8. Data Analysis



8.1 HSE West (Donegal, Sligo, Leitrim & West Cavan

Data files received in Excel format were amalgamated and cleaned. From this, they were imported into Microsoft Access format for analysis (see **Section 9**).

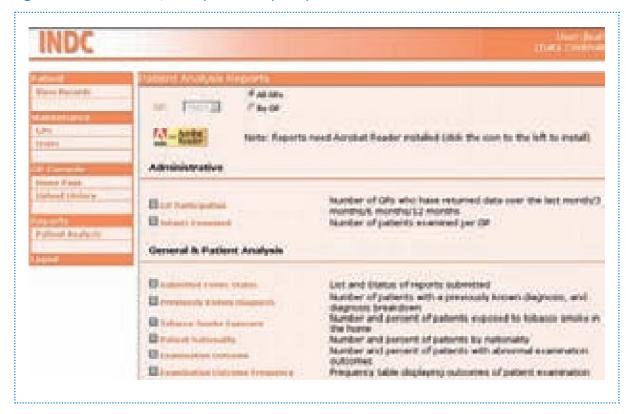
8.2 ICGP Independent National Data Centre

Data recorded by GPs and Practice Nurses were submitted into an online database where records.

Files are generated at practice level and uploaded after log on to the INDC website, using the file upload page within the application page of the site. Files are processed by the windows service that transforms and validates the data, reports on the validation status and finally imports the data into database tables for storage.

The system has a management module that allows administrators of the system to add in practices, GPs and other users. There is a GP console, which enables GPs to query information on their use of the system with a full audit trail on files imported, accepted and rejected. There is also a section which provides a menu of online patient analysis reports.

Figure 15 Screenshot of INDC patient analysis reports section



9. Results



From November 2004 through to August 2005 a total of 284 babies were examined as part of this project.



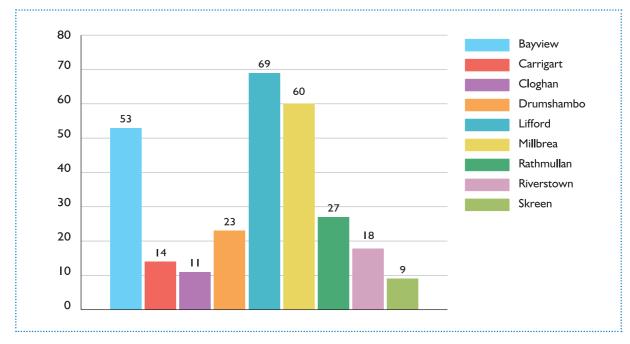
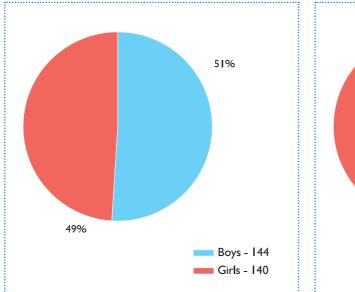
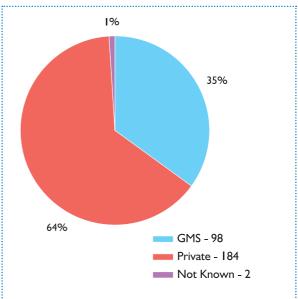


Figure 17 Gender distribution of babies

Figure 18 GMS status of mother





According to HSE National Shared Services Primary Care Reimbursement Services, 44.73% (Donegal 50.09%, Leitrim 41.26%, Sligo 33.67%) of the population in HSE West (Donegal, Sligo, Leitrim & West Cavan) were medical card holders in 2005. An estimate of GMS/ non GMS ratios amongst project practices indicates a wide variation, ranging from 25% to 75% of patients registered with practices holding a medical card. Figures shown here are likely to reflect a relatively high level of economic activity amongst the reproductively active population section.

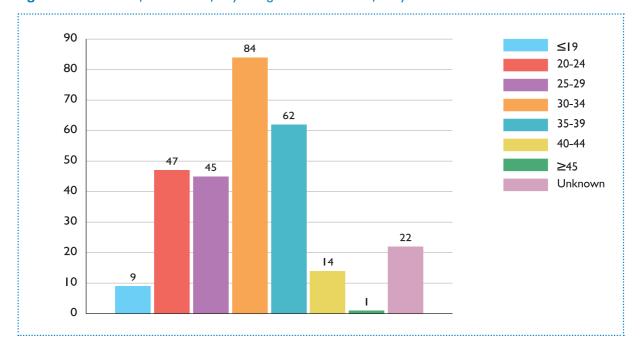


Figure 19 Number of mothers in five year age bands at birth of baby

At birth of their baby, 10% of mothers were younger than 20 years (5%). 16% each came from age groups 20-24 years (14.4%) and 25-29 years (25%). 30% of mothers were aged 30-34 years (32%), 22% came from age group 35-39 years (19%), 5% were aged 40-44 years (no data). (Comparative figures for births statistics from 2003 are given in brackets). ²⁰

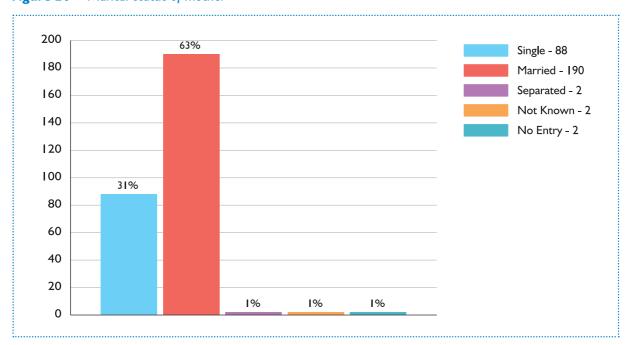


Figure 20 Marital status of mother

Two thirds of mothers (66%) were married at the time of bringing their baby for the 6 week baby check. Almost one third (31%) were single. This compares with 71% and 28% respectively reported in $2003.^{20}$

Figure 21 Percentage of first time mothers

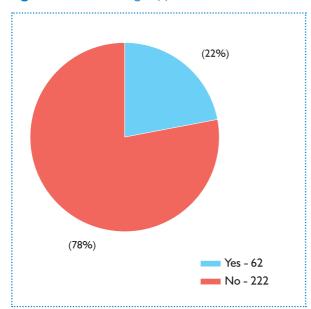
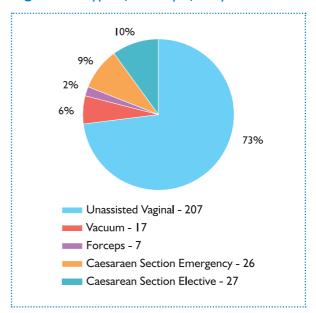


Figure 22 Type of delivery of baby



73% of babies were born by normal vaginal delivery. There was an overall caesarean section rate of 19%.

Figure 23 Admission of baby to special care baby unit for any reason

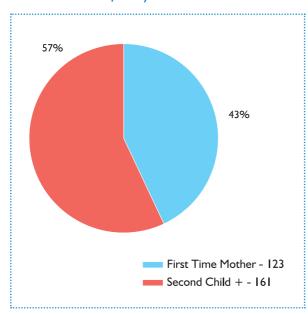
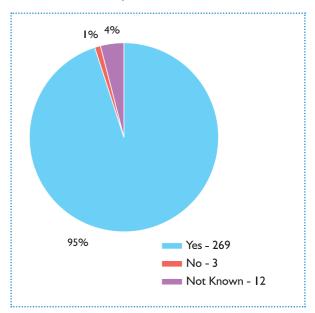


Figure 24 Number (%) of babies having received a visit from the Public Health Nurse



In accordance with the statutory national core child health programme,³ all newborn babies and their mothers should receive a visit from their Public Health Nurse within 48 hours of discharge from maternity care, usually provided in hospitals. 95% of mothers reported having received such a visit, which compares favourably with figures from other parts of ROI and is in line with figures reported for HSE West (Donegal, Sligo, Leitrim & West Cavan) as part of the national Child and Adolescent Health Performance data set.²¹

Figure 25 Admission of baby to hospital following discharge after birth

11% 89% Yes - 30 No - 254

Figure 26 Number (%) of babies seen for 6 week baby check who had a previously known diagnosis

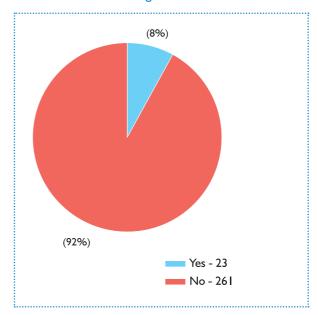


Figure 27 Type of feeding when attending for 6 week baby check

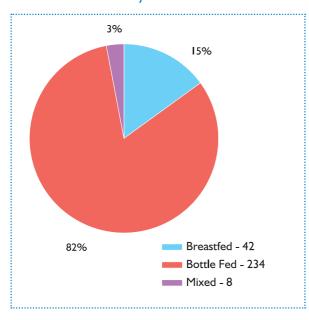
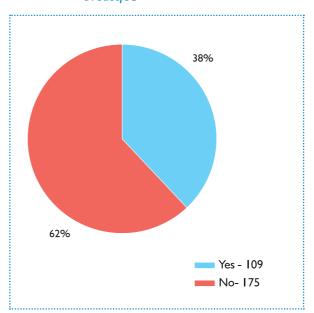


Figure 28 Number (%) of babies ever breastfed



A breast feeding rate of 15% and an additional 3% of babies being fed with a combination of breast and bottle milk was observed.

The rate of 38% for babies ever having been breastfed is in keeping with regional and national data.

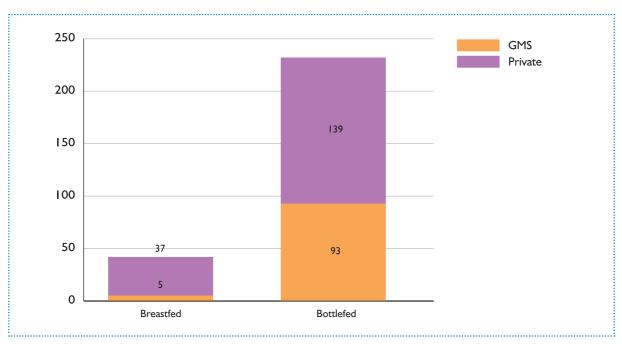


Figure 29 Number of babies breastfed and bottlefed according to GMS status of mother at 6 week baby check

When analysed separately by GMS status, the rate of breastfeeding amongst medical card holders at the 6 week baby check was 5%, compared to 21% for non medical card holders.

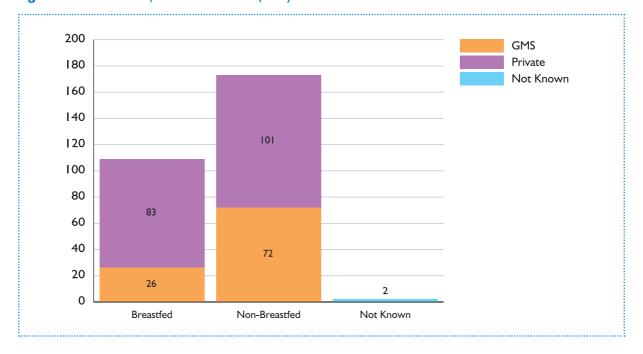


Figure 30 Number of babies ever breastfed by GMS status

26.5% of babies of mothers holding a medical card had ever been breastfed, compared to 45% of babies born to mothers without a medical card.

Figure 31 Number (%) of mothers smoking during pregnancy

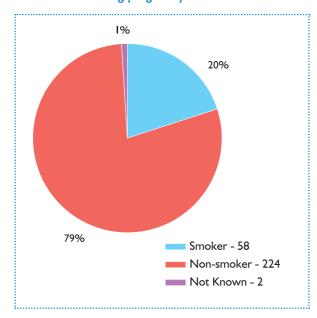
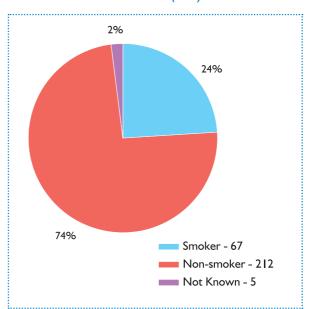


Figure 32 Exposure of baby to environmental tobacco smoke (ETS)



20% of mothers presenting their baby for the 6 week baby check stated that they had smoked during pregnancy.

24% of mothers stated at the 6 week baby check that their baby was exposed to environmental tobacco smoke (ETS) in the home.

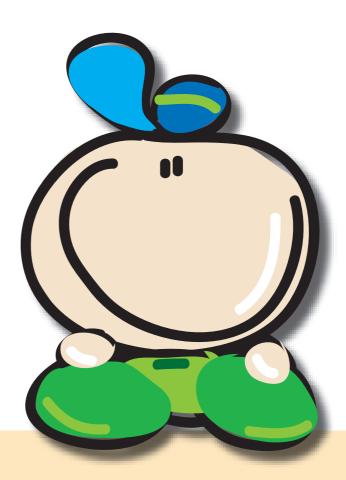




Figure 33 Maternal smoking during pregnancy by GMS status

37% of mothers with a medical card had smoked during pregnancy, compared to 12% of mothers without a medical card.

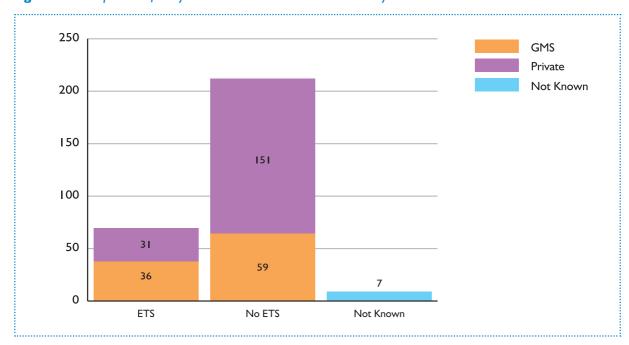


Figure 34 Exposure of baby to environmental tobacco smoke by GMS status

38% of babies whose mother had a medical card at the time of the 6 week baby check were exposed to ETS, compared to 17% of babies with non medical card holding mothers.

 Table 3
 Nationality and ethnicity of babies seen for 6 week baby check

| Nationality | Ethnicity |
|--------------|-----------------------------|
| Irish = 281 | Traveller = 0 |
| Other EU = I | Asylum Seeker / Refugee = 0 |
| Non EU = 2 | Not Applicable = 284 |
| Total = 284 | Total = 284 |

This table shows a very homogenous population not representative of HSE West (Donegal, Sligo, Leitrim & West Cavan), but due to practice selection in the recruitment process, which unintentionally gave preference to practices without significant populations from ethnic minorities.



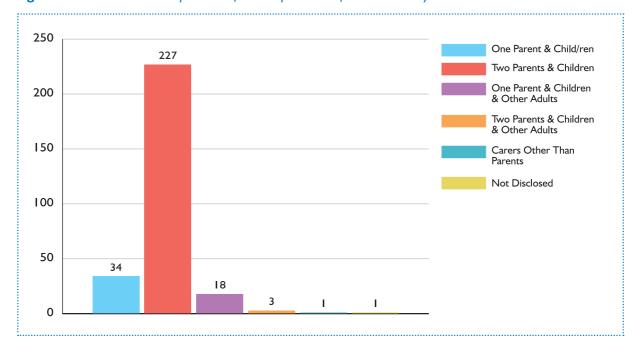


Figure 35 Household composition of babies presented for 6 week baby check

The majority of babies (80%) lived in households with two parents. 12% lived in single parent households, and 6% lived with one parent and other adults.

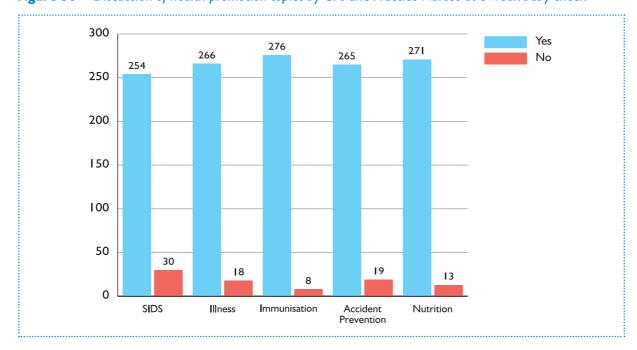


Figure 36 Discussion of health promotion topics by GPs and Practice Nurses at 6 week baby check

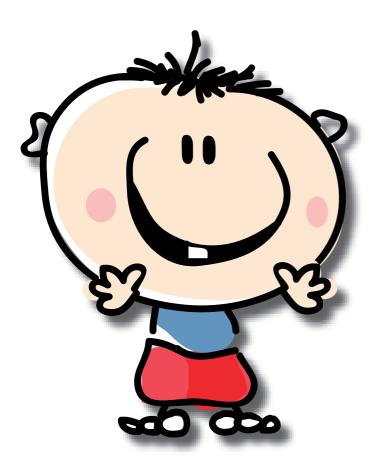
This figure shows that the majority of primary care practitioners reported to have discussed the health promotion topics included in the data set.

Table 4 Number of babies referred as a result of the 6 week baby check

| Examination | Satisfactory | Observation | In Treatment | Refer | Not Examined | Not Recorded |
|----------------|--------------|-------------|-----------------|-------|-----------------|-----------------|
| General | 279 | 0 | 3 | 2 | 0 | 0 |
| Growth | 278 | 6 | 0 | 0 | 0 | 0 |
| Vision | 273 | 1 | 0 | 4 | 0 | 0 |
| Hearing | 279 | 0 | 0 | 0 | I | 4 |
| Cardiovascular | 275 | 5 | I | 0 | 0 | 3 |
| Testes | 142 | 4 | 0 | 0 | П | 127 |
| Hips | 271 | 3 | I | 2 | 2 | 5 |

4 babies had more than one noted abnormal finding.

This table shows that there was a small number of referrals to secondary services as a result of clinical examination at the 6 week baby check. In total eight referrals were made for seven children. Seventeen children were kept under observation for 19 reasons by their primary care provider and five were already receiving treatment for previously diagnosed conditions. Recording errors occurred in relation to testicular examination; there were only 140 boys in the project, but findings are recorded for 146, none of them resulting in referral.



10. Feedback From Parents & Project Participants



10.1 Parents' experience of new model for 6 week baby check in general practice

Methodology

A questionnaire (**Appendix G**) was sent to mothers of babies about whom returns were received from 30th June 2005 until 31st July 2005. Of 57 sent, 27 (47.3%) questionnaires were returned. A thank you and reminder letter was sent in August 2005, but no further replies were received.

Results

Mothers ranged in age from 17-19 years (1), 20-24 (1), 25-39 years (23) and 40-44 years (2); six were first time mothers.

Only four mothers reported having received the information leaflet, which formed part of obtaining informed consent from mothers to participate in the project.

Twenty six mothers agreed or strongly agreed that:

- they were satisfied with the physical examination of the baby
- they felt comfortable asking questions
- enough time had been given to the check

This is how mothers described the perceived benefits of the 6 week baby check:

"introduce our baby to our family doctor"

"we felt it was better to have a 6 week check with our own GP rather than wasting time at the hospital with a stranger"

"very thorough and not rushed, time was taken and everything was covered"

"to see how parents are coping, not just testing the reflexes"

"reassuring", giving "peace of mind", feeling "more confident"

"if there was a problem, it would be picked up at this stage"

"my doctor is very open, you can ask anything that is not covered"

Mothers' postnatal check

Thirteen mothers did not have their check at the same time as their baby, while 14 did. Some mothers expressed dissatisfaction:

"I didn't know there was such a thing"

In one mother's perception, the check up consisted of being asked if she was "OK" and she felt "annoyed at the lack of interest"

Suggestions for improvement

- Issue a card to parents inviting them for the check.
- Provide more information including leafletsone mother wanted more information on sudden unexplained death of infants (SUDI).
- Make sure to talk about how the mother is feeling.
- There should be a clinic for 6 week checks only.
- Mothers should be told during last antenatal appointment with their GP that the 6 week check must be booked and takes longer than an ordinary appointment.
- One mother was confused as she had been told by her Public Health Nurse that the baby would have a 6 week check, but was asked to come at 8 weeks when she contacted her GP.

10.2 GPs' and Practice Nurses' experience of 6 week baby check project

Methodology

A questionnaire was sent to all GPs who had participated in the project after data collection concluded in September 2005. This questionnaire was modelled on the pre project practice assessment questionnaire in order to allow comparative analysis. Of 15 GPs, 13 replied. The table below outlines findings.

Table 5 Delivery of 6 week baby check prior to and during project

| Item | Before | After |
|---|-----------------|-----------------|
| Number of questionnaires returned (sent) | 14 (15) | 13 (15) |
| Number of GPs measuring uptake rates (%) | 4 (29%) | 5 (38%) |
| Measured and estimated uptake rates | 90 - 100% | 90 - 100% |
| Number of GPs examining babies at age 6 weeks | 7 (50%) | 2 (15%) |
| Number of GPs examining baby only (postnatal check for mother during another appointment) (%) | 5 (36%) | 7 (53%) |
| Average time of duration of baby check | 10 - 30 minutes | 20 - 30 minutes |
| Number of GPs involving Practice Nurse in 6 week baby check (%) | 8 (57%) | 11 (78%) |

Measurement of uptake rates

The number of GPs measuring uptake rates increased from four GPs out of 14 in four practices before the project to five GPs out of 13 from five practices.

Examination of baby

Prior to the project, five GPs (36%) out of 14 examined the baby at the age of 6 weeks. This decreased to two GPs (15%) out of 13 after the project, one of whom varied her practice between examination of babies at 6 and 8 weeks of age.

In order to identify previously undiagnosed health problems, the baby check should be carried out at 6 rather than at 8 weeks. In order to increase uptake rates and reduce the number of visits a family need to make to their primary care provider for baby check, postnatal examination of mother and primary immunisations, a balance needs to be struck between the timing preferable from a clinical perspective and the potential inconvenience caused to families.

Combining baby check and primary immunisations

Out of the 11 GPs carrying out the baby check at 8 weeks of age at the end of project, five GPs combined this with immunisations, while six GPs did not

Consultation prior to the project with mothers, whose babies had just undergone the check, highlighted that where immunisation took place at the same visit, this overshadowed the appointment with less attention being given to other issues.

Clinical setting

All practices included appointments for the 6 week baby check in their daily routine surgery sessions, both prior to and after the project. While mothers had expressed a preference for a separate 'baby and parent only' clinic, this might not be feasible in the majority of rural and semi urban practices due to the relatively small numbers of 6 week baby checks to be carried out. The setting up of a designated clinic would require protected staff time and facilities not available for other practice activities.

Staff involved in 6 week examination

During the project, the involvement of Practice Nurses in the delivery of the baby check increased, reflecting a higher level of multidisciplinary service provision and access of service users to a broader range of professional skills.

"caused us to focus and involve other clinical staff"

Content of the clinical examination

GPs welcomed the structure and extended clinical content provided by the new model. Six (46%) out 13 GPs out said that participation in project had changed their clinical practice:

"tend to follow pattern set out in project"

"more detailed examination than before"

"new features and better documented"

"more thorough"

"always check red reflexes and femoral pulses now"

"more structured examination and recording of information"

Health promotion

Ten (77%) out of 13 GPs changed the way in which they discussed health promotion topics listed for inclusion in the 6 week baby check.

"more structured"

"SIDS, accident prevention – I didn't discuss these before"

"more detailed, wider scope"

"more structured as prompted by data entry fields"

"more time spent discussing safety, accident prevention, feeding and recognising illness"

"always discuss hearing and sight now"

Communication with parents

There was no change in the way parents were contacted to attend with their child for the 6 week baby check.

Communication between parents and primary care providers had been described as very satisfactory both by service users and providers prior to the project, and there is little indication for change in this as a result of the project. The

following quotes reflect GPs' open and positive attitude:

"parents seemed to feel they had more opportunity to ask questions and were impressed by detail of examination"

"parents impressed and reassured"

"check list format reassured us"

"tightened up the clinical examination and gave mothers more time to talk"

Of concern is that the information leaflet appears to have been rarely handed out or discussed with parents. It was designed to form part of the informed consent procedure for participation in the project, but more importantly provided information on the 6 week baby check. Parents consulted prior to the project had expressed the need for such information, but feedback from GPs indicated that there had not been a change in the patterns of discussions regarding purpose and clinical content of the 6 week baby check.

Benefits and disadvantages for primary care providers from participating in the project

Despite concern about the feasibility of completing the dataset for collection during consultations, most project participants expressed satisfaction with the overall aims and purpose of the project.

"we felt we were more comprehensive"

"made more aware of what is involved in 6 week check"

"more structured approach"

"well organised, good format"

Time constraints are always a consideration within the busy setting of primary care, and there was some concern expressed regarding this.

"time involved in training and setting up"

Long term feasibility of new model

The majority of GPs, 11 (85%) out of 13, favoured the dissemination of the new model for the 6 week baby check; two (15%) disagreed.

"it is definitely beneficial"

"it would seem a pity not to continue it"

Summary of results from post project GP questionnaires

- · Uptake rates showed no change .
- Time to deliver 6 week baby check increased.
- Practice Nurse involvement increased.
- 46% of GPs changed their clinical examination.
- 77% of GPs changed their health promotion discussion.
- GPs expressed satisfaction with the structure provided for the new model regarding its positive impact on clinical examination and communication with parents.
- Information leaflet and consent were rarely discussed.
- IT programme posed challenges regarding comprehensiveness, functionality and time taken to complete data set for collection.

10.3 Other Feedback

A meeting with project participants and other stakeholders was held in October 2005, where results from project data analysis and evaluation were presented and feedback sought. This was followed by a final meeting of the steering group in December 2005, which provided another opportunity to seek feedback from a range of health service providers who had contributed to the project.

Public health data

Practices selected for the project did not include those known to have a significant ethnic minority population proportion, i.e. members of the travelling, asylum seeking or refugee communities. While the project data analysis reflected this, it did not have the opportunity to demonstrate any differences between health needs and behaviours between different ethnic groups.

Concerns were expressed by primary care providers about the sociodemographic profile demonstrated by the project, showing a high proportion of single mothers, antenatal and postnatal exposure of babies to the adverse effects of smoking and low breastfeeding rates.

Public Health Nurse visiting

Despite concerns expressed by some GPs participating in the project about enquiring of parents whether they had received a visit from their Public Health Nurse, there was strong support for attempts to improve communication between Public Health Nurses and primary care providers to ensure services reach all families, especially those at risk of disadvantage and adverse health outcomes. Particularly in relation to practices located in the border region, there can be difficulty in tracking families, who might opt to attend services in different jurisdictions.

Health promotion and family support

While the 6 week baby check has an established and evidence based role in the core child health programme for screening and surveillance, its

benefits extend to the broader context of the role primary care has in contributing to positive health outcomes for children and their families. Parents are increasingly recognised as experts in identifying concerns regarding their children's development. They require access to and the support of health professionals in optimising this role, and the 6 week baby check offers this, as well as giving primary care professionals an opportunity to identify families in need of support beyond that of a universal child health programme. In this context, it is important to attend to the needs of the mother, while fulfilling the requirements of a quality assured 6 week baby check.

Data collection, sharing and analysis

Data management needs to be an adjunct and support to health service delivery. The development of such systems requires co- operation between a broad range of stakeholders, which in the context of this project fostered improved understanding and working relationships between HSE, ICGP and primary care providers. This has the potential to benefit other areas of work, like the development of an ICT strategy for primary, community and continuing care or governance processes and structures for quality assurance of health service provision.

While uptake rates for the MIS in HSE West (Donegal, Sligo, Leitrim & West Cavan) are traditionally high, this is not the case in many other geographical, particularly urban, areas. Comprehensive patient registration and the development of call-recall systems are required.

11. Costs



GP Project Cost

| | | (| | (| | |
|---|--------|------------|-----------|------------|----------|-------------|
| Staff Category | Number | Pay Costs | Iravel | II Costs | Iraining | lotal |
| Project Manager | 0.2 | €34,468.00 | | | | €34,468.00 |
| Project Officer | 0.2 | €33,000.00 | €3,000.00 | €3,000.00 | | €39,000.00 |
| GPs on Steering Group | 2 | €1,790.62 | €519.17 | | | €2,309.79 |
| Practice Nurse on Steering Group | _ | €164.18 | €597.72 | | | €761.90 |
| GP Contracts | 15 | €6,000.00 | | | | €6,000.00 |
| €40 per baby seen during project | 284 | €11,360.00 | | | | €11,360.00 |
| Skills update refresher course | | | €1,648.39 | | | €1,648.39 |
| Project team meetings | 0_ | | €3,000.00 | | | €3,000.00 |
| INDC Website funded by GPIT Group, DoHC | | | | €15,000.00 | | €15,000.00 |
| Recruitment of Project Officer | | | | | | €1,000.00 |
| Standard development workshop | | | | | | €2,000.00 |
| Service User Consultation | | | | | | €2,000.00 |
| Materials | | | | | | €5,000.00 |
| Software Development | | | | €40,000.00 | | €40,000.00 |
| Evaluation | | | €1,412.80 | | | €1,412.80 |
| Report and dissemination | | | | | | €10,000.00 |
| Clerical Support & Overheads | | €10,000.00 | | | | €10,000.00 |
| Miscellaneous | | | | | | €454.00 |
| Total | | | | | | €185,414.88 |

12. Conclusions and Recommendations



12.1 Existing practice

There is currently wide spread variability regarding the uptake and provision of the 6 week baby check as part of the statutory maternity and infant care scheme. Evidence of effectiveness and current recommendations for a national core child health programme in ROI support the delivery of a 6 week baby check in general practice. In light of changing population health needs and recognition of the pivotal role that primary health care services have in contributing to population health outcomes, the new model for the 6 week baby check presented in this report not only provides an opportunity for the early detection of health problems in infants that are amenable to early intervention and management, but is also designed to contribute to the formation of supportive relationships with primary care providers for children and their families.

12.2 New model

This new model has been developed based on the framework set out in Best Health for Children-Developing a Partnership with Parents, 1999:

- Quality of service provision
- Partnership with parents
- · Flexible and responsive services
- Training
- Equity
- Accountability

The new model:

- Provides clear and evidence based examination protocols,
- Includes a multidisciplinary staff training module,
- Advises on referral criteria,
- Supports open communication between service users and professionals,
- Provides tools for clear documentation of clinical findings and outcome measures, allowing monitoring and evaluation of service provision,

- Integrates data concerning individual children into existing health record systems, e.g. the parent held PHR and immunisation databases,
- Contributes to a national child health information base for quality assurance of primary care led service delivery.

Recommendation I

To include new model for 6 week baby check in national GP contract negotiations and in remodelled statutory MIS

Recommendation 2

To fully utilise the potential of 6 week baby check in facilitating the development of supportive relationships between families and primary care providers by focussing provision of 6 week baby check in primary care

Recommendation 3

To reconsider and develop the provision of maternal care and support as part of statutory MIS in primary care

12.3 Project Findings

The project identified:

- a high proportion of single mothers (31%),
- high levels of maternal smoking during pregnancy (20%),
- high levels of infant exposure to environmental tobacco smoke (24%) and
- low breastfeeding rates (15%).

While these results are in keeping with national trends, it was considered helpful, albeit sobering, for primary care providers to have access to such health behaviour information in relation to their practice populations.

Recommendation 4

To facilitate feedback on health behaviours of practice populations to primary care providers

Primary care providers recognised their role and that of other health service providers in supporting their patients in changing health behaviours.

Recommendation 5

To provide access for primary care providers to smoking cessation, breast feeding support and antenatal education programmes

Recommendation 6

To include assessment of alcohol consumption during pregnancy in maternal health data collection

The project revealed socio economic gradients for health behaviours like low levels of breastfeeding and high levels of smoking prevailing amongst medical card holders, compared to non medical card holders.

Recommendation 7

To raise awareness of the impact of social determinants of health on health behaviours and health inequalities, including educational, economic and environmental disadvantage

The project documented that:

- time taken to complete 6 week baby check lengthened,
- content and focus of health promotion issues improved and
- level of Practice Nurse involvement increased.

While the project was not designed to measure the impact of these changes on child health outcomes, they are in line with recommendations for good practice in primary care.⁴

Recommendation 8

To assess the impact of primary care child health service provision on child health outcomes through research and service monitoring, evaluation and feedback

In line with international recommendations for evidence based practice in child health screening and surveillance, there has been a shift towards screening children for medical problems like congenital heart disease, developmental dysplasia of hips and testicular non descent in early childhood.¹⁹

While there was a small number of instances where children were kept under observation within primary care (19) or referred (8) to further assess clinical problems identified as a result of 6 week baby check, the 6 week baby check provides a key opportunity to assess the health status of all children.

Recommendation 9

To ensure medical assessment of all children at 6 week baby check

Feedback from parents and service providers emphasised the key opportunity for developing and strengthening supportive relationships between families and primary care providers.

Recommendation 10

To facilitate access of all children and families to the 6 week check in primary care by heightening awareness of its potential and availability through information provision and education

12.4 Communication, information and integration

The project has contributed to improved communication amongst service providers in a variety of health care sectors, including primary care, community care, secondary care and population health.

Recommendation 11

To further the development of primary care teams, integrating key service providers of health services to children and families at primary and community care level with strong links to secondary care within community child health

Recommendation 12

To strengthen resources available in Public Health Nursing services for the provision of child health services and integration with other child health service providers

Consultation with mothers identified the need for better information regarding purpose, content and outcome of the 6 week baby check.

Recommendation 13

To include information on the 6 week baby check in PHR to be made available to all parents of newborn children and to ensure better use and distribution of service user information leaflet

The developed software can be configured to print findings from the 6 week baby check for parents to include in the parent held PHR already in operation in HSE West (Clare, Limerick & Tipperary) and soon to be introduced in HSE West (Donegal, Sligo, Leitrim & West Cavan) and HSE Northern Area (Cavan, Monaghan, Louth).

Recommendation 14

To disseminate the parent held PHR nationally

12.5 Monitoring and evaluation

The development of data collection tools and processes posed many challenges. While the project was not designed to primarily focus on information technology developments, it provided an evidence based data set for collection at the 6 week baby check, which allows for service monitoring, evaluation, audit and measurement of outcomes. This can be integrated with other existing electronic child health information management systems and contribute to the development of an electronic child health record (eCHR).

Recommendation 15

To develop a national framework and governance structure for integrating electronic child health information systems

The INDC provides a user friendly electronic interface for data collection, cleaning, reporting, monitoring and feedback based on a previous model within the 'HeartWatch' project.

Data analysis at HSE West (Donegal, Sligo, Leitrim & West Cavan) level was complicated, as there was no functioning electronic interface to integrate data received from primary care practices into a reporting structure for the project.

Recommendation 16

To develop an electronic interface to integrate and exchange child health data between HSE and primary care The main software providers in primary care within ROI contributed to and supported the project. Practices struggled at times to work successfully with a software tool, which remains under development and requires refinement.

Recommendation 17

To improve the functionality of the data management system

Uptake rates for the 6 week baby check were high at 90 - 100% in this project, but could only be estimated in the absence of patient registration.

Recommendation 18

To introduce universal patient registration with health service providers in primary care

12.6 Data sharing, consent and confidentiality

In discussion between HSE, ICGP and data protection experts, concerns regarding data sharing arose that are common to all developments relevant to an eCHR. These include data sharing between service providing agencies, security and levels of access to information on individual clients within organisations, confidentially and consent.

Recommendation 19

To augment the role of the Personal Public Services Number (PPSN) as unique identifier

Recommendation 20

To harmonise data flows between HSE, ICGP and other agencies to facilitate integration of GP generated child health data with existing electronic child health information systems (PHR, immunisations, child care)

The project endeavoured to address the issue of informed consent in the context of existing data protection legislation. Despite the development of a service user information leaflet approved by the Office of the Data Protection Commissioner, this was rarely given to or discussed with parents of babies presenting for the 6 week baby check.

Recommendation 21

To build awareness and capacity in primary care to appropriately deal with requirements under data protection legislation

Recommendation 22

To establish a data protection ethics committee to guide the development and roll out of this and similar projects in light of requirements under the data protection acts, related existing and future legislation

Data transfer of non anonymised data from primary care practices to HSE West (Donegal, Sligo, Leitrim & West Cavan) required a secure mechanism. The existing electronic GP e-mail network proved difficult to use.

Recommendation 23

To improve secure electronic communication mechanisms between primary care providers and HSE and to explore the feasibility of developing web based applications requiring inscription and HL7 messaging standard development

The recent development of nine centile growth charts for Irish children gives an opportunity for inclusion of an electronic version in GP child health software to calculate centiles and identify children where there are concerns about growth, as well as collection of population health data in the context of an obesity epidemic.

Recommendation 24

To develop and make available to child health practitioners in ROI an electronic growth monitoring tool

Data analysis and feedback at the level of practices rather than individual GPs requires a practice identifier not currently available other than within the context of individual projects.

Recommendation 25

To develop practice identification mechanisms for information management and performance monitoring as part of GP contract renegotiations

12.7 Staff training

The skills refresher course was designed to meet the needs of primary care providers in child health. GPs and Practice Nurses welcomed this opportunity to improve their skills in child health service delivery and would have liked more practical training in some aspects of child health examination and promotion.

The training module had been approved for CME credits both by An Bord Altranais and the ICGP, and participants were compensated for expenses and time required to attend. Practitioners are required by their governing professional bodies to engage in continuous professional development, often to be undertaken out of hours and on individuals' initiative.

Recommendation 26

To include training in child health for GPs and Practice Nurses on a multidisciplinary basis as part of the new GP contract to ensure CME activities are part of the working day in primary care, fulfilling requirements under competence assurance

Participation of Practice Nurses within this project was made difficult by the absence of national and regional administrative support and professional development service frameworks for this group of professionals.

Recommendation 27

To strengthen the role of Practice Nurses within primary care service provision by providing a framework for training, accreditation and continuous professional development and support for this at regional and national level

The role of parents as experts in the development of health and well being of their child again became apparent in this project.

Recommendation 28

To provide staff training and awareness raising to strengthen the role of partnership in working with parents

12.8 feasibility of national dissemination

Assessment of existing practice in consultation with service users and providers showed a high level of satisfaction with delivery of the 6 week baby check within general practices in HSE West (Donegal, Sligo, Leitrim & West Cavan). Uptake rates are particularly high in this area, as are Public Health Nurse visiting rates to mothers of newborn babies.

Practitioners participating in the project were chosen based on selection criteria that favoured computerised practices with a high level of multidisciplinary working and experience in participating in similar projects or other quality improvement initiatives. The ability of these practices to support the delivery of a new model for the 6 week baby check cannot be assumed to be in existence throughout primary care in ROI. Amendments to the data set have been made

as a result of the project evaluation, but further testing of revised GP software is required to ensure maximum ease of use and appropriateness of dataset.

Recommendation 29

To develop a national steering and governance process to oversee, support and disseminate the development of projects like the HSE West (Donegal, Sligo, Leitrim & West Cavan) GP child health project

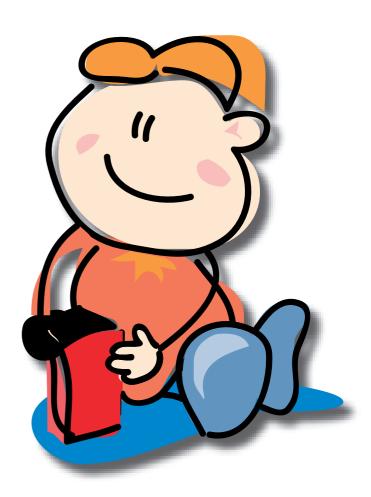
12.9 Cost

Time required to carry out a 6 week baby check with data entry is between 20 and 30 minutes. This needs to be recognised in the fee payable to primary care providers.

The project provided additional remuneration to participating practices in recognition of the additional time required to deliver a comprehensive 6 week baby check.

Recommendation 30

To redesign fee structure for MIS and include new model for 6 week baby check in national GP contract renegotiations



Appendices



Appendix A

Project plan

| Objective | Timeframe | Delivery |
|--|---------------------------|--|
| Recruit project officer | Q2 2003 | |
| • Job description | | ICGP, Regional Child & Adolescent Health Development Officer/HSE NWA (RCAHDO) |
| Advertising by letter/ telephone contact to HSE NWA ICGP GPs and public advertisement in INT | Week starting 01/09/03 | ICGP |
| • Interviews | Week starting 29/09/03 | ICGP/ RCAHDO/ PAC/ paediatrician |
| Convene steering group (GPs DGL& S/L/WC, project officer, PHN, PN, HSE NWA Primary Care Development Unit, RCAHDO, paediatrician- IT, public health researcher, ICGP, PAC, health promotion officer on request) | Q3 2003 | ICGP/ RCAHDO |
| Phase I | Q4 2003- Q1 2004 | HSE NWA/ ICGP |
| Develop standard for six to eight week examination Content Referral criteria and pathways Outcome measures Data requirements | Q4 2003 | Working group convened by project officer: GPs, Practice Nurses, ICGP, PAC, paediatrician, PHN, RCAHDO |
| Recruit test practice | Q4 2003 | Project officer |
| Implement standard | Q4 2003- Q1 2004 | Project officer |
| Identify training needs | Q4 2003- Q1 2004 | Project officer |
| Develop data collection and information feedback mechanism, including consent/ data protection | Q4 2003- Q1 2004 | Project officer with IT support (HSE NWA / ICGP) |
| Establish mechanism to consult with service users | Q4 2003- Q1 2004 | Project officer with research support |
| Develop information materials for service users and providers | Q4 2003- Q1 2004 | Project officer with health promotion support |

Project plan (Continued)

| Objective | Timeframe | Delivery |
|---|------------------|--|
| Phase 2 | Q2 2004- Q3 2005 | HSE NWA/ ICGP |
| Recruit project practices | Q2 2004 | Project officer, ICGP, CME tutors |
| Develop training curriculum | Q2 2004 | BHFC Regional Training &Development Officer/ HSE NWA (RT&DO), Project officer, RCAHDO |
| Deliver training sessions | Q2 2004 | RT&DO, Project officer |
| Implement standard, data collection and information feedback mechanisms, information materials | Q3 2004 | Project officer in co- operation with project practices |
| Deliver standard | Q4 2004- Q3 2005 | Project practices |
| Evaluation of project | Q4 2004- Q3 2005 | Project officer |
| Preparation of Phase 3 &4 | Q3 2005 | Project officer/ ICGP/ PAC |
| Phase 3 | Q4 2005 onwards | ICGP |
| Dissemination regionally and nationally through ICGP educational network | | ICGP in collaboration with PAC |
| Phase 4 | Q2 2006 onwards | ICGP |
| Service initiative through ICGP/ PAC with DoHC/ IMO | | ICGP and PAC |

Appendix B

Six Week Baby Check in General Practice Project

Pre-Implementation GP Questionnaire

| Name of GP | ••••••••••••••••••••••••••••••••••••••• | ••••• | (optional) | | | |
|---|---|------------------------|------------|--|--|--|
| I. Registration / Uptake rate | | | | | | |
| How many new babies register with you approximately per annum? | | | | | | |
| How many babies register with your practice approximately per annum? (Answer this only if you are in a group practice) | | | | | | |
| Do you measure uptake rates for the si | ix-week baby check? | Yes | | | | |
| | | No | | | | |
| If yes, how do you do this? | Manual check of records | | | | | |
| | Computer search | | | | | |
| Other, please state: | | | | | | |
| If yes, what is the current uptake as % | of babies registered? | | | | | |
| If no, what is the estimated uptake as % of babies registered? | | | | | | |
| 2. Current practice | | | | | | |
| a) Timing | | | | | | |
| When is the six-week baby check usual | ly carried out? (Tick one box o | nly) | | | | |
| 6 weeks 8 we | eeks 🔲 | 8 weeks with immunis | sation 🗖 | | | |
| Other, please describe: | | | | | | |
| b) Context | | | | | | |
| Does the mother have her 6-week pos | tnatal check during the same | appointment as the bab | y? | | | |
| Never Rarely | Usually | Al | ways 🔲 | | | |

| c) | Content | | | |
|---------------|----------------------------|--------------------------------|----------------------|------------------|
| Does the p | ractice have a standard | protocol for six-week baby | check? Yes | No |
| How long | (average in minutes) do | you spend on the six week | check? | |
| Apart from | the clinical examination | n, please list any other topic | s, which are covered | during the check |
| up: | | | | |
| | | | | |
| d) | Clinical setting | | | |
| Is the baby | seen during: | Routine surger | у | Special clinic |
| Other, plea | se state: | | | |
| e) | Health care staff | involvement | | |
| Is the baby | seen by: | By GP on | ly 🗖 B | y GP and PN |
| Other, plea | se state: | | | |
| f) | Record of six wee | k baby check (please tick | all that apply) | |
| Is it entered | d on the? | | | |
| 'W | hite card' | | | |
| На | nd written personal file | | | |
| Со | mputer held personal re | ecord | | |
| If data is ke | pt electronically, is cons | ent sought prior to data en | try? Yes | No |
| 3. Co | mmunication betwee | n parents and GP | | |
| How do yo | u contact parents about | t the six-week baby check? | | |
| By letter | | By telephone | | Rely on PHN |
| Other, plea | se state: | | | |
| Do you disc | cuss the general purpos | e of the six-week baby chec | ck with parents? | |
| Never _ | Rarely | , 🔲 Usu | ially 🔲 | Always 🔲 |

| Do you | u discuss the spe | ecific clinical aspec | cts of the six-weel | check with | parent | s? | | | |
|--|--------------------|--|---------------------|------------------|----------|---------|---------|----------|-------|
| Never | | Rarely | l | Usually \Box | I | | , | Always | |
| Do уо | u feel there is en | ough opportunity | y for parents to as | k questions c | during t | he six- | -week | baby ch | eck? |
| 4. | General Infor | rmation | | | Yes | | | No | |
| For ea | ch of the statem | ents below pleas | se circle what mo | st closely ref | lects yo | our opi | inion. | | |
| 5 – Str | ongly Agree | 4 – Agree | 3 – Neutral | 2 – Disaş | gree | ı | – Stroi | ngly dis | agree |
| | | clinical data subr ne six-week baby | | 5 | 4 | 3 | 2 | I | |
| I am clear about referral criteria in relation to clinical findings at the six-week baby check. 5 4 3 2 I | | | | | | | | | |
| I receive adequate feedback about babies whom I refer elsewhere as a result of clinical findings at the six-week baby check. | | | | 5 | 4 | 3 | 2 | I | |
| What o | other aspects of | the current six-w | veek baby check a | re you happy | with? | | | | |
| What | other aspects w | ould you like to i | mprove? | | | | | | |
| 5. Which | Outcome Me | | week baby check | do you think | c should | d be m | easure | d? | |
| | | | | | •••••• | ••••• | ••••• | •••••• | |
| 6. | Previous train | ning | | | | | | | |
| Have y | ou completed a | six-month appro | ved paediatric pos | st? | Yes | | | No | |
| If no, h | nave you had any | specific training | for the six-week b | aby check? | | | | | |
| | | Approv | ved obstetric post? | | | GP r | egistra | r post | |

| Other, please state: | | | | | | | |
|---------------------------------------|-------------------------------------|----------------------------------|--|--|--|--|--|
| • | | | | | | | |
| 7. Refresher Skills Course | | | | | | | |
| In which of the following areas do yo | ou feel you require any updating o | of your skills for the six-week | | | | | |
| baby check? | | | | | | | |
| Clinical | General | | | | | | |
| Growth Measurement | Immunisation | | | | | | |
| Vision | Feeding | | | | | | |
| Murmurs | SIDS | | | | | | |
| Hips | Child Safety Guidelines | | | | | | |
| Testes | Accident Prevention | | | | | | |
| Limb Abnormalities | Other | | | | | | |
| Other | | | | | | | |
| | · | | | | | | |
| If other please state here: | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| If you have any other comments abo | out any aspect of this project plea | se feel free to write them down: | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | •••••• | | | | | | |

THANK YOU FOR FILLING IN THIS QUESTIONNAIRE

Please return in the enclosed SAE, together with the signed contract, before Monday Sept $20^{\rm th}$ 2004.

Appendix C

19th May 2004

Child Health Surveillance and Screening

Invitation to "The Six Week Baby Check in General Practice Project"

Dear Colleague,

You are invited to apply to participate in an innovative new project being conducted, through the ICGP, in the Health Service Executive - North West Area. "The Six Week Baby Check in General Practice Project" has arisen out of recommendations made in the national report "Best Health for Children – developing a partnership with families", published in 1999.

Presently, in the absence of a quality assurance system it is difficult to assess the level of service provision, clinical standards, resources required and service user satisfaction. With existing data information systems it is currently not possible to ascertain uptake figures for the 6-8 week postnatal examination in general practice, other than at the level of individual practices and through separate surveys. Valuable information on health status of infants remains unutilised, and there is no process to measure outcomes.

In this project, which will run in selected practices in the HSE NWA, a standard pro-forma for the six week baby check has been designed to be incorporated into existing GP computer programmes.

Additional remuneration will be paid to each participating practice, and for each individual six week baby check undertaken according to the new clinical standard that has been developed in the course of this project.

Please see attached for:

- I. Description of the project (Appendix I)
- 2. Details of agreed remuneration (Appendix 2)
- 3. Details of GP selection criteria (Appendix 3)
- 4. Application form (Appendix 4)

Please note GPs and Practice Nurses involved in this project will be obliged to attend a half day refresher course in September 2004. Please do not hesitate to contact me should you have any queries. Application forms must be returned to the above address no later than <u>II</u>th <u>June 2004</u>.

Yours sincerely,

Dr. Lynne McBride, Project Officer.

Appendix I

"Six Week Baby Check in General Practice Project"

Supported by the Health Service Executive - North West Area (HSE NWA), the Irish College of General Practitioners (ICGP) and Programme of Action for Children (PAC).

Introduction

In 1996 a national review of child health services for the 0-12 year age group in Ireland was commissioned. The findings and recommendations resulting from this process were published in 1999 in form of a strategic report called Best Health for Children – Developing a Partnership with Families (BHFC).

The National Health Strategy Quality and Fairness – "A Health System for You" published in 2001, endorsed the recommendations in BHFC, which has now become a national programme under the umbrella of the Health Board Executive (HeBE). It has been given an extended role in the development of a national service framework for integrated children's services, the Programme of Action for Children (PAC).

One of the recommendations made in the BHFC report was that an explicit evidence based standard be designed for clinical use and a standard set of data be recorded at the six week baby examination as current data collection and analysis under the Mother and Infant Scheme (MIS) is inadequate.

The HSE NWA in association with the ICGP established the "Six week baby check in General Practice Project" in November 2003. The project is aimed at realising these recommendations for the six week baby check under the current MIS. The project will run in a selected number of general practices in the area of the HSE NWA. This is one of several different demonstration projects being conducted nationally in order to put into practice evidence based recommendations for quality assured child health services delivered in partnership with families. Additional payment to GPs participating in the project will be provided through the current MIS payment system.

Using a Standard Protocol

As part of the project, a standardised model for screening and clinical examination of infants has been developed. This model employs recommendations for best practice drawn from international research based evidence and reflects consultation with service users in the Health Service Executive - North West Area, service providers and members of the multidisciplinary regional steering group.

A data collection tool has also been developed to record the data obtained at the six week baby check and has been designed to be incorporated into existing computer programmes currently in use in General Practice.

Aim of Project

To develop, implement, test and evaluate a new model for the six week examination of infants under the MIS.

Project Objectives

- To use evidence based examination guidelines
- To develop clear referral criteria and pathways
- To employ standardised follow –up procedures
- To improve communication between service users and providers
- To commence data collection and outcome measurement
- To initiate staff training and accreditation
- To develop strategies to reach marginalized children
- To disseminate the findings of the project nationally

To integrate the new standard with current and future IT child health systems - e.g. Immunisations, Parent Held Record, PHN Child Health Database

Stages of Implementation

- Letters of invitation and application forms sent to all GPs in HSE NWA by 12th May 2004.
- Application forms to be returned to Project Officer no later than 11th June 2004.
- Selection of GPs by Project Officer and Regional Child and Adolescent Health Officer by 18th June 2004.
- Confirmation of GP Practice selection at Steering Group Meeting 23rd June 2004.
- Pre training day Questionnaire to be returned to Project Officer by participating GPs and Practice Nurses by 16th July 2004.
- Software installation in selected practices August /September 2004.
- Participating GPs and Practice nurses to attend half day refresher Course September / October 2004.
- October 2004 June 2005: Participating practices undertake to examine all infants in accordance with the new clinical standard at their six week baby check, enter clinical data on computer and return data by email to data controller

GP recruitment and selection

Letters of invitation and application forms will be circulated to all GPs in the North Western Health area using the HSE NWA and ICGP database .The GPs will be selected on the basis of information submitted in their application by the Project Officer and Regional Child and Adolescent Health Officer. Approximately 15 GPs will be selected. Confirmation of those selected will take place in consultation with members of the steering group at the next meeting 23rd June 2004.

Consent

Consent should be obtained by health care staff, explaining to parent(s) that non-anonymised child health data are transferred to the Health Service Executive - North West Area, as previously required under the existing MIS, for analysis and record keeping. Anonymised data are transferred to the Independent National Data Centre (INDC) for statistical purposes.

Computer Records and Confidentiality

Data will be entered in the GP office via the current clinical computer system as part of the child's clinical record. This will require the installation of an extension to the existing software system, which will not incur any costs to GP practices participating in the project.

The data will then be exported to an Excel file format. Non-anonymised data are then transferred to the data controller in the Health Service Executive - North West Area via GP email network for validation, collation, analysis and generation of relevant reports. Requirements under the data protection act will be followed at all times.

Return of the above data to the Health Board will generate payment to GPs as part of existing payment arrangements for the MIS.

Anonymised data are transferred to the INDC via a browser based application. The Centre is independent of ICGP, DoHC and Health Service Executive - North West Area.

Project Management

The Project Officer was recruited by the ICGP on behalf of the Health Service Executive - North West Area in November 2003. The duration of the project is two years. The project is supported by the regional multidisciplinary steering group.

Membership:

A detailed project plan is available on request from the project officer Dr. Lynne McBride.

Appendix 2

GP Remuneration

The rights and responsibilities of participating doctors and their practices will be set out in a contract to be made between the GP and the Health Service Executive - North West Area. On satisfactory completion of the practice selection process the contract will be signed by both parties.

An initial payment of €400 to GPs is available for participation in the project.

GPs will receive a fee of €40 for each completed six week baby check examination. This is in addition to the regular fee under the existing MIS. Payment will be issued on receipt of each completed data set and as part of the ongoing system of remuneration for services provided under the MIS.

Travel expenses will be payable to participants of the half day introductory and refresher course, which is accredited by the ICGP for CME purposes and attracts CAS credits.

Appendix 3

Selection Criteria for General Practitioners wishing to participate

During the implementation of the new standard the following considerations will apply;

- The selected practices must be able to demonstrate that they have the resources to provide the service.
- The practice must be computerised and on the HSE NWA network.

Responsibilities of Participating GPs and Practice Nurses

GPs will agree to undertake the following tasks:

- Attend the half day introductory and refresher course in September or October 2004.
- Complete a questionnaire prior to attendance at the course.
- If a Practice Nurse is involved in the six week check provide him/her with protected time for attendance at half day refresher course
- To enter all patients registered with the practice under the MIS in agreement with the project standard
- To provide suitable facilities and equipment for patient visits.
- To allow sufficient time for discussion of health promotion issues etc
- To obtain consent from parent(s)

Appendix 4

[CLOSING DATE: II June 2004]

Application form

| Section A – Practice Details | Total Practice Population: |
|---|----------------------------|
| Names of GPs in Practice: (Block Letters) Position: Partner/Assistant/L 2 3 4 5 6 7 8 9 10 *FTE = Full | Locum/Other FTE* |
| Practice address: | |
| Tel: Email: | |
| Name(s) of GP Applicant(s) (Block Letters): | |

Section B Essential Criteria for All Practices Tick/Complete as appropriate

No. **YES** NO BI. Will each applicant GP recruit all infants registered with the practice under the MIS? B2. Does each applicant GP undertake to attend recommended training necessary for the project? B3. Will the Practice make suitable space available for patient consultation for the purpose of this project? B4. Will the Practice make suitable space available for visiting ancillary personnel (e.g. computer personnel?) where necessary? B5. Does the practice agree to work closely with the Project officer during this programme? B6. If the Practice employs a Practice Nurse -Will the practice facilitate the Practice Nurse attending all recommended training necessary for the programme?

Section CI

| | Computerisation | | |
|------|--|----------|----|
| No. | | YES | NO |
| CI.I | Is the practice computerised? If yes please detail the practice members who use the computer. | | |
| C1.2 | Which clinical software package is used in the practice? | | |
| C1.3 | Is the practice capable of making electronic returns? | | |
| C1.4 | What percentage of practice population is registered on computer? | % Yes | No |

| C1.5 | Does the practice use a computerised call system for the six week postnatal check? | | |
|------|---|------|--------------|
| CI.6 | Does the practice use any other non computerised call system for the six week postnatal check? | | |
| | C2 – Staffing & Facilities | | |
| C2.1 | How much practice nurse time does the practice currently employ? Please give answer in full time equivalents (FTE). (I FTE = 39 hours /week) | | - - No |
| C2.3 | Please detail the role of the practice nurse in relation to child health service provision within your practice currently? | Tes | INO |

| | C3 – Clinical Management | | |
|------|---|-----|----|
| No. | | Yes | No |
| C3.1 | Has the practice previously been involved in audit? If yes please give details. | | |
| C3.2 | Has the practice previously been involved in data collection? If yes please give details. | | |
| C3.3 | Does the practice have any clinical protocols currently in place? If yes please give details. | | |
| | C4 – Team Working | | |
| No. | | Yes | No |
| C4.1 | Has the practice previously been involved in collaborative working with other practices? If yes please give details. | | |

| C4.2 | Has the practice previously been involved in collaborative working with the Health Board? If yes please give details. |
|------------|--|
| C4.3 | Does the practice currently have collaborative working arrangement with other health professionals within the practice? If yes please give details |
| | C5 – General Information |
| C5 | Please add any further comments, which you feel, will demonstrate the level of interest and enthusiasm the practice has for involvement in this programme. |
| | ock Capitals & Signature) |
| | |
| Practice S | tamp: |

Appendix D

Skills Refresher Course Wednesday 29th of September 2004 Harvey's Country House Hotel, Lough Eske, Donegal Town 2.30- 6.30pm Agenda

| 2.30pm | Registration / Tea & Coffee |
|--------|--|
| 3.00pm | Introduction |
| 3.15pm | Growth Monitoring – Dr Greaney, Consultant Paediatrician 15 minute presentation 10 minute for discussion |
| 3.40pm | Ophthalmic Problems – Dr Kearney, Community Ophthalmic Physician 10 minute presentation 10 minute discussion |
| 4.00pm | Heart Murmurs – Dr Beamish, Specialist Registrar in Paediatrics, Sligo 15 minute presentation 10 minute discussion |
| 4.25pm | Tea/Coffee |
| 4.40pm | Developmental Dysplasia of Hips-Mr Gaine, Consultant Orthopaedic Surgeon 5 minute presentation 25 minutes discussion and model demonstration |
| 5.20pm | Undescended Testes - Dr McBride, Project Officer 10 minute presentation and discussion |
| 5.30pm | Health Promotion – Dr McBride |
| 6.00pm | Data Collection & Evaluation – Dr McMaster, RC&AHDO |
| 6.30pm | Finish (approximately) |
| 7.00pm | Evening Meal |

Appendix E

Contents of the INDC export files

| Field Name | Data Type | Mandatory |
|--------------------|-----------|-----------|
| County | CHAR(2) | yes |
| DOB | DATE | yes |
| Gender | INTEGER | yes |
| ClientID | CHAR(15) | yes |
| GPID | INTEGER | yes |
| PHNVisit | CHAR(I) | yes |
| Place | CHAR(I) | yes |
| HospitalID | INTEGER | yes |
| ExistingDiagnosis | CHAR(I) | yes |
| DiagnosisID | INTEGER | yes |
| Admission | CHAR (I) | yes |
| LiveBirths | INTEGER | yes |
| StillBirths | INTEGER | yes |
| Miscarriages | INTEGER | yes |
| GestationWeeks | INTEGER | yes |
| GestationDays | INTEGER | yes |
| MatSmoke | CHAR(I) | yes |
| Multiple | CHAR(I) | yes |
| BirthOrder | INTEGER | yes |
| DeliveryID | INTEGER | yes |
| PresentationID | INTEGER | No |
| BirthWeight | INTEGER | No |
| BirthCentile | INTEGER | No |
| SCBU | CHAR(I) | yes |
| Smoke | CHAR(I) | yes |
| HouseholdID | INTEGER | yes |
| NationalityID | INTEGER | yes |
| EthnicID | INTEGER | yes |
| StatusID | INTEGER | yes |
| GMS | CHAR(I) | yes |
| ExamDate | DATE | yes |
| Age | INTEGER | yes |
| GeneralExamination | CHAR(I) | yes |
| Respiration | CHAR(I) | yes |
| ColourID | INTEGER | yes |
| SkinID | INTEGER | yes |
| FontanelleID | INTEGER | yes |

| Field Name | Data Type | Mandatory |
|------------------|-----------|-----------|
| Palate | CHAR(I) | yes |
| Hands | CHAR(I) | yes |
| Feet | CHAR(I) | yes |
| GenOutcomeID | INTEGER | yes |
| GenReferID | INTEGER | yes |
| Weight | INTEGER | yes |
| WeightCentile | INTEGER | no |
| Head | INTEGER | no |
| HeadCentile | INTEGER | no |
| Length | INTEGER | no |
| LenghtCentile | INTEGER | no |
| GrowthOutcomelD | INTEGER | yes |
| GrowthReferID | INTEGER | yes |
| ToneID | INTEGER | yes |
| Movement | CHAR(I) | yes |
| MotorOutcomeID | INTEGER | yes |
| MotorReferID | INTEGER | yes |
| EyesID | INTEGER | yes |
| Fix | CHAR(I) | yes |
| RedReflex | CHAR(I) | yes |
| EyesOutcomeID | INTEGER | yes |
| EyesReferID | INTEGER | yes |
| BabyHear | CHAR(I) | yes |
| HearingOutcomeID | INTEGER | yes |
| HearingReferID | INTEGER | yes |
| HeartSounds | CHAR(I) | yes |
| Femoral | CHAR(I) | yes |
| CVSOutcomeID | INTEGER | yes |
| CVSReferID | INTEGER | yes |
| RightTesticleID | INTEGER | No? |
| LeftTesticleID | INTEGER | No? |
| TestesOutcomeID | INTEGER | No? |
| TestesReferID | INTEGER | No? |
| HipID | INTEGER | yes |
| HipExam | CHAR(I) | yes |
| Ortolani | CHAR(I) | yes |
| Galeazzi | CHAR(I) | Yes |
| LegLenght | CHAR(I) | Yes |
| RangeMovement | CHAR(I) | Yes |
| SkinFolds | CHAR(I) | yes |
| HipsOutcomelD | INTEGER | yes |
| HipsReferID | INTEGER | yes |

| Field Name | Data Type | Mandatory |
|------------------|-----------|-----------|
| FeedingID | INTEGER | yes |
| EverBreastFed | CHAR(I) | yes |
| StoppedDays | INTEGER | No? |
| StoppedWeeks | INTEGER | No? |
| SIDS | CHAR(I) | yes |
| Illness | CHAR(I) | yes |
| Immunisation | CHAR(I) | yes |
| Accidents | CHAR(I) | yes |
| Nutrition | CHAR(I) | yes |
| SmokingCessation | CHAR(I) | yes |
| MotherDOB | DATE | yes |

Contents of the health board export files

The health board export files requires all of the fields listed in the INDC file above and the following additional fields.

| Field Name | Data Type | Mandatory |
|-----------------|-----------|-----------|
| Surname | CHAR(25) | yes |
| Forename | CHAR(25) | yes |
| Address I | CHAR(50) | yes |
| Address2 | CHAR(50) | yes |
| Address3 | CHAR(50) | no |
| Address4 | CHAR(50) | no |
| MotherSurname | CHAR(25) | yes |
| MotherForename | CHAR(25) | yes |
| MotherAddress I | CHAR(50) | yes |
| MotherAddress2 | CHAR(50) | yes |
| MotherAddress3 | CHAR(50) | no |
| MotherAddress4 | CHAR(50) | no |
| MotherCounty | CHAR(2) | yes |

Appendix F

The 6 To 8 Week Baby Check - Information for Parents

Your primary care team is taking part in the '6 to 8 week baby check in General Practice project', undertaken by the North Western Health Board (NWHB), the Irish College of General Practitioners (ICGP) and the Programme of Action for Children (PAC). The 6 to 8 week check is part of the Maternity and Infant Care Scheme (MIS) and is available free of charge to all mothers and their new born babies.

The purpose of the 6 to 8 week check is:

- To review the general health of mother and baby
- To examine the baby
- To assess his or her development
- To advise on the management of the baby
- To discuss health promotion topics like accident prevention and immunisation
- To collect and analyse information on the health of the mother and baby
- To strengthen the relationship of the primary health care team with the baby's family

The aim of this project is:

• To improve the quality of services offered to your baby in the six to eight week check

This is being achieved by:

- Asking mothers and members of the primary care team about what works well already and building on this
- Finding out about what works less well and improving on it
- Standardising the content of the 6 to 8 week check
- Educating and training health care staff
- Enhancing data collection and analysis
- Providing more information about the importance of the 6 to 8 week check

Your and your baby's health

The purpose of health services is to improve the health of people as much as possible. In order to do this well, it is necessary for health professionals to work together and share information.

Why information about you and your baby is collected and ways in which it is used

Information is written down in paper records and recorded on computers. Information collected as part of the 6 to 8 week check contains:

- basic details about you and your baby, such as address and next of kin
- notes and reports about you and your baby's health history and needs
- relevant information resulting from examining the baby at the 6 to 8 week check, including referral to other health professionals where required

Information collected about you and your baby under the Maternity and Infant Care Scheme is sent to the health board. This information is treated strictly confidentially and may only be released to you as parents, carers or guardians. Statistical information is shared with other organisations for research and service planning purposes. The aim is to improve health service provision. To make sure that individuals cannot be identified, this shared data is totally anonymous.

How your records are kept secure and confidential

All staff working for the primary care team and the health board have a legal duty to keep information about you and your baby confidential. If you would like to know more about how the information on you and your baby is used, or if you have any concerns about how this information may be used, please discuss this with your general practitioner.

Policy on Protecting your Data

The Data Protection Acts 1988 & 2003 set out important principles and obligations to ensure the privacy of your personal information. The North Western Health Board (NWHB) endorses the requirements of the data protection laws. In particular, we undertake only to collect such information as is necessary to ensure that the quality of service we provide is the best possible. We also undertake to protect your right to confidentiality.

You may contact the NWHB Data Protection Officer at tel. 074 9189154 or contact the Data Protection Commissioner at Block 6, Irish Life Centre, Lower Abbey Street, Dublin 1, tel. 01 8748544 or e-mail info@dataprivacy.ie if you have a query, wish to access further information or make a complaint concerning the privacy and confidentiality of your personal information.

Quotes from Mothers, Service User Consultation Report, NWHB, June 2004

"It's nice to get the baby checked to clear up any worries that you might have. To hear somebody else telling you that she's doing well."

"No problem asking questions, because I think you are in there and you do the best for your child, so you don't mind asking."

"Oh it's more reassurance, especially as a first time mother."

Appendix G

Questionnaire For Parents about 6 week baby check in General Practice

| | Firstly a few questions about yourself: | | |
|----|---|---------------------|-----------|
| | What age are you? | ••••• | •••••• |
| | Are you a first time mother? | Yes | No |
| ı. | Did you see the practice nurse as well as the GP during t | he baby's check up | ? |
| | | Yes 🔲 | No |
| 2. | How long did the check up take (in minutes) including time spent with practice nurse as well as the GP? | | •••••• |
| 3. | Did you have your own postnatal check up at the same t | ime as your baby' o | check up? |
| | | Yes 🔲 | No |
| 4. | Did you receive the information leaflet from your GP about your baby's six week check? | | |
| | | Yes 🔲 | No |
| _ | Diagon water the fellowing statements by ticking the boy. | 4 | |

5. Please rate the following statements by ticking the box which applies to you

| | Strongly agree | Agree | No opinion | Disagree | Strongly disagree |
|---|----------------|-------|---------------|----------|----------------------|
| I was satisfied with the content of the leaflet about the 6 week check up | | | | | |
| I was satisfied with the physical examination of my baby by the doctor | | | | | |
| I felt comfortable asking questions during my baby's check up | | | | | |
| There was enough time given for the baby's check up | | | | | |

| Please tick which of these topics were discussed during (Please tick all that apply) | e and care a care in contains |
|--|-------------------------------|
| Immunisatio | n 🖵 |
| Feedin | g |
| Accident preventio | n 🗔 |
| Preventing sudden infant deat | h 🖵 |
| Recognising signs of illnes | s |
| Baby's developmen | t |
| Were there any other issues you would like to have discussed check? | cussed during your baby's six |
| | Yes No No |
| If yes, please state what else you would like to have discussed | l. |
| | |
| What do you see as the benefits of the six week check | for your baby? |
| Have you any suggestions about how the six week checimproved? | k for your baby could be |
| If you have any other comments about the six week chem here. | eck please feel free to write |
| | |
| | |
| Thank you for filling in this Questionnaire | |

Please return to Dr. Lynne McBride Project Officer in the enclosed stamped addressed envelope.

Appendix H

Six Week Baby Check in General Practice Project

Post- Implementation GP Questionnaire

| Name | of GP | ••••• | •••••• | •••••• | | (optional) |
|---------|-----------|---------------|---------------------------|----------------------|----------------------|------------|
| 1. | Upta | ke rate | | | | |
| Do yo | u meası | ıre uptake ra | tes for the six-week baby | check? | Yes | |
| | | | | | No | |
| If yes, | state up | otake rate as | % | | | |
| If yes, | how do | you do this? | Manual che | ck of records | | |
| | | | Computer | search | | |
| Other, | please | state: | | | | |
| • | | | from project, please stat | | | |
| | | | | | | |
| 2. | Curre | ent practice | | | | |
| | a) | Timing | | | | |
| When | is the si | x-week baby | check usually carried out | t? (Tick one box onl | (y) | |
| 6 weel | ks 🔲 | | 8 weeks | 8 | 3 weeks with immun | isation 🔲 |
| Other, | please | describe: | | | | |
| | b) | Context | | | | |
| Does t | he mot | her have her | 6-week postnatal check | during the same ap | ppointment as the ba | by? |
| Never | | | Rarely | Usually | A | always 🔲 |

| c) | Content | | | |
|--|---------------------|--|----------------|--|
| | How long (ave | rage in minutes) do you spend on | | |
| | | the clinical examination | | |
| | | discussing health promotion topics | | |
| | | completing data entry | | |
| d) | Clinical setting | | | |
| Is the b | oaby seen during: | Routine surgery | Special clinic | |
| Other, | please state: | | | |
| e) | Health care st | aff involvement | | |
| Is the b | oaby seen by: | By GP only | By GP and PN | |
| As a re | sult of this projec | et have you changed your clinical examination? | | |
| If yes, | please describe | | Yes No No | |
| | | | | |
| | | | | |
| ••••• | | | | |
| As a result of this project have you changed your discussion of health promotion topics? | | | | |
| If yes, | please describe | | Yes No No | |
| | | | | |
| ••••• | ••••• | | | |

| 3. | Computer programme |
|----------|--|
| Did you | ı have a problem with any of the following (please tick all that apply) |
| | Installation of programme |
| | Use of programme |
| | Content of dataset |
| | Length of time needed to complete the data set |
| | Interfered with consultation |
| | Difficulty with monthly returns |
| | Problems with nwdoc email link |
| | Other problems |
| | Other problems |
| If you h | ave ticked any of the above please describe the problem further |
| | |
| ••••• | |
| ••••• | |
| 4. | Communication between parents and GP |
| How d | you contact parents about the six-week baby check? |
| By lette | By telephone Rely on PHN |
| Other, | please state: |
| Did any | discussion with parents arise from the leaflet "Information for Parents and Carers"? |
| Never | Rarely Usually Always Always |
| Comm | ent if you wish |
| | |

| Do you discuss the genera | purpose of the six | x-week baby cl | heck with | n parents? | |
|--|-----------------------|------------------|-------------|-------------------|--------------------|
| Never | Rarely | ι | Jsually - | | Always 🔲 |
| Do you discuss the specific | c clinical aspects of | the six-week | check wit | th parents? | |
| Never | Rarely | ι | Jsually - | | Always 🔲 |
| Do you feel there is enoug | gh opportunity for | parents to ask | questions | s during the six | -week baby check? |
| | | | | Yes 🔲 | No |
| 5. General Informa | tion | | | | |
| What were the benefits of | participating in thi | s project? | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| What were the difficulties | you found in this p | roject? | | | |
| | | | | | |
| | | | | | |
| | | | ••••• | | |
| Do you feel this approach as part of your routine wo | | by check is fea | sible in th | he long term | |
| as part of your routine wo | i K. | | | , | 🗇 |
| 16 | | | | Yes 🖃 | No 🕌 |
| If no please state why not | | | | | |
| If h | | | | | |
| If you have any other com | ments about any a | spect of this pi | roject pie | ease feel free to | o write them down: |
| | | | •••••• | | |
| | | ••••••••••• | •••••• | •••••••••• | ••••• |
| | | | •••••• | •••••• | ••••• |

THANK YOU FOR FILLING IN THIS QUESTIONNAIRE

Please return in the enclosed SAE before Monday, 9^{th} September 2005 Lynne McBride, 30^{th} May 2005

Appendix 1

Interview Schedule:

- What information did you receive prior to the 6 week check?
- Can you tell me a bit about the check-up, what it included?
- What was the experience of the check-up like for you?
- Was the information you received at the check-up adequate?
- What information would you like to be given at this time?
- Were you comfortable raising questions with the service providers?
 - Were you satisfied with the answers/information you received?
 - Who would you usually ask for info. on your babies health?
- Were you asked if you thought your baby was developing well?
 - What would you check to see that your baby was developing well?
- What was your opinion on the level of communication during the check-up?
- What are your thoughts on the time taken to complete the check-up?
- What are the advantages/disadvantages of having the check-up?
- Were any of the following discussed during the check:

Family Planning
Feeding practice
Baby Management
Accident Prevention
Review general health of baby
Developmental Exam
Immunisation Plans

Can you please rate the following from 1 – 5:
 (1-unsatisfactory; satisfactory; good; very good; excellent-5)

The 6 week check:

establishing a relationship between family & general practice? providing support? providing health promotion? focusing on the child? focusing on the mum?

- Do you have any further comments to make about the service you received?
- Age:
- Number of Children:
- Who examined at the check GP / Nurse?
- Were you aware that the MIS is available to you for free?

Practices

Practice A

6 week check

Doctor

Practice nurse involvement

No immunisation until 8 weeks

Practice B

8 week check Doctor does everything No practice nurse involvement Immunisations

Practice C

6 week check
Doctor does everything
No practice nurse involvement
No immunisation until 8 weeks

Appendix J

Child Health Screening and Surveillance

"Six Week Baby Check in General Practice Project"

An agreement between North Western Health Board and General Practitioners

I, Dr. of

As a participant in this project agree to undertake the following tasks:

- Provide examination of patients in accordance with project protocol
- Ensure computer records are completed and export files returned to North Western Health Board and Independent National Data Centre monthly
- Participate in skills update course 29/9/04
- · Provide practice nurse, where applicable, with protected time to attend skills update course
- Make suitable space and time available for visiting ancillary staff with regards to software installation and maintenance
- Co-operate with Project Officer
- Co-operate with evaluation of the project
- Maintain full clinical responsibility for patients enrolled in project
- Provide continuity of care for patients participating
- Obtain consent for electronic transfer of information collected as part of the project to the NWHB and INDC
- Enroll all patients eligible under the Mother and Infant scheme, from October 2004 for a duration of approximately nine months, to the project
- Allow sufficient time for discussion of health promotion issues as outlined on the skills update course and in data collection proforma

Payment to Participating General Practitioners:

- An initial payment of € 400 will be issued on return of signed contract and questionnaire.
- Subsequent payments of € 40 per infant examined will be generated on return of completed monthly export file to the NWHB and attached to existing payment process for MIS fees.

This contract does not supersede or replace any of the existing terms of the Maternity and Infant Care Scheme Contract and is additional to existing obligations under the MIS contract as currently held.

| Signed: | | Date: | •••• |
|---------|--------------------------------------|-------|------|
| | (participating General Practitioner) | | |
| Signed: | | Date: | |
| | (Dr. Christine McMaster, NWHB) | | |

Please complete and return the enclosed questionnaire together with the signed contract within 10 working days to:

Dr Christine McMaster, Regional Child and Adolescent Health Development Officer, North Western Health Board, Old Church, Drumany, Letterkenny, Co. Donegal

Appendix K

Data Privacy Policy

Introduction

Following from recommendations in the Department of Health and Children endorsed strategic report Best Health for Children- Developing a Partnership with Families, 1999, this project has been established to develop an improved quality assured standard model for the 6-8 week examination of infants in General Practice, building on existing provision under the statutory Maternity and Infant Care Scheme (MIS) administered by General Practitioners on behalf of and under contract by health boards. Data on children undergoing the 6-8 week check is currently sent by General Practitioners in paper format to health boards for payment purposes, but the clinical information passed on in this manner remains unanalysed. The project provides computerisation of the existing system and its extension into the collection of meaningful clinical and socio demographic data on children and their families.

The project focuses on the development and testing of an improved clinical standard for the examination, based on evidence, best practice and consultation with service users. This is supported by staff training, data collection and analysis processes.

This data privacy policy refers to the pilot phase of the project only, during which the new standard will be tested by 15 GPs in the NWHB area. Data transfer to the health board will occur within the secure firewall of the health board on a dedicated GP e- mail network and server. It will be analysed to test the functionality of the system to provide reports and feedback to practices. Anonymised data will be exported to the Independent National Data Centre (INDC) of the ICGP for statistical analysis.

Following the pilot phase, the project has the potential to be rolled out nationally and contribute to the development of an electronic Child Health Record (CHR) through integration with existing IT developments in areas like immunisation, the parent held Personal Health Record (PHR) and the Child Care Information System (CCIS). It also offers the opportunity to develop a child health information base within Irish General Practice, thereby supporting the central role of primary care for the health of children and their families.

The following areas have been identified for further consideration during discussions between the agencies supporting the project. They are grouped under headings corresponding to eight rules of data protection:

- I. Information is obtained and processed fairly for the explicitly stated purposes of the project as outlined above and in the patient information leaflet. At present, expectant mothers sign a contract for the MIS with their GP. This entails imparting information to the GP in relation to the pregnancy and postnatal care of mother and baby.
- 2. Information will be collected and kept for the purposes of analysis to test the functionality of the system and it's ability to provide relevant reports for quality assurance and feedback to practices
- 3. The information will be used for these stated purposes. It will be accessible only to a small number of named staff (project officer, project manager, senior staff officer management services, staff officer management services, clerical officers x2) within the NWHB. These staff are familiar with and bound by confidentiality and data protection legislation.

- 4. The information will be kept safe and secure on the NWHB GP e-mail network and server. Access will be regulated through log on passwords available only to the named individuals named under 3.
- 5. Data received during the course of the project will be checked for accuracy and queried if deemed inaccurate. Only complete data sets will be accepted for payment and analysis purposes. As this project refers to a once off assessment at a specified age and data are not incorporated into other information existing in relation to individual children, updating is not a relevant consideration. The project has the potential to contribute to the development of an improved data collection process, rendering information held on children by health boards more accurate and complete, as well as up to date.
- 6. Compared to the existing MIS, the project will result in a data collection process that is more adequate and relevant. The wider scope of the data set to be collected will include socio demographic information, allowing the consideration of the influence of known social determinants of health on child health outcomes. Examples here include:
- Health needs of travellers
- Influence of family composition on child health outcomes
- Effect of domestic environmental tobacco smoke on child health

This data set has been defined and agreed in discussion with the ICGP.

- 7. Retention of records will be in line with existing health board policy, 'Guidelines on Record Retention' adopted by all health boards in 1999.
- 8. Requests under the Data Protection Acts are dealt with by designated officers in the health board. Queries may be addressed to the Data Protection Liaison Officer at 074 9189154. Registration under the Data Protection Act is reviewed annually by the Director of Information Systems and updated accordingly. Ultimate responsibility for compliance with the requirements under the Data Protection Act rests with the Director of Information Systems.

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"The gap between what we know and what we don't know is much less than the gap between what we know and what we do"

Don Berwick