get at ways of improving or changing the relationship between professional clinical staff and family members such that the health of young children ultimately benefits. Implicit in this is the belief that the achievement of this goal will probably necessitate a more holistic look at the child and the environment in which he/she is growing up. It is also part of the background understanding that - however health care and family services are divided up, organised and paid for behind the scenes - to the consumer they must appear seamless and accessible. Unless services achieve this transformation they run the risk of failing those who are most vulnerable and least able to battle their way through complex systems.

Much of this shift in the organisation and presentation of services is coming about through major restructuring of professional systems of training, grading and organisation. This study focuses instead at the practice level and attempts to explore whether health visitors in particular have got the correct tools, which will help them to fulfil some of these new roles and demands. It does this through a review of the literature and through discussions with parents and with a broad range of health service personnel. In essence it examines whether the existing system of parent-held records is already sufficient in itself to achieve the goals set for the service by the new public health agendas. It then looks at suggestions for the implementation of a new tool, the Family Health Plan, intended as an addition to the existing Red Book system. In the following sections we look at some of the issues that have emerged and explore what the implications of these findings may be.

5.2 Reviewing the Red Book

The parent-held child health record - commonly referred to as the Red Book - is itself a relatively recent innovation in some areas. In just over a decade of use it has established itself as a useful adjunct to the professional record, and has helped shift the health visiting profession to a modern understanding of the need to develop more collaborative dialogues over health with their clients. Whilst we might always need to 'mind the gap' between rhetoric and reality, the Red Book does seem to have been instrumental in turning around professional attitudes in health visiting, a shift which is most marked when the different professional groups interviewed in this study are compared. There is much to be admired in the way in which health visitors have learned on the whole to perform the difficult trick of being open with clients whilst negotiating the complex professional tasks of ensuring children's safety and well being in some very difficult cases.

Many health boards have themselves, though, begun to review the form and function of the Red Book. Such reviews are appropriate and helpful. Since the Red Book's inception we have moved forward into a different age where information on health is even more freely available through the Internet as well as through more traditional sources. The utility of the Book as a health

information source (only ever an incidental function) may thus be diminished. Similarly the shift in political agendas puts the eradication of inequalities and the necessity for social inclusion high on the agenda. We may need to use limited resources in a different way and target some groups in a more intensive way and shift from the traditional activities of monitoring and recording all children at regular intervals.

These reviews and the evidence from both the literature and the empirical data collected here suggest that – on the whole – parents like holding their child's health record, but that their confidence in its importance and utility is undermined by the partial nature of the information collated. The Red Book has remained very much a health visitor tool and is generally disregarded by GPs, school nurses and by medical and nursing staff in both in-patient and outpatient hospital setting. Parents quickly come to realise that the record is a partial one, and their own determination and desire to keep the record complete by producing it at every encounter soon diminishes as a consequence. If we want to retain the Red Book and reinforce its utility to parents, work must continue to encourage other health service personnel to ask for the record and to read and write in it. Similarly, in introducing it to parents, more must be done to encourage the parent to keep their own records in it and to proffer it when taking their child to appointments.

Parents of children with specific conditions become particularly exasperated by the failure of the document to do anything other than record the barest details of their child's health progress, when health is so high on their agenda of concern. The calls were legion from the parents of children with chronic health problems for a format in which a unitary record of their child's illnesses and treatments could be maintained.

A more complete record would also be of benefit to parents from ethnic communities who experience language difficulties in their contacts with health service personnel. In an ideal world translation facilities would be universally available, and all written materials on offer in a variety of languages. In the real world, however, resources will always limit the availability of such services, and a more complete and comprehensive record would appear to be a reasonable second-best for parents with non-fluent English. Those who accompany their child to the doctor or hospital or clinic and need to explain or point to features about the child's health or progress currently find it useful to use the Red Book in this way, and the reverse process is also apparent, with comments jotted down by health visitors and nurses being taken back to translators in the community who can help to interpret them.

The PHCHR is standardised in terms of its core content in line with the Royal College of Paediatrics guidance published in Hall 4. However, there are local variations in layout, local contact information and so on. The process of review recently or currently engaged in by a number of Scottish health boards is likely to lead to a divergence of format even greater than that already in evidence, yet within the research undertaken for this study the calls for greater standardisation of format were almost unanimous. Population movement between Health Board areas makes the transferability of such records

important. Busy staff pressed to complete the record in a GP surgery or an A&E department are even less likely to be accommodating to the record if it turns up in fifteen different formats.

There is, of course, a conundrum in advocating a standardised format but also wanting to retain the flexibility to serve the needs of different groups within the community, such as those with a child with a specific medical condition. Could this be overcome by having a core document, which has the possibility of additions or extensions? The 'fax' type formats experimented with by some authorities in relation to adolescent health records, for example, would seem to offer this flexibility. Not only could this format provide more space for the records of children who have frequent encounters with medical services, but it would also allow the insertion of directed and appropriate health education information, e.g. where a child has eczema or asthma.

Some of the different parent groups interviewed in this study (e.g. those from different ethnic groups, travelling families, families with children having a disability) might also be better served by such a system which borrowed 'best practice' documents from areas where health boards have invested considerable time and energy in the development of specialist resources.

All of these comments relate, of course to the notion of the Red Book as a record of health and of health assessments. This is its current primary function and is likely to remain so. All health authorities also maintain a parallel professional record of some kind, although the methods of storing and transferring this data vary between different areas in Scotland.

At present few health authorities north of the Border incorporate any document that emphasises review and forward planning for health. Where documents have been developed as family records, they are usually intended simply to outline or record family circumstances. We turn now to examine the case for the introduction of an additional document that aims to focus on family health in a more holistic way in order to plan for the future needs of the child and the community.

5.3 Family health plans

The idea behind the introduction of family health plans is clearly to gain an extra tool which health visitors can use in a variety of novel ways which will help them function in the new roles outlined for them in the various documents alluded to earlier. Thus their new public health role requires them to consider health 'in the round', to move towards planning and prevention rather than just being concerned to react and record, and to gradually build - out of their understanding of the health of individual children - a picture of child and family needs at a community level. Some of the pilot Scottish documents currently in use do fulfil these requirements, but do not answer the additional requirement of creating a parent-held document which thereby returns responsibility to the parent for holding and reviewing the plan.

Because the family health plan concept embodies many of the quite radical shifts in role that health visitors are being encouraged to make, both parents and professionals alike interviewed for this study often found it difficult to conceptualise how such a document might work. Fears that it would be both intrusive and time-consuming were rife, but that view relates very much to the fact that health visitors currently fulfil a health surveillance and support role for all families. The recommendations of Hall 4 and other policy documents, that health visitors move toward a more targeted approach to vulnerable families rather changes the complexion of such arguments. Many of the parents interviewed in this study who were already targeted and singled out as vulnerable and in need of support and surveillance (e.g. those attending Family Centres) already live with services which operate towards them in an intensive and fairly intrusive way. The sorts of review and planning documents that they are already required to participate in regarding their own and their children's behaviour, for instance, indicate that they would be familiar with the approach of the family health plan, though others might not be.

Other parents who had faced taxing circumstances in relation to the poor health or disability of a particular child were usually only too ready for some form of tool. They felt that this would enable them to review the child's health in a more holistic way, and to explore the impact of that on the family as a whole.

Related to the above, evidence from the English study seems to indicate that – as with many other opportunities for health education – timing is everything. The imposition of the need to 'do' the FHP at a specified and similar point in every child's life seems to yield the promise of poor results if it is seen as irrelevant or unnecessary. Conversely, a system where the health visitor has the discretion to choose the moment when the parent/family needs the opportunity to review and to explore what support is available may aid in the presentation of the FHP as a tool which supports rather than acts as a further form of surveillance.

Many of the concerns about the FHP relate to the way in which it might be held, the negotiation of ownership and the potential for breaches of confidentiality. The need to develop a life course approach to health and to avoid the disjunctions in service provision between, for example, the health visitor service and the school nurse service are a potent argument for a record that passes with the child longitudinally as well as laterally. However, it is foolish to imagine that the Red Book/FHP documents must fulfil all these functions. The development of electronic record keeping within the NHS advances apace. The professional record of health events and treatments will be held separately from the parent record and will be available through the life course. It might be desirable for the parent-held record to have a longer life than presently, but there is no necessity for it to do so.

Some of these concerns arise because of an assumption by interviewees that the document would be held in a place or in such a way that they would have to make it available for others to inspect. This would indeed be the case if the

Red Book and the FHP were merged into one document and if attempts were to continue to make the Red Book a multi-professional record of child health. Such problems are easily overcome where the FHP document, as in the Sheffield case, remains an entirely separate document. The adoption of a fax-type ring binder would, of course, give parents the opportunity to keep the documents together or separate them as they thought fit.

Regarding the ownership of the FHP - if the document is to be patient-held - it is difficult to conceive of a position other than that the document becomes the property of the principal caregiver of the child concerned. Giving any other individual or agency the right to inspect the plan would jeopardise from the start the chance of an honest account and review of circumstances. A health visitor wishing to keep a record of the plan could summarise and retain information on an existing record, or the form could be designed in such a way that a carbon tear-off slip of summary actions and plans could be taken away for future use by the health visitor.

Another agenda that sits around the use of the FHP is the concept of life course health. Should the FHP become part of the child's record that passes from health visitor to school nurse and so onwards? This is certainly something to consider in respect of a revised Red Book, but it is doubtful if this would work in relation to the FHP. Since the document is an account of the collaborative conversation between caregiver and health visitor, and relates to family issues as a whole, it is hard to argue for it to become the property of the child him/herself.

The potential of the FHP to function as a community needs assessment tool was roundly welcomed by service managers in this study, but it is probably true to say that neither parents nor health visitors themselves have much vision at this stage of how that might work out in practice. The notion that it might allow health visitors or their representatives to take part in (or even lead) multi-agency initiatives set up to address particular local problems was felt to be rather alarming by many of those on the ground. Clearly, a great deal more training and support will be needed as health visitors try to move towards the complete fulfilment of a public health role.

The Sheffield initiative, where family health plans have been piloted on a slightly broader scale, seems to suggest that health visitors can derive a great deal from sharing and pooling information deriving from the use of FHPs, but this carries implications for the management of the service.

Similarly, the development of the family health plan is symbolic of the shift away from a light touch surveillance of all children's health towards something that is much more focused on the vulnerable families and children within a catchment area. These sorts of planning exercises, however, are likely to throw up the need for team resources that the health visitor can call on, including family support workers with few health skills, but with the ability to support families in other, practical ways. *Starting Well* offers good exemplars of how this is being taken forward in one demonstration area.

5.4 Training implications

If the Family Health Plan becomes incorporated into health visitor practice in addition to existing tools, and as part of the shift to a public health nursing role, there are clear implications for training that will need to be addressed.

Training in the use of the planning tool will need to be incorporated into both initial training and into continuing professional development for those already qualified. The implications for the changing health visitor role outlined in policy documents already imply a need for new aspects to training. Thus, for instance, health visitors will need to develop skills in learning how to develop and manage a targeted case load, how to work within a broader skill-mix team and so on. The use of the family health plans re-emphasises the need to develop the skills and experience which will help the health visitor to judge when the time is right to introduce the FHP and which will help extend the facility with which the health visitor develops collaborative working with the client using the document. The FHP will be started in instances where the need is identified by the health visitor, but there is no guidance about when it will close or be suspended as family circumstances change, or the outcomes are achieved. There are thus training implications regarding the withdrawal of support. Similarly, training can help the health visitor to develop the capacity to use the FHP at a community level to assess need and then to take the assessments into multi-agency fora in the hope that change can be effected. All these are essentially new skills.

Senior staff may also need to be offered training in developing ways of supporting staff in their new roles. As Garside (2002) points out, health visitors will need to be unburdened from 'routine' work and gradually given the opportunities to explore new ways of working within a supportive environment.

There may be a case for other professional groups also to be offered information and training about the change in health visitor roles. This would hopefully enable them to develop an understanding of the type of work that will flow from the new working arrangements and from new tools like the family health plan. In addition one would hope that such training could give them an understanding of their own role in respect of making this transition to a public health role a successful one. It is not reasonable to expect parents – especially the particularly disempowered ones – to force through the change.

A great deal of work still needs to be done concerning the feasibility and implementation of any scheme to introduce Family Health Plans in Scotland. Change is unlikely to happen overnight. New professional roles for health visitors will take a while to evolve and filter down into the consciousness and actions of those working in the field. Confidence will grow gradually with sensible preparation, training and good managerial support. It is hoped that this report adds something to the process of setting the task in motion of helping health visitors work even more effectively for families and children.

5.5 Themes for discussion

Parent held child health record (Red Book)

Although the PCHR (Red Book) was not the *main* focus of this research, in discussing current tools, there are a number of findings related to the PCHR, which raise the following themes. Assuming that the Red book is continued as a document for assessment and recording of pre-school children's health;

- Is a further national review of Red Book use necessary, in order to provide a uniform core document for Scotland, incorporating the 'best practice' from developments around the country?
- How can we take into account the needs of particular groups like those from travelling communities or from different ethnic groups when redesigning the parent-held record?
- How can a re-designed parent-held record take account of the needs of parents of children with disabilities or with chronic medical conditions who often experience the strongest need to have a unitary record of problems, treatments, immunisations and so on?
- Should the Red Book remain as a document to be issued to all parents shortly after birth, even if the health visiting service moves away over time from a universal surveillance role?
- How can other professional groups, who come into contact with the child in the health domain, be encouraged to use the Red Book and not see it as a document whose ownership lies exclusively with the Health Visitor service?

Family Health Plans

Assuming that Family Health Plans are set up as brief and simple documents to be used in health visitor's work with families.....

- Should FHPs always be parent-held?
- Should they become the property of the principal carer of the child in question?
- Should the FHP document be devised to allow the health visitor to leave the main document with the client but to have a detachable summary, which can be taken away for record keeping purposes?
- Can the use of the FHP as a management tool to measure effectiveness against targets or as a means of community needs assessment sit comfortably with the most basic reason for their use?
- Should health visitors be given the discretion to use their professional judgement as to the best time to introduce the FHP into the relationship between health visitor and client?

- What forms of training will best underpin the general shift in health visiting roles in both primary training and in continuing professional development?
- How should the task of using FHPs as a form of community needs assessment be developed?
- How should awareness raising of the new health visitor public health role be undertaken amongst other professional groups?
- In what ways can managers of health visitors best develop and support the new public health role demanded of the service?

References

Abbott, P. and R. Sapsford (1990) 'Health visiting: policing the family?', in P. Abbott and C. Wallace (eds) ***The Sociology of the Caring Professions***. Basingstoke: Falmer

Ahmann, E. (1994) "Chunky stew": appreciating cultural diversity while providing health care for children. ***Paediatric Nursing***, 20(3): 320-4

Appleton, J. (1994) The role of the health visitor in identifying and working with vulnerable families in relation to child protection: a review of the literature. ***Journal of Advanced Nursing***, 20: 167-75

Armstrong, D. (1993) 'From clinical gaze to regime of total health', in A. Beattie, M. Gott, L. Jones and M. Sidell (eds) ***Health and Wellbeing: a Reader***. London: Macmillan

Armstrong, D. (1995) The rise of surveillance medicine. ***Sociology of Health and Illness***, 17: 393-404

Bucket-Milburn, K., S. Cunningham-Burley and J. Davis (2001) Understanding children's perceptions of health inequalities. Paper presented at BSA Medical Sociology conference. York, September 2001

Bedford, H. (2001) cited in BACCH newsletter, Autumn 2001

Bethell, C., C. Peck and E. Schor (2001) Assessing health system provision of well-child care. ***Paediatrics***, 107(5): 1084-93

Boddy F A (1986) Is child abuse preventable? ***Child Abuse Review***, 1, 3: 17-21

Brierley H, Goddard P and Wilbore A (1998) Yes, we have no bananas, but plenty of health care today. ***Health Visitor***, 61, 12: 369-370

Browne, K. (1995) Preventing child maltreatment through community nursing. ***Journal of Advanced Nursing***, 21: 57-63

Campbell, H. and J. Halleran (1993) An evaluation of the personal child health record in Fife. ***Health Bulletin Edinburgh***, 51(6): 399-406

Chalmers, K.I. (1990) **Preventative work with families in the community: a qualitative study of health visiting practice**. University of Manchester: PhD Thesis

Chalmers, K.I. (1992) Working with men: an analysis of health visiting practice in families with young children. ***International Journal of Nursing Studies***, 29(1): 3-16

Chalmers, K.I. (1993) Searching for health needs: the work of health visiting. ***Journal of Advanced Nursing***, 18(6): 900-11

Charles, R. (1994) An evaluation of parent-held child health records. ***Health Visitor***, 67(8): 270-2

Charles, R. (1996) Reforming health visitors records. ***Health Visitor***, 69(3): 101-2

Cook, A. (1999) The Wellfamily Service: a new model of support. ***Community Practitioner***, 72(6): 168-71

Cormack, L., C. Morley, A. Seward and D. Vickers (1998) The personal child health record: attitudes to and usage by parents and professionals. ***Ambulatory Child Health***, 4(4): 375-80

Craig P M and Smith L N (1998) Health visiting and public health: back to our roots or a new branch? ***Health and Social Care in the Community***, 6, 3: 172-180

Darbyshire, P. and H. Morrison (1995) Empowering parents of children with special needs. *Nursing Times*, 91(32): 26-8

Dauncey, J. (1991) Introducing parent-held child health records. *Health Visitor*, 64(7): 229-30

Davies, A. (1999) Parent-held child health records: an evaluation of parental attitudes. *British Journal of Community Nursing*, 4(5): 242-9

Davies, A. (1999) Professional attitudes towards parent-held child health records. *British Journal of Community Nursing*, 4(8): 381-9

Dearlove, J. and S. Illingworth (1999) A controlled trial of parent initiated and conventional pre-school health surveillance using personal child health records. *Archives of Disease in Childhood*, 80(6): 507-10

De'Ath, E. (1982) A preventative approach to family life: the role of the health visitor. *Health Visitor*, 55: 282-4

Department of Health (1999) *Saving Lives: Our Healthier Nation*. London: The Stationery Office

Department of Health (2001) *Health Visitor Practice Development Resource Pack*. London: The Stationery Office

Dingwall R (1982) Community nursing and civil liberty. *Journal of Advanced Nursing*, 7: 337-436

Dingwall, R. and J. Eekeelar (1988) Families and the state: a historical perspective on the public regulation of private conduct. *Law and Policy*, 10(4): 341-361

Dingwall, R. and K.M. Robinson (1993) 'Policing the Family? Health visiting and the public surveillance of private behaviour', in A. Beattie, M. Gott, L.

Jones and M. Sidell (eds) ***Health and Wellbeing: a Reader***. London: Macmillan

Donzelot, J. (1980) ***The Policing of Families***. London: Hutchinson

Drennan V (1988) ***Health Visitors and Groups – Politics and Nursing***. Oxford: Heinemann Nursing

Emond, A., P. Howat and J-A Evans (1995) Reliability of parent-held child health records. ***Health Visitor***, 68(8): 322-323

Foucault, M. (1977) ***Discipline and Punish: The Birth of the Prison***. London: Tavistock

Fraser, N. (1989) ***Unruly Practices: Power, Discourse and Gender in Contemporary Social Theory***. Cambridge: Polity

Garside, M. (2001) ***Family Health Plans: working in partnership to improve health***. Sheffield HAZ. Institute of General Practice and Primary Care, University of Sheffield

Garside, M. (2001b) ***Health and Your Family: guidelines for health visitors***. Sheffield HAZ: Institute of General Practice and Primary Care, University of Sheffield

Glasgow Healthy City Partnership (2000) ***Starting Well Health Demonstration Project: summary version of proposal***.
(<http://www.glasgow.gov.uk/healthycities/ghcp/pdf/startwell.pdf>)

Glasgow Healthy City Partnership (2002) ***Starting Well Health Demonstration Project: Annual Report 2000/2001***.
(http://www.glasgow.gov.uk/healthycities/ghcp/pdf/s_well_ar.pdf)

Goodwin S (1988) Whither health visiting? Keynote address. Health Visitors' Association. London

Habermas, J. (1989) *The Structural Transformation of the Public Sphere*. Cambridge: Polity

Hall, D.M.B. (1996) *Health For All Children*. 3rd edition. Oxford: Oxford University Press

Hall, D.M.B. (2002) *Health For All Children*. 4th edition (draft). (www.health-for-all-children.co.uk/hfac4_draft.htm)

Hall, D. (2000) Change, continuity and function of the community health visitor. *Community Practitioner*, 73(12): 870-2

Hardey, M. (1999) Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health and Illness*, 21(6): 820-35

Henderson, A. (1994) Power and knowledge in nursing practice: the contribution of Foucault. *Journal of Advanced Nursing*, 21: 5-82

Hodes, D. (1990) Child health record books. *Health Visitor*, 63(5): 156

Hooker, L. and J. Williams (1996) Parent held shared care records: bridging the communication gaps. *British Journal of Nursing*, 5(12): 738-41

Jackson, C. (1991) Power to the parent. *Health Visitor*, 64(10): 340-342

Jackson, P. (1996) Health Fax: a pupil-held health record. *Health Education*, 6: 8-10

Jefferis, D. and M. Harris (1993) The personal health record: making it work better for general practitioners. *Australian Family Physician*, 22(8): 1417-27

Jefferies, D., V. Nossar and F. Bailey (1994) Retention and use of personal health records: a population-based study. *Journal of Paediatrics and Child Health*, 30(3): 248-252

Johnson, F. (1988) Personal health record. *The Medical Journal of Australia*, 148(10): 544

Joshi, P., K.V. Jones, R.M. Hanson, G. Alperstein and B. Fasher (1993) Personal health records. *Journal of Paediatrics and Child Health*, 29(5): 400-1

Kendall, S. (1993) Do health visitors promote client participation? An analysis of the health visitor-client interaction. *Journal of Clinical Nursing*, 2(2): 103-9

Knott, M. and S. Latter (1999) Help or hindrance? Single, unsupported mothers' perceptions of health visiting. *Journal of Advanced Nursing*, 30(3): 580-8

Knowles, R., M. Blackburn, M. Zahir, M. Russell, A. Carrier and E. Nevrkla (1999) The implementation of a new parallel child health record. *Child: Care, Health and Development*, 25(4): 253-266

Lakhani, A.D., A. Avery, A. Gordon and N. Tait (1984) Evaluation of a home based health record booklet. *Archives of Disease in Childhood*, 59: 1076-81

Lau, F., A.D. Barner, S. Nickam and J-A. Lawson (1994) Is Canada ready for parent-held child health records? (<http://www.hinf.uvic.ca/ITCH/itch94/papers/lau.htm>)

Lauri, S. (1994) Health promotion in child and family health care: the role of Finnish public health nurses. *Public Health Nursing*, 11(1): 32-7

Lauritzen, S.O. and L. Sachs (2001) Normality, risk and the future: implicit communication of threat in health surveillance. ***Sociology of Health and Illness***, 23(4): 497-516

Liaw, S.T. (1998) The South Australian personal health record. ***Ambulatory Child Health***, 4(4): 381-91

Ling, M.S. and K.A. Luker (2000) Protecting children: intuition and awareness in the work of health visitors. ***Journal of Advanced Nursing***, 32(3): 572-9

London Borough of Brent (1985) ***A Child in Trust: The Report of the Panel of Inquiry into the Circumstances Surrounding the Death of Jasmine Beckford***. London: Borough of Brent

Luker K (1996) Finding a strategy for a primary care led NHS. ***NT Research*** 1, 4: 284-285

Scottish Executive (2001) ***Nursing for Health, A Review of the Contribution of Nurses, Midwives and Health Visitors to Improving the Public's Health***. Edinburgh: HMSO

Luker, K.A. and K.I. Chalmers (1990) Gaining access to clients: the case of health visiting. ***Journal of Advanced Nursing***, 15(1): 74-82

MacFarlane, A. (1992) Personal child health records held by parents. ***Archives of Disease in Childhood***, 67(5): 571-572

MacFarlane, A. and K. Saffin (1990) Do general practitioners and health visitors like 'parent held' child health records? ***British Journal of General Practice***, 40: 106-8

McIntosh J (1986) ***A Consumer Perspective of the Health Visiting Service***. Social, Paediatric, Obstetric and Research Unit, Department of Child Health and Obstetrics, University of Glasgow

McMaster, P., H.J. McMaster and D.P. Southall (1996) Personal child health record and advice booklet programme in Tuzla, Bosnia Herzegovina. **J Res Soc Med**, 89(4): 202-4

McMaster, P., H.J. McMaster, V. Simnovic, N. Selimovic and D.P. Southall (2000) Parent and young person held child health record and advice booklets and their use in Bosnia and Herzegovina. **IPA Journal**, 6(4). (www.ipa-france.net/pubs/inches/inch6_4/mcm.htm)

Mayall B and Foster M (1989) **Child Health Care. Living with Children: Working for Children**. Oxford: Heinemann Nursing

Mielck, A., H. Graham and S. Renburg (2001) 'Targeting groups of 'at risk' children', in J. Mackenbach and M. Bakker (eds) **Policies and Interventions to Reduce Socio-Economic Inequalities in Health**. London: Routledge

Miller, K. and M. Barker (1978) **An evaluation of the use of personal health records**. Adelaide: South Australian Health Commission

Miller, S.A. (1990) A trial of parent-held child health records in the armed forces. **British Medical Journal**, 300 (6731): 1046

Moore, J. (2001) **The effectiveness of a parent-held record for disabled children**. London: Department of Health. Summary report (www.doh.gov.uk/mch/studies/execsum14-11.htm)

Morton P and Hill M (2002) **Child-Held Personal Health Profiles. Report of a Pilot Scheme introducing Child Health Profiles in Scotland**. Glasgow: Centre for the Child and Society

Newton, M.S. (2000) Family-centred care: current realities in parent participation. **Paediatric Nursing**, 26(2): 164-8

Normandale, S. (2001) A study of mothers' perceptions of the health visiting role. **Community Practitioner**, 74(4): 146-50

Nossar, V. (1998) Parent-held child health records - effective but underused. **Ambulatory Child Health**, 4(4): 367-8

O'Flaherty, S., E. Jandera, J. Llewellyn and M. Wall (1987) Personal health records: an evaluation. **Archives of Disease in Childhood**, 62: 1152-1155

Opie, A. (1998) "Nobody's asked me for my view": users' empowerment by multidisciplinary health teams. **Qualitative Health Research**, 8(2): 188-206

Päivi, A-K., H. Hopia and A. Vuori (1999) Family health in everyday life: a qualitative study on well-being in families with children. **Journal of Advanced Nursing**, 29(3): 704-11

Pearson, P. (1985) Parent-held records: What parents think. **Health Visitor**, 58(1): 15-6

Pearson, P. and T. Waterson (1992) **Newcastle parent-held record: report of a pilot study**. Newcastle: Newcastle Health Authority

Peckover, S. (2002) Supporting and policing mothers: an analysis of the disciplinary practices of health visiting. **Journal of Advanced Nursing**, 38(4): 369-77

Philip, K., K. Backet-Milburn, S. Cunningham-Burley and J. Davis (forthcoming) *Practising what we preach*. Working paper 1. RUHBC: Edinburgh

Popay, J., G. Williams, C. Thomas and A. Gatrell (1998) Theorising inequalities in health: the place of lay knowledge. **Sociology of Health and Illness**, 20(5): 619-44

Rifkin, S.B. (1990) ***Community participation in maternal and child health/family planning programmes: an analysis based on case study materials***. Geneva: World Health Organization

Rodger, J.J. (1996) ***Family Life and Social Control: A Sociological Perspective***. London: Macmillan

Saffin, K. (1986) Parents as partners. ***Community Outlook***, September: 11-13

Saffin, K. and A. MacFarlane (1991) How well are parent-held records kept and completed? ***British Journal of General Practice***, 41: 249-251

Scottish Executive (2000) ***Our National Health: a plan for action, a plan for change***. Edinburgh: The Stationery Office

Scottish Executive (2001) ***Nursing For Health: a review of the contribution of nurses, midwives and health visitors to improving the public's health***. Edinburgh: The Stationery Office

Scottish Executive (2001) ***Family Health Nurse Project: Scottish Pilot Project***. (<http://www.show.scot.nhs.uk/sehd/familyhealthnurseproject>)

Scottish Executive (2003) ***A Scottish Framework for Nursing in Schools***. Edinburgh: The Stationery Office

Scottish Executive Press Releases (2000) 'Glasgow to lead national action to improve child health'. (<http://www.scotland.gov.uk/news/2000/11/se2966.asp>)

Scottish Office (1999) ***Towards a Healthier Scotland – a White Paper on Health***. Edinburgh: The Stationery Office

Shucksmith, J., K. Philip, C. King and J. Calow (2001) ***Child and Family Health: A Strategic Assessment***. Report to the Health Education Board for Scotland

Shucksmith, J. and C. King (2002) ***The Care of Children with Chronic Medical Conditions: Examining Health Service Providers' Views on Inter-Agency Working with Education Staff***. Report to Chief Scientist Office, Scottish Executive

SNMAC (Standing Nursing and Midwifery Advisory Committee) (1995) ***Making It Happen***. London: Department of Health

Suppiah, C. (1994) Working in partnership with community mothers. ***Health Visitor***, 67(2): 51-3

Symonds, A. (1991) Angels and interfering busybodies: the social construction of two occupations. ***Sociology of Health and Illness***, 13(2): 249-264

Talbot, M. (2002) Parent responses to the parent-held child health record. (<http://www.healthpro.org.uk/publications/35.html>)

Taylor, J. and B. Daniel (2000) The rhetoric vs. the reality in childcare and protection: ideology and practice in working with fathers. ***Journal of Advanced Nursing***, 31(1): 12-9

Taylor S and James D (1987) Children at risk: the changing role of the health visitor. ***Health Visitor***, 10, 6: 329-330

Taylor S and Tilley N (1989) Health visitors and child protection conflict: contradictions and ethical dilemmas. ***Health Visitor***, 62: 273-275

Thoburn, J., A. Lewis and D. Shemmings (1995) **Paternalism or partnership? Family involvement in the child protection process.** London: HMSO, University of East Anglia

Trivette, C.M., C.J. Dunst, D.W. Hamby and N.J. LaPointe (1996) Key elements of empowerment and their implications for early intervention. ***Infant-Toddler Intervention: The Transdisciplinary Journal***, 6(1): 59-73

UKCC (1994) ***The Future of Professional Practice – the Council's Standard for Education and Practice Following Registration.*** London: UKCC

Volkmer, R.E., M.A. Gouldstone and C.P. Ninnis (1993) Parental perception of the use and usefulness of a parent-held child health record. ***Journal of Paediatrics and Child Health***, 29(2): 150-153

Whitney, G., S. Holland, E. Emms, J. Phillips and A. McNaughton (1993) Preparing for parent-held child health records. ***Health Visitor***, 66(4): 138-139

Appendices

Appendix A	Steering group membership
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Members of Steering Group:

Ann Kerr (Chair)	Programme manager, HEBS
Ann Gow	Nurse consultant in Public Health, Glasgow Primary Care Trust
David Holton	General practitioner
Jackie Hyland	Child Health Commissioner, Fife NHS Board
Anne-Marie Knox	Health visitor
Liz Whelan	Community midwife, Fife
Kate Woodman	Research specialist, Children & Families, HEBS

Research Team:

Janet Shucksmith	Senior lecturer, University of Aberdeen
Caroline King	Research fellow, University of Aberdeen
Susan Brown	Research assistant, University of Aberdeen
Kate Philip	Senior research fellow, University of Aberdeen
Gavin Smith	Research assistant, University of Aberdeen

Invited speakers to Group:

Fiona Dagge Bell
Saskia Gavin
Lesley Whyte

B.1 Sampling for practitioner study

Fieldwork comprised both telephone interviews with individuals (many in posts of responsibility), and focus groups with a range of health service and family centre workers closely involved with families in the field.

Twenty-eight telephone interviews were completed from 14 of the 15 health board areas (not able to reach 2 contacts in Ayrshire and Arran Health Board). Of these 28:

- 10 were Lead Nurses - Health Visiting
- 8 were Public Health Practitioners
- 3 were Directors of Nursing Services
- 2 were Child Protection Advisors
- 1 was a Health Visitor
- 1 was a Nurse Consultant in Public Health
- 1 was a Family Health Nurse
- 1 was a Children's Services Manager
- 1 was a Community Paediatrician

Fourteen focus groups were completed in 5 different Health Board areas, namely Grampian, Lothian, Borders, Dumfries and Galloway and Greater Glasgow. Of the groups:

- 5 groups were of health visitors (including one group from the *Starting Well* health demonstration project)
- 2 groups were of school nurses
- 2 groups were of community paediatric nurses
- 1 group was of A and E staff at a children's hospital
- 1 group was of outpatient department staff at a children's hospital
- 1 group was of GPs
- 1 group was of co-ordinators of the *Starting Well* health demonstration project
- 1 group was of family centre staff

In general we have not identified staff with their Health Board area, as this undermines the confidentiality of respondents. The exception to this is clearly *Starting Well* staff, whose singular status in relation to being the only health demonstration project of this kind in Scotland is impossible to conceal.

B.2 Sampling for parent study

Interviews took place in three areas selected on the basis of their different use of personal child health records: Tayside (Angus), Grampian, Fife. Other

contacts were also made however in relation to specific issues e.g. West Lothian / Dumfries and Galloway in relation to travelling families; Glasgow in relation to parents currently seeking asylum. As proposed, Starting Well were also approached. Due however to the particularly heavy level of internal and external evaluation currently taking place it was felt inappropriate to carry out further interviews with parents within the time scale of this current study.

In order to give an indication of the nature of the sample the following details may be noted:

	Area, number of parents interviewed and how accessed	Circumstances
1	Grampian; individual; personal contact	Rural White British Mother: Professional / Part-time Father: Professional Children: 2 under 5
2	Grampian; individual; International Centre	Rural Chinese Mother: Professional / Part-time Father: Professional Children: 2 under 5
3	Grampian; pair; International Centre	Urban Pakistani Mothers: Housewife Fathers: Business Children: 3 to 9 years
4	Angus; group; Health Visitor / Mother and Toddler	Urban White British Mothers: Housewives ?? Fathers: ?? Children: ??
5	Angus; group; Health Visitor / Mother and toddler	Urban White British Mothers: Housewives ?? Fathers: ?? Children: ??
6	Grampian; individual; International Centre	Suburban Nigerian Mother: Housewife Father: Professional Children: ??
7	Fife; group; Family Centre	Urban / area of deprivation White British Mothers: ?? Fathers: ?? Children: 2 to 15 years

8	Grampian; group; Family Centre	Urban / area of deprivation White British Mothers: ?? Fathers: ?? Children: 3 weeks to 18 months
9	Grampian; individual; personal contact	Rural White British Mother: Housewife Father: Professional Children: 3 and 6
10	Grampian; individual; Family Centre	Urban / area of deprivation White British Mother: Housewife Father: Unemployed Children: 2 to 9
11	Grampian; individual; Family Centre	Urban / Area of deprivation White British Mother: Deceased Father: Unemployed Child: 3 years
12	Grampian; individual; Family Centre	Urban / Area of deprivation White British Mother: Housewife Father: Separated Children: 2 to 9
13	Grampian; individual; postnatal group	Urban White British Mother: Professional / part-time Father: Professional Child: 1 year
14	Grampian; individual; postnatal group	Semi-urban German Mother: Professional / part-time Father: Professional Child: 1 year
15	Fife; group; Family Centre	Urban White British Mothers: Housewives; Student Fathers: ?? Children: 3 months to 15 years
16	Tayside; group; Family Centre	Urban White British Mothers: Housewives Fathers: Separated Children: 8 months to 2 years
17	Grampian; individual; postnatal group	Suburban White British Mother: Professional Father: Professional Child: 2 years

18	Grampian; group; Surestart group for children with special needs	Rural White British Mothers: ?? Fathers: ?? Children: ??
19	Grampian; individual; Traveller Project	Urban White British Mother: Housewife Father: Business Children: ??
20	Tayside; pair; Family Centre	Urban White British Mothers: Housewives Fathers: ?? Children: 6 months to 5 years
21	Grampian; individual; Sure Start	Rural White British Mother: Housewife Father: Professional Children: 4 to 10
22	Grampian; individual; Sure Start	Semi-urban White British Mother: Housewife Father: Service industry Children: 5 months and 9 years
23	Grampian; individual; Sure Start	Semi-urban White British Mother: Housewife Father: Professional Child: 8 months

Appendix C Research instruments

C.1 Practitioner study

Individual telephone interviews were semi-structured and based on the following schedule:

Section A Background Information

- A1** What is your post title?
- A2** How long have you been in post?
- A3** Who is your employing body?
- A4** Which geographical area do you cover?
- A5** Please indicate what stage thinking has reached in terms of Family Health Plans in your health board area?

Section B Current Practice

- B1** How do Health Visitors currently record information about child and family health in your area?
 - a) record held by parent (sole record)
 - b) record held by professional (sole record)
 - c) record held by family, but with parallel record for **all** cases
 - d) record held by family, but with parallel record for **some** cases
- B2** What are your experiences of the current Personal Child Health Record?
 - a) benefits to parents
 - b) benefits to professionals
 - c) associated problems for professionals and for parents
- B3** In your experience are there any groups in society which the PCHR does not work well with?
- B4** For those groups where the PCHR does **not** work well, what measures are in place to ensure adequate record keeping?
- B5** In your experience which of the following professionals use the PCHR? health visitors, gps, clinic doctors, A/E staff, hospital staff, professions allied to medicine, social workers, any other groups?
- B6** Do you think there is a need for further development of the PCHR?
- B7** In what ways do you think improvements could be made to the current PCHR ?
- B8** Do you think the PCHR contains 'user friendly' language for parents?
- B9** Do you think it is of any benefit to include health promotion material in the PCHR?

B10 Do you think the PCHR contains the correct amount of information?

Section C Family Health Plans

- C1** What would you see as the potential benefits of a Family Health Plan?
- C2** If a Family Health Plan existed, which was held by the family, do you think it would be necessary to have a parallel record?
- C3** Do you think a Family Health Plan would allow parents to play a more active role in healthcare decisions for their family?
- C4** With the introduction of a Family Health Plan what issues would you foresee arising in the context of :
- a) child protection
 - b) confidentiality
 - c) multi-agency information sharing
 - d) raising expectations of services which can be offered
- C5** It is envisaged that Family Health Plans would have a long term use (as opposed to PCHRs which are rarely used past the age of 5). Would you see any benefits of this or do you have any concerns regarding this?

Section D Change in Professional Role

- D1** With the introduction of Family Health Plans would you envisage any change in the role of the Health Visitor?
- D2** What are the implications for the workload of Health Visitors with the introduction of the Family Health Plan ?
- D3** When the PCHR was introduced was extra training offered to health visitors to assist in its implementation?
- D4** In retrospect, what lessons can be learned from the way in which the PCHR was introduced?
- D5** Do you think Health Visitors would require further training to implement a Family Health Plan?
- D6** What forms of training do you think Health Visitors would require?
- D7** What kind of extra support do you think Health Visitors might require to implement a Family Health Plan?

Section E Other Issues

Are there any other issues relating to Family Health Plans which you would like to highlight or discuss?

Focus groups with practitioners were inevitably less structured than the telephone interviews, though they pursued the same issues as had been covered in the telephone interviews. In addition, participants were shown examples of pilot Family Health Plans from elsewhere and asked for their responses.

C2 Parent study

The following schedule was used with parents when interviewed individually:

Family Health Plans: Parent Study

Interview Schedule

Section 1: Introduction to the research interview

- Outline research - what it is about, reasons for doing it etc. (provide leaflet)
- Discuss interview process – no right or wrong answers etc
- Discuss confidentiality / anonymity – how data will be anonymised, used in reports etc
- Negotiate recording of interview
- Negotiate length of interview – no more than one hour

Section 2: About your family

Could you tell me a bit of **background** about your family e.g. how many children, ages, etc., partner or not, work or not etc.

Section 3: Recording information

Ask open question first

3.1 How do you **currently 'record' health information** in relation to your child(ren)? E.g. Health problems, developmental goals, achievements etc.

3.2 Parent Child Held Record

3.2.1 Do you have a 'little red book'?

3.2.2 When it was given to you what was your understanding of its purpose?

3.2.3 Now that you have it, what do you use it for? (*Prompt for examples, e.g. recording immunisations, use health promotion materials etc.*)

3.2.4 What do you see the **benefits** of the 'LRB' to be?

3.2.5 Are there periods when you have **used it more / less**? *E.g. with first child*

3.2.6 When recording information, **who** takes responsibility for this? (*Prompt e.g. Parent, Health professional – which people tend to write in it? HV's only, social workers, family centre workers etc Does their input depend on parent asking them to? Both / partnership?*)

3.2.7 How / who decides **what** information will be recorded?

3.2.8 Do you find having **possession** of your own record for your children in your home useful? The fact that you hold the record - how does this impact on **ownership** of the record / information?

3.2.9 As a record is it **accessible** in terms of e.g. language used, knowing where to record information?

3.2.10 Have you used the **health information**? Explore if flexible / interactive enough? Are there other places you get health information from?

3.2.11 Is the LRB just a '**record**' or does it provide a means of assessing health / developmental problems, planning solutions, knowing what support is available from different agencies / professionals etc?

3.2.12 To your knowledge, is any professionally held record / plan currently made of issues relating to your children's health? i.e. a parallel record

3.2.13 Do they think professionals should have a record on their family's health?

3.2.14 What **rights of access** would they want to this?

Section 4: Family Health Plans

Family Health Plans are a new way of making a record of health issues which are of importance to you and your family. They are likely to be given to you by health visitors when a family has a new child, but parents will be asked to help record things about the health of their whole family, and plan for the future. It is hoped that this will allow parents and professionals to work together to solve problems and promote the health and well being of children and families.

Family Health Plans (highlight proposed difference between these and PCHR's)

- Do you have any experience of using a Family Health Plan? (N.B. this line of questioning will most certainly differ depending on the response to this question)
- Would parents find it useful to have a document which allowed you (in conjunction with your health visitor) to **assess, plan, record events**?
- Does this way of working (i.e. assessing, planning, solving problems in partnership with professionals) ring true to their experience of their relationships with HVs etc so far?
- Would they find potential increased input / support helpful / intrusive?
- Does professional input into e.g. problem solving major in terms how they solve / deal with issues relating to their children?
- Are there issues which you feel you would want input into / have appreciated more support e.g. chronic illness, social issues etc

Confidentiality and information sharing

- Do they think it is important to have the record in their home (as with PCHR)?
- Similar to LRB - Would they keep it? Feel ownership over it? Lose it?
- Is 'confidentiality' important? Have they ever felt it has been compromised by professionals?
- To what extent do they perceive that information is currently shared between professionals?
- What about between family members? E.g. immediate vs extended family members, sharing information with children when older etc.

- Do they feel that information is shared enough / not enough? In what circumstances should information about family members e.g. children be shared / not be shared? Give examples, e.g. if child has acute appendicitis, if parent has mental health problems, if partner is using illegal drugs
- In a family health plan there is potential for there to be information recorded about all family members. Would they feel happy about this?
- Would they feel happy for different family members to read / have access to the plan?

Section 5: Current contact and relationships with professionals

(Bring these questions in as and when appropriate in terms of discussion):

- Look at current relationship with / role of their health visitor at different stages – ask to recount contact and experiences of this. E.g. first contact, key events etc
- What about other people e.g. social workers, GPs etc. – when have they had contact and why?
- In current contacts with professionals who tends to drive the agenda – is it professionally dominated, parent led, jointly negotiated?
- Would they find that actual recording of information (as in a FHP) inhibiting in any way to discussing issues, asking advice with HVs?

Section 6: Other issues

- Look at issues as they relate to different groups e.g. minority ethnic groups – ensure to look at issues of language / communication, relationships with professionals etc
- Be careful not to make assumptions about family dynamics and sharing of information for example.

Section 7: Conclusion of interview and feedback from the study

- Ask if any other issues would like to discuss
- Give information relating to feedback from study and potential time scales for this
- Get details of where to send information

In addition, when parents were interviewed as a group, the following set of vignettes was used to generate the initial discussion, before elements from the schedule above were asked as appropriate.

**VIGNETTES AND EXERCISES FOR FAMILY HEALTH PLANS
GROUP INTERVIEWS**

1 Look at different aspects of Sheffield Family Health Plans

2 Present following vignettes in sequence to explore which of these issues they would wish to share with health professionals/would feel were appropriate to record on a family health plan:

a) Jane and Jim have three children, Andrew and Colin, who are 5 and 3, and a baby, Emma who is 6 months. They live in a flat. Jim is out of work and has been for the last 10 weeks. Recently Jane has started to worry about Jim, he has been shouting at the kids more than usual. He seems to be really agitated all the time and not sleeping well.

b) Jane has bottle fed both Andrew and Colin. She would like to try to breastfeed Emma but doesn't know how she would manage, especially with two young boys.

c) Jane decided to breast feed and managed well until 7 weeks when Emma started to lose weight.

d) Jane has concerns about Colin. His behaviour is getting worse and worse. It is difficult to say exactly how. Recently she was in the doctor's surgery and he just seemed to be everywhere, on top of surfaces, and wouldn't sit still. Jane realises that the time she has to spend with Colin is often limited since Emma was born. Getting out to play is also difficult since they live in a flat.

e) Ever since Emma was born Jane has been feeling really down. She has been tired and had some really black days. She knows that it is quite common after having a baby to feel pretty down, but some days she really feels like throttling her kids when they start misbehaving. When she thinks about it she was probably feeling like this since before the kids were born. When she met Jim she moved area and hasn't really made that many friends since.

f) Colin has had an on-going kidney problem since he was born. He has ended up in hospital a number of times and has on-going treatment with antibiotics. Every time Colin is in hospital his treatment seems to change.

g) Outside Jim and Jane's flat is a road that people seem to go flying up and down much faster than the speed limits. Jane and Jim feel concerned about their children's safety.

Appendix D Current systems of recording
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Table showing current method of recording information in each of the health board areas :

Health Board	HV Record	PCHR	Family Record
Argyll and Clyde	Yes	Yes	Yes
Ayrshire and Arran	Yes	Yes	Yes
Borders	Yes	Yes	No
Dumfries and Galloway	Yes	Yes	Yes – pilot scheme
Fife	Yes	Yes	Yes
Forth Valley	Yes	Yes	Yes
Grampian	Yes	Yes	Under development
Greater Glasgow	Yes	Yes	No – exception Starting Well pilot scheme
Highland	Yes	Yes	No
Lanarkshire	Yes	No	No
Lothian	Yes	Yes	No
Orkney	Yes	Yes	No
Shetland	Yes	Yes	Yes
Tayside	Yes	Yes except Angus	No
Western Isles	Yes	Yes	No