Evaluation of the pilot
Parent-held Personal Child Health record programme
in the Mid-Western Health Board Region

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1.0 EXECUTIVE SUMMARY

The parent-held personal child health record (PHR) is a parent-held record that has been instituted on a pilot basis within the Mid-Western Health Board since 1 May 2001. It has been given to all parents of children born since 1 May 2001 in the Limerick Community Care area.

The present study was commissioned by the Mid-Western Health Board as a one-year evaluation of the pilot PHR programme. Three specific research questions were identified for examination:

1. Identify the extent of use of PHRs amongst parents and health professionals
2. Explore attitudes towards and experiences of PHRs as a method of child health record keeping
3. Identify the impact, if any, of PHR on the uptake of child health services

Participants in this study were selected from two populations - parents and health professionals (please see Flow Chart 1, p. 20, for a summary of the sampling of research participants).

All parents residing in the Limerick Community Care Area who gave birth during May, June and July, 2001 were given a PHR (n=464). From this group we randomly selected 232 parents which we designated as the intervention sample group.

The intervention sample group was divided into two smaller groups. The first group (intervention group I) consisted of 115 parents who participated in interviews immediately following their babies’ 7-9 month developmental check. The majority of these interviews were conducted between January and June, 2002 (81 parents out of the total 115 parents in intervention group I responded, thus achieving a 70.4% response rate). The second group (intervention group II) consisted of 117 parents who received self-administered questionnaires distributed to them during their babies’ 7-9 month
developmental check. The majority of these questionnaires were distributed between January and June, 2002 (80 parents out of the total 117 parents in intervention group II responded, thus achieving a 68.3% response rate).

All parents residing in the Clare and Tipperary/North Riding Community Care Areas who gave birth during May, June and July, 2001 (n=696) were identified as the control group population. A total of 232 parents were randomly sampled from this population which we designated as the control sample group. The control sample group received self-administered questionnaires distributed to them during their babies’ 7-9 month developmental check. The majority of these questionnaires were distributed between January and June, 2002 (196 parents out of the total 232 parents in the control group responded, thus achieving a 84.4% response rate).

The health professional sample group was recruited from all the Area Medical Officers, General Practitioners and Public Health Nurses whose names were identified during examination of PHRs in the course of interviews with intervention group I (n=61). The health professional group received self-administered questionnaires distributed to them through the post in July, 2002. 48 health professionals out of the total 61 health professionals in the group responded, thus achieving a 78.6% response rate. A subset of this group of health professionals (n=16) also participated in 20 minute, semi-structured, one-on-one interviews with the lead researcher in August, 2002. This subset included two Area Medical Officers, six General Practitioners and eight Public Health Nurses. The sampling method used to select health professionals (i.e., purposive sampling) does not allow for generalisations amongst the entire Limerick Community Care area health professional population.

The major instrument utilised in this study was a structured, interviewer-administered questionnaire administered to intervention group I. This questionnaire consisted of 64 questions including open-ended and closed pre-coded questions. The questionnaire was designed to address the specific objectives of the study as outlined in the introduction. Intervention group II parents received a postal, self-administered questionnaire consisting
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of 32 questions including open-ended and closed pre-coded questions. Control group parents received a postal, self-administered questionnaire consisting of 26 similar questions. The health professional group received a postal, self-administered questionnaire consisting of 14 closed pre-coded questions.

One of the key research objectives in this study was to examine parental satisfaction with the PHR. A total of 99%, (n=153) of intervention group I and II parents were ‘very satisfied’ or ‘satisfied’ with their PHR. Just 1% (n=2) of parents reported that they were neither satisfied nor dissatisfied with using the PHR. None of the parents reported dissatisfaction with using the PHR.

A second research question addressed the extent of use of the PHR amongst intervention group I and II parents. Parental retention of the PHR was high - 90% of respondents in intervention group I brought the PHR to their child’s 7-9 month developmental check (n=73). A total of 86% of respondents in intervention group II indicated in response to the postal questionnaire that they brought the PHR to their child’s 7-9 month developmental check (n=69).

Extent of use was also gauged through parental reported reading of the booklets - 98% of intervention group I parents (n=77), indicated that they had read at least one section of the PHR and 88% (n=68) indicated that they had read the entire PHR. Additionally, PHRs were examined by the lead researcher at the 7-9 month developmental check to determine parental usage of the PHR. We found that 97% of parents (n=70) had written information in their booklets.

Attitudes towards using the PHR were also explored with the control group parents, 97% of whom indicated that they would be willing to keep a PHR for their child (n=187).

Another theme investigated by this research examined whether the PHR impacted on uptake of child health services such as infant immunisations. 90% of intervention group I and II parents (n=132) and 89% of control parents (n=171) stated their children had
received all required immunisations up to six months old. Statistical analysis revealed that the PHR had no impact on uptake of immunisations.

Qualitative interviews with the group of 16 health professionals addressed a range of themes including levels of satisfaction with using the PHR; the question of whether the PHR fostered communication between health professionals and between health professionals and parents; and suggestions for ensuring maximum use of the PHR by all relevant parties.

The following extracts indicate the range of responses offered by health professionals when asked to comment on their level of satisfaction with using the PHR. Responses ranged from expressions of satisfaction to dissatisfaction with using the PHR.

“...I am very satisfied with it, I think its great, and I think its great that the parents have it. And you can start off your consultation by asking for it and you can say – you see the child has had this and that. And it kind of helps you to structure your consultation”. (AREA MEDICAL OFFICER)

“I think it is an impossibly complex book to go leafing through every time there’s a surgery or consultation…. I’m not sure of what the point is of the booklet….going around now with this booklet seems to me to be a step backwards.” (GENERAL PRACTITIONER)

“I think it’s a great tool, it’s a great way of documenting, it’s all together, the colour coding makes it much easier to use; I just feel it’s a great tool.” (PUBLIC HEALTH NURSE)

Professionals were asked if they felt the PHR could serve as a useful communication tool between health professionals. Responses ranged from expressions of caution to guarded support of the PHR as a communication tool between health professionals. The following extracts indicate responses to this question.

“Well, between health professionals, I don’t know if it is really great because I don’t know how many of the General Practitioners are actually putting in their information, some of them are and some of them aren’t. So then you’re wondering, is stuff there because it didn’t happen, or because the GP didn’t particularly want to fill it out.” (AREA MEDICAL OFFICER)
“These other health professionals don’t remember to give it to us at all in the first place. In most cases the Area Medical Officers are doing their own thing and I’m not sure, if it were going to be a two-way process…I can’t see the usefulness of it myself, to be honest with you.” (GENERAL PRACTITIONER)

“I think it has to be…if the notes are kept well, even for social workers working with public health nurses, it’s a good way of keeping records. Or for the area medical officers or for the General Practitioners, for vaccinations, it is a great way.” (PUBLIC HEALTH NURSE)

Health professionals were also asked if they felt the PHR could serve as a useful communication tool between health professionals and parents. Responses were supportive, although concerns were also raised. The following extracts indicate responses to this question.

“….recently there was a problem with the BCG vaccinations, and a few parents rang up and said that they saw from their book that they have the dodgy batch, and from that point it was very useful. Because it was on the 6 pm news and they just took out their books and read it.” (AREA MEDICAL OFFICER)

“Now there are ones [parents] who would have difficulties keeping things and getting their vaccines done and following up problems – they’re the ones who would be least likely to use the booklet as well.”(GENERAL PRACTITIONER)

“I think its good because first and foremost, you’re letting it to them, you know. It is theirs to write into, and most of them I’ve met, particularly when I do back-up visits to the home, the first thing they give me is the booklet, and they do seem to be inputting into it well.” (PUBLIC HEALTH NURSE)

Finally, both health professionals and parents were asked to suggest ways in which the PHR could be improved upon. Suggestions pertained to the layout, content and usage of the PHR.
These findings suggest that parents appreciate using the PHR and value its role as a method of child health record keeping. It is also clear that parents not yet issued with a PHR may be receptive to using one. Professional responses to the PHR have been mixed. Qualitative analysis has uncovered professional concerns surrounding duplication of records, extent of professional usage, and usefulness of the PHRs. In the main, Public Health Nurses and Area Medical Officers were satisfied with using the PHR. The study has revealed a large degree of support from the parents and most of the health professional categories studied. However, the findings suggest that there is some resistance from General Practitioners. Their concerns will have to be addressed if they are not to prove detrimental to the successful operation of the PHR scheme.

These findings offer a comprehensive illustration of both parental and professional attitudes and opinions of the pilot PHR programme. These data will contribute to mapping the future role and function of the PHR programme.
2.0 INTRODUCTION

2.1 RATIONALE FOR THE EVALUATION

The parent-held personal child health record (PHR) is a parent-held record that has been instituted on a pilot basis within the Mid-Western Health Board since 1 May 2001. No previous evidence is available regarding the use and usefulness of a PHR programme in this country. Although anecdotal evidence has surfaced regarding parental and professional opinions of the pilot PHR programme, the PHR has not yet been formally evaluated.

An evaluation of the pilot PHR programme has been cited as the principal activity of the fourth and final phase of the Mid-Western Health Board's overall PHR project. It was planned that the evaluation phase should commence after approximately six months active usage of the PHRs in the Limerick Community Care Area. The requirement to conduct a formal evaluation of the pilot PHR programme, as stipulated in phase four of the project outline, provided the impetus to undertake this study.

2.2 BACKGROUND TO THE EVALUATION

The mode of record keeping utilised in the pilot PHR programme replaces an older system in use in the Mid-Western Health Board since the early 1970s. This older system relied on medical cards held by Public Health Nurses. Health professionals entered information, such as immunisation and developmental details, onto these cards for babies who were born in or who entered the Mid-Western Health Board region. A Working Group was established by the Mid-Western Health Board's Community Care Programme in 1997 to examine recording systems for child health surveillance. The Working Group identified several disadvantages with the system of card-based record keeping. Concurrently, the Working Group investigated health record systems used in other Irish Health Boards and overseas. Their investigation included examination of parent-held child health records used in the United Kingdom, New Zealand and in other countries. The review of this literature uncovered several advantages to both parents and professionals in using a parent-held personal child health record.
Findings from the Working Group’s research informed the creation of the Mid-Western Health Board's Child Health Strategy (1999). This report mandated the introduction of a parent-held personal child health record as a key component of the Health Board's child health promotion campaign. Acting on this mandate, the Mid-Western Health Board secured funding from the Department of Health to pilot a parent-held personal child health record programme. The programme consisted of a two and a half year project involving four phases. These phases included: phase 1) pre-planning; phase 2) systems planning; phase 3) active implementation of the PHR; phase 4) final evaluation.

2.3 FUNCTIONS OF THE PHR

The functions and purpose of the pilot PHR, as outlined by the Mid-Western Health Board, can be summarised as follows:

- To increase partnership between parents and professionals
- To improve communication between professionals caring for the child
- To provide parents with health information relevant to their child
- To provide statistical information relevant for service planning and management of the service.

These functions are predicated on an understanding of the PHR as 1) an affirmation of the key role parents play in child health care and 2) a tool in fostering the principles of working in partnership and empowering parents.

2.4 LITERATURE REVIEW

PHRs have been used in various countries since the 1980s. Pilot programmes within segments of health districts and authorities have generally fared well, resulting in more widespread PHR use with an extension to health districts and areas. Previous studies have examined the use of PHRs within specific health care areas and evaluated parental and professional use of the records.
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A literature review was conducted of currently available research in English on PHR use unrestricted by country. A search of Medline up to 2002 was conducted using the key words "personal health record" and "parent held child health record" to ensure comprehensive coverage of the topic. The following information highlights important findings that address the research question.

2.4.1 Findings regarding parental use of PHRs

Several evaluations have been conducted on the use of PHRs by parents. These studies have been conducted between six months and 10 years after initial introduction of the PHR in the participating health authority region.

Research evaluating parental impressions, when first given a PHR, suggests that the majority of parents like the PHR, bring it with them to health appointments, and write in it themselves. In a 1991 survey in Oxfordshire, 49% of respondents stated that they would like to see their health record and that having a summary of their health record was a good idea. Only 30% of respondents felt that their health was solely the responsibility of their doctor; 62% said they would like more information about their health.

A survey of 104 parents given the PHR in Fife indicated even higher parental acceptance and use of the PHR. All 104 parents said that it was important or very important that they have a copy of their child's health record. 95% of parents liked their PHRs and found the information contained in it useful. Only one PHR had been lost, compared to 77% who kept the PHR for at least six months. The high usage of the PHR suggested by these findings supports the rationale behind the introduction of the PHR in Fife - namely that the PHR provides a useful method of improving communication between parents and professionals and supports the parent-professional partnership in care.

The value of PHRs in empowering parents regarding child health is underscored when compared with opinions of parents not using PHRs. In an Oxfordshire evaluation, 75% of parents given a PHR thought parents should be responsible for their child's health
record. Comparatively, only 25% of parents not given a PHR thought they should have one. Worries about losing the record were cited as a reason to leave it with health professionals. This fear has been echoed by other parents not familiar with PHRs, but it may be largely unfounded. A study involving parents in the armed services who were given a PHR found that after 12 months, 97% of these parents still had their original PHR.

It is noteworthy that parents are more satisfied with their PHRs after prolonged use than after only six months experience with the PHR. A study conducted in South Australia evaluated parental and professional use of a PHR ten years after its introduction and compared these results with those obtained from a survey conducted soon after the PHR was introduced. Ten years experience with the PHR seems to have increased parental and professional use of the PHR and satisfaction with it. Asked ten years after its introduction, 91% of parents found the PHR useful; whereas in the first survey most parents were unaware that the PHR was for their own use. Additionally, approximately 80% of parents in the second survey indicated that their doctor had written in their PHR, whereas previously professional use of the PHR was low.

2.4.2 Findings regarding professional use of PHRs

Medical professionals generally acknowledge that PHRs can only attain their full use and benefit if health professionals make a commitment to read and write in PHRs. In light of this it is encouraging to find that a majority of health professionals surveyed by various researchers stated that they liked the idea of the PHR and felt it was a benefit to child health, surveillance, and effective patient-professional relationships.

An evaluation conducted in one area of the North Staffordshire health district reported that 87% of health professionals felt that the parent-held PHR improved communication between professionals and parents. Moreover, 85% of professionals in this survey believed that use of the PHR promoted greater mutual trust and respect between professionals and parents. Research on the Child Health Passport used in Alberta, Canada, found that 97% of community health nurses thought the passport was a good
idea. 86% of community health nurses stated that they worked in collaboration with parents when recording entries in the passports. Nurses in Alberta felt that joint entries, versus exclusion of parental input, provided opportunities for nurses to discuss notes with parents. This discussion in turn encouraged active parental participation and communication with nurses and other health professionals.

However, other studies of professional PHR use have indicated that health professionals have not been universally supportive of PHRs. Several studies suggested that health professionals, perhaps more than parents, had concerns regarding use of the PHR. These concerns have largely included potential violations of confidentiality, loss of the record by parents, duplication of information, and extra work involved in writing in PHRs.

Some concerns may be ameliorated once professionals become familiar with PHRs. For example, General Practitioners who had no experience with PHRs were more concerned about possible loss of records than those with experience of PHRs - in one survey, 60% compared to 40% of General Practitioners using PHRs. A survey conducted in South Australia on professional opinions of the PHR found that 23% of General Practitioners were unaware of the parent health information section of the PHR and 39% never referred parents to this section. This omission might hamper communication between doctor and parent, as any notes contained in the parent health information would not be discussed. Nonetheless, even against the backdrop of these concerns many professionals felt that the PHR was of benefit in improving doctor-parent communication and relationships. 80% of a group of General Practitioners in South Australia felt that the PHR made parents feel more responsible for their child's health and 88% thought the PHR was beneficial to child health management.

Health professionals surveyed thus far seem aware of PHRs and use them. A few objections have been raised by health professionals, although more so by non-users of the PHR than those familiar with it. Concerns with the PHR have been acknowledged, but most health professionals state they are familiar with PHRs and agree with their value as communication and education tools. It is encouraging that in a 1987 study in
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Oxfordshire, 136 out of 137 doctors who had experience of the PHR were satisfied to continue using the PHR with their clients. These positive results led to the introduction of the PHR throughout the whole Oxfordshire district since 1989.

2.4.3 Conclusion

Parent held PHRs have been successfully instituted in many health authority regions. Parents report that they feel more empowered with a copy of their child’s health information. This sense of empowerment includes a greater sense of trust and equality with their doctors. Likewise, medical professionals have largely commended PHRs as a means of including parents in child health maintenance. Health professionals, such as General Practitioners and Public Health Nurses have commended PHRs as useful to parents and as aides in health professional-parents communication. Prior to the introduction of PHRs established medical orthodoxy situated the medical professional as the active participant and the parent as the passive recipient in doctor-parent communication and relationships. Parent-held PHRs have great potential to counteract this unequal relationship and instead accommodate a more balanced and mutually satisfying doctor-parent environment.
3.0 SPECIFIC OBJECTIVES OF THE EVALUATION

The principal objective of this evaluation was to:

"...evaluate...PHRs...with an emphasis on extent of use, outcomes of use and experiences of this method of recording child health from both parental and professional perspectives."
(Proposal to evaluate the pilot implementation of parent-held health records in the Mid-Western Health Board Region, 2001).

Three key elements were identified to address the principal research objective. These three key elements were:

1) Identify the extent of use of PHRs amongst parents and professionals
2) Explore attitudes towards and experiences of PHRs as a method of recording child health
3) Identify the impact, if any, of PHRs on uptake of child health services

Several research questions were included under each key element as items for closer examination. The research questions pertaining to each key element include the following:

1) Identify the extent of use of PHRs amongst parents and professionals
   - does parent still possess PHR at 7-9 month developmental check
   - does parent want to use PHR
   - extent of use by parents in terms of bringing PHR to health related visits and extent of actual parental recording
   - extent of use by professionals
   - extent of professional recording of other health related visits
   - extent of unrecorded health related visits
   - extent of use by socio-economic groups and other demographic variables
2) Explore attitudes towards and experiences of PHRs as a method of recording child health
   - assess attitudes amongst parents and professionals towards parents possessing a copy of the child health record
   - assess parent and professional satisfaction with the PHR as a method of recording child health
   - assess parent and professional perceptions of utility of PHR
   - identify factors impacting on why parents/professionals did/did not use PHR
   - explore impact of PHR on parent/professional partnership and communication
   - explore parent and professional reaction to the inclusion of sensitive information

3) Identify the impact, if any, of PHRs on uptake of child health services
   - impact of PHR on parents attending/not attending for allocated developmental check appointments
   - impact of PHR on parental knowledge and comprehension of developmental checks
   - impact of PHR on uptake of immunisations
   - impact on duration of breastfeeding
   - impact on referral to specialist child health services
4.0 METHODOLOGY

4.1 OVERVIEW

Participants in this study were selected from two populations - parents and health professionals (please see Flow Chart 1, p. 20, for a summary of the sampling of the participant groups). The parental group was subdivided into a parental intervention group (n=232) and a parental control group (n=232). Participants in the health professional group consisted of Area Medical Officers, General Practitioners and Public Health Nurses in the Limerick Community Care Area who had exposure to PHRs in their practices and clinic-based work, as evidenced by their comments in PHRs (n=61).

This study utilised both quantitative and qualitative data collection techniques. Quantitative and qualitative data were obtained from the parental group through interviewer-administered and self-administered questionnaires. Quantitative data was collected from the health professional group through a single self-administered questionnaire, and qualitatively through semi-structured interviews.

4.2 PARENTAL GROUP DATA COLLECTION

4.2.1 Selection of parental intervention group participants

The researchers were provided with a database from the Mid-Western Health Board of the total population of parents given a PHR in May, June and July, 2001 (n=464). Exactly one half of the study population was sampled to participate in the evaluation. This intervention group, that is parents provided with a PHR, were sub-divided into two groups of 115 and 117 parents respectively. It was decided that intervention group I parents (n=115) would be interviewed face-to-face during their baby’s 7-9 month developmental check and that their PHR would be examined by the lead researcher. Due to time constraints, intervention group II parents (n=117) received a self-administered questionnaire by post as it would not have been feasible to interview all the participants in intervention groups I and II.
Participants in intervention groups I and II were selected using a block randomisation sampling method. This method was used to ensure that we would obtain a representative sample of parents spread throughout the three month pilot implementation phase.

In summary the sample intervention groups consisted of:

Intervention Group I (n=115) - 38 babies born in May, 38 in June and 39 in July,
Intervention Group II (n=117) - 39 babies born in May, 39 in June and 39 in July.

Intervention groups I and II provided essential data on attitudes, experiences and satisfaction with PHRs. With regard to use of the PHR, findings relating to intervention group I are presented separately to group II. The rationale for presenting these results separately was that findings pertinent to intervention group I were based on actual examination of the PHR by a researcher, thus giving a definitive account of extent of use by parents and professionals. Parents in intervention group II were asked to indicate their use of the PHR, hence the data provided is based on parental assessment of PHR use and not a researcher assessment.
Flow chart 1: Sampling of study population

INTERVENTION GROUP POPULATION:
All parents given PHRs during May, June and July, 2001 (n=464)

CONTROL GROUP POPULATION:
All parents residing in the Clare and Tipperary/North Riding Community Care Areas who gave birth during May, June and July, 2001 (N=696)

232 parents randomly sampled as the intervention group

232 parents randomly sampled as the control group

115 parents participated in interviews conducted from January to June, 2002 (81 respondents; 70.4% response rate)

117 parents received self-administered questionnaires distributed from January to June, 2002 (80 respondents; 68.3% response rate)

232 parents received self-administered questionnaires distributed from January to June, 2002 (196 respondents; 84.4% response rate)

61 health professionals purposively sampled to receive self-administered questionnaires and participate in interviews from July to August, 2002 (48 respondents; 78.6% response rate)

(NB: health professional names gathered during examination of PHRs)
4.2.2 Selection of parental control group participants

The population from which the control group was sampled consisted of all parents residing in the Clare and Tipperary/North Riding Community Care areas who gave birth in May, June and July 2001 (n= 696). Parents in these two care areas who gave birth in May, June and July 2001 were not issued with PHRs.

The sample size decided for the parental control group – 232 participants - was divided equally between the two community care areas. Thus, 116 parents from the Clare Community Care area and 116 parents from the Tipperary/North Riding Community Care area were selected to form the parental control group sample. A database of all parents residing in the Clare Community Care area who gave birth in May, June and July, 2001 was provided by the Mid-Western Health Board. A total of 116 parents were randomly selected from this database to participate in the parental control group. A second database of all parents residing in the Tipperary/North Riding Community Care area who gave birth in May, June and July, 2001 was provided by the Mid-Western Health Board. A total of 116 parents were randomly selected from this database to participate in the parental control group.

4.2.3 Design/Procedure

Intervention group I

Interviewers met with intervention group I parents at health clinics during their babies’ scheduled 7-9 month developmental check. The 7-9 month developmental check was selected as the most appropriate occasion to collect data as it was considered a crucial developmental check and would provide a key indicator of PHR use.

Interviews were facilitated in liaison with Public Health Nurses who provided the lead researcher with the dates, times and locations of 7-9 month developmental checks for intervention group I parents. Intervention group I parents were invited to participate in the evaluation and informed consent was obtained. Parents were requested to allow the researcher to examine their PHR to determine extent of use. All parental and professional
recordings were documented by the lead researcher. Following examination of the PHR, parents were interviewed using a structured questionnaire. Interviews sought data on attitudes and experiences of PHRs and parental satisfaction with this method of recording child health. All parents were guaranteed absolute confidentiality.

Parents were also provided with a self administered questionnaire to complete at home. Information was sought on developmental check attendance, immunisation history, breastfeeding rates and attendance at specialist child health services. This questionnaire sought to address key element three.

If a participant did not attend the scheduled 7-9 month developmental check and was re-scheduled for a later date, the lead researcher attended the subsequent appointment(s). The lead researcher attempted to contact participants who missed several appointments and were eventually recorded by the attending Public Health Nurse as “non-attenders”. In these instances, the lead researcher asked the attending Public Health Nurses to contact those who never attended a 7-9 month developmental check to seek permission to be contacted by telephone.

Qualitative data was also collected from intervention group I parents. Parents were asked several open-ended questions and unstructured responses were encouraged. These responses were not edited or truncated in any way and were fully transcribed during the interview. The transcribed responses were read back to the participants at the conclusion of the interview to confirm accuracy in transcribing.

Intervention group II
Public Health Nurses working with participants in intervention group II were contacted several weeks before the estimated start of 7-9 month developmental checks, for babies born during the target time period (i.e, May, June and July, 2001). Public Health Nurses were asked to distribute research packs to every intervention group II participant. The research packs contained a cover letter, a postage paid, addressed envelope and a questionnaire.
Public Health Nurses were asked to distribute the research packs because it was thought response rates would be improved if participants received their questionnaires from a familiar and respected source, rather than anonymously through the post. The packs were distributed during the 7-9 month developmental check because this was the occasion designated for contact with participants in the first parental intervention group.

Public Health Nurses were asked to assure all participants that completion of the questionnaire was voluntary and responses would be confidential. Public Health Nurses were also asked not to make any special or extraordinary contact with participants who missed appointments in order to deliver research packs. All undelivered research packs were returned to the lead researcher with a note explaining why the packs were not given to the relevant participants.

This questionnaire sought information on parental use, attitudes, experiences and satisfaction with PHRs. Similar to the intervention group I questionnaire, information was also sought from intervention group II on developmental check attendance, immunisation history, breastfeeding rates and attendance at specialist child health services. Duplication of content and mode of administration were purposely designed so that intervention groups I and II and the control group were presented with the same questions, in the same format, thus allowing for direct comparison.

Control group
Researchers contacted every Public Health Nurse in the Clare Community Care area and the Tipperary/North Riding Community Care area working with parents who had been included in the control sample group. Nurses were contacted several weeks before the estimated start of 7-9 month developmental checks for babies born in the target months (May, June and July, 2001). Public Health Nurses were asked to distribute research packs to those identified control group participants during the 7-9 month developmental check. The research packs intended for each control group participant contained a cover letter, a postage paid, addressed envelope and a questionnaire for the control group participant to complete and post back to the researchers.
Public Health Nurses were asked to assure all participants of the voluntary and confidential nature of their participation. Public Health Nurses were also asked not to contact participants who missed appointments in order to deliver research packs. This questionnaire sought comparative data on key element three.

In summary, four research instruments were designed and implemented for use with intervention groups I and II and the control group. The instruments consisted of the following:

- interviewer administered, structured questionnaire administered to intervention group I (following which, parents were probed for further detail)
- self administered, postal questionnaire distributed to intervention group I (to provide directly comparable data with group two and control group)
- self administered, postal questionnaire distributed to intervention group II
- self administered postal questionnaire distributed to control group

4.3 HEALTH PROFESSIONAL GROUP DATA COLLECTION

4.3.1 Selection of participants

The population from which the health professional sample group was selected consisted of Area Medical Officers, General Practitioners and Public Health Nurses working in the Limerick Community Care area during May, June and July, 2001.

Sampling for the health professional group commenced approximately mid-way through data collection with intervention group I. This time lapse in sampling between the parental and the health professional group was necessary to assess actual health professional use of the PHR. Health professionals’ first-hand use of the PHR was defined as evidence of any writing entered into the PHR by the health professional. Writing in the PHR included signatures, notes, or any other comments recorded by the health professional anywhere in the PHR.
Health professionals who recorded in the PHR were identified. If an interviewer recorded a health professional’s signature, notes, or any other comments in a PHR, this information was flagged. Parental consent was sought to contact health professionals who had written in PHRs. If consent was given, the name and address of the health professional was noted.

After interviewers had met with all the participants in intervention group I, a list of names was compiled of all the health professionals who had written in the PHRs. Health professional usage of the PHR was confirmed for all health professional names taken from PHRs. After confirmation of consent and usage, a final sample group was compiled of 61 Area Medical Officers, General Practitioners and Public Health Nurses with confirmed use of the PHR.

4.3.2 Design/Procedure

The collection of data from the health professional group utilised both quantitative and qualitative data collection techniques. Quantitative data was collected from the health professional group using a self-administered questionnaire. The self-administered questionnaire was distributed to the 61 health professionals included in the sample group by post. Non-responders were followed up with another copy of the questionnaire. The questionnaire sought data on professional usage and attitudes towards PHRs.

Semi-structured interviews were conducted with professionals who agreed to participate. The final question on the self-administered questionnaire posted to all health professional participants asked if they would be willing to participate in a qualitative interview to discuss in greater detail their opinions and experiences of the PHR. Participants were asked to indicate “Yes” or “No” to this question and include a daytime telephone number and address if they agreed to participate in an interview. All the General Practitioner respondents who indicated that they would like to participate in interviews were contacted directly to arrange dates and times for the interviews.
Three Area Medical Officers agreed to participate in qualitative interviews; two were contacted to arrange dates and times for interviews (one Area Medical Officer was not contacted due to scheduling constraints). Twenty Public Health Nurses agreed to participate in qualitative interviews, eight of whom were purposively sampled for participation. The criteria used to select Public Health Nurses for interviews was the location of their health clinic. Four Public Health Nurses were selected from the rural health clinics and four from the urban health clinics. All interviews were recorded onto a hand-held tape recorder and fully transcribed for analysis.

4.4 DATA ANALYSIS

Qualitative data was coded to identify key themes and issues that emerged from the data. The coded data was analysed to identify dominant professional and parental views and attitudes, while taking into account divergent opinion.

Quantitative data was inputted and analysed using SPSS. Descriptive and appropriate inferential statistics were computed to address the key research aims. Statistical analysis sought to identify any trends or patterns in attitudes towards and use of PHRs.
5.0 RESULTS

5.1 RESPONSE RATES

5.1.1 Parental group response rates

464 parents were sampled to participate in this study, 232 formed the parental intervention group and 232 formed the parental control group. The parental intervention group was further subdivided into intervention group I (n=115) and intervention group II (n=117) parents. Four participants in intervention group I were unknown to their local Public Health Nurses and a further twelve had moved prior to contact by researchers or otherwise couldn't be contacted. Eighteen participants did not attend their 7-9 month developmental checks, refused to be interviewed and/or could not be reached by telephone. The remaining 81 participants were followed up to complete an interviewer-administered questionnaires. Thus, the final response rate for the intervention group I was 81 out of 115 participants, or 70%.

Two parents in intervention group II were unknown to their local Public Health Nurses and one refused to participate in the study and was removed from the sample group. A total of 114 participants in intervention group II received questionnaires. In total, 70% (n=80) returned completed questionnaires. All 232 participants in the parental control group were issued a questionnaire, 84% of whom (n=196) responded.

5.1.2 Health professional group response rates

61 participants formed the health professional sample group. Seven participants in this sample group were Area Medical Officers; 25 were General Practitioners; and 29 were Public Health Nurses. Five Area Medical Officers, 15 General Practitioners and 27 Public Health Nurses returned completed questionnaires. Three Area Medical Officers agreed to participate in a qualitative interview, two interviews were conducted; one of the three Area Medical Officers was unavailable during the time reserved for interviews. A total of six General Practitioners agreed and participated in a qualitative interview.

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1 This includes 71 one-to-one interviews and 10 telephone interviews.
Sixteen Public Health Nurses also agreed to interviews, eight of whom were purposively sampled to participate.

5.2 PARENTAL EXPERIENCES, ATTITUDES AND USAGE OF PHR

This section of the report presents parental experiences, attitudes and usage of PHRs. Data relating to parental experiences and attitudes towards PHRs as a method of child health recording was obtained from intervention groups I and II (n=161) and is presented together as the complete intervention group response.

Data relating to parental usage (possession and recording) of PHRs is presented separately for intervention group I and intervention group II. The rationale for presenting this data separately is based on the method of data collection. In intervention group I, PHRs were examined by a researcher to establish the extent and nature of parental recording. Intervention group II parents were asked, through the postal questionnaire, to indicate their usage of the PHR, hence their reported recording practices are not confirmed by a researcher.

INTERVENTION GROUP I:

5.2.1 Key element one: does parent still possess PHR at 7-9 month developmental check

The vast majority of intervention group I parents were in possession of their PHR at their child’s 7-9 month developmental check, 90% of parents (n=73) brought the PHR to this health check. Just eight parents did not possess the PHR at the 7-9 month developmental check, six of whom indicated that they simply forgot to bring it on this occasion, one parent reported that the PHR was ‘destroyed’ and one parent could not find it. Parents were also asked to indicate how often they bring the PHR to child health visits, 63% (n=50) reported that they ‘always’ do so, 35% (n=28) ‘usually’ do so and just one parent reported that they ‘rarely’ do so.
Seventy-three per cent (n=58) of parents reported that they were provided with the PHR at their baby’s primary health visit, and 27% reported receiving the PHR within the first week of their baby’s birth at a time other than the primary visit.

Parents displayed a sound working knowledge of the PHR, 98% (n=77)\(^2\), reported that the purpose of it had been fully explained to them upon receipt. Parents viewed the PHR as a tool for both parental and professional usage. The PHR was not just considered as a document for professionals to record in but also a resource for parents. Typical comments expressed by parents relating to the purpose of PHRs included:

"to keep as a record of baby's medical history"

"to have all the details of what was done to my child and to take the PHR with me to all visits"

"it's a record to be kept and looked at and to keep track of all health visits"

"to keep a record of my baby's health for school, for the doctor's use and my own information"

"keep it when I go to the doctor and use it for myself"

"it's a record for baby and everything would be recorded"

"I can record baby's health and growth and medical information and the health professionals can record baby's progress"

"it's for parents own personal use"

"it's to record all medical information and to keep medical information in one place"

5.2.2 Key element one: extent of actual parental recording

Permission was sought from all parents in intervention group I to allow a researcher examine their PHR for the purpose of assessing parental recording. Just one parent wasn’t happy for the researcher to do so, hence data was obtained from 72 PHRs following the 7-9 month developmental check.

\(^2\) Missing data - 2
The vast majority of parents, 97% (n=70), made some recording on the PHR. Seventeen per cent (n=12) recorded in all sections of the PHR where relevant up to the 7-9 month developmental check. This included completing the introductory section with details of their child’s name, date of birth, sex, the name of the family’s General Practitioner and family history; section one including the hearing and sight checklists; section two – signing the vaccination consent and record form; section three – 6 week health check, 3 month health check and 7-9 month health check; and section five – other parental comments. A further 46% (n=33) made considerable usage of the PHR in terms of recording but did not complete all five sections and 35% (n=25) completed the introductory section and signed the vaccination consent and record form in section two, with no recording in section three, four or five.

63% of parents can be described as actively using the PHR and were coded as the ‘high use’ category. High use was defined as parents who fully completed sections one and two and completed at least one of the remaining sections. A further 35% of parents made limited recordings in the PHR and were coded as ‘low use’. Low use of the PHR was defined as parents who completed some of section one and two. Just 3% (n=2) of parents made no recordings whatsoever.

Table 1 outlines the sections that parents could write in the PHR, the percentage of PHRs where parents wrote information, and the number of PHRs where parents wrote information.
Table 1: Nature of parental recording

<table>
<thead>
<tr>
<th>Information that parents could write in PHR</th>
<th>Percent of PHRs with information written (%)</th>
<th>Number of PHRs with information written (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's name</td>
<td>88</td>
<td>63</td>
</tr>
<tr>
<td>Child's date of birth</td>
<td>89</td>
<td>64</td>
</tr>
<tr>
<td>Child's sex</td>
<td>88</td>
<td>63</td>
</tr>
<tr>
<td>Name of General Practitioner</td>
<td>79</td>
<td>57</td>
</tr>
<tr>
<td>Family history</td>
<td>85</td>
<td>61</td>
</tr>
<tr>
<td>Hearing checklist</td>
<td>42</td>
<td>30</td>
</tr>
<tr>
<td>Sight checklist</td>
<td>42</td>
<td>30</td>
</tr>
<tr>
<td>Signed vaccination consent</td>
<td>94</td>
<td>68</td>
</tr>
<tr>
<td>Notes in 6 week check section</td>
<td>29</td>
<td>21</td>
</tr>
<tr>
<td>Notes in 3 month check section</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td>Notes in 7-9 month check section</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td>Notes in comments section</td>
<td>38</td>
<td>27</td>
</tr>
</tbody>
</table>

Parents were asked to rate each section of the PHR, in terms of overall helpfulness, information and comprehension. Table 2 outlines the percentage and number of respondents who indicated that they would "agree" that each section of the PHR was "easy to understand", "informative" and "helpful overall.\(^3\)"

\(^3\) missing data – 5
Table 2: Parental rate of each section of PHR

<table>
<thead>
<tr>
<th>Section of PHR</th>
<th>Percentage of respondents who &quot;agree&quot; (%)</th>
<th>Number of respondents who &quot;agree&quot; (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section One</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easy to understand</td>
<td>96</td>
<td>73</td>
</tr>
<tr>
<td>Informative</td>
<td>88</td>
<td>67</td>
</tr>
<tr>
<td>helpful overall</td>
<td>90</td>
<td>68</td>
</tr>
<tr>
<td>Section Two</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easy to understand</td>
<td>100</td>
<td>75</td>
</tr>
<tr>
<td>Informative</td>
<td>95</td>
<td>72</td>
</tr>
<tr>
<td>helpful overall</td>
<td>95</td>
<td>72</td>
</tr>
<tr>
<td>Section Three</td>
<td></td>
<td></td>
</tr>
<tr>
<td>easy to understand</td>
<td>95</td>
<td>72</td>
</tr>
<tr>
<td>Informative</td>
<td>93</td>
<td>71</td>
</tr>
<tr>
<td>helpful overall</td>
<td>93</td>
<td>71</td>
</tr>
<tr>
<td>Section Four</td>
<td></td>
<td></td>
</tr>
<tr>
<td>easy to understand</td>
<td>92</td>
<td>70</td>
</tr>
<tr>
<td>Informative</td>
<td>92</td>
<td>70</td>
</tr>
<tr>
<td>helpful overall</td>
<td>92</td>
<td>70</td>
</tr>
<tr>
<td>Section Five</td>
<td></td>
<td></td>
</tr>
<tr>
<td>easy to understand</td>
<td>76</td>
<td>58</td>
</tr>
<tr>
<td>Informative</td>
<td>86</td>
<td>66</td>
</tr>
<tr>
<td>helpful overall</td>
<td>85</td>
<td>65</td>
</tr>
</tbody>
</table>

As table 2 outlines, 96% of parents agreed that section one was easy to understand, 88% felt it was informative and 90% felt that, overall, it was helpful. Parents experienced the most difficulty with understanding section five, however the majority of parents, 76%, agreed that it was easy to understand. Overall, 48% or parents (n=30) indicated that the immunisation record was most helpful, 32% felt that the developmental check section
was the most helpful, 8% found the general advice the most helpful, 13% found the height and weight and comment sections the most helpful\(^4\).

Intervention group I parents were asked to indicate what sections of the PHR they had read. A total of 98% (n=77) of respondents indicated they had read at least one section of the PHR. 88% of respondents indicated they had read the entire PHR (n=68), 9% (n=7) read section three only, 1% read section one only and 1% read section four only\(^5\).

**INTERVENTION GROUP II:**

5.2.3 Key element one: *does parent still possess PHR at 7-9 month developmental check*

86% of intervention group II parents indicated that they had brought the PHR to their 7-9 month developmental check (n=69); most of the eleven parents who noted that they did not bring their PHR cited ‘forgot’ as the reason. These results compare favourably to intervention group I parents. A total of 90% of parents indicated that they "nearly always brought" the PHR to developmental checks (n=72), 8% noted that they usually do and 3% (n=2) rarely do so.

5.2.4 Key element one: *does parent want to use PHR*

Virtually all parents in intervention groups I and II were "very satisfied" or "satisfied" with using the PHR, 99%, (n=153). Just 1% (n=2) of parents reported that they were neither satisfied or dissatisfied. None of the parents reported dissatisfaction\(^6\).

Parents were probed for more detail, through the use of open-ended questions, to elucidate the reasons for their satisfaction with PHRs. Almost all parents were enthusiastic and pleased to retain a copy of their child’s primary health record. The dominant theme to emerge from the data was that parents, overwhelmingly, viewed the PHR as helpful, convenient and informative. The qualitative findings indicate overwhelming support for PHRs with most parents in favour of their continued use.

\(^4\) missing data-18 
\(^5\) missing data-4
Many parents commented that the PHR provided them with a permanent record of their child’s development and health. Parents identified possession of a copy of their child’s health record as a key factor in their satisfaction with the PHR.

Typical comments included:

"I am very satisfied with using my PHR because I will always have a record of my baby's progress'
"it is excellent because you always have records and in time it's something that my baby can keep" 
"I am very satisfied because I have a full record all together of my baby's health" 
"I think it's excellent, I'm very satisfied because it keeps a good record of my baby’s details" 
"it is fantastic to have a track of my son's development, it is lovely to look at it and refer to it, I find it very reassuring" 
"...nice to keep a record of baby’s development and I can easily record and keep track of baby’s development without referring to doctor’s information.” 
“"I can keep track of baby’s immunisations and development with PHR.” 
"It’s good to have a record of my baby’s health and development.” 
“"I can use the PHR as a reference to track baby’s development, weight, etc.” 
"You can refer to the PHR for information on vaccinations, and can track the progress of baby...”"

Almost all parents commented on the usefulness of having a permanent record of their child's health and development. The PHR was regarded as a comprehensive resource which parents can refer to. Parents also felt that the PHR offered them reassurance as all health information relating to their child was recorded in the booklet and retained by the parent. As exemplified by one parent "the booklet reassures me so I don't need to check with the doctor for everything, the checks in it are very reassuring for checking my baby's progress". Another parent commented that ‘this record makes me feel reassured that my baby is making good progress’.

Parents also expressed satisfaction with the advice and information contained in the PHR. In addition to having a record of their child's health, the advice and information sections of the PHR were welcomed by parents and identified as a useful and important resource. Typical comments included;
“It is informative and somewhere you can keep all the information regarding baby, especially the height and weight charts.”
“Information is all at your fingertips and the information is easy to obtain and conveniently stored.”
“The PHR is helpful in alerting parents to details regarding immunisations.”
“If my baby is sick, I can look back on the PHR as a reference.”
“There is good information in the PHR and it is good for keeping records.”
“Information in the PHR is very good.”
“There is a lot of useful information in the PHR.”
“The booklet is very clearly organised and displayed, it contains useful advice.”
“For a first time mother it provided very good guidelines regarding what to expect.”
“There was information in it regarding development, I knew of developmental milestones to look out for.”

Convenience:
The convenient nature of the PHR was also identified as a key factor relating to satisfaction. The PHR was considered as convenient method of tracking their child’s health and development. The following extracts typify parental responses.

“It is handy to have it…”
“Having the PHR saves in questions medical professionals might ask…”
“I can easily keep track of all relevant information in one book…”
“It is convenient that all my baby’s health information is recorded and kept in one place…”
“It has everything I need in it…”
“It is more convenient to have records at home where I can see them versus ringing the doctor every time you want information regarding your baby’s health.”
“It is very handy to have everything in one booklet.”
“It is convenient to take with us when we travel…”

5.2.5 Key element two: identify factors impacting on why professionals did/did not use PHR

Intervention group I parents were asked about their experiences of health professionals recording health related information in the PHR. 64% (n=49) felt that health professionals were happy to and voluntarily recorded in the PHR. However, 36% (n=28) indicated that they needed to ask a health professional to do so. Most parents indicated that this health professional was their General Practitioner. One parent noted that they always had to request their Public Health Nurse to record in the PHR.
5.2.6 Key element one: *extent of use by socio-economic groups and other demographic variables*

Socio-demographic data was obtained for intervention groups I and II. 55% (n=88) of babies included in the study were male and 45% (n=72) were female. 41% (n=66) of parents were aged thirty or under and 59% (n=94) were over thirty years of age. 80% (n=128) of respondents indicated that they were married and living with their spouse, 11% (n=17) were lone parents, 9% were not married but living with a partner and 1% were married but not living with their spouse. Respondents were also asked to indicate at what stage they had left full time education, 3% (n=5) completed their education after primary school, 19% (n=30) completed the junior cycle of second level and 29% (n=46) completed the leaving certificate. 49% (n=78) attended third level education at either certificate, diploma or degree level.

Regarding ethnicity, the majority of respondents, 92% (n=145) indicated that they were members of the Irish settled community, 3% (n=4) were members of the Irish travelling community and 6% (n=9) were non-Irish nationals. 72% (n=57) had private health insurance, 13% (n=10) had a medical card, 3% (n=2) had both and 13% (n=10) had neither.

Social class data was categorised using the codes provided by the Central Statistics Office. Social class categorisations were as follows; Social class one, professional workers – 19% (n=35); social class two, managerial and technical – 21% (n=35); social class three, non-manual – 26% (n=42); social class four, skilled manual – 9% (n=14); social class five, semi skilled manual, 9% (n=14); social class six, unskilled- 9% (n=14) and social class seven, other – 7%.

Chi-square tests were conducted to measure the association between extent of PHR use amongst intervention group I and socio-economic variables. Extent of use was divided into low/no use and high use of the PHR. Low PHR use was defined as cases where the parent had not recorded in the PHR, had completed the introductory and/or signed the vaccination consent and record form. High PHR use was defined as cases where the
parent had written in all the sections of the PHR and parents who written more than name, address, family history data and signed the vaccination consent and record form, but had not written in all five sections of the PHR. A total of 27 respondents were classified into the low PHR use category and 45 respondents were classified into the high PHR use category. Educational attainment, social class and age were the selected socio-economic variables.

Fifty-six per cent (n=20) of parents who completed third level education were categorised as high users of the PHR, compared with 71% (n=25) of parents who did not attend third level (p=.165). 72% (n=18) of parents aged under thirty years were categorised as high users of the PHR compared with 59% (n=27) of parents aged over thirty (p=.266). In terms of social class, 60% (n=30) of non-manual workers were high users as were 68% (n=15) of manual workers, (p=.509). Overall, there was no significant impact of age, education or social class on whether parents recorded in the PHR in an extensive or limited way. Socio-economic status does not appear to impact on whether parents recorded in the PHR.

5.2.7 Key element one: extent of use by socio-economic groups and other demographic variables

The vast majority of parents in intervention groups I and II were members of the settled Irish community, four parents were members of the travelling community and nine parents were non-nationals. All four members of the travelling community possessed their PHR at the seven to nine month developmental check and were very satisfied with holding their child’s health record. Of the nine non-nationals, six parents brought the PHR to the 7-9 month check. The three parents who did not bring the PHR noted that they usually did so but forgot on this occasion. All nine parents were satisfied with being provided with a PHR.

5.2.8 Key element two: explore parents’ reaction to the inclusion of sensitive information

Intervention group I parents were asked if they had any concerns regarding use of the PHR, such as inclusion of sensitive information. A total of 99% indicated that they had
no concerns regarding use of the PHR, such as the inclusion of sensitive information (n=76).

Ninety-seven per cent of control parents (n=187) indicated that they would like to hold a copy of their child’s health record. 81% cited ‘better informed regarding child’s health’, 46% cited more responsible for child health and 13% felt that it would help them to manage medical appointments more efficiently⁷.

5.2.9 Key element three: impact of PHR on parents attending/not attending allocated developmental check appointments

Intervention groups I and II and control group parents were sent a questionnaire seeking data to address key element three. Response rates of 83% (n=67), 70% (n=80), 84% (n=196) were achieved respectively.

Participants in intervention groups I and II were asked if they attended all developmental checks required for babies up to nine months old. A total of 82% of respondents indicated that they had attended all required developmental checks (n=121), with the remainder attending at least one. 78% of control respondents also indicated that they had attended all required developmental checks (n=149)⁸.

Chi-square tests were conducted to measure the association between the intervention and control groups (ie, those in possession of a PHR and those not) upon attendance at developmental checks. The "p" value was 0.286, therefore, there was no statistically significant relationship between PHR ownership and attendance at developmental checks (P<0.05).

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⁷ Adds to more than 100% - multiple response
⁸ missing data- 4
5.2.10 Key element three: *impact of PHR on uptake of immunisations*

A total of 90% of intervention groups I and II respondents indicated that their children had received all required immunisations up to six months old (n=132), this included BCG, 1st, 2nd and 3rd Diphtheria/Tetanus/Whooping cough/Hib/Meningitis C and Polio.

Control group parents were also queried regarding uptake of immunisations. A total of 89% of respondents indicated that their children had received all required immunisations up to six months old (n=171).

Chi-square tests were also conducted to measure the association between the intervention and control groups and uptake of required immunisations. There was no statistically significant relationship between PHR ownership and uptake of required immunisations; P=.98; (P<0.05).

5.2.11 Key element three: *impact of PHR on duration of breastfeeding*

64% of intervention groups I and II respondents indicated that they had never breastfed their babies (n=94), 30% indicated that they had breastfed their babies at some time (n=44) and 6% indicated that they were still breastfeeding (n=9).

52% of control group respondents indicated that they had never breastfed their babies (n=102), 40% indicated that they had breastfed their babies at some time (n=79) and 8% indicated that they had breastfed beyond three months (n=15).

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9 missing data - 1
10 missing data - 2
Graph 3 depicts duration of breastfeeding for intervention and control group parents.

Graph 3:

Chi-square tests were also conducted to measure the association between the intervention and control groups and duration of breastfeeding. There was a significant difference between the intervention and control groups upon the duration of breastfeeding; \(P=0.032; (P<0.05)\). The proportion of intervention groups I and II parents who never breastfed was higher than the proportion of control group parents who never breastfed, therefore there was a negatively significant relationship between possession of the PHR and breastfeeding.

5.2.12 Key element three: *impact of PHR on referral to specialist child health services*

Participants in intervention groups I and II and control groups were asked if they had scheduled appointments with any specialist child health services. 31% of intervention groups I and II parents \((n=43)\) and 28% of control group parents \((n=53)\) indicated that they had scheduled appointments with specialist child health services.

Chi-square tests revealed no statistically significant relationship between PHR ownership and scheduling of appointments with specialist services; \(P=.236; (P<0.05)\).
5.3 HEALTH PROFESSIONAL EXPERIENCES, ATTITUDES AND USAGE OF PHR

5.3.1 Key element one: *extent of use by professionals*

This section of the report presents health professionals’ usage, experiences and attitudes towards PHRs. The main outcome measure used to gauge extent of use by Area Medical Officers, Public Health Nurses and General Practitioners was professional recordings in the developmental checks’ sections of the PHR. A total of 99% of PHRs contained notes in the 7-9 month developmental check section written by an Area Medical Officer (n=71). 99% of PHRs also contained Public Health Nurse recordings in the primary visit and 3 month check section. In 89% of PHRs the General Practitioner had written notes in the immunisation record and 64% (n=46) contained written General Practitioner notes in the 6 week check section.

Regarding extent of use, health professionals were asked who they thought should write in the PHR. Respondents could select parents, Area Medical Officers, General Practitioners, Public Health Nurses, and hospital staff as those who should write in the PHR. All five Area Medical Officers indicated that all the above should write in the PHR. Just under half of General Practitioners (n=7) indicated that all the above should write in the PHR. Virtually all Public Health Nurses (n=26) indicated that all the above should write in the PHR.

Qualitative interviews also yielded data on the extent of health professionals recording information not specifically required in the PHR. The main category to emerge from the data indicated a low level of health professional PHR usage, beyond that specifically required in the PHR. Typical comments by Area Medical Officers, General Practitioners and Public Health Nurses included the following

**Low level of health professional recording in PHR**

“....as well other health professionals....they are not using it or using it improperly. But basically not using it.” (AREA MEDICAL OFFICER)
“There was a notion that this booklet would be used at every point of contact with the parents. That would mean that if I saw 30 children, that means that I would have to sit down and do 30 extra clerical jobs. And that is a pure waste of time. I don’t think very many of use have used the booklet for every surgery visit anyway. If the parent brings in the booklet to us, we would record the vaccinations, but we don’t record every other visit in it.” (GENERAL PRACTITIONER)

“No, they [hospital doctors] are not [writing in the PHR]. Lots of time children are seen out of hours for emergency stuff, and that’s the stuff that doesn’t get passed on.” (GENERAL PRACTITIONER)

“….they are being half filled out by some General Practitioners, some people are filling them, others aren’t…. ” (GENERAL PRACTITIONER)

“….the feedback I got back from the mums in relation to filling it [the PHR] in, in the hospital setting is that the other health professionals hadn’t filled it in... I do know [one] mum had asked for it and had been told, ‘oh, we don’t have time for it’, which is fine, but she wasn’t actually given an awful lot of information either.” (PUBLIC HEALTH NURSE)

“….there is no information coming from General Practitioners at the moment....” (PUBLIC HEALTH NURSE)

“Parents are reluctant or forgetful to ask professionals to write in the booklet; parents don’t normally produce the booklet in hospitals because its just alien to them at the moment.” (PUBLIC HEALTH NURSE)

“the only placed I have seen it filled in is any the public health nurses if they have been weighing the child.” (AREA MEDICAL OFFICER)

“I haven’t seen it filled in by hospital staff, but then again maybe the mothers don’t remember to bring it with them.” (GENERAL PRACTITIONER)

Overall, health professionals acknowledged that usage of the PHR did not extend the minimum required. In particular, Public Health Nurses felt that other health professionals were not fully capitalising on the PHR. General Practitioners were of the opinion that they themselves were not recording all visits into the PHR primarily due to time constraints and dissatisfaction with the PHR.

Health professionals were asked to estimate how often parents brought the PHR to consultation or clinics. All five Area Medical Officers indicated that parents always brought the PHR to clinics, just two of the 15 responding General Practitioners indicated that parents always brought the PHR to consultations and 81% (n=22) of Public Health Nurses indicated that parents always brought the PHR to clinics.
Semi-structured interviews sought to qualitatively address health professionals mixed experiences of parents bringing the PHR to child health visits. Area Medical Officers and Public Health Nurses were of the opinion that parents generally brought the PHR to their child's developmental checks. General Practitioners were mainly of the view that parents brought them to developmental checks but not to other General Practitioner consultations, although some General Practitioners felt that parents were not presenting with the PHR beyond their child's vaccinations.

“Definitely those that I’ve met, they’re definitely bringing it in here and they’re writing into it and anything new and they’re very responsible for it” (PUBLIC HEALTH NURSE)

“Well what I have noticed with it is that the parents are very good to bring it to the clinic with them, and this is a very much disadvantaged area, you have the odd one alright that won't bring the book but most of them bring it all the time” (PUBLIC HEALTH NURSE)

“the vast majority of people have it” (AREA MEDICAL OFFICER)

“they all have it for the first visit, a lot of them bring it for the first vaccination, but a lot of cases they don't bring it and then that's the end of it” (GENERAL PRACTITIONER)

“most mums tend to bring it in to me for the developmental check-ups or vaccinations, they don't tend to bring it to me if the child has an ear ache for example of a sore throat...I haven't been given it generally by parents for those things” (GENERAL PRACTITIONER)

For another General Practitioner, parents were generally not bringing the PHR to developmental checks or vaccination consultations, 'I'd say probably a third of the people that come for the six week check, the book has gone missing, I'd be seeing it for maybe half the immunisations, very few parents are bringing the record to checks' (GENERAL PRACTITIONER). However, another General Practitioner had differing experiences with parental possession of PHRs, 'well in my experience so far, parents are bringing it to checks'.
5.3.2 Key element one: *assess professional satisfaction with the PHR as a method of recording child health*

Satisfaction rates with PHRs as a method of recording child health were mixed. Two Area Medical Officers expressed satisfaction with using the PHR, while two expressed dissatisfaction (one Area Medical Officer was neither satisfied or dissatisfied). General Practitioners also expressed varied satisfaction rates – five were satisfied with using the PHR, four were neither satisfied nor dissatisfied and three were dissatisfied. Almost all Public Health Nurses (n=26) indicated they were either very satisfied or satisfied with the PHR, one Public Health Nurse noted that they were neither satisfied nor dissatisfied. Qualitative interviews sought to establish the reasons for professional satisfaction or dissatisfaction with PHRs. One Area Medical Officer commented ‘*I am very satisfied with it, I think it’s great and I think it’s great that parents have it*’. However, another Area Medical Officer noted that the space available to them to record the necessary information in the 7-9 month developmental check was extremely limited, ‘*a lot of us have that problem, but that is my only problem with it now, everything else I have no problem with, I think it is great*’.

Public Health Nurses were generally very satisfied with using the PHR and identified its convenience and layout as key factors impacting on their satisfaction, ‘*I am very satisfied with it, it's concise and it's clear and it doesn't waffle...there is sufficient information in it without being overly detailed...it is well laid out and user friendly*’. Other Public Health Nurses commented that ‘*I’m really satisfied with it, everything’s together in it...there’s less writing in it than before*’; ‘*I feel all the documentation is very clear in it and it’s all there... it’s very together*’.

General Practitioners reported varied satisfaction rates with PHRs. Some General Practitioners expressed dissatisfaction with the PHR based on the extra work required to complete the PHR and its general layout, ‘*it’s a terrible cumbersome thing, with rakes of pages in it about all kinds of different things...it sets out to become kind of a something*

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11 3 missing responses
that is nearly impossible [to use]. This General Practitioner also felt that ‘its an absolute duplication of work’. Other General Practitioners expressed dissatisfaction with the introduction of PHRs and identified a lack of consultation in the planning stage of the PHR, ‘if it had been properly negotiated and organised I would be very satisfied with it, I don’t have any difficulties with personal health records per se, I think they are a good idea...I feel that as a general practitioner I should have been consulted in the development of it prior to its initiation’. Similarly, another General Practitioner commented, ‘I think the actual idea of [PHR]...I am totally in favour of it...but in terms of am I satisfied with using it at present, in the context of how it was introduced I am not’

Other General Practitioners expressed satisfaction with the PHR, commenting ‘I am satisfied with it, I do think the PHR is useful, I do think it has a role to play’; ‘I think it [PHR] is good, I think it encourages the parents to be more sort of participating in their child’s health care. I think the theory behind it is very good’. What clearly emerges from interviews is that General Practitioners have no objections to the concept of PHRs but expressed dissatisfaction with the introduction and layout of this PHR.

Qualitative analysis also yielded data on why health professionals did or did not use the PHR. Two main themes emerged from the data. One theme situated the PHR as an aide to health professionals’ work and therefore was used. The other theme situated the PHR as an encumbrance to health professionals’ work and therefore was not used. The following extracts typify comments related to each theme.

The PHR as an aide to health professionals' work

“I feel it [writing in PHR] is very useful time....initially I thought – God, look at all this, will I get it all done, will I forget anything. Now I don’t even think like that.” (PUBLIC HEALTH NURSE)

“....no problems with filing of course, because the mum has her PHR, there are repository files and....they are very easily stored away, they are not bulky or anything like that. And it is easy to store the carbon copies in the repository files and it is easy to get them again from the repository file once they are stored away correctly. I am not writing anything extra.” (PUBLIC HEALTH NURSE)
“..you can start off your consultation by asking for it and you can say...you see the child had this and that, and it kind of helps you to structure your consultation” (AREA MEDICAL OFFICER)

“I frequently have people coming in when their kids are starting school or they're leaving school asking want vaccinations their kid has had and when they had it, and to try and track down records and someone's vaccination may have been done in school some may have been done in health centres, some may have been done in General Practitioners. If its written in the book that the kid has been vaccinated, then you are not looking for this, so I think its better to have it in the book” (GENERAL PRACTITIONER)

The PHR as an encumbrance to health professionals' work

Some health professionals, primarily General Practitioners, felt that recording on the PHR was time consuming and duplicative of current recording practices.

“I wouldn't be very satisfied with it because it is very time consuming. We're filling in our own records, our paper records...so it's time consuming enough” (GENERAL PRACTITIONER)

“....if I have to fill out this booklet every time I see a child, as well as record in my own record system – that's just a duplication of work that serves no useful purpose.” (GENERAL PRACTITIONER)

“I think the people who dreamed up this booklet didn’t realise the volume of work that some people would be seeing every day. It would be safe to assume that on a busy Monday I would see 15 to 20 or 25 children and if I have to make extra notes for every one of those, its going to make another couple of hours onto my day – for no end result – no useful reason for doing it. Other than the fact that somebody in the health board said this was a good thing to be doing.” (GENERAL PRACTITIONER)

“I would say that the next time they try it, we will just say no. I have been filling [the PHRs] out, but unless it is done through my union and done properly, I would never again fill out one of these pieces of paper...so they may wonder why – it's because it's a form of protest by the General Practitioners.” (GENERAL PRACTITIONER)

“Our paperwork is increasing on a daily basis...the more duplication that has to be done can become a bit tedious, it's increasing our work as health professionals” (GENERAL PRACTITIONER)

In the main Public Health Nurses and Area Medical Officers felt that the PHR was a useful aide while some General Practitioners considered it an encumbrance.
5.3.3 Key element two: assess attitudes amongst health professionals towards parents possessing a copy of the child health record

Despite the concerns expressed by General Practitioners regarding the feasibility of documenting child health information in the PHR, almost all of the interviewed health professionals were supportive of the concept of parents possessing a copy of the child health record. Health professionals, in the main, did not object to the concept of parents retaining a copy of their child's health record. Typical comments included the following:

**Health professional support of parents possessing a copy of the child health record**

“Philosophically, I suppose, I think that it is the right idea…..the whole concept of the parents and the family having that sort of record, I think is very good. And families are far more mobile, relationships are far more mobile, all those sorts of things...I think its good that they have that.” (AREA MEDICAL OFFICER)

“On a philosophical base, I am for it, I think overall it is a good idea' (AREA MEDICAL OFFICER)

“I think it encourages the parents to be more sort of participating in their child’s health care. I think the theory behind it is very good....”(GENERAL PRACTITIONER)

“I don’t have difficulties with personal health records, per se. I think they are a good idea... I think the idea of a personal health record is of a huge advantage, particularly with an increasing migrant population .... And it is important that people would be aware of relevant health issues. Plus, I think if patients hold....the health record, they are much more likely to be aware of what’s in it.”(GENERAL PRACTITIONER)

“....most of [the parents] ....the first thing they give me is the booklet, and they do seem to be inputting into it well. And the booklet gives them a little more responsibility and they are certainly delighted with that... the fact that they have a little bit more now, something to fill in, empowers them a bit more.”(PUBLIC HEALTH NURSE)

“I think you have to share information....the book helps in this because you are actually encouraging them to contribute to it and encouraging them to write in it, whatever they want at whatever level.”(PUBLIC HEALTH NURSE)

“I think the theory behind it is very good, but the whole thing needs to be tightened up a little bit” (GENERAL PRACTITIONER)

“nice idea but not very practical” (GENERAL PRACTITIONER)
These comments indicate that General Practitioners’ concern with the additional work involved in recording in PHRs and the perceived duplication of records did not detract from their attitude towards parents possessing a copy of their child’s health record. Professional objection to PHRs was not rooted in antipathy towards parental possession of their child’s health record. However, objections were based on the requirement placed on health professionals to record in this PHR. One General Practitioner commented 'I think there are a lot of little changes that could be made to improve it, and it is a lot better than nothing at all, like being able to find ones way around the booklet a little more easily…I think it is worthwhile' (GENERAL PRACTITIONER). This General Practitioner raised objections to the perceived extra duplicative work but felt that the PHR was a worthwhile enterprise.

5.3.4 Key element two: explore impact of PHR on parent/professional partnership and communication

Mixed views were expressed regarding the impact of PHRs on communication and information sharing amongst health professionals. In the main Area Medical Officers felt that the PHR has not, as yet, improved communication with General Practitioners, '…as of yet it is not good [communication], it should be, maybe later with refinement, but it certainly isn't at the moment'.

Another Area Medical Officer commented 'between health professionals, I don't know if it [communication] is really great because I don't know how many General Practitioners are actually putting in their information, some of them are and some of them aren't, so your wondering is stuff there because it didn't happen or because the GP didn't want to fill it in …some General Practitioners don't want to get involved in it and then you are wondering what do you take then as the whole story?'.

Area Medical Officers also felt that the current layout of the PHR was problematic for effective communication with other health professionals. A lack of recording space, in particular the 7-9 month developmental check, was identified as a barrier to communication, 'it needs to be modified, it needs to be enlarged and more headings for
us...’, another Area Medical Officer felt that the PHR was not adequate in terms of communication as ’my own piece is far too small’

Public Health Nurses expressed enthusiasm for the potential of the PHR to improve communication. One Public Health Nurse felt that the PHR has indeed improved the flow of information amongst health professionals, 'I think the PHR helps in communication between professionals. We already have a success story with this, one of the babies had a health issue and myself, the parents and the GP all wrote in the booklet and we were all aware of the problem and the issue has been dealt with' (PUBLIC HEALTH NURSE). General Practitioners did not identify a positive impact of PHRs on professional communication. For one General Practitioner ' there isn't any clear mechanism for it to be a tool for information between health professionals...there is no area of recognised sharing information in the book other than the comment in the check'. Another General Practitioner commented 'these other health professionals don't remember to give it to us at all in the first place, in most cases Area Medical Officers are doing their own thing and I'm not sure if it is going to be a two-way process...I can't see the usefulness of it myself' (GENERAL PRACTITIONER). However, another General Practitioner felt that the PHR is a useful tool for communication between professionals, ‘Yes, I think it is, I think it is a good idea’.

5.3.5 Key element two: explore professional reaction to the inclusion of sensitive information

Health professional attitudes towards the inclusion of sensitive information in the PHR was explored. The main category to emerge from the data suggested that health professionals were hesitant to include sensitive information in the PHR. Typical comments included the following.

Hesitancy in writing sensitive information in the PHR

“....If I’ve reached the point where I feel this child needs to be seen by a specialist service, then I don’t mind putting down.... I would write something down to that effect. And that’s where I am worried....where I haven’t really written down what I wanted to say. I am afraid that maybe if I am not there the next time, doing the next clinic or whatever, what information has the next person looking at it.”(AREA MEDICAL OFFICER)
“If you were going to use the booklet for [writing sensitive information]....you certainly could not put anything in the booklet that you were afraid might jump up and bite you later.” (GENERAL PRACTITIONER)

“....you just have to be careful of what you write, wherever you write it....if you had a concern but no specific diagnosis, you would be more likely to contact the relevant professionals directly and not necessarily write it in the book. You put facts in the book, you don’t put possibilities.” (GENERAL PRACTITIONER)

“....my biggest concern....would be about child protection concerns. So if I had child protection concerns, I don’t write them into the booklet.” (PUBLIC HEALTH NURSE)

“say for instance now you saw a child whom you thought was being abused, you wouldn’t write down in the child’ personal health record that you thought the child was a victim you would have to be careful there are a lot of solicitors out there who are trying to get business” (AREA MEDICAL OFFICER)

Overall, all of the Area Medical Officers and Public Health Nurses felt that the PHR programme should be continued with under half of the General Practitioners (n=6) supporting the continued use of the PHR.

5.4 PARENTAL AND HEALTH PROFESSIONAL RECOMMENDATIONS

Both parents and health professionals offered comments and suggestions regarding the efficacy of the PHR and how it may be improved for future use. The following qualitative data is based on intervention group I parents’ and health professionals’ responses to the query: “Can you recommend any changes to the PHR that would make it easier for you to use it?” Three main categories of recommendations emerged from parents' and health professionals' responses. These categories were: 1) recommendations regarding usage of the PHR; 2) recommendations regarding the layout of the PHR; and 3) recommendations regarding the content of the PHR. The following data is divided into parental and professional qualitative data. The professional data is further sub-divided into Area Medical Officer, General Practitioner and Public Health Nurse qualitative data.
5.4.1 Parental qualitative data

Recommendations regarding usage of the PHR

1) Parents remarked that Area Medical Officers, General Practitioners, Public Health Nurses and any other health professionals in contact with the PHR should be encouraged to write comments in the PHR.

"....doctors & other health professionals should be encouraged to write in it...."
"....doctors should write more information in PHR for parents' future reference regarding their babies."
"....have one section or page exclusively for medical professionals to fill in and record progress and their comments."
"....doctors in hospital should be encouraged to fill out PHR if a baby goes to hospital."

Recommendations regarding the layout of the PHR

1) Parents noted that section five of the PHR, the comments section, should be redesigned so that comments can be written throughout the PHR.

"....add room for comments at end of each section - instead of just in section five...."
"....include a more detailed table of contents in the beginning of the booklet."
"....set comments page out better so that comments are readable and there is sufficient pages to write comments."
"....the two pockets on the front cover of the book should be moved to inside and made bigger so they can easily hold information; cover page should have a table of contents for quick reference."
"....the PHR needs an index and a more detailed table of contents with colour-coded tabs for each chapter."

Recommendations regarding the content of the PHR

1) Parents also stated that the PHR should contain more advice and information on a range of health related matters of interest to parents.

"....include a bit more information on the MMR debate & info about both sides of this issue...."
"....provide more advice, such as on burns, choking, etc...."
"....include more information on baby's development...."
"….include more information regarding feeding baby...."
"….include information on weaning and types of food you can give babies as they develop."
"….provide more information on both pros and cons of immunisation debate (like MMR controversy)."

2) Parents suggested that the height and weight charts used in the PHR could be simplified.

"….make height and weight charts easier to understand...."
"….make height & weight charts a bit more simple & easier to understand...."
"….make the height charts in a simpler form...."

5.4.2 Professional qualitative data – Area Medical Officers

Recommendations regarding the use of the PHR

1) One Area Medical Officer stated that the PHR should not seek data relating to breastfeeding during the 7-9 month developmental check.

"There is a survey in [the 7-9 month developmental check page] regarding breastfeeding. If they want to do a survey on breastfeeding, that's fine, but not using me during the consultation. I think it should be done by someone else, by the Public Health Nurse at some other visit."

Recommendations regarding the layout of the PHR

1) Area Medical Officers suggested that the layout of the 7-9 month developmental check page could be re-designed so that more comments could be entered instead of simply ticking boxes.

"[the 7-9 month developmental check page] was designed with computerisation in mind, rather than consultation. The parental concern bit – it's just ticking boxes, "yes" or "no". There is no "yes" or "no" for some of these things. And things like – "mildly", "moderately" – it doesn't cover the human spectrum at all, that is a computer question, it is not a human question at all."

"Change the categories [on the 7-9 month developmental check page] a bit. They are trying to pack everything into one tiny little page so they can input [into] their computers. I don't have the scope, on this page, to write down exactly what I have in mind. And you need that somewhere in the book, or, if its sensitive [information], to indicate that [another health professional] better check the file if there is a re-check."
"The layout of the 7-9 month [developmental check page] needs to be modified. It needs to be enlarged, and more headings for [Area Medical Officers]…like the section on "physical". "Physical" on the old form was 10 or 15 different boxes and now they are gone."

Recommendations regarding the content of the PHR

1) One Area Medical Officers noted that the absence of perinatal information was problematic.

"I also have problems [that]…perinatal information is not in the book."

5.4.3 Professional qualitative data – General Practitioners

Recommendations regarding the layout of the PHR

1) General Practitioners offered suggestions regarding the layout of the index and table of contents in the PHR.

"….the PHR needs an index & a more detailed table of contents with colour-coded tabs for each chapter."

"….include a more detailed table of contents in the beginning of booklet…."

"….have a little more detail on the index…."

"….if the section I needed was more easily labelled, I would probably find it a bit more quicker."

2) General Practitioners recommended that the PHR should be re-organised so that all documentation relevant to health professionals is clearly separated from advice and other information relevant to parents.

"….prioritise the book so that for example the first page would be the child’s vaccination record, which is the thing you would look for the most. And a second page maybe for child problems…."

"….if there was some…[for example]….doctor’s part, patient’s part. It’s not very obvious from the tabs on the side which section it is that I [as a health professional] am looking for. So it would be much easier if there was parent information, doctor’s input, or something like that."
"...easier identification of what I [as a health professional] am looking for in the book, and easier identification of where anybody else might be writing something of relevance to me."

3) General Practitioners made specific recommendations regarding the layout of the codes and name and address information contained in the six week developmental check page.

"...with the six week check page, the "Other" codes including referral details at the bottom of the page, it is very small. I would like an area, maybe on the side where...a real space for you to make substantial comments...."

"I don't understand what this is [the codes at the bottom of the six week check].....it is not obvious what your response should be...."

"...a lot of information....for us to fill out onto the six week check, like name, PHI number,.....that should be entered before the book is ever presented to me, that should be automatically in the book, on the day of presentation to the parent. Why not print [a label with name and address information] off the computer record, onto a sticky pad, and stick it onto [the six week check page]?"

"...rather than all the little codes at the bottom of the page, I think it should be: "yes" or "no", "normally", and a tick, rather than all the little codes."

4) One General Practitioner recommended that section two of the PHR, the immunisation section, should be re-designed so that General Practitioners could insert their own printouts of immunisation information.

"...why not have a section in the book that will take a paper printout? I can print out all vaccinations beautifully, telling me name, date, type, brand, expiration, the whole lot, no problem."

Recommendations regarding the content of the PHR

1) General Practitioners recommended that the PHR should contain a section reserved exclusively for health professional comments and should possibly include a "tick-box" segment.

"...have one section or page exclusively for medical professionals to fill in & record progress & their comments...."

"...include even one page with a list of specific illnesses that [health professionals] could tick and date if the child was diagnosed with any of them, and you could literally
tick and date. Likewise…episodes of glue-ear, or tonsillitis, when there may be a
question of referring because of persistent or recurring problems. So it would be done
more like a chart, with all the things, and then the date of when [the child] got it."

5.4.4 Professional qualitative data – Public Health Nurses

Recommendations regarding usage of the PHR

1) Public Health Nurses noted that parents using the PHR should also be encouraged
to write in the PHR.

"….it needs to be made clearer that parents can write in it...."

"….if you encourage [parents] to keep records [in the comments section] for instances
where the kid has an infection or whatever. If they could make more use of that...."

Recommendations regarding the layout of the PHR

1) Public Health Nurses suggested that the comments section of the PHR should be
more user-friendly.

"Make the comments pages lined, so they are easier to write in...."

2) Public Health Nurses also recommended design modifications to the family
history page and to the developmental checks section.

"A carbon sheet be inserted behind the Family History page, so that Area Medical
Officers can have this information available to them during the 7 month check...."

"The font size should be increased on the developmental check pages in section three,
especially where the codes are printed at the bottom of each page...."

Recommendations regarding the content of the PHR

1) Public Health Nurses noted that the PHR should contain advice and information
on topics such as breastfeeding and weaning, a breastfeeding centile chart and
birth notification.

"….the booklet should include more information on breastfeeding generally...."

"….two pages of information on weaning included in the PHR would be very beneficial to
the booklet...."
"....the booklet should include a centile chart for breastfeeding...."

"....what could be added actually is a photocopy of the birth notification."
6.0 DISCUSSION

Several important findings emerge from this evaluation. First, virtually all parents were “very satisfied” or “satisfied” with using the PHR, (99%). The vast majority of intervention group I parents, (90%), kept the PHR until at least the 7-9 month developmental check and made some recording on the PHR (97%). This represents significant active usage of the PHR in terms of parental attitudes towards the importance of retaining the PHR and presenting it to professionals at key child health visits. Statistical analysis revealed no impact of key socio-economic variables on use of PHR. This finding suggests that parents, regardless of socio-economic background, use the PHR and are satisfied with it.

Whilst the intervention group I and II parents used and enjoyed using the PHR, the PHR seemed to make little difference in health related issues such as uptake of immunisations. A total of 90% of the intervention group I and II parents indicated that their babies had received all the required immunisations up to six months old. The control group parents, those with no exposure to the PHR, achieved an 89 % rate for uptake of immunisations.

Qualitative parental results taken from those parents issued with a PHR largely concur with intervention group I quantitative data. Three main themes emerged when researchers asked parents why they liked the PHR. These three themes were: having a record of their child’s health; useful advice and information contained in the PHR; and the convenience of having their own copy of their child’s health record.

Examination of PHRs revealed extensive health professional recordings. 99% of PHRs were recorded in by both Area Medical Officers and Public Health Nurses and 64% contained recordings by General Practitioners. In terms of professional satisfaction with PHRs, Area Medical Officers and Public Health Nurses were generally satisfied using the PHR. However, findings indicate that General Practitioners did not object to the concept of parents possessing a record of their child’s health, but expressed dissatisfaction with the introduction and layout of the PHR
Finally, results from this evaluation suggested that both parents and health professionals offered recommendations to enhance PHR usage. Three main categories of recommendations emerged from parents' and health professionals' responses. These three categories of recommendations were: 1) recommendations regarding usage of the PHR; 2) recommendations regarding the layout of the PHR; and 3) recommendations regarding the content of the PHR.

The findings presented here generally concur with results obtained in previous research. As mentioned above, 90% of the parents issued with a PHR were able to produce their PHR at least seven months later and 99% were satisfied with using the PHR. Previous research conducted in Fife found that 77% of parents issued with a PHR in this sample kept their PHR for at least six months and 95% were satisfied with the PHR.

Health professional data presented here also mirrors a large body of previous research on professional opinions and usage of the PHR. For example, sixteen out of twenty seven Public Health Nurses here indicated they were “very satisfied” with using the PHR. Data collected on the Child Health Passport used in Alberta, Canada found that 97% of community health nurses thought the passport was a good idea. Moreover, 86% of community health nurses stated that they worked in collaboration with parents when recording entries in the passports.

More guarded health professional responses have also been uncovered in previous literature. As suggested above, health professionals here were not uniformly pleased with the PHR - only two out of fifteen General Practitioners indicated that they were “very satisfied” with using the PHR. Qualitative data also suggested concerns regarding use of the PHR. Several previous studies suggested that health professionals, perhaps more than parents, had concerns regarding use of the PHR. These concerns have largely included potential violations of confidentiality, loss of the record by parents, duplication of information, and extra work involved in writing in PHRs.
This evaluation examined parental and health professional use of the PHR only nine months after introduction of the PHR as a pilot programme. Consequently, long-term assessments of the use and usefulness of the PHR in Ireland are necessarily unavailable. However, previous research conducted elsewhere several years after introduction of the PHR has suggested that both parental and health professional usage and acceptance of the PHR increases with time.\textsuperscript{7,9}

Therefore, if positive long-term findings reported elsewhere are to be realised with an Irish PHR, steps will need to be taken to ensure maximum parental and health professional usage and satisfaction with the PHR. The study has revealed a large degree of support from the parents and most of the health professional categories studied. Research has also revealed that there is some resistance from General Practitioners. Their concerns will have to be addressed if they are not to prove detrimental to the successful operation of the PHR scheme. Consequently, a recommendation would be that the Mid-Western Health Board should continue the operation of the PHR scheme, and indeed contemplate extending it as appropriate. However, the Health Board should also seek ways to minimise the potential resistance to the PHR scheme already demonstrated by some General Practitioners.

As the recommendations presented here suggest, specific practical measures to ensure maximum efficacy and participation would include modifications of the design and content of the existing PHR. Greater health professional involvement in the design stages of the PHR and more attention paid to training health professionals in its usage may also enhance the use and usefulness of the PHR.

These research findings offer a comprehensive illustration of both parental and professional attitudes and opinions of the pilot PHR programme. These data will contribute to mapping the future role and function of the PHR programme. The recommendations outlined by both parents and professionals may address existing concerns regarding the PHR and ultimately enable all interested parties to gain full benefit from the PHR programme.
7.0 REFERENCES


## APPENDICES

1) Intervention group one parents clinic based questionnaire  
2) Intervention group one parents take home questionnaire  
3) Intervention group two parents postal questionnaire  
4) Control group parents postal questionnaire  
5) Health professionals postal questionnaire  
6) Topics for discussion in qualitative interviews
Appendix One: Intervention group one parents clinic based questionnaire

(please see attached)
Section ONE:
VISUAL INSPECTION OF PHR (key element 1)

1) Did the parent bring the PHR to the developmental check?
Yes……………………………………………………………………………………….1
No……………………………………………………………………………………….2

2) If the parent did bring the PHR, does the parent allow a visual inspection of the PHR?
Yes……………………………………………………………………………………….1
No……………………………………………………………………………………….2

3) Has the parent written in the PHR?
Yes……………………………………………………………………………………….1
No……………………………………………………………………………………….2

4) Has the parent completed the following from the introductory section of PHR?

a) Child's name
Yes…………1
No…………2

b) Child's DOB
Yes…………1
No…………2

c) Child's sex
Yes………1
No………2

d) Name of General Practitioner
Yes………1
No………2

e) Family History
Yes………1
No………2
5) Has the parent written in Section One?

Yes………………………………………..1
No…………………………………………2

6) If "Yes" to Q. 3, indicate how much of the **hearing** checklist is completed

Mostly filled in…………………………………………………………………1
Partially filled in……………………………………………………………….2
Minimal completion……………………………………………………………3

7) If "Yes" to Q. 3, indicate how much of the **sight** checklist is completed

Mostly filled in…………………………………………………………………1
Partially filled in……………………………………………………………….2
Minimal completion……………………………………………………………3

8) Has the parent signed the Vaccination Consent form in Section Two?

Yes………………………………………………………………………1
No………………………………………………………………………..2

9) Has the Area Medical Officer/Public Health Nurse written in the Vaccination Consent form in Section Two?

Yes………………………………………………………………………………1
No………………………………………………………………………………..2
If "Yes", please give name of Area Medical Officer/Public Health Nurse____ (3)

10) Has the General Practitioner/Area Medical Officer/Public Health Nurse written in the Immunisation Record?

Yes…………………………………………………………………………………..1
No……………………………………………………………………………………2
If "Yes", please give name of General Practitioner/Area Medical Officer/Public Health Nurse___________________________ (3)

11) Has the Public Health Nurse written in the **Primary Visit** section of Section Three?

Yes…………………………………………………………………………………..1
No……………………………………………………………………………………2
If Yes, please give name of Public Health Nurse_______________________ (3)
12) Has the parent written in the first page of the **6 Week Health Check** in Section Three?

Yes…………………………………………………………………………………………..1  
No…………………………………………………………………………………………2

13) Has the General Practitioner written in the **6 Week Health Check** in Section Three?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2  
If Yes, please give name of General Practitioner____________________ (3)

14) Has the parent written in the first page of the **3 Month Health Check** in Section Three?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2

15) Has the Public Health Nurse written in the **3 Month Health Check** in Section Three?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2  
If Yes, please give name of Public Health Nurse____________________ (3)

16) Has the parent written in the first page of the **7-9 Month Health Check** in Section Three?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2

17) Has the Area Medical Officer/Public Health Nurse written in the **7-9 Month Health Check** in Section Three?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2  
If Yes, please give name of Area Medical Officer/Public Health Nurse_________ (3)

18) Has the parent written in the Comments page in Section Five?

Yes………………………………………………………………………………………….1  
No…………………………………………………………………………………………2  
If "Yes", approximately how many lines are written? ________ (3)
19) Has the Public Health Nurse /General Practitioner written in the Weight Chart in Section Five?

Yes…………………………………………………………………1
No…………………………………………………………………..2

20) Has the Public Health Nurse/General Practitioner tracked growth on any of the following charts? (circle as many as apply)

Boy's/Girl's Weight - Birth - 1 yr…………………………………………………….1
Boy's/Girl's Length - Birth - 1 yr……………………………………………………..2
Boy's/Girl's Head Circumference - Birth - 1 yr………………………………………3

Section TWO:
SOCIO-ECONOMIC/DEMOGRAPHIC INFORMATION (key element 1)
(ask the parent for the following information)

1) Is your child

Male………………1
Female……………2

2) Is this your first child?

Yes………………..1
No………………….2

3) Including this baby, how many children do you have?

1…………………………………1
2…………………………………2
3…………………………………3
4…………………………………4
5+.……………………………5

4) Please indicate your age range

15 – 20………..1
21 – 25………..2
26 – 30………..3
31 – 35………..4
36+………………5

5) How would you best describe your current living arrangement

I am married and living with my husband/wife………….1
I am married and not living with my husband/wife………2
I am living with my partner……………………………3
I am divorced………………………………………4
I am single………………………………………5

6) At what stage did you leave full time education

In primary School………………………………………1
At the Group Certificate level………………………2
At the Junior/Intermediate Certificate level…………3
At the Leaving Certificate level……………………4
At third level………………………………………5

7) If you have obtained a third level qualification, please specify the type

Third level certificate…………………………………1
Third level diploma…………………………………2
Third level degree…………………………………3
I entered third level studies but did not receive a qualification……4

8) In which of the following ethnic groups would you place yourself?

Member of the Irish settled community………………1
Member of the non-Irish settled community……………2
Member of the Irish travelling community………………3
Member of the non-Irish travelling community…………4
Other (please specify)………………………………5

9) At present are you

A homemaker………1
Employed full time….2
Employed part time….3
Unemployed seeking work…4
Unemployed not seeking work…5
Self employed………………6
Engaged in full or part time education….7

10) What job have you done for the longest period of time?

11) What job has your spouse/partner done for the longest period of time?

12) Do you have (circle as many as apply)

A medical card……………………………1
Private health insurance…………………2
Both………………………………………3
Neither……………………………………4
Section THREE: USE OF PHR (key element 1)

(ask the parent for the following information)

1) When did you receive your copy of the PHR?

Before your baby's birth.................................1
At your baby's birth...............................................2
Within the first week of your baby's birth......................3
At your baby's primary visit...................................4

2) Was the purpose of the PHR explained to you when it was first given to you?

Yes..........................................................................................1
No...............................................................................................2
Don't remember........................................................................3

3) If "Yes" to Q. 2, what is the purpose of the PHR, as explained to you:

________________________________________________________________________
________________________________________________________________________

4) Have you read any sections of the PHR?

Yes..........................................................................................1
No...............................................................................................2

5) If "Yes" to Q. 2, which section(s) have you read? (multiple responses permitted)

Section One.................................................................1
Section Two...............................................................2
Section Three.........................................................3
Section Four.............................................................4
Section Five..............................................................5
All sections.........................................................................6

6) When you take your baby to the Health Clinic or GENERAL PRACTITIONER, how often do you remember to take the PHR with you?

Always.................................................................................1
Usually..................................................................................2
Rarely.....................................................................................3
Never....................................................................................4
Don't attend...........................................................................5
7) When you take your baby to the Health Clinic or General Practitioner, does the Public Health Nurse/Area Medical Officer/General Practitioner fill in the PHR voluntarily, or do you need to ask the Public Health Nurse/Area Medical Officer/General Practitioner to complete it?

Public Health Nurse/Area Medical Officer/General Practitioner all fill in PHR voluntarily ........................................1
I need to ask Public Health Nurse/General Practitioner/Area Medical Officer to complete it (circle which professionals need to be asked) ......2

8) Have you been to a specialist or to the hospital with your baby?

Yes .............................................................................................................1
No (go on to question 12) .................................................................2

9) If you have been to a specialist or the hospital with your baby, how often did you remember to bring your PHR with you?

Always .................................................................................................1
Usually ....................................................................................................2
Rarely .......................................................................................................3
Never .......................................................................................................4

10) If you have been to a specialist or the hospital with your baby and also brought your PHR, did you record the visit(s) in your PHR?

Yes .............................................................................................................1
No .............................................................................................................2

11) If you have been to a specialist or the hospital with your baby and brought your PHR but didn't record it in your PHR, why have you not recorded these health visit(s)?

Forgot ....................................................................................................1
Thought it was unnecessary .............................................................2
Didn't know where to record information ........................................3
Didn't want to record it in the PHR ....................................................4

12) If you did not bring the PHR, may I ask where it is?

Kept elsewhere ..................................................................................1
Lost .......................................................................................................2
Destroyed .............................................................................................3
Forgot to bring it ..................................................................................4
Don't know/other ................................................................................5
13) If your PHR is lost, stolen or destroyed, have you tried to get a replacement for it?

Yes..................................................................................................................1
No.....................................................................................................................2
Don't remember...............................................................................................3
Don't need it.....................................................................................................4

14) Have you written anywhere in the PHR information regarding your baby?

Yes.....................................................................................................................1
No.....................................................................................................................2

15) If you have recorded information regarding your baby, what sort of information have you included? (multiple responses permitted)

Baby's illnesses................................................................................................1
Height/Weight development.............................................................................2
Information regarding developmental stages (ie, date of first tooth, walking, etc.)...3
Information regarding feeding baby...................................................................4
Baby's clinic appointment dates/reminders.......................................................5
Other (please specify)____________________________________________________6

16) Where did you include this information?

In the Comments section.................................................................................1
In another section (please specify)__________________________________________2

17) If you haven't written anywhere in the PHR, why haven't you done so?

Didn't think it was necessary to do so ...............................................................1
Didn't want to record this information in PHR...............................................2
Didn't know where to include this information in PHR.................................3
Thought booklet was only for Public Health Nurse/Area Medical Officer/General Practitioner to record information...........4

Section FOUR:
ATTITUDES TOWARDS AND EXPERIENCES OF PHR (key element 2)

(ask the parent for the following information)

1) Of the following, which section of the PHR have you found most helpful?

Immunisation record (section two) .................................................................1
Developmental checks (section three) ............................................................2
General advice (section four) .........................................................................3
Height/Weight charts and Comments (section five) .....................................4
2) Please rate the following statements regarding Section One of the PHR

a) I found Section One easy to understand
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

b) I found the information in Section One informative.
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

c) I found Section One helpful overall.
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

3) Please rate the following statements regarding Section Two of the PHR

a) I found Section Two easy to understand
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

b) I found the information in Section Two informative.
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

c) I found Section Two helpful overall.
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

4) Please rate the following statements regarding Section Three of the PHR

a) I found Section Three easy to understand
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3

b) I found the information in Section Three informative.
   Agree.................................................................1
   Neutral..............................................................2
   Disagree...........................................................3
c) I found Section Three helpful overall.

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

5) Please rate the following statements regarding Section Four of the PHR

a) I found Section Four easy to understand

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

b) I found the information in Section Four informative.

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

c) I found Section Four helpful overall.

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

6) Please rate the following statements regarding Section Five of the PHR

a) I found Section Five easy to understand

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

b) I found the information in Section Five informative.

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

c) I found Section Five helpful overall.

Agree.................................................................1
Neutral...............................................................2
Disagree...........................................................3

7) Do you have any concerns about using the PHR?

Yes.................................................................1
No.................................................................2

8) If "Yes" to Q. 7, what are your concerns about using the PHR?

___________________________________________________________________
9) Do you think the PHR should continue to be given to parents for their new babies?

Yes.................................................................1
No.................................................................2
Don't Know....................................................3

10) Do you think the PHR should contain more or less information than is currently provided?

Should contain more information.................................1
Should contain less information....................................2
Currently contains sufficient Area Medical Officer's information.................................3

11) If you feel the PHR should contain more information than currently, what information do you think should be added?

More advice..........................................................1
More room for comments..........................................2
More information on immunisations/developmental checks.................................3
Other ........................................................................4

12) If you feel the PHR should contain less information than currently, what information do you think should be taken out

Immunisations section................................................1
Developmental checks section....................................2
Advice section........................................................3
Height/Weight charts...............................................4
Comments section...................................................5

13) Overall, how satisfied were you with using the PHR?

Very satisfied.........................................................1
Satisfied...............................................................2
Neither.................................................................3
Dissatisfied............................................................4
Very dissatisfied.....................................................5

14) Please explain why you were satisfied or not with using the PHR:

________________________________________________________________________
________________________________________________________________________
15) Can you suggest any changes to the PHR that would make it easier for you to use it?

________________________________________________________________________
________________________________________________________________________

Thank the parent for his or her time. Give the parent a research pack and explain its' contents. Ask the parent if there are any questions. Conclude by assuring the parent that all information given here and any they provide on the take-home questionnaire remains strictly confidential.
Appendix Two: Intervention group one parents take home questionnaire

(please see attached)
Intervention group one parents take home questionnaire

Personal Health Record Survey
University College Cork

The following are general questions about you and your new baby. Please answer each question by placing a tick (✓) in the box that best describes you and/or your new baby (please ignore the numbers next to the boxes)

1) Has your baby received any vaccinations?
Yes [ ] (1)
No [ ] (2)

2) If your baby has received vaccinations, which ones has s/he received? (tick as many as apply)

- B.C.G. (given at birth) [ ] (1)
- 1st Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are two months old) [ ] (2)
- 2nd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are four months old) [ ] (3)
- 3rd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are six months old) [ ] (4)
- All of the above [ ] (5)
- My baby has received vaccinations, but I am unsure of which ones [ ] (6)

3) If your baby has not received vaccinations, why haven’t they been administered?

- Do not attend developmental checks [ ] (1)
- Unaware of the purpose of vaccinations [ ] (2)
- Feel vaccinations are unnecessary [ ] (3)
- Feel vaccinations present health risks to my baby [ ] (4)
- Ethical/moral objections [ ] (5)

4) Have you ever breastfed your baby?

- Yes, I breastfed but I have stopped doing so [ ] (1)
- Yes, I breastfed and I am still doing so [ ] (2)
- No, I never breastfed my baby [ ] (3)

5) If you have breastfed, why did you choose to do so?

- Better for baby’s health [ ] (1)
- Doctor or nurse’s recommendation [ ] (2)
- Breastfed my other children [ ] (3)
- Convenience [ ] (4)
- Prefer breast milk to bottled milk [ ] (5)
- Foster emotional bond with my child [ ] (6)
6) If you breastfed but have stopped doing so, how old was your baby when you stopped breastfeeding? ____________________

7) If you never breastfed, why did you choose not to?
   Not enough support [ ] (1)
   Breast problems [ ] (2)
   Milk supply concerns [ ] (3)
   Baby’s ill health [ ] (4)
   Mother’s ill health [ ] (5)
   Prefer formula milk [ ] (6)

8) Have you attended any scheduled developmental checks with your baby?
   Yes [ ] (1)
   No [ ] (2)

9) If "Yes" to Q.8, which developmental checks have you attended? (tick as many as apply)
   Primary visit [ ] (1)
   Six week check [ ] (2)
   Three month check [ ] (3)
   Seven to nine month check [ ] (4)
   All of the above [ ] (5)

10) If "No" to Q.8, why have you missed developmental checks?
    Do not attend developmental checks [ ] (1)
    Out of area [ ] (2)
    Forgot appointment [ ] (3)
    Appointment scheduled at inconvenient time [ ] (4)
    Transportation difficulties [ ] (5)

11) Have you scheduled appointments for your baby with any medical specialist(s) (for example, with a paediatrician, eye doctor or physiotherapist)?
    Yes [ ] (1)
    No [ ] (2)

12) Please explain what you believe is the purpose of developmental checks:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you very much for taking the time to complete this questionnaire. Please return your completed questionnaire in the enclosed stamped envelope. All responses will be treated in the strictest confidence.
Appendix Three: Intervention group two parents
postal questionnaire

(please see attached)
Intervention group two parents postal questionnaire

Personal Health Record Survey
University College Cork

The following are general questions about you and your new baby. Please answer each question by placing a tick (√) in the box that best describes you and/or your new baby (please ignore the numbers next to the boxes)

Section One:

11) Is your child?
   Male [ ](1)
   Female [ ](2)

12) Is this your first child?
   Yes [ ](1)
   No [ ](2)

3) Including this baby, how many children do you have? __________

4) Please indicate your age range
   15 – 20 years old [ ](1)
   21 – 25 years old [ ](2)
   26 – 30 years old [ ](3)
   31 – 35 years old [ ](4)
   36 or more years old [ ](5)

5) How would you describe your current living arrangement?
   I am married and living with my husband/wife [ ](1)
   I am married and not living with my husband/wife [ ](2)
   I am living with my partner [ ](3)
   I am divorced [ ](4)
   I am single [ ](5)

6) At what stage did you leave full time education?
   In primary school [ ](1)
   At the Group Certificate level [ ](2)
   At the Junior/Intermediate Certificate level [ ](3)
   At the Leaving Certificate level [ ](4)
   At third level (please specify type of qualification) __________ [ ](5)

7) In which of the following ethnic groups would you place yourself?
   Member of the Irish settled community [ ](1)
   Member of the Irish travelling community [ ](2)
   Other nationality (please specify) _________________ [ ](3)
8) At present are you
A homemaker [ ](1)
Employed full time [ ](2)
Employed part time [ ](3)
Unemployed and seeking work [ ](4)
Unemployed and not seeking work [ ](5)
Self employed [ ](6)
Engaged in full or part time education [ ](7)

9) What job have you done for the longest period of time?

__________________________________________________________

10) What job has your spouse/partner done for the longest period of time?

__________________________________________________________

11) Do you have
A medical card [ ](1)
Private health insurance [ ](2)
Both [ ](3)
Neither [ ](4)

Section Two:

1) Did you bring your PHR to your 7-9 month developmental check?
Yes [ ](1)
No [ ](2)

2) If "No" to Q. 1, why didn't you bring your PHR to your 7-9 month developmental check?
______________________________________________________

3) On average, how often did you bring your PHR to health checks?
Nearly always brought PHR [ ](1)
Occasionally brought PHR [ ](2)
Rarely brought PHR [ ](3)

4) Have you written in your PHR?
Yes [ ](1)
No [ ](2)

5) If "Yes" to Q. 4, which section(s) of the PHR have you written in? (tick as many as apply)
Section One (Health and Advice) [ ](1)
Section Two (Vaccination Consent Form) [ ](2)
Section Three (Health and Developmental Checks) [ ](3)
Section Five (Comments) [ ](4)
All of the above [ ](5)

6) Has your General Practitioner or Public Health Nurse written in your PHR?
Yes [ ](1)
No [ ](2)

7) If "Yes" to Q. 6, which sections of the PHR has the General Practitioner or Public Health Nurse written in? (tick as many as apply)
Section Two (Vaccination Consent Form and Immunisation Record) [ ](1)
Section Three (Health and Developmental Checks) [ ](2)
Section Five (Comments and Growth Records) [ ](3)
All of the above [ ](4)

8) Overall, how satisfied were you with using the PHR?
Very satisfied [ ](1)
Satisfied [ ](2)
Neither [ ](3)
Dissatisfied [ ](4)
Very dissatisfied [ ](5)

9) Please explain why you were satisfied or not with using the PHR
________________________________________________________________
________________________________________________________________
________________________________________________________________

Section Three:

2) Has your baby received any vaccinations?
Yes [ ](1)
No [ ](2)

2) If your baby has received vaccinations, which ones has s/he received? (tick as many as apply)
B.C.G. (given at birth) [ ](1)
1st Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are two months old) [ ](2)
2nd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are four months old) [ ](3)
3rd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are six months old) [ ](4)
All of the above [ ](5)
My baby has received vaccinations, but I am unsure of which ones [ ](6)
3) If your baby *has not* received vaccinations, why haven't they been administered?

- Do not attend developmental checks [ ] (1)
- Unaware of the purpose of vaccinations [ ] (2)
- Feel vaccinations are unnecessary [ ] (3)
- Feel vaccinations present health risks to my baby [ ] (4)
- Ethical/moral objections [ ] (5)

4) Have you ever breastfed your baby?

- Yes, I breastfed but I have stopped doing so [ ] (1)
- Yes, I breastfed and I am still doing so [ ] (2)
- No, I never breastfed my baby [ ] (3)

5) If you *have* breastfed, why did you choose to do so?

- Better for baby's health [ ] (1)
- Doctor or nurse's recommendation [ ] (2)
- Breastfed my other children [ ] (3)
- Convenience [ ] (4)
- Prefer breast milk to bottled milk [ ] (5)
- Foster emotional bond with my child [ ] (6)

6) If you breastfed but *have stopped doing so*, how old was your baby when you stopped breastfeeding? ____________________________

7) If you *never* breastfed, why did you choose not to?

- Not enough support [ ] (1)
- Breast problems [ ] (2)
- Milk supply concerns [ ] (3)
- Baby's ill health [ ] (4)
- Mother's ill health [ ] (5)
- Prefer formula milk [ ] (6)

8) Have you attended any scheduled developmental checks with your baby?

- Yes [ ] (1)
- No [ ] (2)

9) If "Yes" to Q.8, which developmental checks have you attended? (*tick as many as apply*)

- Primary visit [ ] (1)
- Six week check [ ] (2)
- Three month check [ ] (3)
- Seven to nine month check [ ] (4)
- All of the above [ ] (5)
10) If "No" to Q.8, why have you missed developmental checks?
   Do not attend developmental checks [ ](1)
   Out of area [ ](2)
   Forgot appointment [ ](3)
   Appointment scheduled at inconvenient time [ ](4)
   Transportation difficulties [ ](5)

11) Have you scheduled appointments for your baby with any medical specialist(s) (for example, with a paediatrician, eye doctor or physiotherapist)?
   Yes [ ](1)
   No [ ](2)

12) Please explain what you believe is the purpose of developmental checks:

________________________________________________________________
________________________________________________________________
________________________________________________________________

Thank you very much for taking the time to complete this questionnaire. Please return your completed questionnaire in the enclosed stamped envelope. All responses will be treated in the strictest confidence.
Appendix Four:  Control group parents postal questionnaire

(please see attached)
Control group parents postal questionnaire

Health Services Survey
University College Cork

The following are general questions about you and your new baby. Please answer each question by placing a tick (√) in the box that best describes you and/or your new baby (please ignore the numbers next to the boxes)

Section One:

13) Is your child?
   Male [ ](1)
   Female [ ](2)

14) Is this your first child?
   Yes [ ](1)
   No [ ](2)

3) Including this baby, how many children do you have? __________

4) Please indicate your age range
   15 – 20 years old [ ](1)
   21 – 25 years old [ ](2)
   26 – 30 years old [ ](3)
   31 – 35 years old [ ](4)
   36 or more years old [ ](5)

5) How would you describe your current living arrangement?
   I am married and living with my husband/wife [ ](1)
   I am married and not living with my husband/wife [ ](2)
   I am living with my partner [ ](3)
   I am divorced [ ](4)
   I am single [ ](5)

6) At what stage did you leave full time education?
   In primary school [ ](1)
   At the Group Certificate level [ ](2)
   At the Junior/Intermediate Certificate level [ ](3)
   At the Leaving Certificate level [ ](4)
   At third level (please specify type of qualification) [ ](5)

7) In which of the following ethnic groups would you place yourself?
   Member of the Irish settled community [ ](1)
   Member of the Irish travelling community [ ](2)
   Other nationality (please specify) [ ](3)
Evaluation of the pilot Personal Health Record programme

8) At present are you
A homemaker [ ](1)
Employed full time [ ](2)
Employed part time [ ](3)
Unemployed and seeking work [ ](4)
Unemployed and not seeking work [ ](5)
Self employed [ ](6)
Engaged in full or part time education [ ](7)

9) What job have you done for the longest period of time?

__________________________

10) What job has your spouse/partner done for the longest period of time?

__________________________

11) Do you have
A medical card [ ](1)
Private health insurance [ ](2)
Both [ ](3)
Neither [ ](4)

Section Two:

1) Has your baby received any vaccinations?
Yes [ ](1)
No [ ](2)

2) If your baby has received vaccinations, which ones has s/he received?
(tick as many as apply)
B.C.G. (given at birth) [ ](1)
1st Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are two months old) [ ](2)
2nd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are four months old) [ ](3)
3rd Diphtheria/Tetanus/Whooping Cough, Hib, Meningitis C, Polio (given when babies are six months old) [ ](4)
All of the above [ ](5)
My baby has received vaccinations, but I am unsure of which ones [ ](6)

3) If your baby has not received vaccinations, why haven't they been administered?
Do not attend developmental checks [ ](1)
Unaware of the purpose of vaccinations [ ](2)
Feel vaccinations are unnecessary [ ](3)
Feel vaccinations present health risks to my baby [ ](4)
Ethical/moral objections [ ](5)

4) Have you ever breastfed your baby?
Yes, I breastfed but I have stopped doing so [ ](1)
Yes, I breastfed and I am still doing so [ ](2)
No, I never breastfed my baby [ ](3)

5) If you have breastfed, why did you choose to do so?
Better for baby's health [ ](1)
Doctor or nurse's recommendation [ ](2)
Breastfed my other children [ ](3)
Convenience [ ](4)
Prefer breast milk to bottled milk [ ](5)
Foster emotional bond with my child [ ](6)

6) If you breastfed but have stopped doing so, how old was your baby when you stopped breastfeeding?____________________________

7) If you never breastfed, why did you choose not to?
Not enough support [ ](1)
Breast problems [ ](2)
Milk supply concerns [ ](3)
Baby's ill health [ ](4)
Mother's ill health [ ](5)
Prefer formula milk [ ](6)

8) Have you attended any scheduled developmental checks with your baby?
Yes [ ](1)
No [ ](2)

9) If "Yes" to Q.8, which developmental checks have you attended? (tick as many as apply)
Primary visit [ ](1)
Six week check [ ](2)
Three month check [ ](3)
Seven to nine month check [ ](4)
All of the above [ ](5)

10) If "No" to Q.8 why have you missed developmental checks?
Do not attend developmental checks [ ](1)
Out of area [ ](2)
Forgot appointment [ ](3)
Appointment scheduled at inconvenient time [ ](4)
Transportation difficulties [ ](5)
11) Have you scheduled appointments for your baby with any medical specialist(s) (for example, with a paediatrician, eye doctor or physiotherapist)?

Yes [ ]\(^{(1)}\)
No [ ]\(^{(2)}\)

12) Please explain what you believe is the purpose of developmental checks:

________________________________________________________________
________________________________________________________________
________________________________________________________________

13) If given the choice, would you be willing to keep a copy of your child's health record?

Yes [ ]\(^{(1)}\)
No [ ]\(^{(2)}\)

14) If "Yes" to Q.13, why would you be willing to keep a copy of your child's health record?

Better informed regarding child's health [ ]\(^{(1)}\)
More responsible for child's health [ ]\(^{(2)}\)
Better able to manage medical appointments [ ]\(^{(3)}\)
Greater convenience [ ]\(^{(4)}\)

15) If "No" to Q.13, why wouldn't you be willing to keep a copy of your child's health record?

Risk of losing record [ ]\(^{(1)}\)
Unfamiliar with maintaining health records [ ]\(^{(2)}\)
Feel records best kept by medical professionals [ ]\(^{(3)}\)
Afraid of completing record incorrectly [ ]\(^{(4)}\)

Thank you very much for taking the time to complete this questionnaire. Please return your completed questionnaire in the enclosed stamped envelope. All responses will be treated in the strictest confidence.
Appendix Five: Health professionals postal questionnaire

(please see attached)
Health professionals postal questionnaire

Personal Health Record Survey
University College Cork

The following are questions regarding the pilot Personal Health Record (PHR) programme initiated in the Mid-Western Health Board. Please answer each question by placing a tick (✓) in the box that best matches your response (please ignore the numbers next to the boxes). Please tick only one box for each question except where specified otherwise.

1) Have you come in contact with parents in your medical practice who possess a PHR?
   Yes       [ ](1)
   No        [ ](2)
   Don't remember     [ ](3)

2) If "Yes" to Q. 1, please approximate roughly how many of the parents attending your practice possess a PHR: ________________

3) Generally, how often do those parents whom you know have a PHR bring it to consultations?
   Always bring PHR      [ ](1)
   Sometimes bring PHR     [ ](2)
   Never bring PHR      [ ](3)

4) Would those parents in possession of a PHR generally present it to you during a consultation or do you need to ask for it?
   Parents present PHR to me       [ ](1)
   I need to ask parents for PHR      [ ](2)
   Don't remember        [ ](3)

5) In what you would consider an average consultation, do you feel you have time to write in the PHR?
   Yes, always have time       [ ](1)
   Sometimes have time        [ ](2)
   No, never have time        [ ](3)

6) Who do you think should write in the PHR? (multiple responses permitted)
   Parents         [ ](1)
   General Practitioners        [ ](2)
   Public Health Nurses        [ ](3)
   Area Medical Officers       [ ](4)
Hospital staff [ ] (5)
All of the above [ ] (6)
Other (please specify) [ ] (7)

7) In your opinion, is the PHR an effective communication tool between health professionals?
Yes [ ] (1)
Sometimes [ ] (2)
No [ ] (3)
Don't know [ ] (4)

8) In your opinion, is the PHR an effective communication tool between health professionals and parents?
Yes [ ] (1)
Sometimes [ ] (2)
No [ ] (3)
Don't know [ ] (4)

9) Do you think parental possession of a PHR is a useful tool in encouraging their responsibility for their child's health?
PHR is a useful tool in this area [ ] (1)
PHR is a useless tool in this area [ ] (2)
PHR makes no difference in this area [ ] (3)

10) Do you think the PHR is a duplication of existing medical information?
Yes [ ] (1)
Partially [ ] (2)
No [ ] (3)
Don't know [ ] (4)

11) Do you think the PHR programme should be continued?
Yes [ ] (1)
No [ ] (2)
Don't know [ ] (3)

12) Overall, how satisfied are you with using the PHR?
Very satisfied [ ] (1)
Satisfied [ ] (2)
Neither [ ] (3)
Dissatisfied [ ] (4)
Very dissatisfied [ ] (5)
13) What do you feel would improve your usage of the PHR? (please check "Yes" or "No" to each option)

<table>
<thead>
<tr>
<th>Option</th>
<th>&quot;Yes&quot;</th>
<th>&quot;No&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing the space throughout to record findings</td>
<td><a href="1a">     </a></td>
<td><a href="1b">     </a></td>
</tr>
<tr>
<td>Printing on the front cover that it should be brought to all consultations</td>
<td><a href="2a">     </a></td>
<td><a href="2b">     </a></td>
</tr>
<tr>
<td>Provide information for health professionals on increasing their use of the PHR</td>
<td><a href="3a">     </a></td>
<td><a href="3b">     </a></td>
</tr>
<tr>
<td>More information for parents throughout PHR</td>
<td><a href="4a">     </a></td>
<td><a href="4b">     </a></td>
</tr>
<tr>
<td>Index at the back listing all topics included in PHR</td>
<td><a href="5a">     </a></td>
<td><a href="5b">     </a></td>
</tr>
<tr>
<td>No changes needed</td>
<td><a href="6a">     </a></td>
<td><a href="6b">     </a></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td><a href="7a">     </a></td>
<td><a href="7b">     </a></td>
</tr>
</tbody>
</table>

14) We are hoping to conduct short in-depth interviews (20 minutes duration) with medical professionals regarding their impressions of the PHR. Would you be willing to participate in a short interview scheduled at your convenience?

Yes (if "Yes", please provide your address and telephone number below)   | [     ](1)
No                                                                           | [     ](2)

Address and telephone number:

Thank you very much for taking the time to complete this questionnaire. Please return your completed questionnaire in the enclosed stamped envelope as soon as possible. All responses will be treated in the strictest confidence.
Appendix Six: Topics for discussion in qualitative interviews

1) The following theoretical concerns have been raised regarding possible drawbacks to using PHR (i.e., duplication of work; parental loss of record; issues surrounding confidentiality). Do you agree with any of these concerns? Do you share any of these concerns? Why or why not? Do you have any theoretical concerns regarding PHR use?

2) The following have been cited as positive outcomes of professional use of the PHR (i.e., shared decision making between professionals and parents; parents more responsible for child's welfare; parents less likely to contact health professionals regarding minor problems; promotes continuity of care and information). Have you experienced any of these benefits in your own use of the PHR? Have you experienced any other benefits not mentioned here? If so, which ones? Can you imagine any positive outcomes of your use of PHR?

3) Do you feel there could be instances where in your judgement a parent ought not have access to some part of his/her baby's medical record? If so, in what instances? How would this affect your use of the PHR?

4) Do you feel there are any groups of parents with whom the PHR programme would be difficult or inappropriate? If so, for what reasons? Can you suggest any individual, local or state-wide changes that would ameliorate any of these difficulties?

5) Do you feel the PHR programme should be implemented throughout Ireland on a permanent basis? Please explain yes or no? Do you think there could be obstacles to nationwide implementation?.

6) Do you feel there are any differences between urban and rural parents' use of PHR? If so, of what kind?

7) Do you have any other comments/suggestions/complaints regarding PHR or its use?